"A Window of Opportunity": Describing and Developing an Evidence, Theory, and Practice-Informed Occupational Therapy Intervention for People Living with Early-Stage Dementia.

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Abstract

Aim

There is a scarcity of evidence generated in a UK context to inform the practice of occupational therapists working with people living with early-stage dementia. This Thesis' overarching aim was to describe and develop an evidence, theory, and practice-informed occupational therapy intervention for people living with early-stage dementia.

Methods

In accordance with the MRC Framework for the Development and Evaluation of Complex Interventions, an Intervention Mapping approach was utilised to guide the development process. Thesis Objectives were developed based on Intervention Mapping Steps 1 – 3, and to meet these objectives, this Thesis consists of three studies.

Study 1 (a two-stage mixed methods evidence synthesis) and Study 2 (semi-structured interviews with people affected by dementia and occupational therapy practitioners) sought to understand the intervention population and context, as well as identify existing research and practice-based interventions. Study 3 involved describing and developing an intervention programme theory and programme design.

Findings

Studies 1 and 2: Multiple personal and environmental (social, physical, and occupational) determinants associated with the occupational performance problems that people living with early-stage dementia may experience were identified. Existing research and practice-based interventions were heterogenous in nature and no programme theories were reported; however, strategies that problem-solve occupational performance problems were identified as a primary intervention component. In practice contextual barriers were associated with resources, other professionals' awareness and understanding of occupational therapy, and a lack of control and influence over service development and policy.

Study 3: A logic model of the problem and population, matrices of change, and a simple intervention logic model were developed to articulate a proposed programme theory. A broad overview of the

proposed interventions' design, including components and context, were specified and key uncertainties outlined.

Conclusion

This research has developed a robust foundation for further development work at Intervention Mapping Steps 4 – 6, including developing theoretically informed implementation strategies and producing materials in preparation for a feasibility evaluation.

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Abbreviations

AD	Alzheimer's Disease
ADL	Activities of Daily Living
BADL	Basic Activities of Daily Living
CASP	Critical Appraisal Skills Programme
CDR	Clinical Dementia Rating
COPM	Canadian Occupational Performance Measure
DEEP	Dementia Engagement and Empowerment Project
EPPI-Centre	Evidence for Policy and Practice Information and Co-ordinating Centre
HCPC	Health and Care Professions Council
IADL	Instrumental Activities of Daily Living
ICD	International Classification of Diseases
IM	Intervention Mapping
JBI	Joanna Briggs Institute
LEAG	Lived Experience Advisory Group
MAS	Memory Assessment Service
MMSE	Mini Mental State Examination
MOHO	Model of Human Occupation
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute of Clinical Excellence
ONS	Office of National Statistics
OP-CMHT	Older Persons Community Mental Health Team
OT	Occupational Therapy / Therapist
PICOS	Population, Interventions, Comparators, Outcomes, Study design
PPI	Patient and Public Involvement
PHW	Public Health Wales
RCPsych	Royal College of Psychiatrists
RCOT	Royal College of Occupational Therapists
SCT	Social Cognitive Theory
VD	Vascular Dementia
WG	Welsh Government
WHO	World Health Organisation

Glossary

Intervention development is a cross-disciplinary activity and therefore, profession specific language has been minimised in this Thesis. This glossary provides an overview of key terminology used.

Occupation: The word occupation is often used interchangeably by occupational therapists with the words 'activities' or 'tasks', and this is the approach adopted in this Thesis. Occupation in its broadest sense encompasses everything individuals 'do' to 'occupy' their time. It is not confined to is conventional association with work, rather it includes the myriad of activities a person does to occupy their time, from making a meal, driving a car, to going on holiday.

Occupational Performance: Constitutes the act of doing or carrying out an occupation or activity. It is often used interchangeably with the word 'functioning'.

Behaviour: Observable actions required to perform an occupation or activity.

Occupational Therapy Practitioners: An inclusive term that refers to occupational therapists, occupational therapy technicians, assistants, and support workers.

Activities of Daily Living (ADL): Any and all types of occupations or activities a person may perform day to day.

Basic Activities of Daily Living (BADL): Occupations or activities that are necessary for basic survival, e.g., eating, using the toilet, dressing, personal hygiene, mobilising.

Instrumental Activities of Daily Living (IADL): Occupations or activities that are necessary for independent living that are considered to involve greater skill complexity compared to BADL, e.g., cooking, shopping, managing finances, managing medication, using public transport, and communicating with others.

People affected by dementia: On the advice of the programme of work's Lived Experience Advisory Group (LEAG), the phrase 'people affected by dementia' has been used to refer to anyone affected by dementia personally, this includes people living with dementia as well as their families, supporters, and unpaid caregivers.

Caregivers: Where possible, the above phrase has been used to refer to people who are personally affected by dementia. However, the term caregiver has been used when needing to distinguish between people living with dementia and those who provide unpaid day to day support or care.

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Chapter 1: Background and Rationale

1.1. Introduction

This initial Chapter provides a background and rationale to the programme of research contained in this Thesis. As such it will introduce the intervention population: people living with early-stage dementia in the community; the intervention: occupational therapy; as well as the national policy and practice context. It concludes by summarising the programme's rationale and outlining its overarching aim.

1.2. Intervention Population

1.2.1. Dementia: A Group of Neurodegenerative Diseases

Dementia is considered a syndrome or group of neurodegenerative diseases characterised by a chronic and progressive decline in cognitive functioning [1-3]. This decline is not restricted to memory alone; for a diagnosis, two cognitive domains must be affected, which in addition to memory can include "*executive functions, attention, language, social cognition and judgment, psychomotor speed, visuo-perceptual or visuo-spatial abilities*" [1] no page number. As a syndrome or group of neurodegenerative diseases, dementia has multiple aetiologies and subtypes. Alzheimer's Disease (AD), which accounts for up to two-thirds of all diagnoses, is characterised by an insidious decline in short and then long-term memory, when onset is after 65 years [2]. In contrast, people living with Vascular Dementia (VD) typically experience difficulties planning, making decisions, problem-solving, concentrating, and processing information, with memory less impaired [2]. Mixed dementia, dementia with Lewy bodies and fronto-temporal dementia are less prevalent subtypes [2]. In addition to cognition, people living with dementia can experience symptoms associated with mood and personality, particularly those living with fronto-temporal and vascular dementia, with people living with Lewy Body dementia likely to experience hallucinations, and difficulties mobilising akin to Parkinson's Disease [4].

Whilst an understanding of underlying aetiology and associated cognitive, neuro-psychological and physical symptoms are important for this programme of research and the practice of occupational therapists, of particular significance are the International Classification of Diseases (ICD) 11's requirement that symptoms "*significantly interfere with independence in the person's performance of*

activities of daily living" [1] no page number, for a diagnosis to be made. The impact on the performance of activities of daily living (ADL) and independence will be elaborated upon in Section 1.2.2.

1.2.1.1. Prevalence and Demographics

Globally, the World Health Organisation (WHO) [3] estimates that 55 million people are living with dementia and that this will increase to 78 million in 2030, and 139 million in 2050. In the United Kingdom, prevalence is projected to increase by 40% between 2014 and 2025 and 157% by 2051 [5]. Whittenberg [6] estimated that 46,800 people over the age of 65 were living with dementia in Wales in 2019, and that due to a growing older population, by 2040 this figure will increase by 70%. Prevalence increases with age, with 91% of people living with dementia over 65 years of age [3]. Dementia is also gender biased, with women accounting for two thirds of those diagnosed [5] and 65% of deaths due to dementia [3]. Disability adjusted life years is also around 60% greater for women and they account for 70% of unpaid carer hours, as the primary providers of informal care [3].

1.2.1.2. Impact: Health and Economic

As a progressive condition without a cure, dementia is now the leading cause of death in the UK for women, and the second leading cause of death for men [7]. People living with dementia report a considerably lower quality of life compared to the general population, and quality of life decreases in accordance with dementia severity significantly [8-10]. A diagnosis of dementia and living with the impact dementia has day-to-day can have significant emotional and psychological consequences, with 48% concerned about "*becoming a burden*" [11] p34.

In 2019 it was estimated that the annual economic impact of dementia in the UK was £34.7 billion [6]. However, 45% of the total cost, £15.7 billion, was associated with indirect costs associated with unpaid care, which highlights the significant burden dementia has for individuals and families. In 2014, there were an estimated 700,000 unpaid carers, caring for approximately 850,000 people living with dementia [9]. Twenty-seven percent of carers report feeling "*cut-off from society*" and only 17% feel that there is adequate support for carers [11] p8. This ultimately has a negative impact on caregivers' health and quality of life, with 61% reporting that their health had suffered as a consequence [11]. Forty percent of the annual economic costs associated with dementia, reported by Wittenberg et al

[6], were attributed to social care, yet, in England[1], 60.6% of this cost was funded by individuals privately. The Alzheimer Society's report *Dementia the True Cost* [12] shines a light on the "*catastrophic costs*" that people living with dementia and their families must pay for basic social care and support, which is difficult to access and is often of "*poor quality*" (p6). Significantly, healthcare accounted for only 16% of the overall total costs associated with dementia [6].

1.2.1.3. Lived Experience

In addition to symptoms and statistics, it is important to acknowledge that dementia is fundamentally something that is experienced and lived. As Macdonald et al [13] state: "*Little of this information [about symptoms and disease trajectories] assists people [to]* ***live*** *with dementia*" (p2). Since Kitwood's [14] seminal work on personhood, a shift in focus from a biomedical symptom-based approach to one that is social, relational, and experiential is purported by an increasing number of people affected by dementia, researchers, clinicians and activists [13]. Today, the lived experiences of people affected by dementia are increasingly being centred, albeit not enough, through published personal testimonies [15], activists and advocates living with dementia [16], networks and organisations like the Dementia Empowerment and Engagement Project (DEEP) [17], and established charitable organisations like the Alzheimer's Society. Whilst it would be impossible to do justice to all lived experiences in this section, it is important to highlight a number of areas where significant progress has been made, including increased: emphasis on a human rights-based approach [18]; awareness about the experiences of younger people living with dementia, and young caregivers [19]; emphasis on empowering people themselves to record and share their day-to-day lived experiences of dementia [20]; peer support [17]; and awareness about the lived experiences of accessing services, including the lack of post-diagnostic support [11].

1.2.2. Early-stage Dementia

The ICD-11 is a World Health Organisation (WHO) developed, global classification system for clinical diagnosis and research purposes, and provides clinicians with an opportunity to record dementia severity using the words "*mild*", "*moderate*" and "*severe*" [1]. It is important to note that the terms early-stage, middle-stage, and late-stage are also frequently utilised to denote severity and

[1] No figures were provided for the UK.

correspond with the terminology used in the ICD-11 (Table 1). The term early-stage dementia will be utilised in this Thesis and should be understood as synonymous with mild dementia.

Table 1: Dementia Severity / Stage

ICD-11 Severity [1]	**WHO** [3]**, Alzheimer's Society** [21]
Mild	Early-stage
Moderate	Middle-stage
Severe	Late-stage

Unfortunately, the ICD-11 itself does not elaborate on what constitutes "*mild*", "*moderate*" and "*severe*", and throughout this programme of work a lack of a standardised definition regarding what constitutes early-stage dementia became apparent. It is a theme which will be revisited throughout this Thesis, and to provide a context for this ongoing theme, three of the most common approaches towards describing early-stage dementia will be summarised in Sections 1.2.2.1-1.2.2.3.

1.2.2.1. Symptoms Associated with Early-stage Dementia

As described in Section 1.2.1., the symptoms people living with early-stage dementia experience will vary in accordance with dementia subtype. Accordingly, Table 2 provides an overview of the most common symptoms reported during the early stages. For people living with AD, early symptoms will include short-term memory loss rather than difficulties with longer-term memories, whilst people living with vascular dementia may experience changes in mood and difficulties with executive functioning.

1.2.2.2. Impact on Independence

Despite the absence of guidance in the ICD-11 itself about what constitutes early-stage dementia, the ICD-10 Diagnostic Criteria for Research [22][2], describes severity in relation to dementia's impact on Activities of Daily Living (ADL) and independence (Appendix A). During the early-stages the impact dementia has upon independence is described as *"…sufficient to interfere with everyday activities, though not severe as to be incompatible with independent living",* with difficulties experienced carrying out "*complicated daily tasks or recreational activities*" [22] (no page number).

[2] An equivalent publication in relation to ICD 11 has not yet been published. ICD 11 was released in 2018.

Table 2: Symptoms Associated with Early-stage Dementia According to Sub-type (Adapted from Alzheimer's Society [23] and Prince et al [4]).

Dementia Sub-type	Symptoms Associated with Early-Stage Dementia
Alzheimer's Disease	• Short term memory loss • Difficulty recalling things that happened recently or learning new information. • Apathy and depression
Vascular Dementia	• Difficulties with executive functioning: problems thinking, organising and planning. • Apathy, depression, and fluctuations in mood
Dementia with Lewy Bodies	• Variable attention, difficulty planning and disturbed sleep. • Hallucinations • Problems with movement e.g., like those seen in Parkinson's Disease.
Fronto-temporal Dementia	• Personality changes – may act out of character, seem rude or compulsive. • Language – difficulties remembering words or speaking fluently. • Mood changes • Disinhibition

1.2.2.3. Standardised Assessments and Dementia Severity

Clinical Dementia Rating (CDR) [24] and the Mini Mental State Examination (MMSE) [25] are the most frequently used standardised assessments to determine severity for research purposes. Whilst the CDR has a clear scoring system (No dementia 0; Possible Dementia / MCI 0.5; Mild 1; Moderate 2; Severe 3), a variety of cut off scores and ranges have been proposed in relation to the MMSE as outlined in Table 3. In 2018, after this programme of research commenced, the Memory Services National Accreditation Programme (MSNAP) identified an MMSE of 21 or above as indicative of early-stage dementia [26], which is in line with the definitions provided by the National Institute for Health and Care Excellence (NICE) [27] for Alzheimer's Disease (Table 3). Despite its prominence in research and the MSNAP's recommendations, since revisions to its copyright [28], the MMSE is not used frequently in clinical practice in the UK, and reflecting this, NICE [29] recommend a number of cognitive assessments, including the 10-point cognitive screener (10-CS), the 6-item cognitive impairment test (6CIT), the Memory Impairment Screen (MIS) and more, suggesting that there is no uniformity in clinical practice.

Table 3: Dementia Severity Using the MMSE

Source	No Dementia	Early-Stage	Middle-Stage	Late-Stage
Juva et al [30]	24-30	18-23	12-17	0-11
Tombaugh and McIntyre [31]	24-30	18-23	NR	0-17
NICE [27] (AD only)	27-30	21–26	10–20	0-9
Perneczky et al [32]	30 (26-29, questionable)	21-25	10-20	0-10

1.3. Intervention

1.3.1. Occupational Therapy

Occupational therapy is the second largest profession regulated by the Health and Care Professions Council (HCPC) in the UK, with 38,509 registrants and 2,040 registered in Wales [33]. It has a global history spanning over 100 years, with the first school of occupational therapy in the UK opening in 1930 [34]. As Duncan [35] asserts, occupational therapy has a "*broad knowledge base*" (p3) spanning the medical and social sciences, humanism, phenomenology and pragmatism. Reflecting this, occupational therapists work with people across the lifespan who have a wide variety of physical and mental health conditions in the NHS, social care, and the private and voluntary sectors. The Royal College of Occupational Therapists' (RCOT) [36] public-facing definition states that occupational therapy:

"…provides practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them. This support increases people's independence and satisfaction in all aspects of life" (no page number).

Occupational therapy is a holistic profession, which means that occupational therapists seek to understand and assess the physical, cognitive, psychological and environmental (social, physical and occupational) factors that impact on someone's ability to carry out their occupations [37]. Interventions target these physical, cognitive, psychological, and environmental factors using a number of approaches, dependent on the person and their circumstances.

1.3.1.1. Occupation

Occupation, as understood by occupational therapists in its broadest sense encompasses everything individuals 'do' to 'occupy' their time [38]. Occupation is therefore not limited to its conventional association with work and includes the myriad of activities a person does to occupy their time, from making a meal, driving a car, to going on holiday. The word occupation is often used interchangeably by occupational therapists in clinical practice with the words 'activities' or 'tasks', and this is the approach adopted in this Thesis. This reflects the RCOT's public facing definition of occupation:

"'Occupation' as a term refers to practical and purposeful activities that allow people to live independently and have a sense of identity. This could be essential day-to-day tasks such as self-care, work or leisure" [36] (no page number).

As highlighted by RCOT, occupation and occupational therapy is not only concerned with 'doing': it is also concerned with the meaning occupations have for people, including the roles and identities people derive from, and associate with their occupations. It is also important to emphasise here that the words 'functioning' and 'performance' are frequently used by occupational therapists to denote the act of 'doing' or carrying out an occupation, activity, or task [38]. Both words have been used in this Thesis accordingly.

1.3.1.2. Clinical Practice

Whilst the number of occupational therapists working with people living with dementia or early-stage dementia in the UK is not currently recorded or reported on, two surveys of occupational therapy practice in the UK attest that occupational therapists routinely work with people living with dementia of all severities in hospital and the community [39, 40]. However, there is a dearth of UK based research reporting on the practices, experiences and interventions delivered by occupational therapists working specifically with people living with early-stage dementia. Practice-based evidence is also scarce; however, it indicates that occupational therapy interventions for people affected by early-stage dementia, drawing on occupational therapists' core skills, typically involve pragmatic interventions or solutions to address or overcome difficulties people experience doing day-to-day activities [41, 42]. These interventions are usually described as environmental adaptation (both social and physical) including caregiver training, education, or advice, as well as cognitive or memory strategies [39, 40]. As well as interventions based on their core skills, occupational therapists can also deliver generic interventions for example cognitive stimulation and reminiscence.

1.3.1.3. Existing Evidence

Reflecting NICE's [2] recommendation to 'consider' occupational therapy for early to middle-stage dementia, its evidence base is not as established compared to alternative non-pharmacological interventions, for example cognitive stimulation. Chapters 3 – 5 (Study 1) provide a comprehensive synthesis of the evidence and a summary is provided here for context. Globally, Graff et al [43-45] in the Netherlands, and Gitlin et al [46, 47] in the USA, have significantly contributed to the evidence base for occupational therapy among cohorts of participants living with early to late-stage dementia and were reviewed by NICE [2] to inform their guidelines. However, no studies reporting on occupational therapy interventions were reviewed by NICE [2] in 2018, which were conducted in the UK. This is significant, since effective occupational therapy interventions for people living with early and middle-stage dementia used by NICE to underpin its guidance, have not produced similar outcomes when delivered in a different country and context: Community Occupational Therapy in Dementia (COTiD) resulted in a large to very large effect size on all outcomes in the Netherlands [43-45] however, in Germany it was no more effective than the control [48]. In 2021 the results of COTiD UK, conducted in England were published, which akin to Voight Radhloff et al [48], reported no differences on any outcomes compared to treatment as usual [49]. There is currently a lack of UK based research to underpin the interventions occupational therapists deliver based on their core skills with people affected by dementia.

Sikkes et al [50] note that the "*key challenges*" for occupational therapy intervention research for people living with dementia constitute *"…determining the optimal characteristics of the treatment dose, methods of service delivery, and subgroups most likely to benefit from treatment*" (p264). The heterogeneity of intervention mode, location of delivery, and characteristics is a key finding of Study 1 (Chapters 3 – 5) as well as the tendency for intervention programmes to be designed for people of all stages, as opposed to specific subgroups e.g., early-stage dementia. Significantly, no occupational therapy intervention programmes were reviewed or reported by NICE that were specifically designed for people living with early-stage dementia [2]. However, independence, ability to retrieve long-term memories regarding occupational performance and the capacity for new learning to incorporate adaptive strategies into daily routines, differs between individuals with early and middle-stage dementia [39]. Moreover, the organisational and service context within which occupational therapy is delivered for early and middle-stage dementia diverges, the former predominantly in primary care and the latter in secondary care [26, 39].

1.4. National Context: Policy and Practice

1.4.1. Early Diagnosis and Intervention

In light of increased prevalence, successive UK governments have recognised the need to improve and innovate the way health and social care services for people living with dementia are delivered [51-54]. A significant emphasis has been placed on timely and early diagnosis and intervention, which echo global policy initiatives from the World Health Organisation [55] and European wide initiatives, including the Glasgow Declaration [56]. The Wales Dementia Action Plan [51] outlines seven outcomes, upon which the action plan is structured, with four pertaining to early diagnosis and post diagnostic support or intervention. The benefits of early diagnosis are widely advocated, including the ability to access pharmacological and psychosocial interventions early during the progression of the disease [57]. Early intervention can delay the need for long-term residential care, prevent the length and number of acute hospital admissions and enable the person and their significant others to make plans for the future [26, 51]. The Wales Dementia Action Plan [51] does not provide extensive detail about interventions post-diagnosis, however, of relevance to occupational therapy, it makes a number of references to the provision of advice, practice and training in relation to "*memory strategies*" post-diagnosis; emphasises that people should have access to allied health professionals, including occupational therapists "*to delay loss of skills and maintenance of life roles for longer"*; and highlights the importance of access to assistive technology, equipment and "*making adaptations to the environment to maintain or improve a person's independence, safety and wellbeing*" (p19).

Despite policy initiatives, only 66% of individuals living with dementia in the UK have a diagnosis and this ranges from 53% in Wales to 73% in Northern Ireland [58]. Whilst this represents an increase in those diagnosed over time in the UK, variation in diagnostic rates around the UK remains low, and overall, 34% remain undiagnosed. In Wales, the percentage of those diagnosed has risen slower from 48% in 2013-2014, to 53% between and 2017-2018, leaving just under half of those living with dementia without a diagnosis [58]. Late diagnosis or no diagnosis is a significant barrier to accessing early-intervention and the Wales Dementia Action Plan [51] has set a target of increasing diagnostic rates yearly by 3%. Professionals' attitudes are cited in the Prime Minister's Challenge on Dementia 2020 [53] as a particular barrier to diagnosis, including perceptions that no treatment or therapy can be provided to people in the early-stages. Nevertheless, receiving a diagnosis is not a guarantee that post-diagnosis support or intervention will be available [53].

1.4.2. Memory Assessment Services

In practice, policy initiatives advocating for early diagnosis and intervention have resulted in an increased emphasis on service provision in primary care through the development of multi-disciplinary Memory Assessment Services (MAS), also known as 'memory clinics' or 'memory services' in the UK [26, 59]. There is a wide variation across the UK in terms of MAS funding, staffing and service models, leading the MSNAP to highlight that emphasis should be placed on the 'function' of the service in their national accreditation standards, which comprises: assessment; diagnosis; pharmacological treatment; and psychosocial interventions [26]. They outline a number of standards for psychosocial interventions which services must meet, with those of relevance to occupational therapy including: -

- *"Input from psychologists and occupational therapists is sufficient to provide evidence-based interventions" (p44).*
- *"The service provides timely access to psychosocial interventions for occupational and functional aspects of dementia" (p 45).*

Whilst the MSNAP is a UK wide accreditation scheme, only one MAS from Wales and one from Northern Ireland are currently accredited under the scheme [26]. In relation to Wales, where data generation occurred during this Thesis, there is an absence of research pertaining to MAS, and only one audit of MAS in Wales, in 2014, has ever been made public [59]. This makes it difficult to describe the current state of services when this Thesis commenced in 2017, and again towards its completion in early 2022. However, in order to provide a context, in 2014, there were 28 memory clinics across Wales' seven Health Boards. Two Health Boards had a standalone memory clinic service model with the remaining five reporting that their MAS were part of a wider service model, which also comprised Older Persons Community Mental Health Teams (OP-CMHT). A wide variation between Health Boards relating to service capacity, funding and services provided was reported. For example, the number of people living with dementia seen yearly as a percentage of the total population living with dementia per Health Board ranged from 16.7% in Cwm Taf Morgannwg University Health Board to 65.7% in Aneurin Bevan University Health Board. In relation to the topic of this Thesis, Public Health Wales' (PHW) audit in 2014 did not ask about MAS staff composition nor the provision of occupational therapy, and therefore it is unclear if occupational therapists were working in MAS and what interventions they were delivering. The audit also noted that services did not routinely record dementia staging at the time of diagnosis [59].

1.5. Personal Context

1.5.1. Prior Research in this Area

Before commencing this Thesis, I had conducted a national cross-sectional survey of occupational therapy practice with people affected by dementia (all stages) in the Welsh NHS, as well as 23 semi-structured interviews with people affected by dementia and occupational therapy practitioners (REC: 15/WA/0083). Of 106 survey respondents across 7 Welsh Health Boards, only 4.5% identified MAS or primary care as their primary practice setting, with the majority of participants working in secondary or inpatient services [39]. Qualitative data generated during the survey corroborated this finding, with one service manager reflecting on the barriers to the delivery of occupational therapy for early-stage dementia in their Health Board:

"…there has never been and there are no plans for an OT establishment within the Memory Clinic Team. Consequently, there is no post diagnostic OT service which could be invaluable to the person and carer to start to consider strategies for enablement and optimal function and social inclusion across the progression of the condition. There are no OT specific post in Primary Mental Health Support Teams or GP surgeries. …OT services to people living with dementia and their carers should be developed at primary and post diagnostic point of care." (p39)

This study was the first survey of occupational therapy practice with people living with dementia in Wales and highlighted the potential gap in practice in primary care, including MAS, and the barriers experienced in developing this area of practice. As well as describing current practice, a key research objective pertained to exploring what occupational therapy at the 'right time' meant to participants as well as perceptions about whether occupational therapy was currently being delivered at the 'right time' in Wales. This aim was based on the emphasis in the National Dementia Vision for Wales [60], Social Services and Wellbeing (Wales) Act 2014 and the Strategy for Older People 2013-2023 [61] on delivering services for older people living with dementia "*at the right time and in the right place*". Three out of five themes identified from qualitative deriving data from the survey and semi-structured interviews in relation to the 'right time', were about early intervention. This comprised: -

- The identification of the delivery of occupational therapy early in the progression of dementia as a window of opportunity, with additional funding and posts in this area of practice called for.

- During the early-stages participants advocated that capacity for new learning is least impacted, which enables compensatory adaptations and coping strategies to be embedded into daily routines and activities early, which can remain into the moderate states.
- The prevention of crises and complex presentations in secondary and tertiary services was purported as an outcome of early intervention, as well as the ability to remain living at home.

1.5.2. Researcher in Residence

The Researcher in Residence Model seeks to overcome barriers in translating research findings into clinical practice, as well as "*co-creating knowledge*" between researchers and practitioners by embedding researchers in clinical practice settings [62]. In this vein, I became a researcher in residence and research occupational therapist at Taliesin Health Board[3] in 2014 within the Older Persons Mental Health Occupational Therapy Team (OP-CMHT). In this role I became aware of the local practice context, which coupled with my prior research in this area (Section 1.5.1.), led to a decision to conduct the current programme of research contained in this Thesis. A brief summary of this context is provided in the paragraph below.

In 2014 occupational therapists working within Taliesin's OP-CMHT, had been dedicating one day a week to MAS to aid the diagnostic process, by conducting specialist functional and environmental assessments. In 2015, due to the increased volume of work in OP-CMHT's, coupled with time pressures associated with the Welsh Government's (WG) referral to treatment targets [63], occupational therapists had to withdraw their diagnostic input from MAS. I was informed by my colleagues that no additional funding had been received for occupational therapy when MAS was established in the Health Board, with colleagues describing their input as a sign of 'goodwill'. Given the increasing pressures in OP-CMHT's, my colleagues, who were all lone practitioners in their services, could not envisage returning to MAS unless additional posts were created, for which there was no money.

As a research occupational therapist within the team, I began to reflect on what I could contribute to addressing this problem. As described in Section 1.5.1., the results of my prior work indicated that occupational therapists may also not be working in MAS in other Health Boards in Wales, and that early-intervention was deemed a particular priority for participants. Furthermore, the survey generated data on the types of interventions delivered by occupational therapists in Wales, with no

[3] Pseudonyms have been used to maintain anonymity in this Thesis.

participants reporting that they were delivering manualised or standardised intervention programmes. I had also conducted a scoping review of the literature on occupational therapy interventions for people living with dementia (all stages) in 2015 and had noted the lack of studies conducted in the UK. I was offered funding to pursue a PhD by the Health Board in early 2017 to build on my prior study, and owing to the local practice gap, the likelihood that this practice gap was not confined to Taliesin Health Board and the absence of research in this area, it felt like a worthy area of investigation.

1.6. Rationale

The preceding sections in this Chapter have provided a background to the programme of research contained in this Thesis. Section 1.2. introduced dementia, a condition that leads to a progressive decline in cognition, with a global deterioration in ability to carry out day-to-day activities a defining diagnostic criterion [2]. Whilst there are several ways in which early-stage dementia can be defined, during the early-stages, the impact dementia has upon independence is likely to be *"sufficient to interfere with everyday activities, though not severe as to be incompatible with independent living"*, with more complex activities affected [22]. Occupational therapy was described in Section 1.3., as a profession concerned with enabling people to carry out their day-to-day activities or occupations, that NICE [2] and the MSNAP [26] recommend as an intervention for early-stage dementia and MAS (Section 1.4.). However, despite WG policy [51] and practice guidelines [26], there is a practice gap in Taliesin Health Board (Section 1.5.2.), and a survey of practice in the Welsh NHS [39], suggests that this gap may also extend to other Health Boards (Section 1.5.1.). No standardised or manualised programmes of intervention were being used by occupational therapists who participated in this survey, and Section 1.3. described the dearth of research pertaining to occupational therapy interventions for early-stage dementia in the UK.

1.7. Aim

To address current gaps in practice and research, and in preparation for a future evaluation, the programme of research contained in this Thesis aimed to: -

- **Systematically describe and develop an evidence, theory and practice-informed occupational therapy intervention for people living with early-stage dementia.**

1.8. Chapter Conclusion

This Chapter has introduced the intervention population: people living with early-stage dementia in the community; the intervention: occupational therapy; and the national policy and practice context in the UK and Wales, as the context within which data generated during this Thesis was conducted. It concluded by summarising the programme's rationale and outlining its overarching aim. Chapter 2 will provide an overview of this Thesis' overall design as well as an outline of its structure.

Chapter 2: Approach and Methodology

2.1. Introduction

Chapter 1 provided a background and rationale to the programme of research contained in this Thesis, including the overall Thesis' aim, which is to describe and develop an occupational therapy intervention for people living in the community with early-stage dementia, in preparation for a future evaluation. In this Chapter, the approach taken to describe and develop an occupational therapy intervention will be outlined, followed by an overview of the overall programme of research's design and philosophical and theoretical underpinnings. The role of stakeholder engagement and an overview of the Thesis' structure is also provided.

2.2. Approach: Complex Intervention Research

2.2.1. Medical Research Council's Framework

The Medical Research Council's (MRC) Framework for the development and evaluation of complex interventions have been used internationally across professional disciplines and areas of clinical practice to guide the development and evaluation of complex interventions [64, 65]. This section will discuss what a complex intervention constitutes, as well as how the MRC's Framework informed this programme of work. Towards completion of this Thesis in 2021, the MRC's Framework was revised by Skivington et al [65], however, Craig et al's [64] framework was current when planning and whilst conducting this programme of research, and therefore both guidelines have been referenced where appropriate.

2.2.1.1. Complexity

Whilst Craig et al [64] state that "*there is no sharp boundary between simple and complex interventions"* (p7), they describe a number of characteristics that help determine if an intervention is complex. These include: -

- The number of intervention components and / or outcomes.
- The extent to which the intervention will be personalised and tailored.

- The number of actions necessary by interventionists and / or people receiving the intervention, and their difficulty.
- The amount and degree of interaction between intervention components.
- The intervention target, including the number of organisational levels and groups.

As well as the above, in the revised MRC Framework, there is a greater emphasis on complexity associated with context, including how the intervention context interacts with the intervention itself [65]. Pentland et al [66] purport that occupational therapy can be considered a complex intervention since it is composed of multiple components "*leading to practices that entail numerous and various configurations to achieve the best outcomes*" (p 51), and it is delivered in a dynamic context, which includes interpersonal, intrapersonal, and organisational sub-systems.

2.2.1.2. Phases

Craig et al's [64] MRC Framework described four key phases during complex intervention research (Figure 1). The initial phase, 'development' comprised three actions (identifying the evidence base; identifying or developing theory; and modelling process and outcomes) and constituted this Thesis' primary focus.

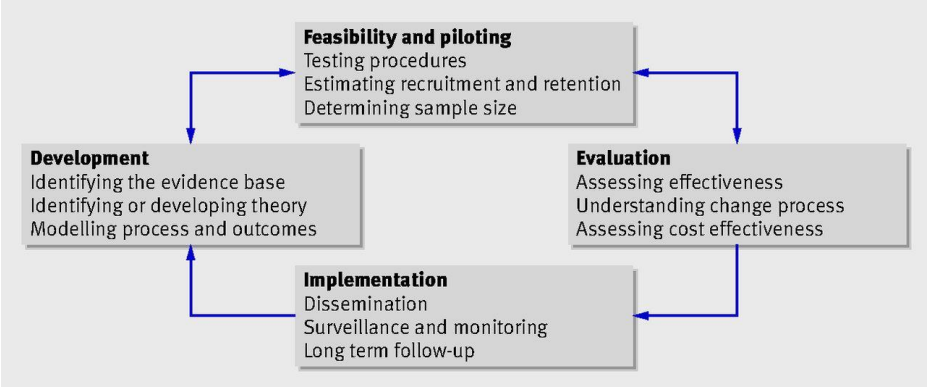

Figure 1: The MRC Development and Evaluation Process Craig et al [64]

The revised MRC Framework [65] updated what it calls the 'intervention development or identification' phase, in recognition of instances where interventions in policy and practice already exist (Figure 2). Given this revision, this Thesis' aim (Section 1.7.) which initially utilised the word 'develop' only, was revised to 'describe and develop', to make explicit the influence of existing research and clinical practice on this programme of work, as well as the need to develop an intervention programme theory. Whilst the revised MRC Framework implies that identification and

development are mutually exclusive with their use of the word 'or', during this Thesis, the variability identified in clinical practice as well as the absence of a manualised or standardised approach (Study 2, Chapters 6 – 9), in addition to the variability identified in the research evidence and the absence of any published programme theories (Study 1, Chapters 3 -5), 'development' was also necessary.

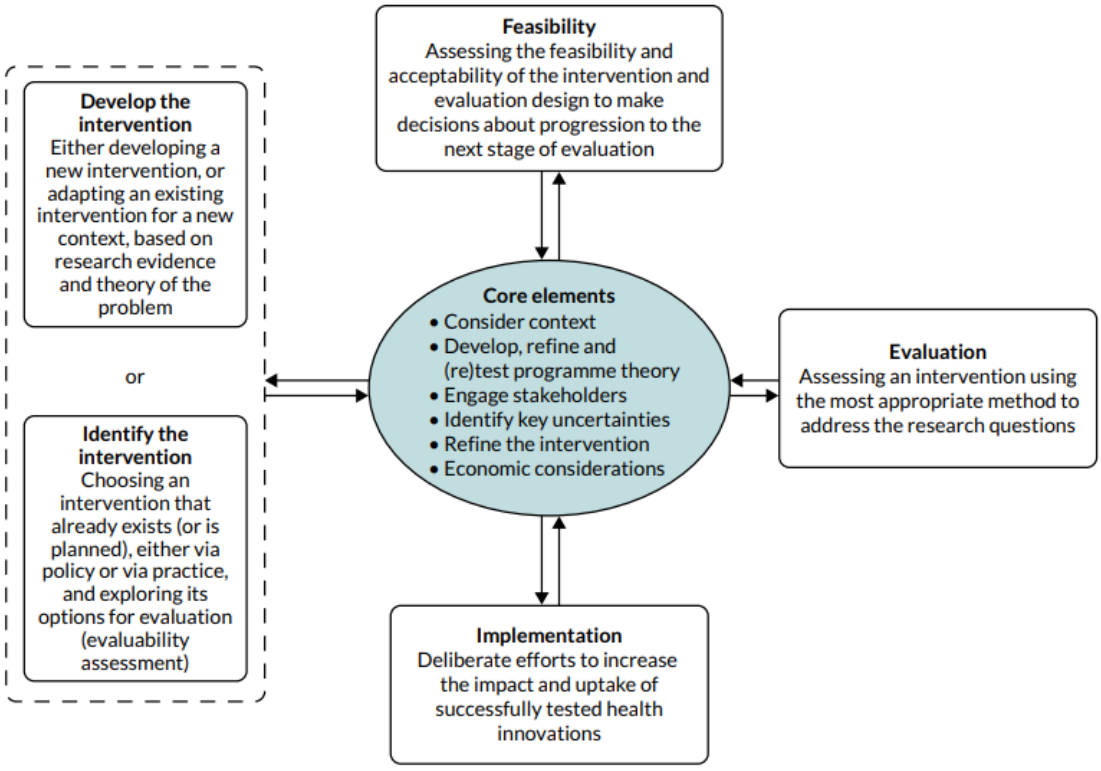

Figure 2: The Revised MRC Development or Identification and Evaluation Process [65]

2.2.1.3. Actions

Craig et al's [64] MRC framework provided a broad overview of the iterative process from intervention development to implementation. Unfortunately, they did not provide specific and detailed guidance about how to develop a complex intervention [67]. Therefore, to supplement Craig et al [64], and in the absence of intervention development approaches deriving from the profession of occupational therapy, an Intervention Mapping approach (Section 2.2.2.) was utilised to inform and guide the development and identification process [68]. This is in concurrence with the revised MRC Framework [65], which along with O'Cathain et al [69], highlight that there is currently a lack of research about which development approach is best, and therefore recommend that at least one published approach is utilised.

Significantly, the revised MRC Framework [65] provides greater detail about what actions should be taken during intervention development, and replicate the actions outlined by O'Cathain et al's [69] INDEX Study. Since an Intervention Mapping approach was utilised, these actions were taken during this programme of work and Table 4 provides an overview of where these actions are described in this Thesis, which are expanded upon in Section 2.3.

Table 4: Framework of Actions for Intervention Development (O'Cathain et al [69], cited by the Revised MRC Framework [65])

Actions	This Programme of Work
1. Plan the development process.	Chapters 2 and 10.
2. Involve stakeholders, including who will deliver, use and benefit from the intervention.	Chapters 2 (Section 2.4), 6, 10 and 11.
3. Bring together a team and establish decision-making processes.	This action was not taken owing to confined resources.
4. Review published research evidence.	Chapters 3, 4 and 5.
5. Draw on existing theories.	Chapters 2, 10 and 11.
6. Articulate programme theory.	Chapters 10 and 11.
7. Undertake primary data collection.	Chapters 6, 7, 8 and 9.
8. Understand context	Chapters 6, 8, 10 and 11.
9. Pay attention to future implementation in the real world.	Chapters 7 and 11.
10. Design and refine the intervention	Chapters 10 and 11.
11. End the development phase.	This Thesis reports on Intervention Mapping Steps 1 – 3 only and therefore it would not be appropriate to end the development phase.

2.2.2. Intervention Mapping

To support the development and identification process, Intervention Mapping, as an internationally recognised approach was utilised [68]. Intervention Mapping provides a detailed and methodical approach to guide the development, production and implementation of theory and evidence-based complex interventions, including occupational therapy [70]. It is now in its fourth edition and has six key Steps (Figure 3), with the initial three Steps reported upon in this Thesis, which correspond with both Craig et al's [64] MRC Framework and the revised MRC Framework's [65] development and development or identification phase, respectively.

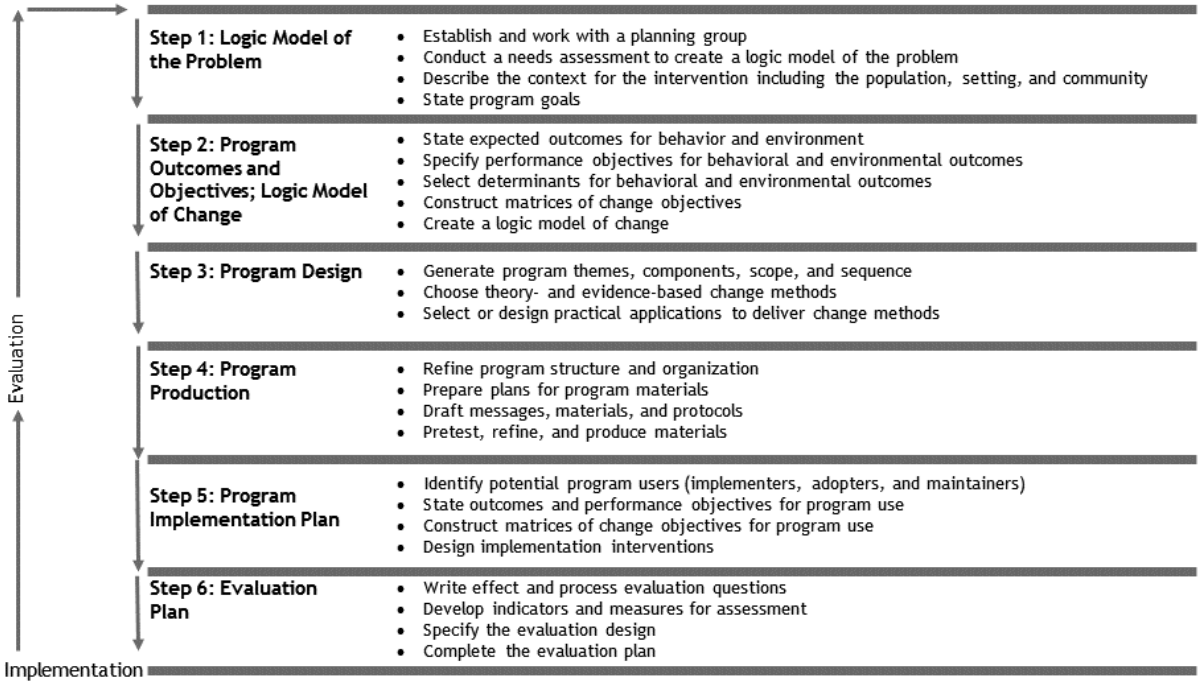

Figure 3: Intervention Mapping Steps (Bartholomew Eldredge et al [68])

Like occupational therapy theory, in particular the conceptual model of practice the Model of Human Occupation (MOHO), Intervention Mapping draws its theoretical foundations from systems thinking and the social ecological model [71]. This means that like occupational therapy, it recognises the impact that a person's environment has on health and wellbeing, particularly the social environment. Whilst providing a highly detailed and methodical approach, Intervention Mapping is not prescriptive and permits flexibility. It can be adapted for the 'real world', where time and resources may be limited. Section 2.3 and Chapters 10 - 11 will provide an account of how Intervention Mapping's Steps and associated activities were conducted during this research.

2.3. Research Programme Design

As is common practice when developing complex interventions and advocated by Intervention Mapping [68], and the revised MRC Framework [65], multiple methods were used during the development process and are reported upon in this Thesis in three studies. Figure 4 depicts this programme of research's overall design, its three studies, as well as stakeholder engagement.

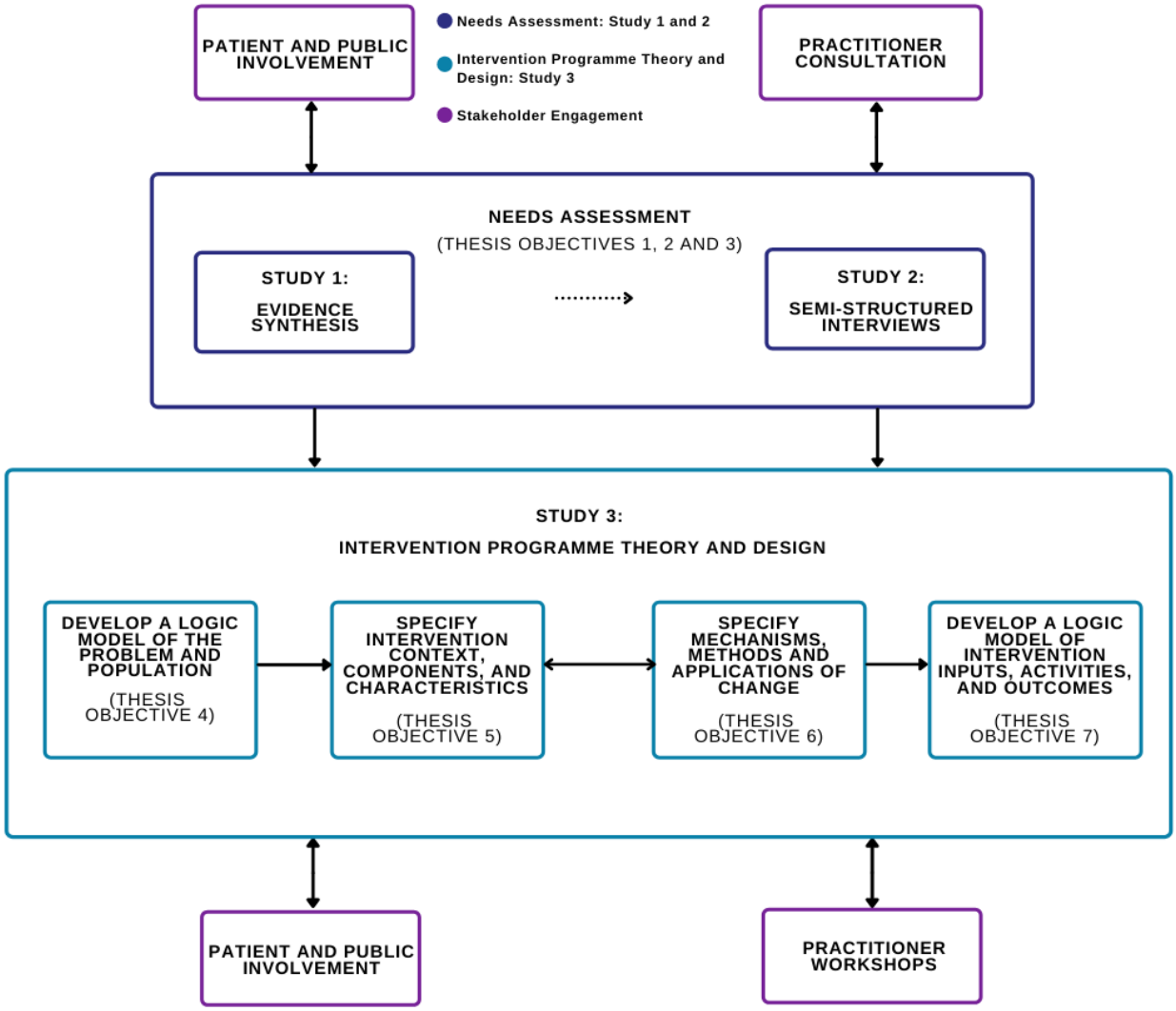

Figure 4: Research Programme Design

2.3.1. Needs Assessment: Study 1 and Study 2

At the outset of the intervention development process, Intervention Mapping advocates conducting a needs assessment to understand the intervention population and context or setting, to inform a logic model of the problem or situation [68], which is also described by O'Cathain et al [69]. This needs assessment was extended to include the identification of existing clinical or research-based occupational therapy interventions for people living with early-stage dementia in the community, reflecting the revised MRC Framework's development or identification phase [65].

An evidence synthesis (Study 1) and semi-structured interviews (Study 2) were utilised to inform this needs assessment, with three Thesis Objectives developed to guide this process: -

- **Thesis Objective 1**: Understand the intervention population.
- **Thesis Objective 2**: Understand the intervention setting and context.
- **Thesis Objective 3**: Identify existing practice and research-based occupational therapy interventions.

Research questions were developed for both studies in accordance with these objectives and are described in further detail in Chapters 3 and 6. As depicted in Figure 4, Study 1 and Study 2 were conducted concurrently. However, owing to the preparatory work and time required in obtaining ethical approval, it was possible for some findings deriving from Study 1 to inform interview questions in Study 2. This partial relationship is denoted by the dotted arrow between Study 1 and Study 2. An evidence synthesis, as well as generating primary data to inform the development of an intervention is recommended by the revised MRC Framework [65] and Intervention Mapping [68].

2.3.2. Intervention Programme Theory and Design: Study 3

As portrayed in Figure 4, Study 3 synthesises data generated during Study 1 and Study 2 with methods utilised to engage stakeholders. As per the revised MRC Framework [65], Study 3 involved developing the interventions' programme theory as well as describing intervention content, format and delivery. Four action-orientated Thesis Objectives were developed based on Intervention Mapping Steps 1 – 3:-

- **Thesis Objective 4**: Develop a logic model of the problem and population.
- **Thesis Objective 5:** Specify intervention context, components, and characteristics (programme design).
- **Thesis Objective 6**: Specify mechanisms, methods, and applications of change.
- **Thesis Objective 7:** Develop a logic model of intervention inputs, activities, and outcomes.

Whilst Craig et al's MRC Framework [64] provided scant information about what constituted "*identifying or developing theory"* (p8), and "*modelling process and outcomes*" (p8), the revised MRC Framework [65], citing O'Cathain et al [69] provides greater guidance about what it calls programme theory:

"*Programme theory describes how an intervention is expected to lead to its effects and under what conditions. It articulates (1) the key components of the intervention and how they interact; (2) the mechanisms of the intervention; (3) the features of the context that are expected to influence those mechanisms; and (4) how those mechanisms may influence the context*" (pxxiv).

The revised MRC Framework [65], highlights that a range of methods can be utilised to represent and articulate programme theory, including logic models, matrices, and maps. Significantly they emphasise that logic models depicting intervention inputs, outputs, and outcomes only, do not on their own, articulate an intervention's full programme theory. In this context, Intervention Mapping and Study 3 utilises multiple logic models and matrices, which collectively articulate the intervention's programme theory. Further details relating to methods utilised during Study 3 can be found in Chapter 10.

2.4. Stakeholder Engagement

Stakeholder engagement is identified as a core element of complex intervention research [65, 69], and also features prominently in Intervention Mapping [68]. During this programme of work, stakeholders were defined as people who could be intervention recipients, as well as occupational therapy practitioners who could be interventionists.

2.4.1. Patient and Public Involvement

Patient and Public Involvement (PPI) was an important element of this research and commenced before the study was conceived through contact with the Dementia Engagement and Empowerment Project (DEEP) [17] and members of their network. Initial Thesis ideas were discussed informally with members, who confirmed that early-intervention and post-diagnostic support from an occupational therapist was an area of priority for them. Regular contact was maintained with the DEEP regional network and its events between 2017 and 2019, which offered multiple opportunities to informally consult with members about this programme of research. A Lived Experience Advisory Group (LEAG) was established on initiation of this research, which met on five occasions between 2017 to 2019. Unfortunately, a change in my employment and the COVID-19 pandemic prevented further meetings beyond October 2019. Funding from the United Kingdom Occupational Therapy Research Foundation (UKOTRF) (Section 2.6.3.) was utilised to pay honorariums and travel expenses for members of the LEAG. The influence PPI had on this work is described in relation to Study 2 and 3 in Chapters 6 and 10. Minutes from the initial LEAG can be found in Appendix B, during which members echoed the sentiment of initial conversations with members of the DEEP network pertaining to the Thesis topic. They also expressed positive views about the support they had received from occupational therapists: -

"I owe them my life…I'd be dead now"

"they were the first out of the blocks"

"they open doors"

2.4.2. Practitioner Consultation and Workshops

Like PPI, consultation with practitioners occurred prior to study conception to ensure that the research topic was of relevance to them. As a researcher in residence, embedded within a clinical team (Section 1.5.2.), the views of practitioners who had worked in this area of clinical practice influenced the development and conduct of this programme of work. Practitioners confirmed that occupational therapy services and intervention for people living with early-stage dementia was a priority area for them, which was supported by prior research conducted in this area (Section 1.5.1.). Before a change in employment in October 2019, occupational therapy practitioners were regularly consulted in relation to this programme of research to ensure it was relevant to their practice. As well as informal consultation, a series of workshops were held to enable practitioners to input into the development of the intervention's programme theory and design and this is described in greater detail in Study 3, (Chapter 10).

2.5. Philosophical and Theoretical Framework

2.5.1. Pragmatism

As an applied piece of research that seeks to address a real-world problem, a pragmatic philosophy or approach underpins this work. Unlike post-positivism and constructivism, pragmatism is not concerned with dualistic ontological assumptions about the nature of reality or truth: the existence of a singular objective external reality (post-positivism) or multiple subjective realities (constructivism) [72, 73]. The philosopher John Dewey, frequently cited as a prime influence on pragmatism as a research paradigm, emphasised that philosophical inquiries must be "*rooted in life itself"* rather than abstract discussions about the nature of reality or truth [74] p3. His concept of inquiry as real world, action-orientated problem-solving, is aligned with Intervention Mapping, and occupational therapy's problem-solving and action orientated approach. As Creswell and Creswell [72] assert, when taking a pragmatic approach, truth is what works in a particular context at a particular time to solve a particular problem. Given this, pragmatism is pluralistic in its stance about research methods, accepting that methods or research strategies associated with post-positivism and constructivism

have value in so far as they are useful in answering a particular research question [72, 73]. In accordance with this stance, this research, as described in Section 2.3. utilises multiple methods to describe and develop an evidence, theory and practice-informed occupational therapy intervention. Owing to the exploratory and descriptive nature of Study 1 and Study 2, qualitative methods and sources were primarily used, however, Study 1 additionally synthesised studies utilising quantitative methods.

2.5.2. Theoretical Lens

This Thesis is primarily concerned with generating theory, by developing an intervention programme theory, rather than testing an established theory. However, it is important to acknowledge that multiple theories were utilised pragmatically, albeit critically, during this programme of work to develop an intervention, as recommended by Intervention Mapping [68]. Therefore, the overall use of theory during this Thesis can be described as both inductive (developing an intervention programme theory) and deductive (using existing theory critically and pragmatically) [72].

2.5.2.1. Intervention Development

As discussed in Section 2.2., the MRC Frameworks [64, 65] and Intervention Mapping [68] were utilised to guide and structure this Thesis. Therefore, this programme of work was conducted through the lens of current research, guidelines, and theories pertaining to complex intervention research. Intervention Mapping and both MRC Frameworks [64, 65] also emphasise utilising existing theories of change where relevant to aid the development of an interventions programme theory. Social Cognitive Theory (SCT) [75-78], developed by Albert Bandura, was the primary theory utilised during Study 3. SCT identifies multiple determinants (e.g., self-efficacy, skills, knowledge) relating to the person, as well as methods of change relating to these determinants (e.g. information, guided practice, active learning), that have been utilised extensively to inform interventions across diverse populations and settings [75].

2.5.2.2. The Model of Human Occupation

Multiple conceptual models of occupational therapy practice exist and there is no consensus in the UK about which model should be used when working with people living with early-stage dementia. Evidence from surveys of clinical practice, indicate that the Model of Human Occupation (MOHO) [79],

the Canadian Model of Occupational Performance and Engagement (CMOP-E) [37] and the Model of Adaptation through Occupation [80] are used in Wales and the UK with this population [39, 40]. This Thesis makes reference to the MOHO, which like all conceptual models of occupational therapy practice, conceptualises the interaction between the person, their occupations, as well as their social, physical and occupational environments.

A pragmatic approach is also utilised by occupational therapists when they utilise theory from disciplines outside the profession, which are commonly referred to as "*frames of reference*" [81]. Frames of reference are always used in conjunction with conceptual models of practice, and this is the approach utilised in this study when using theories relating to intervention development and theories of change, including SCT.

Whilst the MOHO is referenced in this Thesis, since intervention development is a cross-disciplinary activity, and given the diverging terminology utilised by different conceptual models of occupational therapy practice, the language used in the thesis does not derive necessarily from the MOHO. For example, the MOHO utilises the word volition to refer to what is widely known as motivation, however, the word motivation is used in this Thesis given its shared understanding across disciplines.

2.6. Research Ethics and Governance

2.6.1. Ethical and Organisational Approval

Ethical approval was received for this research from a Health Research Authority (HRA) NHS Research Ethics Committee (REC): REC Reference: 18/WA/0107. The ethical principles of the Declaration of Helsinki [82] were adhered to, and in line with organisational requirements, Good Clinical Practice training was undertaken. Ethical considerations pertaining to Study 2, including informed consent and confidentiality are described in further detail in Chapter 7. Taliesin Health Board, acted as Study Sponsor and provided indemnity for the study. In addition to ethical approval, organisational approval was received from all five participating Health Boards' Research and Development Departments.

2.6.2. Project Management

Having carried out the role on a prior study, I undertook the role and responsibilities of Chief Investigator, as per the UK policy framework for health and social care research [83]. This included

preparing the study protocol, completing REC review documentation, attending REC review independently, obtaining organisational approvals and maintaining all site files. Throughout the study monthly supervision was received from my academic supervisors at Cardiff University and email support as required.

2.6.3. Funding

Funding for this research derived primarily from Taliesin Health Board, who paid costs associated with salary and tuition fees. Additional funding was obtained from the UK Occupational Therapy Research Foundation (UKOTRF) through a Research Career Development Grant 2017. This was used to pay for costs associated with transcription, evidence review software and PPI.

2.7. Thesis Structure

The remainder of this Thesis is structured in accordance with its three studies, as described in Section 2.3. Chapters 3 – 5 pertain to Study 1, a two-stage mixed-methods evidence synthesis and Chapters 6 – 9 comprise Study 2 which consisted of semi-structured interviews with people affected by early-stage dementia and occupational therapy practitioners. Both Study 1 and 2 aimed to generate data in relation to Thesis Objectives 1, 2 and 3 as described in Section 2.3.1. Study 3 is reported on in Chapters 10 – 11 and describes the process and results relating to the development of the intervention's programme theory and its design, in accordance with Thesis Objectives 4, 5, 6 and 7 (Section 2.3.2.). Chapter 12 brings this Thesis to a close with a conclusion and implications for research and practice.

2.8. Chapter Summary

In this Chapter, Intervention Mapping, the approach utilised in this Thesis to develop an occupational therapy intervention for people living with early-stage dementia has been described along with the MRC Frameworks for complex intervention research. The programme of research's overall design has also been outlined, including this Thesis' three studies. An overview of pragmatism, the paradigm underpinning this work has been introduced, along with the Thesis' theoretical framework. The Chapter concluded with an overview of the Thesis' structure.

Study 1: Evidence Synthesis

Chapter 3: Methods

3.1. Introduction

As outlined in Chapter 2, to describe and develop an occupational therapy intervention for people living in the community with early-stage dementia, this Thesis contains three inter-related studies, with Study 1 comprising a two-stage mixed-methods evidence synthesis. This is Study 1's first Chapter, and as such Study 1's aims, objectives and methods will be presented, with Study 1's findings and discussion reported in Chapters 4, and 5.

3.2. Aims, Objectives and Research Questions

Multiple methods are advocated when developing a complex intervention and the revised MRC Framework [65] and Intervention Mapping [68] recommend identifying the existing evidence base. A prior scoping review identified that no pre-existing evidence syntheses specifically on the topic of occupational therapy and early-stage dementia had been conducted. Whilst evidence syntheses were identified, for example Smallfield and Heckenlaible [84] and Bennett et al [85], these pertained to studies using an experimental and quasi-experimental methodology only and people living with early, middle and late-stage dementia. With this background, Study 1's primary aim was:

- **To identify, describe, appraise, and synthesise peer-reviewed research relating to occupational therapy and people affected by early-stage dementia living in the community.**

Thesis Objectives for this programme of research were outlined in Section 2.3. These were used to develop research questions for Study 1, as follows: -

- **Thesis Objective 1:** Understand the intervention population.

  Study 1 Research Question:

  1.1.1. What impact, if any, does early-stage dementia have on the occupational (activity) performance of people living in the community?

- **Thesis Objective 3[4]:** Identify existing practice and research-based occupational therapy interventions.

Study 1 Research Questions:

1.3.1. What is the nature of occupational therapy intervention for people living with early-stage dementia in the community?

1.3.2. What outcomes are reported in relation to occupational therapy intervention for people living with early-stage dementia in the community?

1.3.3. What are people's views and experiences of occupational therapy intervention for people living with early-stage dementia in the community?

1.3.4. What barriers and facilitators are described in relation to occupational therapy intervention for people living with early-stage dementia in the community?

3.3. Methodology

3.3.1. Design

The Evidence for Policy and Practice Information and Co-ordinating Centre's (EPPI-Centre) guidelines for multi-stage mixed methods reviews were utilised to inform the design of a two-stage mixed methods evidence synthesis [86]. An advantage of using a multi-stage mixed methods review included being able to identify a diverse body of evidence in terms of topic and design (Stage 1) and synthesise this evidence thematically and methodologically (Stage 2), without having to conduct multiple separate reviews. Figure 5 depicts the evidence synthesis' overall design, its two stages, as well as its two syntheses which were thematically based on Thesis Objectives 1 and 3 and their associated research questions.

[4] Objective 2 - To understand the intervention context, was not specifically studied in Study 1, however, data about intervention context was generated in the context of Objective 3 and is reported upon in Chapter 5.

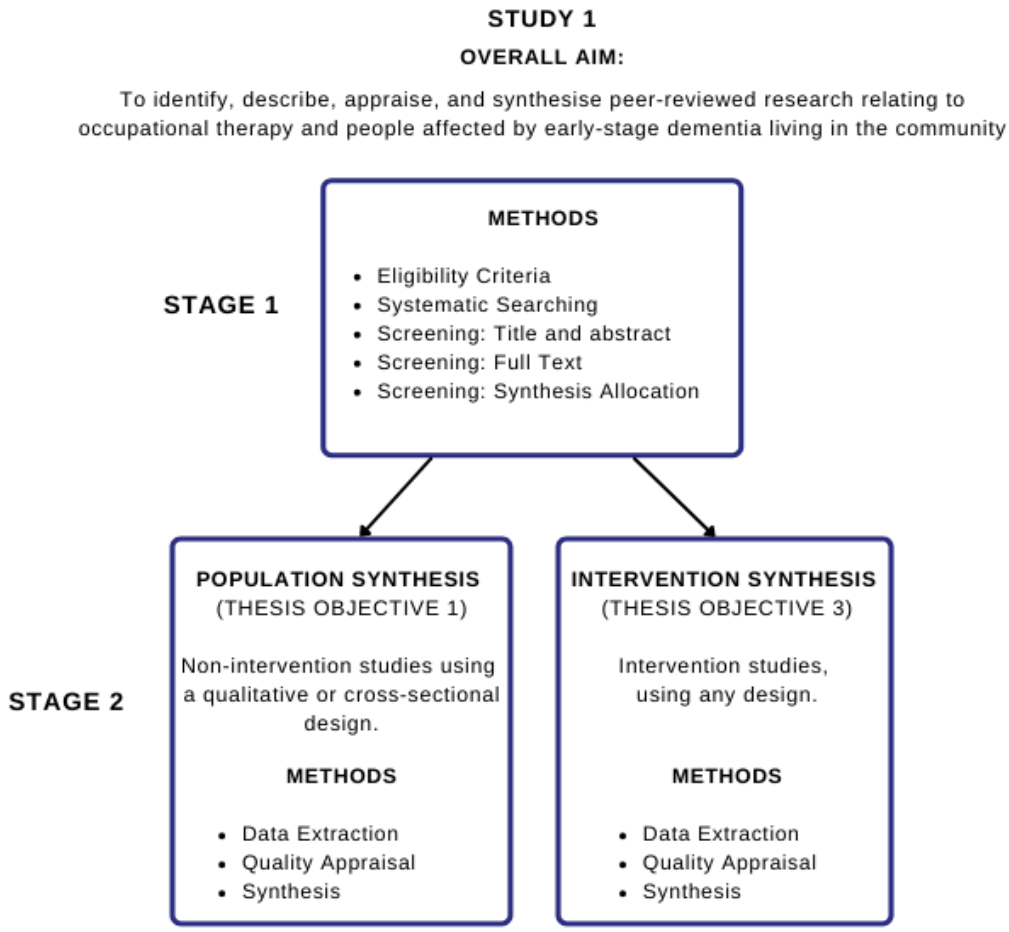

Figure 5: Evidence Synthesis Design

3.3.2. Methods

3.3.2.1. Eligibility Criteria

To ensure a systematic and transparent approach towards inclusion, eligibility criteria were developed utilising the PICOS acronym (Population, Interventions, Comparators, Outcomes, Study design) [87]. As the PICOS was developed for intervention studies, 'Phenomenon of Interest' from the SPIDER acronym (Sample, Phenomenon of Interest, Design, Evaluation, Research type) [88], was additionally used to ensure non-intervention studies were identified. Eligibility criteria were also developed pertaining to publication type, year of publication and language, and all criteria are presented in Appendix C. Methodologically, non-intervention studies using a qualitative or observational, cross-sectional design were eligible for inclusion in the Population Synthesis (Thesis Objective 1). For the Intervention Synthesis (Thesis Objective 2), all study designs were eligible, including experimental, quasi-experimental, qualitative and process evaluations (Figure 5).

Criteria relating to the study population were refined iteratively during full text screening due to the diverging ways early-stage dementia was defined across studies, ranging from a Mini Mental State Examination (MMSE) score of ≥15 to ≥21 [25] (Appendix C). Reflecting the lack of consensus within the wider literature about MMSE cut off scores for mild or early-stage dementia, as outlined in Chapter 1, a mean sample MMSE of ≥18 was determined as a key inclusion criterion for this review. This was based on the criteria used by Clare et al [89] in their study investigating the intervention Goal Orientated Cognitive Rehabilitation. Further criteria were developed for studies not using the MMSE, including those utilising a non-experimental methodology and are outlined and justified in Appendix C. Whilst the MMSE is not used prevalently in clinical practice in the UK since the introduction of its copyright regulations [28], it was the most widely used measure of cognition by studies eligible for this synthesis.

3.3.2.2. Information Sources and Search Strategy

The following bibliographic databases were utilised to search the evidence: MEDLINE, CINAHL, AMED, EMBASE, HMIC, PSYCHInfo, JBI and OT Seeker. All were searched separately utilising a free text Boolean search strategy, and by additionally using database keywords or controlled terms e.g., MeSH. The free text search strategy utilised across databases is presented in Table 5, which was developed utilising the PICOS, the additional 'Phenomenon of Interest' from SPIDER, and keywords used by the current NICE Dementia Guidelines in 2017 [90] to search the evidence. The search was conducted on the 15.2.2017 and no restrictions were placed on year of publication. All search results were uploaded to EPPI Reviewer 4 [91] for screening, storage, and management, with search string, database, date, and number of citations logged. As presented in the evidence synthesis' PRISMA [92] flow diagram (Figure 6), 949 citations remained from database searches after duplications were removed. An additional strategy was employed, which involved searching included studies' reference lists [93], with 92 publications identified as potentially eligible for inclusion, and as per PRISMA 2020 [92], their inclusion was determined during full text screening.

Table 5: Boolean Search Strategy

1. neurocognitive disorder*
2. dementia
3. dement*
4. Alzheimer*
5. Alzheimer* Disease*
6. Alzheim*
7. Primary Aphasia*
8. Progressive Aphasia*
9. Primary Progressive Aphasia*
10. Mesulam*
11. Mesulam* Syndrome*
12. Vascular Dementia*
13. Arteriosclerotic Encephalopath*
14. Binswanger* Disease*
15. Binswanger* Encephalopath*
16. Binswanger*
17. Subcortical? Encephalopath*
18. Subcortical? Dementia*
19. Leukoencephalopath*
20. Multi-infarct? Dementia*
21. Multiinfarct? Dementia*
22. Lacunar Dementia*
23. CADASIL
24. Diffuse Neurofibrillary? Tangle*
25. Kosaka-Shibayama? Disease
26. Kosaka Shibayama? Disease
27. Frontotemporal? Dementia*
28. Frontotemporal? Degeneration
29. Frontotemporal? dysfunction*
30. Corticobasal? Degeneration
31. Corticobasal? Dementia*
32. Corticobasal? Dysfunction
33. Frontal lobe Dementia*
34. Frontal lobe Degeneration
35. Frontal lobe dysfunction
36. Pick* Disease*
37. Pick* complex
38. Primary Progressive Nonfluent? Aphasia*
39. Kluver-Bucy? Syndrome*
40. Kluver Bucy? Syndrome*
41. Temporal Lobectomy Behavior Syndrome*
42. Temporal Lobectomy? Behavior? Syndrome*
43. Temporal Lobectomy? Behaviour Syndrome*
44. Lewy Body Disease
45. Lewy Body Dementia*
46. Lew* Bod*
47. DLBD
48. Posterior cortic* atroph*
49. PCA

50. Mixed Dementia*
51. Benson* syndrome
52. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51.
53. Early
54. early stage
55. early-stage
56. mild
57. early intervention
58. 53 or 54 or 55 or 56 or 57
59. occupational therapy
60. Occupational Therap*
61. occupation*
62. OT
63. 59 or 60 or 61 or 62
64. 52 and 58 and 63

3.3.2.3. Study Selection: Screening and Synthesis Allocation

Screening occurred in three phases and was managed utilising EPPI-Reviewer 4 [91].

Screening: Title and Abstract

Using study eligibility criteria outlined in Appendix C, all titles and abstracts deriving from database searches were reviewed, with three potential outcomes per citation: relevant, potentially relevant, and not relevant. Citations deemed not relevant were coded to denote the primary reason for exclusion, with 787 excluded at this stage and 162 remaining (Figure 6).

Screening: Full Text

Full text publications were obtained for 162 citations deemed relevant or potentially relevant deriving from database searches, with a second stage review of reports in full. 92 publications identified from citation searching were also reviewed in full. During this stage there were two potential outcomes: include or exclude. Contact was made with 5 authors [94-98] to clarify the involvement of an occupational therapist in the delivery, design, or management of the intervention under investigation, leading to the inclusion of these publications. After full text screening, 65 publications met inclusion criteria.

Screening: Synthesis Allocation

Using EPPI-Reviewer and in preparation for the review's second stage, publications were coded in accordance with relevance to either the Population Synthesis or Intervention Synthesis. At this stage, 13 publications were excluded: eight pertained to the development of an assessment or its psychometric properties [99-106]; three publications [107-109] reported on the outcome of assessments that generated data on a person's performance capacity, as defined by the Model of Human Occupation (MOHO) [79] (e.g. cognition, visual-spatial abilities), rather than the performance of an occupation; one reported on assessment practices in Memory Assessment Services (MAS) by members of the multi-disciplinary team (MDT) [110]; and one was a lab based intervention that aimed to improve motor skills in response to a computer programme [111]. Twenty-two publications were allocated to the Population Synthesis (Thesis Objective 1) and 31 to the Intervention Synthesis (Thesis Objective 3) as outlined in Figure 6. One study, Nygård and Johansson [112] was included in both syntheses.

3.3.2.4. Data Extraction

Data were extracted manually on studies' substantive and methodological characteristics, including methodology, publication, participants, and findings, and can be found in Chapters 4 and 5 as well as Appendices G, H, I and J.

3.3.2.5. Quality Appraisal

Population Synthesis (Thesis Objective 1)

Studies included in this synthesis utilised a qualitative or observational, cross-sectional design. The Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist [113] was used to appraise studies using a qualitative approach, as a widely recognised and used checklist by health service researchers [114]. Studies were appraised using the checklist prompts to provide a more detailed assessment, as per Monforte-Royo et al [115]. Observational, cross-sectional studies were appraised using the Appraisal tool for Cross-Sectional Studies (AXIS) [116].

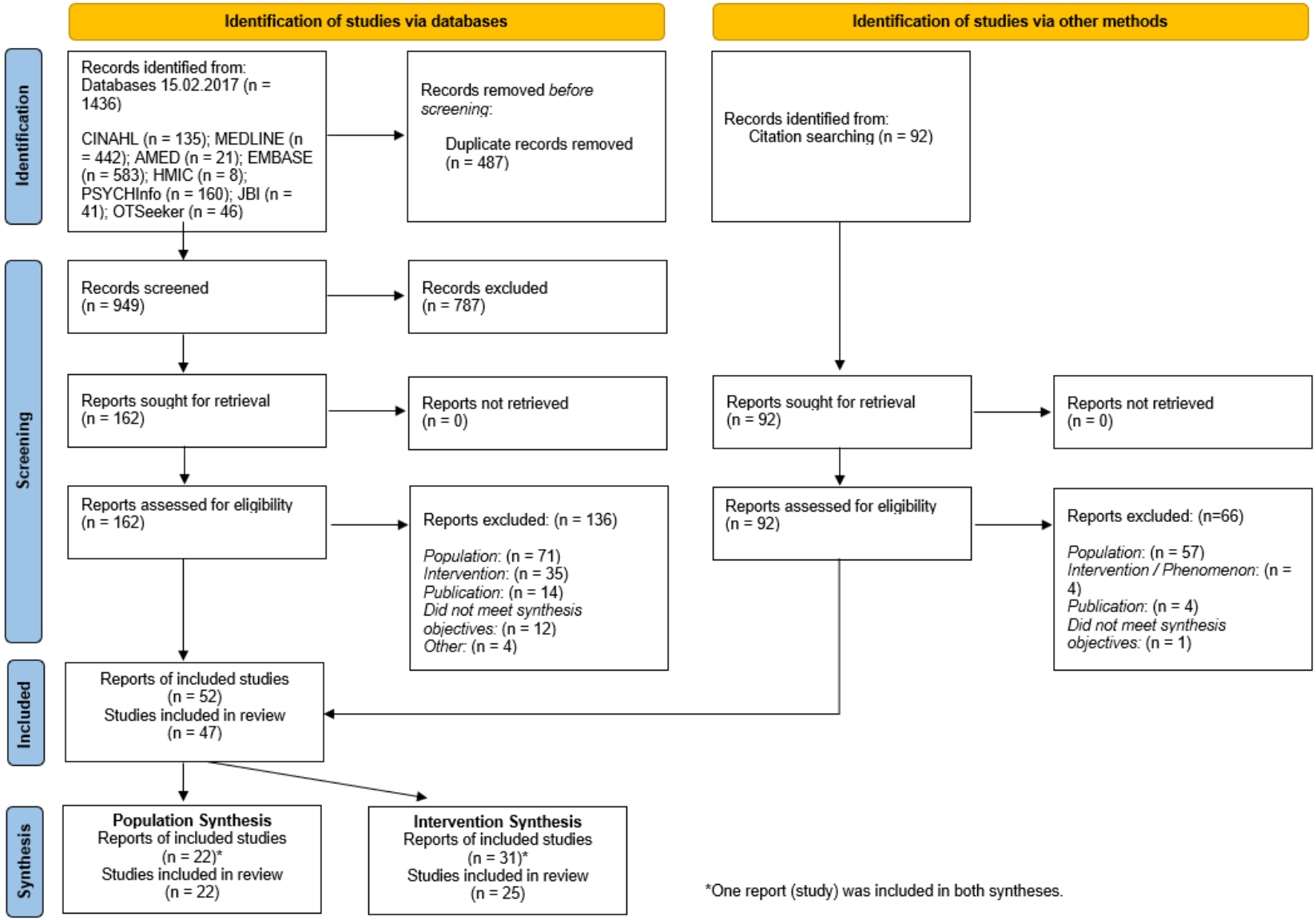

Figure 6: Prisma 2020 Flow Diagram

Intervention Synthesis (Thesis Objective 3)

Studies included in this synthesis used a wide range of methodologies and reflecting this, four quality appraisal tools were used. Three tools deriving from the Joanna Briggs Institute (JBI) were utilised: the Critical Appraisal Tool for Randomised Controlled Trials [117]; the Critical Appraisal Tool for Quasi-experimental Studies [117] to appraise Controlled Trials, studies using a one group pre-post design and those using a retrospective cohort design; and the Critical Appraisal Tool for Case Reports [118] to appraise case studies and case reports. Since the CASP Qualitative Studies Checklist [113] was utilised to appraise qualitative studies during the Population Synthesis, it was used again during this synthesis rather than a JBI tool.

3.3.2.6. Synthesis

Population Synthesis (Thesis Objective 1)

Studies included in this synthesis were exploratory and descriptive, using a qualitative or cross-sectional design, and were synthesised thematically as outlined by Thomas et al [119]. A thematic synthesis was deemed appropriate since it can facilitate the synthesis of a diverse range of study designs, and takes an inductive approach to theme generation to ensure themes are "*systematically grounded in the studies*" [119] p190. Since this synthesis included studies reporting on the lived experience of dementia, the latter was deemed particularly important, to ensure that the voices and experiences of people living with dementia, as reported by studies, were foregrounded. In accordance with Thomas et al [119], studies were synthesised in three stages. Firstly, this involved re-reading studies' findings sections in full to facilitate familiarisation with the data, with provisional coding / thematic memos made. Secondly, data was read and re-read, and provisional codes developed during familiarisation, revised iteratively. Codes were descriptive and in vivo (Table 6), which are described by Miles et al [120] as "*elemental*" and "*foundational*" coding methods (p74). A formal description of 'themes' (codes) and 'sub-themes' (sub-codes) is presented in Chapter 4. Thirdly, an analytical approach was taken, building on descriptive themes to answer Research Question 1.1.1. (Section 3.2.). This formed the synthesis' discussion and is again contained in Chapter 4. Analysis was conducted by hand, using hard copies.

Table 6: Elemental Coding Methods (Adapted from Miles et al [120])

Coding method	Description	Examples from Synthesis
Descriptive	A word (most typically a noun) or short phrase that summarises data	Self-initiated adaptations and strategies
In Vivo	Words or short phrases deriving directly from primary sources.	"*Problems*", "*difficulties*" and "*critical incidents*"

Intervention Synthesis (Thesis Objective 3)

This synthesis included studies generating quantitative data pertaining to intervention outcomes using experimental, quasi-experimental and case report methodologies, as well as studies generating qualitative data on views and experiences of interventions. Given the heterogeneity of study designs, interventions, and outcome measures used, a thematic summary approach towards synthesis was utilised as described by Thomas et al [119]. Thematic summaries are often referred to as 'narrative syntheses' and seek to summarise unchanged the results of studies [119]. As Thomas et al [119] assert, syntheses using this approach typically utilise a review's conceptual framework as an organising structure. Studies were therefore thematically summarised using the four research questions outlined in Section 3.2. To structure summaries relating to the nature of occupational therapy interventions (Research Question 1.3.1.), sub-titles or themes informed by the TIDieR Checklist [121] were used (Table 7). TIDieR is a world-renowned checklist that aims to facilitate the description of published interventions and whilst its use is intended for primary studies to enable the reporting of interventions, its use here proved an effective way of structuring a summary of the interventions included in this synthesis.

Table 7: Sub-Themes Informed by the TIDieR Checklist Used in Study 1

• Intervention Rationale, Theory or Goal.
• Content and Components
• Mode and location of delivery
• Duration and Intensity
• Interventionist

Consideration was given to splitting this synthesis into a quantitative and qualitative synthesis, however, there were insufficient studies utilising a qualitative approach to make this feasible. Furthermore, heterogeneity in terms of interventions, outcomes measured, population and quality,

prevented an aggregative or meta-analysis by pooling quantitative data across studies [122]. Combining experimental, descriptive, and qualitative studies in a single narrative or descriptive synthesis has precedent, including Coutinho et al [123] who synthesised literature about the impact of informal caregiving, and Whelan et al [124] to synthesise the literature on interventions to foster resilience among people living with dementia.

3.3.3. Strengths and Limitations

A number of methodological limitations must be acknowledged, most notably, the lack of multiple reviewers, which Aromataris et al [125] and Shea et al [126] highlight can be a source of bias. Only studies published in the English language were eligible for inclusion, which is a recognised bias in systematic reviews and health related publications [127]. Accordingly, it was not possible to determine if two studies [128, 129] were eligible to be included in this synthesis, which were written in Dutch. Both reported on the development of Community Occupational Therapy in Dementia (COTiD) and its practice guidelines. Another possible limitation included the number of studies that were excluded because the severity of participants' dementia was not reported qualitatively or quantitatively, as well as the lack of a consistent definition of early-stage dementia across included and potentially eligible studies themselves.

3.4. Synthesis Update

In order to remain abreast of the current literature, the evidence was searched again on the 9.02.2022. Eligibility criteria, search strategies and study selection largely remained as described above, with only minor amendments which are described in Appendix D. The search was limited to evidence published from 2017 onwards and a PRISMA 2020 diagram for this update is presented in Figure 7. Fifteen publications were allocated to the Intervention Synthesis, however, no publications met criteria for the Population Synthesis. The results of this update are reported as narrative, descriptive summaries at the end of Chapter 4 (Population Synthesis) and Chapter 5 (Intervention Synthesis). Studies were not quality appraised during this update and data was not extracted.

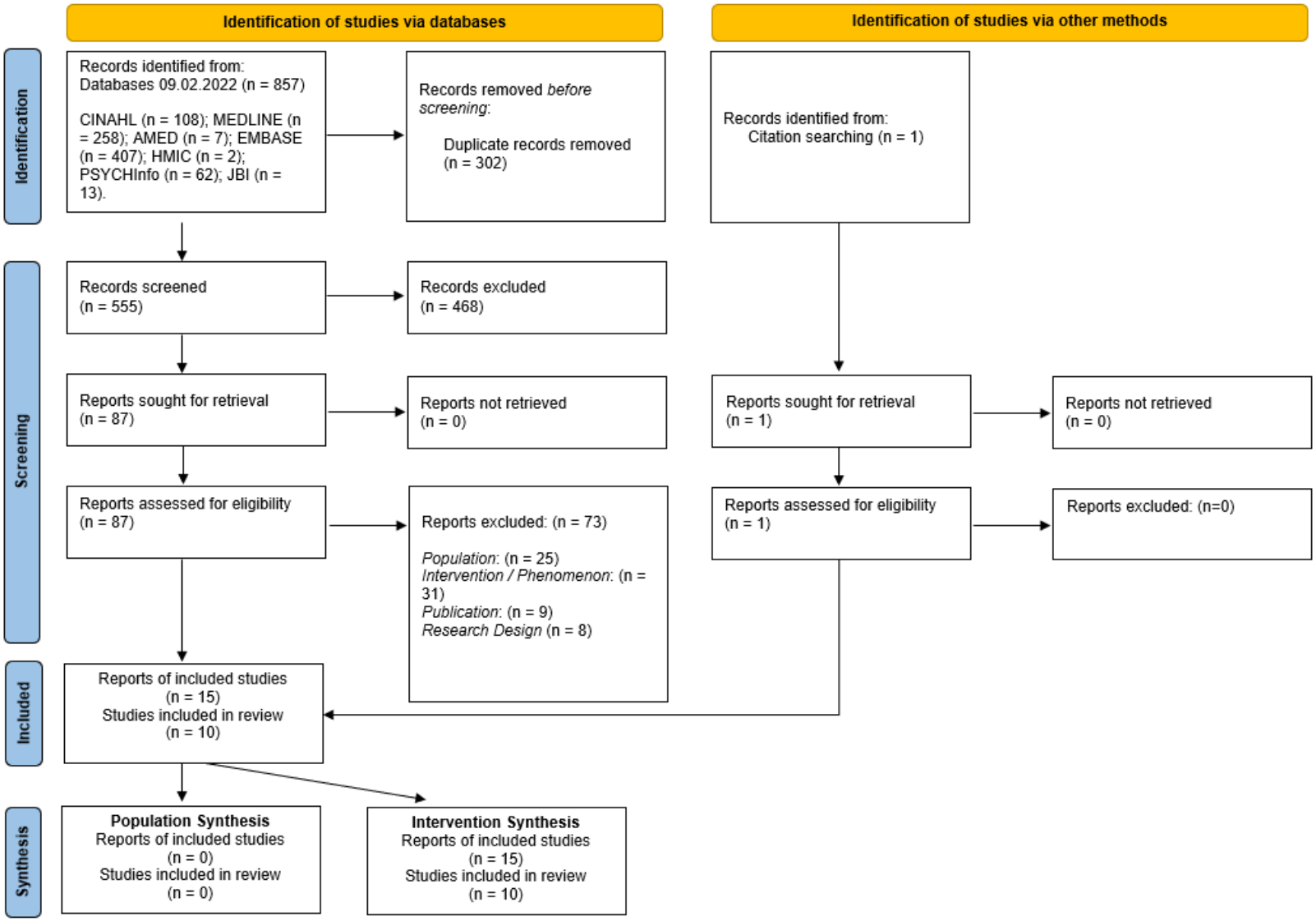

Figure 7: Prisma 2020 Flow Diagram

3.5. Chapter Conclusion

Study 1's overall aim: To identify, describe, appraise, and synthesise peer-reviewed research relating to occupational therapy and people affected by early-stage dementia living in the community; and its two objectives: 1. To understand the intervention population, and 3. To identify existing practice and research-based occupational therapy interventions, have been outlined in this Chapter. Associated research questions to meet these objectives have also been discussed. The evidence synthesis design – a mixed-methods multi-stage review, along with methods utilised to search, quality appraise and synthesise the evidence have been outlined. Study 1's findings will now be reported in Chapter 4 (Population Synthesis) and 5 (Intervention Synthesis).

Chapter 4. Population Synthesis

4.1. Introduction

Contained in this Chapter are Study 1's Population Synthesis' findings. This synthesis aimed to answer the research question:

1.1.1. What impact, if any, does early-stage dementia have on the occupational (activity) performance of people living in the community?

This question was based on Thesis Objective 1 (Section 3.2.) and synthesis methods have been described in Chapter 3, which outlined that non-intervention studies, including those using a qualitative and observational cross-sectional design were eligible for inclusion. In this Chapter, included studies' methodological and substantive characteristics and quality appraisal will be described, followed by a thematic synthesis of studies' findings and a discussion.

4.2. Included Studies

22 publications and 22 studies were included in this synthesis, with Figure 6 (Chapter 3) depicting the synthesis' PRISMA flow diagram. Sixteen studies utilised a qualitative design, generating qualitative data through observational methods and / or interviews [130-145], and six were cross-sectional studies generating quantitative data [146-151]. Twenty studies were conducted by researchers from the Karolinska Institute, Sweden [112, 130, 131, 133, 134, 136-145, 147-151]. Of the remaining two, one was conducted in Belgium [146] and one in the UK [132]. Given the programme of research conducted at the Karolinska Institute, a number of publications identified were inter-related, often using the same populations. In this synthesis, however, all publications have been treated as individual studies since they each specified different aims and data was analysed separately.

Sample sizes ranged from n = 2 [134] to n = 30 [143] for studies using a qualitative design, with the majority reporting a sample size of less than 10 participants. Overall, sample sizes were larger for studies using an observational, cross-sectional design, ranging from n = 35 [150] to n = 157 [147], however, these studies also included participants with Mild Cognitive Impairment (MCI) and those without cognitive difficulties as comparison groups. Across the 19 studies reporting mean or individual Mini Mental State Examination (MMSE) scores for participants living with dementia, a mean

MMSE of 23.1 was reported, ranging from 19.8 [136] to 26.5 [132]. Of the nineteen studies that reported dementia sub-type, eleven included people living with dementia who had Alzheimer's Disease (AD) only. A mean age of 70.3 was reported across the nineteen studies reporting mean or individual age, with a range of 55.5 [134] to 81.7 [136]. Further details about included studies' methodological and substantive characteristics, including design, aims and methods are presented in Tables 8 and 9.

4.3. Quality Appraisal

4.3.1. Qualitative Studies

Studies utilising a qualitative approach were quality appraised using the CASP [113] Checklist (Section 3.3.2.5.) and the outcome of this appraisal can be found in Appendix E. Overall, all 16 qualitative studies included in this synthesis appropriately used a qualitative methodology, were explicit in their description of methods utilised to generate and analyse data, with an in-depth description provided in relation to themes reported by all. However, there was a notable lack of critical reflection by 14 studies [130, 132-134, 136-145] about researcher bias and influence, in addition to the nature of their relationship with participants. Six studies [136-139, 143, 144] did not report if ethical approval had been received and 10 studies [132-134, 136-139, 144, 145] did not discuss ethical issues pertaining to the study, for example informed consent or confidentiality.

4.3.2. Cross-sectional Studies

Six studies using an observational, cross-sectional design were appraised using the AXIS tool [116], with results presented in Appendix E. Again, in relation to these studies, a cross-sectional, observational design was appropriate to meet study aims, and methods and findings were described in detail. Across studies, an area of weakness pertained to potential sampling bias, since randomisation or alternative methods to minimise sampling bias were not reported. Furthermore, only one study [149] recorded reasons for non-response, therefore it was not possible to ascertain the characteristics of the participants who declined to participate, which raises concerns about non-response bias.

Table 8: Included Qualitative Studies: Substantial Characteristics

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Findings / Themes
					PLWD		Other Participants	
Nygård and Borell [134] **Sweden**	To map out and describe how difficulties caused by dementia emerge in the daily lives of two women and how they tried to compensate for and adapt to these difficulties.	Qualitative, comparative longitudinal study.	Participant observation, informal interviews, and conversations on 10 occasions. Analysis: Comparative method.	Dementia diagnosis, volunteer, still performing occupations autonomously, below age 65, participants should have different living conditions, marital status, and profession.	n = MMSE: Age: Education: Female: AD:	2 22 (range: 20-24) 55.5 (range 54-57) NR 100% 50%		1. Difficulties in everyday life. 2. Compensation based on spontaneous actions. 3. Compensation based on concretizing and caution. 4. Consequences of the difficulties of compensating for loss of ability.
Nygård et al [133] **Sweden**	To explore and enhance understanding, from an occupational perspective, how early-stage dementia is experienced and perceived by two participants.	Qualitative, comparative longitudinal study.	Participant observation, informal interviews, and conversations on 10 occasions. Analysis: Comparative method.	**Nygård and Borell** [134]	**Nygård and Borell** [134]			1. Perspectives on one's own ability in homemaking activities. 2. Perspectives on former work role. 3. Responding to difficulties. 4. Attributing the disease.
Nygård and Borell [145] **Sweden**	To describe from a phenomenological, occupational therapy perspective, the structure, and the unfolding process of dementia experienced over a 3-year period, as expressed in the everyday lives of two persons with early-onset dementia.	Qualitative, comparative longitudinal study, using a phenomenological approach.	Participant observation, informal interviews, and conversations over the duration of 3 years. There were 3 periods of data collection of 6-8 months' duration. Assessment of ability to perform IADL's using the AMPS.	**Nygård and Borell** [134]	**Nygård and Borell** [134]			1. A Lifeworld of altered meaning. 2. A threat to order and control of the lifeworld.

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Findings / Themes
					PLWD		Other Participants	
			Analysis: Empirical, Phenomenological, Psychological (EPP) method.					
Nygård and Johansson [112] **Sweden**	To describe experiences and management of time and temporal problems in everyday life among people who have dementia.	Qualitative comparative case study.	Interviews, observation. Analysis: Comparative method.	Dementia diagnosis, experience of temporal difficulties, motivated and willing to participate, able to participate in interviews.	n =	5		1. Experiences of time in everyday life: - • Temporal rhythms. • Temporal extension. 2. Experienced problems related to temporality: - • Temporal relationships and coherence. • Knowing 'when'. • Knowing 'how long'. 3. Strategies for managing temporal difficulties: - • Adjusting occupational demands and occupational habits. • Taking a surplus amount of time. • Checking, organizing and anticipating for control. • Trusting others for assistance. • Reminders in the environment. • Time aids. 4. Consequences of and attitudes towards temporal problems.
					MMSE:	20.2 (range: 14-27)		
					Age:	63 (range: 54 – 69)		
					Education:	NR		
					Female:	60%		

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Findings / Themes
					PLWD		Other Participants	
Nygård and Öhman [136] **Sweden**	To describe how individuals with dementia respond to and manage difficulties and changes in their occupational everyday lives.	Qualitative.	Multiple interviews (number not provided), participant and non-participant observation. Analysis: Phenomenological approach, based on the EPP method.	Mild - moderate dementia diagnosis, preferably Alzheimer's Disease, living at home, ability to articulate experiences. Age, gender, vocational background, and social and marital status to vary across participants.	n =	7		1. Strategies for overall management of changing occupational conditions: - • Acceptant attitude to present conditions despite self-accusations. • Normalizing. • Balancing between taking on and avoiding challenges. • Training and activating. 2. Strategies for managing difficulty in occupation: - • Environmental. • Habituation. • Cognition.
					MMSE:	26.7 (range: 24-29)		
					Age:	71 (range: 62-78)		
					Education:	NR		
					Female:	42.9%		
					AD:	100%		
Nygård and Starkhammar [137] **Sweden**	To describe and map out difficulties and response strategies when older people living at home alone with dementia use the phone.	Inductive, explorative, qualitative approach.	Observations and interviews. Analysis: Comparative approach, based on Grounded Theory.	Diagnosis of dementia, 65 or older, live alone in own home, use the telephone.	n =	10		1. Difficulties when using the telephone: - • Knowing what: 'What next?' 'What is this?' 'What is missing?' • Knowing Where. • Knowing How. • Overcoming motor, perceptual, and environmental obstacles. 2. Participants' responses to problems in telephone use: - • Environmentally related strategies. • Strategies related to cognition.
					MMSE:	19.3 (range 11 – 27)		
					Age:	81.7 (range 75-86)		
					Education:	NR		
					Female:	70%		
					AD:	60%		

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Findings / Themes
					PLWD		Other Participants	
Öhman and Nygård [140] **Sweden**	To describe the meanings and motives for self-chosen daily life occupations among community dwelling individuals with Alzheimer's Disease.	Qualitative, explorative approach.	Multiple Interviews: 2-4 per person, participant and non-participant observation. Analysis: Qualitative comparative method.	**Nygård and Öhman** [136]	n =	6		1. Maintaining their ordinary pattern of everyday life. 2. Being a person in a coherent context. 3. Communicating certain identity characteristics. 4. Finding and creating a private sphere. 5. Using occupation to stay active. 6. Double-edged keys crucial to occupation. 7. Two modes of making sense of the cessation of occupations.
					MMSE:	21.7 (range: 15-28)		
					Age:	72.7 (range: 65-80)		
					Education:	NR		
					Female:	50%		
					AD:	100%		
Vikström et al [143] **Sweden**	To identify self-initiated support strategies that caregivers provide when performing an occupation with their partner with dementia and to identify negative aspects of caregiver support.	Qualitative.	Observation and field notes. Analysis: Constant comparative approach.	Mild – moderate dementia AD or VD, MMSE 16 or above, cohabiting with significant other, problems remembering and performing everyday occupations.	n =	30	Caregivers: n = 30; Female: 53.33%; Age 74 median, range 58-84; Education: 26.67% university educated.	1. Supportive working climate. 2. Supportive practical involvement. 3. Negative aspects of caregiver support.
					MMSE:	21 (median) (range 16 – 24)		
					Age:	78 (median) (range 68-85)		
					Education:	20% university educated.		
					Female:	46.7%		
					AD:	NR		
Nygård and Starkhammar [138] **Sweden**	To identify and characterise difficulties in using everyday technology among individuals with mild – moderate dementia.	Qualitative, ethnographic.	Open ended interviews and participant observation.	Mild-moderate dementia diagnosis, living at home on their own, manage the majority of ADL/IADL independently.	n =	8		1. Conditions that interfere as hindrances in technology use. 2. Limitations in the participants' knowledge of the technology and its potential. 3. Communication difficulties in the use of technology.
					MMSE:	24.9 (range: 19-28)		
					Age:	69 (range: 57-82)		
					Education:	NR		
					Female:	62.5%		
					AD:	87.5%		

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Findings / Themes
					PLWD		Other Participants	
Nygård [139] **Sweden**	How is the meaning of everyday technology, particularly in terms of its utility, experienced by people with early-stage dementia who live alone?	Qualitative, explorative, phenomenological approach.	Multiple interviews and observations Analysis: EPP	**Nygård and Starkhammar** [138]	**Nygård and Starkhammar** [138]			1. Patterns and choices of technology use in everyday life. 2. Technology's utility and meaning in relation to doing. Technology's utility and meaning in relation to being. Technology's utility and meaning in relation to managing and adjusting.
Öhman et al [141] **Sweden**	To explore and describe the characteristics of the phenomenon of awareness of the consequences of having AD on everyday occupations.	Qualitative, phenomenology	Multiple interviews. Analysis: Modified EPP approach.	**Nygård and Öhman** [136]	**Öhman and Nygård** [140]			1. Discovering and managing changes in occupational and social interactions. 2. Reflecting on a changing life situation.
Vikström et al [144] **Sweden**	To identify and describe how people living with dementia and their caregiving spouses perceive their own, their spouses' and their mutual engagements in everyday activities.	Qualitative.	Semi-structured Interviews. Analysis: Constant comparative method.	**Vikström et al** [143]	n =	26	Caregiver spouses: n = 26; Age 74 median, range 59-86; Education: university educated 26.92%; Female: 53.84%;	1. Perceived changes in activity engagements. 2. Consequences of experienced changes. 3. Dilemmas experienced by the caregivers. 4. Caregivers' management approaches to handle changes.
					MMSE	21.8 (mean) range 16 - 24		
					Age	78 (median) range 62 - 85		
					Education	19.23% University education		
					Female:	46.15%		
					AD:	NR		

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Findings / Themes
					PLWD		Other Participants	
Brorsson et al [130] **Sweden**	To describe experiences of accessibility in public space by people with AD, with a specific focus on places, situations and activities found important in their daily life.	Qualitative, exploratory study.	Repeated in-depth interviews (2 per person, aside from one participant who had 1).	Diagnosis early-stage AD, age 55 or older, living at home alone or with a partner.	n =	7		1. Activities and use of places: • Familiarity and comfort. • Individual motives and interests. • Planning and protecting. 2. Places and problematic situations: - • Everyday technologies. • Crowded places with high tempo and noise. • Change of landmarks. 3. Accessibility as a constantly changing experience.
					MMSE:	23.1 (range: 18-30)		
					Age:	68.9 (range: 63-80)		
					Education:	NR		
					Female:	71.4%		
					AD:	100%		
Brorsson et al [131] **Sweden**	To use a critical incident approach to discover and describe problematic situations and critical incidents when people with AD grocery shop.	Qualitative, exploratory study using a grounded theory approach.	Participant observation with additional data deriving from **Brorsson et** al's [130] interviews.	Early-stage AD, living at home with a partner or alone, participate in some activities independently in a public space, age 55 or over.	n =	6		Core category: A challenging and unstable process of meeting critical incidents in grocery shopping. Categories: • Remembering to bring things when leaving home. • Finding the way to and from the grocery shop without getting lost. • Finding a way through traffic when not feeling safe. • Finding objects when organisation is disrupted. • Choosing when a lot of objects and products are available. • Finding a method to pay when payment opportunities are restricted.
					MMSE:	22.8 (range: 18 – 30)		
					Age:	69.7 (range: 63-80)		
					Education:	NR		
					Female:	66.7%		
					Diagnosis AD/	100%		

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Findings / Themes
					PLWD		Other Participants	
Rosenberg and Nygård [142] **Sweden**	To explore how people with MCI (G2) and early-stage AD (G1) try to prohibit, avoid or solve problems in everyday technology use, maintain skills and learn to use new technology.	Qualitative.	Interviews and observations using the META. Analysis: Based on Grounded Theory.	Early-stage AD (MMSE 17 - 30), age 55 or older, uses technology in everyday life. Only data pertaining to participants with early-stage AD have been included in the synthesis.	n =	10	Participants with MCI: n = 10	Core Category: Learning and using everyday technology in an intertwined process: - • The significance of others. • Communicating with everyday technology. • Management strategies when approaching everyday technology.
					MMSE:	25.9 (range 17-30)*		
					Age:	68.2 (range 56-87)*		
					Education:	11 (range: 5-19.5)*		
					Female:	60%*		
					AD:	100%		
Chaplin and Davidson [132] **UK**	To describe the experiences of people who develop dementia whilst still in employment in the UK.	Qualitative, exploratory study based on Interpretive Phenomenological Analysis (IPA).	Semi-structured Interviews. Analysis: IPA.	Dementia diagnosis, in employment or left employment in last 12 months.	n =	5		1. The realisation that something is wrong. 2. Managing the situation in the workplace. 3. Trying to make sense of the changing situation. 4. Coming to terms with retirement or unemployment.
					MMSE:	26.5 (based on MMSE of 4 participants. 5th participant = no data) (range: 25-28)		
					Age:	64.4 (range: 58-74)		
					Education:	NR		
					Female:	20%		
					AD:	80%		

Abbreviations: Not Reported (NR), Standard Deviation (SD), Mild Cognitive Impairment (MCI), Alzheimer's Disease (AD), Vascular Dementia (VD), Mini Mental State Examination (MMSE), Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), Management of Everyday Technology Assessment (META), Empirical, Phenomenological, Psychological Method (EPP), Assessment of Motor and Process Skills (AMPS). * Sample data was not reported separately for individuals with AD and MCI.

Table 9: Included Cross-Sectional Studies: Substantial Characteristics

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Results
					PLWD		Other Participants	
Rosenberg et al [147] **Sweden**	To compare perceived relevance of, and difficulty in using everyday technology amongst older adults without cognitive impairment (G3), with MCI (G2) and mild dementia (G1).	Cross-sectional.	Quantitative data generated using the ETUQ.	Living at home, 55 or older, expected to carry out IADL. G1: Dementia diagnosis; G2: MCI diagnosis.	n =	G1: 34	G2: 30 G3: 93	Participants with early-stage dementia perceived everyday technology as less relevant compared to those without cognitive impairment (p <0.001), but not MCI. Participants with early-stage dementia reported experiencing greater difficulties using everyday technology compared to those without cognitive impairment (p <0.001) and those with MCI (p <0.001).
					MMSE =	G1: 24 (16-29)	G2: 27 (20-30) G3: 28 (24-30)	
					Age:	G1: 73 (55-87)	G2: 74 (59-87) G3: 74 (60-98)	
					Education:	NR	NR	
					Female:	G1: 53%	G2: 57% G3: 60%	
					AD:	NR	NR	
Malinowsky et al [149] **Sweden**	To compare the management of everyday technology between individuals with mild dementia (G1), MCI (G2) and no cognitive impairment (G3).	Cross-sectional.	Quantitative data generated using the META, an observational assessment.	Living at home, 55 or older, expected to use technology. G1: Diagnosis of AD or mixed dementia, minimum MMSE = 18; G2: MCI diagnosis.	n =	G1: 38	G2: 33 G3: 45	Participants with early-stage dementia differed significantly in their ability to manage everyday technology from participants without cognitive impairment (p <0.001; Cohen d = 1.87) and MCI (p <0.001; Cohen d = 1.23).
					MMSE:	G1: 23.5 (17-29)	G2: 27.52 (24-30) G3: 29.27 (27-30)	
					Age:	G1: 75.29 (58-89)	G2: 70.45 (57-87) G3: 73.22 (55-92)	
					Education:	NR	NR	
					Female:	G1: 53%	G2: 42% G3: 64%	
					AD:	G1: 100%	NA	

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Results
					PLWD		Other Participants	
Öhman et al [150] **Sweden**	To examine the relationship between occupational performance and awareness of disability in older adults with MCI (G2) or dementia (G1).	Cross-sectional.	Quantitative data generated using the AMPS and ADD.	MCI (G2) or dementia (any diagnosis) (G1); lives in own home, referred to occupational therapy due to concerns with occupational performance, able to understand and participate in an interview.	n =	G1&2: 35		G1&2 mean scores for process and motor ability on the AMPS were below cut off scores for older people living alone independently, both reaching statistical significance (p <0.001). Participants with MCI had higher overall mean AMPS process and motor ability scores that those with dementia. Trends in the data revealed that participants living with dementia had an overall lower mean AAD score than participants with MCI, with participants with AD demonstrating a greater awareness than participants with other forms of dementia. 43% of participants with MCI or dementia were not aware of one or more occupational performance limitations resulting in unacceptable outcomes (defined as an unacceptable delay, effort, risk of personal or environmental injury or need of assistance). Correlation co-efficient between AMPS motor skills and awareness of disability was significant r = 0.67 (p <0.01) and for AMPS process skills r = 0.44 (p <0.01).
					MMSE:	G1&2: 21.6 (12-29)		
					Age:	G1&2: 77.9 (59-92)		
					Education:	NR		
					Female:	G1&2: 77.14%		
					AD:	G1: 66.7%		

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Results
					PLWD		Other Participants	
Nygård et al [151] **Sweden**	What is the relationship between perceived difficulty in everyday technology (ET) use and cognitive status, mood state and involvement in IADL in older adults with and without MCI or dementia?	Cross-sectional.	Quantitative data generated using the revised ETUQ, FAI, MMSE and GDS.	Diagnosis of MCI (G2) or early-stage AD (G1), 55 years or older, uses ET, motivated and able to take part. Older adults with no known cognitive impairments were also recruited (G3).	n =	G1: 37	G2: 37 G3: 44	Perceived Difficulty: All three groups differed significantly: G1 vs G3: p <0.001; G1 vs G3: p <0.001; G2 vs G3: p <0.05. Perceived difficulty across groups as measured on the ETUQ correlated positively with the FAI (r = 0.56 p <0.01), negatively with the GDS (r = -0.31 p <0.01) and positively with the MMSE (r = 0.46 p <0.01). Perceived Relevance: All three groups differed significantly: G1 vs G3: p <0.001 d 1.68; G1 vs G3: p <0.001 d 1.26; G2 vs G3: p <0.05 d 0.82.
					MMSE:	G1: 25.4 (18-29)	G2: 27.5 (19-30) G3: 29.1 (27-30)	
					Age:	G1: 72 (52-89)	G2: 67 (56-82) G3: 69 (55-91)	
					Education:	G1: Years 11.4 (6-18)	G2: 12.6 (6-20) G3: 13.2	
					Female:	G1: 54%	G2: 49% G3:59%	
					AD:	G1: 100%	NA	
Ryd et al [148] **Sweden**	To explore associations between ADL performance and perceived ability to use everyday technology among older adults with early-stage AD and MCI.	Cross-sectional.	Quantitative data generated using AMPS and the S-ETUQ.	AD Diagnosis - early-stage (MMSE at least 18) (G1) or MCI (G2), age 55 or older, a need to use ET in daily life and not completely dependent upon another person when using everyday technology.	n =	G1: 39	G2: 28	Participants with early-stage AD scored lower on ability to use everyday technology (p <0.05), AMPS process ability (p <0.001), and number of every day technologies perceived as relevant to themselves (p <0.001) compared to those with MCI. Differences on AMPS motor ability were not statistically significant. Correlation between process ability and ET use among those who had early-stage AD was p <0.05 however, this was not observed for motor ability.
					MMSE:	NR	NR	
					Age:	G1: 75.74 (SD 7.41)	G2: 76.9 (SD 7.19)	
					Education (Years):	11.08 (SD 3.27)	12.20 (SD 3.41)	
					Female:	54%	43%	
					AD:	100%	NA	

Study & Country	Aims	Design	Methods	Inclusion Criteria	Sample (Reported as means unless otherwise stated)			Results
					PLWD		Other Participants	
Vermeersch et al [146] **Belgium**	To investigate the relationship between functional decline in the use of everyday technology, driving and complex economic activities in people with AD (G1), MCI (G2) and cognitively healthy controls (G3).	Cross-sectional, correlational study.	Quantitative data generated using MMSE, a-ADL-CDI and CAMCOG.	Diagnosis of AD (G1) or MCI (G2) or cognitively healthy (G3), age 65 or older, living in the community.	n =	G1: 48	G2: 45 G3: 50	Individuals with early-stage dementia (or proxies) perceived everyday technology, driving and economic activities as more difficult to use compared to those without cognitive impairment or dementia, reaching statistical significance (p <0.001, for all). Statistically significant differences were also reported between individuals with early-stage dementia and those with MCI (driving: p<0.01, economic activities: p =<0.001), with the former reporting greater difficulties. MMSE and CAMCOG scores differed significantly between those with AD and those with MCI (p<0.001) and controls (p<0.001), with those with AD reporting lower scores. Participants with dementia engaged in less activities, which reached statistical significance compared to those with MCI (p<0.001).
					MMSE:	G1: 21.8 (15-29)	G2: 26.8 (24-30) G3: 28.9 (26-30)	
					Age:	G1: 80.8 (69-91)	G2: 80.39 (67-90) G3: 79.5 (65.9-91)	
					Education:	G1: 10.8 (6-18)	G2: 10.6 (6-18) G3: 13.2 (6 – 18)	
					Female:	G1: 75%	G2: 51% G3: 62%	
					AD:	G1: 100%		

Abbreviations: Standard Deviation (SD), Mild Cognitive Impairment (MCI), Alzheimer's Disease (AD), Everyday Technology (ET), Not Applicable (NA), Not Reported (NR).
Assessments and Outcome Measures: Mini Mental State Examination (MMSE), Cambridge Cognition Examination (CAMCOG), Advanced Activities of Daily Living – Cognitive Disability Index (a-ADL-CDI), Assessment of Motor and Process Skills (AMPS), Shortened Everyday Technology Use Questionnaire (S-ETUQ), Geriatric Depression Scale (GDS), Frenchay Activity Index (FAI), Assessment of Awareness of Disability (AAD), Management of Everyday Technology Assessment (META), Everyday Technology Use Questionnaire (ETUQ).

4.4. Thematic Synthesis

Included studies were thematically synthesised, in accordance with Thomas et al [119] (Section 3.3.2.6.), with five themes identified across studies (Table 10), which will be described in the remainder of this section.

Table 10: Population Synthesis: Themes

Themes	Studies Contributing to Theme	
	n =	
• "*Problems*", "*Difficulties*" and "*Critical Incidents*"	14	[112, 130-134, 137, 138, 145-149, 151]
• Self-Initiated Adaptations and Strategies	11	[112, 130-134, 136, 137, 140, 142]
• Strategies Initiated by Others	4	[132, 140, 143, 144]
• An Awareness of Change	5	[132, 133, 139, 141, 150]
• Meaning and Motivation	3	[130, 139, 140]

4.4.1. "*Problems*", "*Difficulties*" and "*Critical Incidents*"

Fourteen studies [112, 130-134, 137, 138, 145-149, 151] generated data on the "*difficulties*", "*problems*" and "*critical incidents*" that individuals living with early-stage dementia experience or were observed to experience whilst performing occupations at home and / or in the community. Whilst the terms "*difficulties*" and "*problems*" were widely used across studies, often interchangeably, they were seldom defined a priori. Thus, the nature of problems and difficulties and what constituted a difficulty or problem was typically identified in studies' findings. However, Brorsson et al [130] and Brorsson et al [131] were outliers in this respect, defining both "*problematic situations*" and "*critical incidents*". The former was described as "*the especially challenging phases of grocery shopping and as the basis and prerequisite of human actions*" (p293) and the latter as "*any potentially hazardous aspect of a problematic situation that required some responsive kind of actions by informants*" (p293). Owing to the mixed methods nature of evidence synthesised under this theme, the following thematic synthesis will be structured in accordance with evidence type.

4.4.1.1. Quantitative Evidence

Four cross-sectional studies utilised self-report or proxy-report questionnaires to investigate perceived difficulty in using everyday technology. Rosenberg et al [147] and Nygård et al [151] utilised the Everyday Technology Use Questionnaire (ETUQ); Ryd et al [148] a shortened version of the ETUQ, the SETUQ; and Vermeersch et al [146] used the Advanced activities of daily living's (a-ADL) everyday technology subscale. A fifth study, Malinowsky et al [149], utilised the observational assessment Management of Everyday Technology Assessment (META), to evaluate ability to manage everyday technology by therapist observer-assessors. Everyday technology was defined broadly as inclusive of newly developed technology, including the internet and mobile phones, as well as traditional technology, for example the oven and radio [147].

Rosenberg et al [147], Nygård et al [151] and Vermeersch et al [146], reported that individuals with early-stage dementia perceive everyday technology as more difficult to use compared to those without cognitive impairment or dementia, reaching statistical significance (p = <0.001 for all three studies). Statistically significant differences were additionally observed on the ETUQ and SETUQ in comparison to individuals with MCI (p = <0.001 [147]; p = <0.001 [151]; p = <0.05 [148]). However, this was not replicated by Vermeersch et al [146] on the a-ADL, with authors concluding that the a-ADL may not be sensitive to the decline in functioning that occurs between MCI and the early-stages of dementia. It is important to acknowledge that Rosenberg et al [147], Nygård et al [151], Ryd et al [148] and Vermeersch et al [146] all utilised self-report or proxy-report questionnaires. However, Malinowsky et al [149] attests their findings utilising the therapist-rated observational assessment META. Between group analyses demonstrated that participants with early-stage dementia differed significantly in their ability to manage everyday technology from participants without cognitive impairment (p = <0.001 Effect Size 1.533) and MCI (p <0.001 Effect Size 0.883).

In addition to everyday technology, Vermeersch et al [146] generated data using the a-ADL on perceived (proxy and self-report) difficulties whilst driving and carrying out complex economic activities. Complex economic activities were defined by the a-ADL as electronic banking, including using an ATM as well as complex economic administration, including managing investments. Like everyday technology, Vermeersch et al [146], reported that individuals with early-stage dementia (or proxies) perceived driving and complex economic activities as more difficult compared to those without cognitive impairment or dementia, reaching statistical significance (driving and economic activities p = <0.001). Statistically significant differences were also reported between individuals with

early-stage dementia and those with MCI (driving: p = <0.01; economic activities: p =<0.001), with the former reporting greater difficulties.

4.4.1.2. Qualitative Evidence

Nine qualitative studies [112, 130-134, 137, 138, 145] generated data on the difficulties experienced by individuals with early-stage dementia whilst performing occupations using interviews and observational methods. Whilst the occupations and activities under investigation differed between studies, given the similarities evident in the difficulties described, although unique to every individual, seven sub-themes have been utilised to synthesise data across studies (Table 11). The initial four sub-themes were identified by Nygård and Johansson [112] and Nygård and Starkhammar [137] and proved a suitable way of synthesising data across studies.

Table 11: "Problems", "Difficulties" and "Critical Incidents": Qualitative Evidence, Sub-Themes

Theme	Sub-Themes
"*Problems*", "*Difficulties*" and "C*ritical Incidents*"	Knowing "*What"*
	Knowing "*Where"*
	Knowing "*When*"
	Knowing "*How"*
	Executive Functioning
	Mobility and Sensory Impairments
	Emotional Wellbeing

Knowing "What"

Being able to correctly identify or recognise aspects of the physical environment, including objects and spaces was reported as a prevalent difficulty. Nygård and Borell [134] and Nygård and Starkhammar [137, 138] reported difficulties correctly identifying objects in the home environment, both familiar and regularly used, and unfamiliar and infrequently utilised: *"the washing machine could be confused with the tumble dryer, the remote control with a calculator, an electrical plug with a telephone plug, or the television set with the computer"* [138] p149-150. Outside the home environment, difficulties correctly identifying objects within, and characteristics of, the physical environment were also evident [130, 131], for example, changes to product labels led to difficulties identifying desired items when shopping, leading Brorsson et al [131] to state: "*With those changes, a well-known shop could become unfamiliar to the informants"* (p297).

Problems identifying and recognising extended beyond aspects of, or objects within, the physical environment, and included being unable to identify the source of familiar noises and sounds, for example cars and roadworks [130, 131] or the identity of a person on the phone [134]. Difficulties recalling the identity of services and organisations also proved problematic when information was delivered verbally [134], as well as in writing, including recognising familiar and unfamiliar names, phone numbers and passwords [137, 138].

Nygård and Starkhammar [137] and Nygård and Borell [134] additionally highlighted difficulties knowing "*what*" the next step or action in an activity was, which the former noted was most prevalent when the demands of an activity involved multiple steps, requiring people to keep in mind the overall purpose of an activity. Nygård and Borell [134] reported that this led to disruptions in the activities continuity and flow, and Nygård and Starkhammar [137] noted that activities took an extended amount of time and effort to complete, if at all. Due to difficulties knowing 'what next', Nygård and Borell [134] identified that participants repeated an activity unnecessarily or neglected aspects of an activity, for example cleaning certain areas in a house multiple times, whilst other areas were left uncleaned.

Knowing "Where"

Remembering or knowing where to find items and objects were identified as difficulties in both the home environment and in the community [131, 134, 137, 138]. This was particularly evident when there were a number of objects "…*visible and ready to be used*" or when the location of items had recently changed [131] p297, with one of Nygård and Borell's [134] participants describing the experience as ''*a damned search for missing things*" (p75). In addition to locating objects and items, studies which explored occupational performance in the community highlighted difficulties in orientating and finding the way to desired locations without getting lost on foot, and when using public transport [130, 131, 134, 138]. Being unable to find and identify signs in a public space and position on a map were described in the context of difficulties knowing 'where' [130]. Topographical disorientation was noted as being particularly problematic in an unfamiliar environment, as well as previously familiar environments which had recently changed, as Brorsson et al [130] illustrates in the following extended extract:

"…a barrier to finding one's way in public space was the constant change in places and landmarks that they used for finding their way. This happened when the built environment had changed due to

something like reconstruction of formerly well-known houses or roads. This often created difficulties when the informant's personal landmarks had disappeared. For example, the informants told of getting lost even in familiar places when the houses in the neighbourhood had been repainted in a different colour or when pieces of art had been removed in the hospital corridors" (p 595-596).

'Knowing "When"

As a key study aim, difficulties associated with temporal orientation were primarily identified by Nygård and Johansson [112], and additionally by Nygård and Borell [134] and Nygård and Starkhammar [138]. Knowing 'when' to carry out an activity was identified as a significant problem, which was associated with difficulties reading and interpreting a clock face and in determining the day and time from contextual information [112, 134]. This posed problems when seeking to engage in activities that required orientation to date, day and time, for example paying bills, using public transport and keeping health related meetings and appointments [112].

In addition to knowing 'when', Nygård and Johansson [112] identified further difficulties in determining the passage of time, and thus, knowing 'how long' an activity or situation would last. Examples included knowing how long they had been waiting, for example for a taxi or a spouse to return home. Remembering and understanding temporal relationships, between the past, present and future were also identified as problematic [112, 134], and some participants demonstrated difficulties in being able to describe and explain events in time and their relationships, for example when telling a story [134]. Uncertainty about what happened yesterday was reported and thinking about events in the future proved difficult with some commenting that there was "*not much to plan for*" (p89). Finally, the temporal sequence of steps during task completion was also noted as problematic: *"Actions suggesting difficulty in using the telephone in a logical manner were also in evidence, such as dialling the code before lifting the receiver…"* [137] p 243.

Knowing "How"

Whilst not as prevalent across studies, difficulties knowing 'how' to perform an activity were identified by Nygård and Starkhammar [137, 138] and described as a "*lack of embodiment*" [138] p149. For example, with everyday technology this comprised an observed uncertainty about how to physically handle and manipulate items. This included not knowing how to utilise buttons on a phone and using too little or too much force when pressing buttons, resulting in numbers not registering when using

the phone, or increasing the volume on the television too loudly [137, 138]. Studies prominently highlighted difficulties understanding or knowing the appropriate function and application of items of everyday technology, for example, Nygård and Starkhammar [138] noted that participants would use a home portable phone as a mobile phone. Whilst not noted by Nygård and Starkhammar [138], it is unclear if observed difficulties 'knowing how' were associated with difficulties in 'knowing what' – that is, the individual was unable to identify the item / object correctly and therefore did not use it correctly.

Executive Functioning

Problems or difficulties associated with executive functioning, namely, attention and concentration, problem-solving and judging were also described. Difficulties arising from participants not 'noticing' environmental cues were reported when having to attend to multiple aspects of a task simultaneously, for example, when cooking multiple items or using the phone [137, 138]. Being unable to attend when cooking could lead to difficulties or risks, for example a pan boiling over, and secondary difficulties if the person also did not notice the pan boiling over [134, 138]. Not noticing information communicated by everyday technology, for example a wrong password display on a computer or mobile phone were also reported [138]. When information generated by everyday technology was noticed and recognised, difficulties understanding and responding to these complex environmental cues was also described as difficult, for example, being unable to follow instructions from an automated telephone service or answer phone [138]. Brorsson et al [131] highlighted that challenges crossing the road resulted from difficulties maintaining attention, concentration, and focus, and making decisions, judgements and solving problems in the moment were also identified as areas of difficulty. In the context of shopping, the latter included difficulties making a decision about which product to purchase or which trolley to use [131].

Mobility and Sensory Impairments

Whilst not identified by all studies, difficulties arising from co-morbid conditions, for example physical and sensory conditions, were noted by Brorsson et al [131] and Nygård and Starkhammar [137]. This included difficulties mobilising to answer the phone in time, visual impairments leading to difficulties seeing the phone or phone numbers as well as hearing impairments causing difficulties comprehending and communicating when using the telephone [137]. Brorsson et al [131] also identified difficulties physically mobilising through traffic and when crossing the road.

Emotional Wellbeing

The impact of experiencing difficulties and problems on the person living with dementia's thoughts, feelings and wellbeing were described, although not frequently. Brorsson et al [130] and Brorsson et al's [131] studies described instances where participants felt vulnerable, stressed, fearful, unsafe, and uncertain when performing activities in the community, which was also reported when performing activities at home [112, 145]. Significantly, Nygård and Starkhammar [138] highlighted that feelings of stress and uncertainty could be a more "*obstructive influence*" (p149) on ability to use technology than difficulties associated with memory for some participants. Brorsson et al [130] noted feelings of being excluded and perceptions of spaces and services as inaccessible, whilst some of Nygård and Borell's [134] participants expressed fears of embarrassment when thinking about others becoming aware of their difficulties.

4.4.2. Self-Initiated Adaptations and Strategies

Eleven qualitative studies [112, 130-134, 136, 137, 140, 142] reported on the adaptations and problem-solving strategies initiated and utilised by people living with dementia to prevent and respond to difficulties during occupational performance. In accordance with included studies' aims and objectives, strategies were observed and described in relation to difficulties experienced whilst using everyday technology [137, 142], performing everyday occupations at home [112, 133, 134, 136], in the community [130, 131], and at work [132]. Across studies, four sub-themes were identified, as outlined in Table 12. Significantly, a distinction was made across studies between spontaneous and in the moment strategies used to respond to difficulties, and those that were pre-planned to prevent difficulties from occurring [142]. It is important to note that strategies were susceptible to failure, did not always solve problems, were not always sufficient to solve a problem, or no strategies were used, leading to secondary problems [134]. Furthermore, whilst similarities were evident within studies regarding strategies utilised, Nygård and Borell [134] emphasise that strategies were used in an individual manner.

Table 12: Self-initiated Adaptations and Strategies: Sub-Themes

Theme	Sub-Themes	
Self-Initiated Adaptations and Strategies	Cognitive Strategies	Anticipatory and Preventative
		Being Present and Alert
		"*In the moment*" Corrective Acts
	Environmental Strategies	Visual, Tactile and Auditory Cues
		Equipment and Aids
		Help and Support from Others
	Habituation	
	Accepting Changing Occupational Conditions	
	Cessation and Avoidance	

Cognitive Strategies

Nygård and Öhman [136] provide a detailed account of cognitive strategies used by their participants, which were categorised in three clusters: Anticipatory and Preventative Strategies, Being Present and Alert, and Corrective Acts. These have been utilised to structure this brief synthesis about cognitive strategies described across studies. Whilst the majority of strategies identified involved cognitive processing, only strategies that are primarily based upon cognition are discussed here.

Anticipatory and Preventative: Anticipatory and preventative strategies were described by Nygård and Öhman [136] as strategies that aim to prevent difficulties from occurring in order to "*stay one step ahead of the possible consequences of their disease*" (p76). These strategies primarily involved being able to anticipate potential difficulties, making plans to avoid potential difficulties, and checking to ensure potential difficulties did not occur. One of Nygård and Johansson's [112] participants explains her anticipatory strategy: "*I try to anticipate certain problems that might pop up, to forestall them, so as to know how to act then. I sort of have to foresee how things will turn out…"* (p90).

To prevent anticipated difficulties or problems, individually tailored preparatory and planning strategies were described, including planning for a surplus of time by arriving early, making one appointment only a day, or using a high value note which would cover all purchases when shopping to overcome difficulties counting money [112, 131, 134, 136]. Taking time to plan and organise work related tasks was also reported by Chaplin and Davidson [132], which involved utilising diaries, filing systems, and cognitively running through steps involved in an activity. However, even with these

strategies, Chalpin and Davidson [132] noted that participants still found difficulties managing in a work environment. Checking was also described as a preventative strategy and involved repeatedly checking to ensure that problems did not occur, for example checking the door was locked [136], checking temporal reminders [112] and checking to see if the stove was switched off [134]. However, checking, was noted to be repetitive and involved checking and rechecking, taking up a considerable amount of time [137].

Being Present and Alert: Nygård and Öhman's [136] second cluster of cognitive strategies comprised those that were utilised by participants to ensure that they were present and alert to potential difficulties or problematic situations whilst performing activities. This was described as both an awareness of the need to be cautious "*in case anything should happen*" [136] p77 and behaviour based upon this awareness [130, 131, 136]. The latter included: minimising distractions whilst engaging in a potentially risky activity, for example whilst ironing and crossing the road [130, 131, 134]; ensuring attention and concentration is focussed on the activity at hand by taking a 'one thing at a time' approach [131, 134, 136]; limiting the number of aspects to a particular task which required divided or simultaneous attention [136]; as well as stopping and taking time, and doing things slowly [131, 134].

"In the moment" Corrective Acts: A third cluster comprised cognitive strategies utilised by participants themselves to respond to problems in the moment. Participants were observed and described by Nygård and Öhman [136] stopping an activity and reflecting or waiting, *"…hoping to regain what was lost or to discover what had failed*" (p77). Other in the moment strategies involved reversing the latest actions, for example tracing steps backwards when looking for an item and repeating actions or starting a task or activity again [134, 136, 137, 142]. However, Nygård and Öhman [136] noted that in the moment strategies were not always successful and "*expressed as somewhat uncertain*" (p77). Differences were evident within and across studies about the rationales provided by participants engaging in strategies which involved repeating or re-starting. Brorsson et al [131] additionally described the "*haphazard*" (p297) nature of participants' searching for items when shopping, which comprised walking around in an "*unstructured manner*" (p297) hoping to find the required item. A final in the moment strategy involved "*taking a chance*" [136, 142], and was characterised as an attempt to do something in the hope that it would be done successfully or a solution to the problem would come to mind. For example, Nygård and Öhman [136] describes a participant who found a piece of paper whilst shopping and decided to purchase items on the paper as they "*looked very good*" (p78).

Environmental Strategies

All 11 qualitative studies [112, 130-134, 136, 137, 140, 142] contributing to the theme 'Self-initiated Adaptations and Strategies' reported the use of environmental strategies, with three distinct categories identified: Visual, Tactile and Auditory Cues, Equipment and Aids, and Help and Support from Others.

Visual, Tactile and Auditory Cues: Sensory strategies utilising visual, auditory, and tactile environmental cues were described by all studies and were primarily used to support the identification or location of an object or to prompt action. Visual strategies, both spontaneous and planned, emerged as most prevalent and frequently involved strategically locating objects in visible areas for example on the kitchen table, hall, or door handle [112, 131, 134, 136, 137]. Nygård and Öhman [136] and Nygård and Starkhammar [137] describe the use of "*habits and habitual places*" (p244), where frequently utilised objects were kept and used in the same place. In addition to the strategic location of objects and items, written notes, diaries, and calendars were utilised to prompt participants' memory in the home environment about tasks that required doing, and in particular, appointments [112, 130, 134, 136, 137]. Written notes and instructions were also utilised to support performance whilst using technology to aid remembering numerical codes and passwords, for example to start a computer or phone [130, 136, 142] and to prompt action, for example shopping lists [131, 136]. Nygård and Borell [134] also describe one participant who used photos to "*concretise*" (p29) and make tangible the identity and relationship of people whom she spoke about.

Significantly, Brorsson et al [131] highlights that strategies based on prompting through the strategic location of items and notes were difficult to implement outside the home, since participants had little influence or control over the environment. Furthermore, written notes and shopping lists utilised external to the home environment were susceptible to failure if they were forgotten and a number of Brorsson et al's [131] participants had abandoned this strategy. Akin to environments external to the home, planned strategies based on visual cueing within the home environment were not failure free, particularly when the home environment was disorganised or was susceptible to interference or disruption from others [112, 131, 136, 137]. Nygård and Öhman [136], Nygård and Johansson [112] and Brorsson et al [131] additionally emphasised the vulnerability of cueing strategies, since they depend upon the ability to remember and recognise the intended cue, remove unwanted or unneeded cues from view, update notes and diaries and maintain order within the home environment.

Owing to these difficulties, spontaneous or in the moment visual cues and strategies were typically used outside the home environment, including looking for signs to identify a place [131, 136] and using pictures on packaging to identify products [131]. In the moment visual strategies were also used at home when seeking to identify objects and items, although did not feature as prominently across studies as those which were planned. At home, in the moment visual strategies appeared to be combined with other sensory strategies based on auditory and tactile cueing illustrated by Nygård and Öhman [136]: "*One participant, when checking the content of her refrigerator before shopping, simultaneously named and touched each item. She said, "Eggs I have got", and touched the egg box, then she did the same with the cheeses, the potato bag, the tomato bag etc*" (p75). Auditory strategies additionally included reading letters or information aloud, commenting out loud about occupational performance, and asking and then answering questions. Auditory cues from the environment were additionally used to orientate to an activity, for example the noise of boiling water reminding a participant that they were making a hot drink [136], and to identify an object and its location, for example following the ringing of the telephone [137]. Tactile strategies were rarely described, although manipulating and touching to aid identification of an item were described by both Nygård and Öhman [136] and Nygård and Starkhammar [137].

Equipment and Aids: Across studies, equipment and aids were rarely described, although some participants utilised dosettes to manage medication, and items of everyday technology were used as time aids. The latter involved using a timer or egg clock when cooking, an alarm clock to prompt to take medication, and a speaking watch to orientate to time [112, 134, 136, 139]. Nygård [139] noted that simpler technology would be used to compensate for difficulties using more complex technology (e.g., an egg timer instead of a more complex timer on a cooker). However, strategies based on equipment and minor aids were not always used or led to further difficulties. For example, multiple dosette boxes were used by one of Nygård and Borell's [134] participants, leading to confusion about which dosette box was the correct one. Furthermore, participants also expressed not wanting to use or not liking assistive devices, for example timers. Other participants forgot to use their assistive devices or the devices were not fit for the purposes required, for example, a speaking watch was not water proof and thus interfered with daily chores [112].

Help and Support from Others: Seeking help and support from others was described by all studies, however, was not noted as prevalently as cognitive and other environmental strategies. Furthermore, detailed information about the nature and degree of social support strategies was seldom provided. Strategies described included asking for support to complete an element of an activity when

difficulties were experienced. For example, when calling an unfamiliar phone number [137], when using everyday technology [142], when feeling disorientated in the community, and when paying for items whilst shopping [131, 134]. In a work environment, Chaplin and Davidson [132] also identified that help from others was utilised to assist with tasks that were considered by the person to be difficult. Implicit and explicit role modelling was also described by Nygård and Öhman [136], with participants following a spouses' routine and activity when cleaning the house. Another strategy when accessing the community included performing activities in the presence of others, to provide reassurance, or to be at hand if support was required in particular in the afternoon and evening when participants expressed difficulties in finding the way [130]. A strategy primarily utilised by participants living with a spouse included leaving certain tasks and activities to the spouse, for example timekeeping [112] and using a cash machine [142].

Habituation

Although not a strategy described by all studies, Nygård and Öhman [136] highlighted the importance their participants placed on using familiar routines, for example following the same daily routines and sequences of activities. Brorsson et al [130] also noted participants' use of familiar "*space-time patterns*" (p592) in the community, including doing the same things at the same time in the same place, for example attending the same shop on the same day and time every week. Using familiar places and activities was perceived by Brorsson et al's [130] participants as an important way of enabling them to perform occupations independently outside the home environment. Familiarity of the home environment itself was emphasised by one of Öhman's [140] as enabling and supporting, with one participant having returned to where she grew up to "*come home*" (p92). In addition to space and time, strategies based on habituation were also evident in relation to objects and items. Brorsson et al [130] described the importance participants placed on purchasing the same product brand to facilitate familiarity, whilst Nygård's [136] participants compared unfamiliar items with familiar ones to aid identification. It must be noted, however, that Brorsson et al [130] identified that habituation and familiarity confined and limited their participants' access to outside space, which could be a negative consequence of pursuing such a strategy.

Accepting Changing Occupational Conditions

In contrast to other strategies, which were specifically concerned with preventing and responding to difficulties manifested during occupational performance in the short-term, Nygård and Öhman [136]

described a number of strategies which were utilised by some participants to manage and come to terms with the cumulative difficulties and changes in occupational performance over time. Based upon an appraisal of current ability and difficulties experienced, this longer-term strategy appeared to facilitate both an attitudinal and behavioural change. Emphasis was placed by both Nygård and Öhman [136] and Nygård and Johansson's [112] participants on accepting that their abilities to perform occupations had changed, and that their expectations for performance required modifying. Detailed information about strategies utilised to facilitate acceptance were not prevalent, however, Nygård and Öhman [136] and Öhman et al [141] noted that their oldest participants utilised a normalising strategy: participants derived comfort from knowing that others their age had difficulties with their memory. Other participants described how they facilitated an attitudinal change by laughing at mistakes, thinking about the "*here and now*" (p73), not giving up, remaining open to adjustments, and being determined to meet future goals. However, Nygård and Öhman [136] noted that maintaining an acceptant attitude to present circumstances was difficult and participants still spoke about feelings of anger and irritation when experiencing difficulties. Furthermore, for some of Öhman et al's [141] participants, a normalising strategy, or comparing to others was not experienced as comforting, with one stating *"…the worst thing is that I now compare myself with him, and this is…horrifying*" (p48).

Accepting changing occupational conditions typically resulted in longer-term adaptations to patterns of occupational performance, habits, routines, and choices [112, 130, 131, 136]. A prominent strategy comprised adjusting routine tasks and activities to meet perceived competence, for example utilising smaller shops within walking distance rather than larger ones further away [131] and avoiding busy times e.g. rush hours, or writing by hand rather than utilising a computer [138]. Another strategy involved changing occupations of a complex nature to ones that were less demanding, for example, listening to the radio instead of TV [136], or performing manual activities rather than intellectual ones. Conversely, some participants described starting new occupations or activities, for example completing difficult crosswords to prevent deterioration [136]. Nygård and Öhman [136] characterise the process of making adjustments as a continuous process as competence changes: "…a *balancing act seemed to take place between keeping active and still protecting themselves and others from the possible consequences of their deficient ability*" (p73).

Cessation and Avoidance of Occupations

Strategies based on avoiding or stopping occupations and ceasing to use certain items of everyday technology were also described, sometimes in the context of a longer term self-initiated strategy, as described above, [140] and sometimes as an in the moment strategy in response to difficulties or problems [138]. However, Nygård [139], Öhman and Nygård [140] and Brorsson et al [130] also reported that some participants attributed the cessation of occupations to the consequences of ageing or significant life events or changes, for example retirement, the death of a spouse or changing interests. The cessation of occupations due to others was also described, for example on the advice of a doctor, or due to family members, as described in the theme 'Strategies Initiated by Others' (Section 4.4.3.). The consequences of strategies based on cessation and avoidance were described, including an increasingly restricted repertoire of activities which were limited to the home environment [130, 134, 138].

4.4.3. Strategies Initiated by Others

The third theme identified pertained to adaptations and strategies initiated by others, namely caregivers, family and employers, with four studies [132, 140, 143, 144] utilising a qualitative design contributing to this theme. Only Vikström et al [143] aimed to specifically explore carer initiated social support through observation, however, Vikström et al [144], Öhman and Nygård [140] and Chaplin and Davidson [132] also generated data on support initiated by carer, family or employers through semi-structured interviews. Vikström et al [143] identified strategies that had a positive and negative impact on the occupational performance of a person living with dementia whilst making tea and the dilemmas caregivers face when caregiving, which have been used to synthesise data across studies (Table 13).

Table 13: Strategies Initiated by Others: Sub-Themes

Theme	Subthemes
Strategies Initiated by Others	Positive Aspects of Support
	Negative Aspects of Support
	Dilemmas Faced by Caregivers

Positive Aspects of Support

Strategies supportive of occupational performance included enabling and supporting the person living with dementia's "*own doing*" by adopting what Vikström et al [143] called *"an attentive and permissive approach*" (p152). Firstly, an attentive approach included being available, aware, and attentive to both the person living with dementia's emotional needs during occupational performance as well as the demands of the activity. In relation to the latter, Vikström et al [143] observed that caregivers took overall responsibility for the activity in an indirect manner, by '*keeping an eye'* on progress and by ensuring the task remained on track. This was also noted by Öhman and Nygård [140], with three participants' spouses taking a "*lead role*" (p94) when performing occupations together. Practical support was also provided by Vikström et al's [143] participants, including adapting the physical space within which the activity was being performed. This involved removing unnecessary items from the environment and placing forwards items necessary for the activity. Adapting the activity to make it easier, for example completing difficult steps, including those that were difficult to understand or remember e.g., turning on a coffee maker or by initiating or completing the first step, were also identified as strategies [140, 143]. As well as practical support, verbal guidance and reminders prior to encountering difficulties were perceived by Vikström et al [143] as supportive, particularly when delivered as short instructions and cues. Suggesting solutions when problem solving or making decisions and providing confirmation that actions were correct was also observed as helpful. To meet the person living with dementia's emotional needs, caregivers were observed providing verbal encouragement and reassurance, for example "*I'm over here if you need me*" and "*Take your time*" [143] p152; and by providing compliments and positive reinforcement "*That's the way to do it*" and "*Looks good"* [143] p153. Caregivers were also observed providing time for the person to solve problems themselves without pressure or interference.

Secondly, a permissive approach comprised accepting that the task was not being completed as intended, or to the standard expected by caregivers [143, 144]. This was demonstrated through verbal strategies including minimising any failures or shortcomings by articulating reasonable explanations about why something went wrong, or by caregivers demeaning themselves. In addition to verbal strategies, caregivers were observed discreetly correcting mistakes and by sensitively providing verbal corrections or suggestions about how the activity could be completed.

Negative Aspects of Support

Negative aspects of caregiver support were described by Vikström et al [143] as strategies that were "*insufficient",* "*inappropriate*" or "*failed to respond to support needs"* (p 152). These typically resulted in confusion and consequently difficulties for people living with dementia and appeared to directly contrast with an attentive and permissive approach.

Firstly, evidence of being inattentive included not acknowledging in a timely manner signs of hesitation, insecurity, and frustration, not being in the environment to support performance, and not '*guide[ing]*' or *'steer'[ing]* the activity if the person living with dementia deviated from the task, leading to mistakes. Secondly, evidence of not being permissive included responding in a dismissive manner, for example '*You should not need to ask that*' [143] p156, and by taking over rather than supporting the persons' own doing [143, 144]. The latter was also reported by Öhman and Nygård [140], who additionally described how one of their participants perceived their spouse as an interference since they did not allow them to carry out their activities in the way they wanted to: *"…she [spouse] did not allow him to go out on his own to prevent him from getting lost, which left him with a feeling of "being in captivity""* (p94). A third category of negative caregiver support identified by Vikström et al [143] included providing inappropriate support through ambiguous or incomplete verbal prompts, providing too little or too much information, and by delivering support too quickly without providing an opportunity for the person to think and try the task themselves.

Evidence of an inattentive, non-permissive and inappropriate approach was also described by Chaplin and Davidson [132] in a work environment. Chaplin and Davidson [132] described how employers increased their observation of employees with dementia without discussion, leading some participants to feel they were being "*watched covertly*" (p153). Whilst some employees were offered minor adjusted duties, some were advised to take sick leave and had their employment terminated without consultation [132]. A lack of effort on the part of employers to make reasonable adjustments under the Equality Act (2010) was noted as well as a failure to recognise their remaining skills and adapt work roles to support the persons own doing.

"Dilemmas" Experienced by Caregivers

During interviews with spouses, Vikström et al [144] identified a number of "*dilemmas"* that they experienced every day, which provided a context to the positive and negative aspects of support

outlined above. They described that spouses experienced a dilemma between allowing the person living with dementia to continue to perform complex activities that they do not have the competence to carry out anymore, which could have negative or risky consequences, or to prevent this from occurring and infringe on the persons autonomy and freedom. A further dilemma was noted in relation to whether the spouse put their own needs or those of the person living with dementia first. Many were reluctant to receive support from others since they were concerned about the impact this would have on their spouse with dementia. However, the demands of being the sole caregiver led to isolation, feelings of exhaustion, experiencing a lack of time for themselves, and not being able to leave the person living with dementia alone. This in turn led to feelings of frustration, which led to negative caregiving patterns, for example, some caregivers described taking over chores at home to avoid conflict, rather than making their spouse upset that they had completed the task incorrectly.

4.4.4. Awareness of Change

Four qualitative studies [132, 133, 139, 141], and one cross-sectional study [150] generated data on people living with dementia's awareness and insight into the impact dementia had on their ability to perform everyday occupations. Awareness was described by Öhman et al [141] and Öhman et al [150] as an of awareness of the consequences of dementia on everyday occupations, the disability or limitations it causes, and the impact it has on independence. Whilst Nygård et al [133], Nygård [139] and Chaplin and Davidson [132] did not specifically explore the phenomenon of awareness, both generated data through interviews and observations about participants' awareness and insight into their ability, in relation to homemaking activities, everyday technology and work (respectively).

4.4.4.1. Quantitative Evidence

Öhman et al [150], utilising the Assessment of Awareness of Disability (AAD) after conducting an observational assessment of performance using the Assessment of Motor and Process Skills (AMPS), reported that participants living with dementia had an overall lower mean AAD score than participants with MCI, with participants living with Alzheimer's Disease (AD) demonstrating a greater awareness than participants with other forms of dementia. However, Öhman et al [150] notes that the score range was large, with considerable overlap between those with AD and MCI, and that performance ability did not always predict awareness.

4.4.4.2. Qualitative Evidence

Öhman et al's [141] participants described awareness retrospectively as something that they experienced gradually, "*little by little*" (p46), which typically commenced by becoming aware that they were having difficulties with discrete elements of a task, for example counting money or finding required objects. This was also described by Chaplin and Davidson's [132] participants, who became aware that they were experiencing changes in their ability to write in the correct location, forgetting place names and being unable to adjust to new tasks. However, at this early-stage, Chaplin and Davidson [132] reported that participants did not consider these difficulties to be symptoms of dementia or another serious health condition, attributing them to other factors, including work pressures and poor eyesight. Significantly, Öhman et al [141] reported that some participants reflected that changes were difficult for themselves to see, with one stating that their awareness was facilitated following notification from others. However, over time they recounted experiencing a "*growing gap*" (p46) between what they could do prior to dementia and their actual performance. This awareness resulted in a realisation that an incongruence existed between their expectations about their ability, and their actual ability. Some participants expressed attempting to test their capabilities by trying to carry out complex activities, for example a participant who was a skilled baker, continued to bake in order to discover where her limits were [141].

In contrast to Öhman et al's [141] participants, Nygård's [139] participants demonstrated inconsistencies in their awareness of their ability to manage everyday technology. Despite being aware that they had dementia and had made adaptations to their activities, they did not express when questioned that their ability to use everyday technology had changed. However, they became aware of difficulties when asked to demonstrate their use of everyday technology, yet despite experiencing difficulties, continued to maintain the view that their ability to manage technology had not changed. Akin to Nygård [139], Nygård et al's [133], participants typically expressed ambivalent, contradictory statements that they had not noticed any differences in their day-to-day life, however on other occasions expressed anxiety about their ability to cope with day-to-day activities or described that things took longer to do. Nygård et al [133] postulated that conflicting perceptions of ability among their participants derived from a "*twofold experience of both being competent, based on former experiences, and at the same time experiencing possible incompetence, due to new problems in everyday activities*" (p131). Nygård [139] identified multiple alternative explanations for this inconsistency, including the incorporation of everyday technology "*…in the daily routine to such an extent that the management of it was taken for granted"* (p493), and that participants did not

attribute changes in their use of technology to dementia, but rather due to life events e.g. the death of a spouse and retirement. Furthermore, Nygård's [139] participants also did not perceive being unable to use technology that they did not regularly use at home as problematic. This was associated with perceptions of what was considered acceptable and the 'norm' by society, for example they all felt that being unfamiliar with technology used in a workplace situation, for example a computer, was acceptable. However, all felt that they should be able to manage technology within their own homes, thus whilst not managing a computer was acceptable, using routine technology for example the iron was expected: "*This seemed to reflect a norm for them concerning what was 'normal' in terms of technological competency and what was not, in response to the expectations they had of themselves and those they perceived from society*" (p491).

4.4.5. Meaning and Motivation

The fifth and final theme pertained to people living with dementia's motivation to perform activities, as well as the meaning associated with occupations, with three studies [130, 139, 140] utilising a qualitative design contributing to this theme. Öhman and Nygård [140] and Nygård [139] and Brosson et al [130] generated qualitative data through interviews and observations with three subthemes utilised to synthesise data across studies (Table 14).

Table 14: Meaning and Motivation: Sub-Themes

Theme	Sub-theme
Meaning and Motivation	A Sense of Normality
	Autonomy and Freedom
	Maintaining Identity

A Sense of Normality

Being able to continue with day-to-day habits and routines that they enjoyed prior to having dementia were expressed as important by Öhman and Nygård's [140] participants, and evidence of "…*things not being too bad*" (p92). Whilst specific daily occupations appeared not to be significant in and of themselves to participants, the pattern and routine collectively appeared to convey a sense of normality by "*doing the things we do*" (p92). Whilst Öhman and Nygård's [140] participants appeared to be motivated by an internal sense of normality, Nygård [139] noted that their participants sought to convey a sense of normality to others through their use or non-use of everyday technology. Some

participants expressed concerns that failure to use technology, for example a cash machine, would convey a sense of abnormality to others. In contrast, another participant chose not to use a timing device when cooking, since this would convey difference to others.

Autonomy and Freedom

A feeling of autonomy and freedom was also expressed as important by Öhman and Nygård's [140] participants, which included being able to do things for themselves, on their own terms, without external influence. To do this, participants described creating a personal, private space for specific occupations, at home or alone in the community, where they could be free to do things their way, which they associated with feelings of enjoyment and inner peace and independence. Brorsson et al's [130] participants highlighted the importance of staying independent and active, doing as much as they can in order to maintain their health and skills.

Maintaining Identity

Both Nygård [139] and Öhman and Nygård [140] identified that occupations and the context within which they were performed were associated with maintaining a person's sense of self and identity. Whilst both studies noted that perceptions of self were individualised, they appeared to influence motivation for certain occupations. For example, one of Nygård's [139] participants perceived herself as an active person and therefore felt that using everyday technology was important as it enabled her to do what she expected an active person to be doing. In contrast, another participant did not use his computer or cameras since they were no longer of use to him as someone who viewed himself as retired. Another participant who did not consider herself competent with everyday technology, enjoyed learning how to use a computer since making mistakes doing so did not compromise her identity and provided her with the freedom to fail without negative consequences to her sense of self. Both Nygård [139] and Öhman and Nygård [140] identified that doing things for others was highly valued for some participants, leading to a sense of "*being someone*" in relation to others (p92). Öhman and Nygård's [140] participants also placed a significant emphasis on maintaining identity through temporal and topographical contexts, for example carrying out occupations that were family traditions, being surrounded by family photos and carrying out occupations in locations from their past.

4.5. Discussion

This synthesis aimed to describe, appraise, and synthesise non-intervention studies reporting on the impact early-stage dementia can have on occupational or activity performance. Twenty-two studies met inclusion criteria: 16 using a qualitative design, and six using an observational cross-sectional design generating quantitative data. There was a notable lack of studies from the UK, with only one study conducted in a UK context [132]. Five primary themes were identified across studies: '"*Problems*", "*Difficulties*" and "*Critical Incidents*"', 'Self-initiated Adaptations and Strategies', 'Strategies Initiated by Others', 'An Awareness of Change', and 'Meaning and Motivation'. These were generated inductively and have been described in the preceding sections in detail. Whilst this synthesis has remained inductive, staying close to data and themes generated by included studies, it aimed to answer the question: 1.1.1. *What impact, if any, does early-stage dementia have on the occupational (activity) performance or people living in the community?* The discussion will therefore move briefly to answer this question.

4.5.1. Impact on Occupational Performance

It is important to acknowledge that impact on occupational performance was reported by studies using a qualitative approach to be highly individual and dependent on a person's individual context, therefore the impacts described in this synthesis may not be universal. With this caveat, the initial theme (Section 4.4.1.) identified that people living with early-stage dementia experienced or were observed to experience "*problems*", "*difficulties*", and "*critical incidents*" when performing occupations, namely Instrumental Activities of Daily Living (IADL), work and activities involving everyday technology. Studies generating quantitative data also highlighted that people living with early-stage dementia subjectively perceive IADL as difficult.

Problems and difficulties were typically discussed by studies utilising a qualitative approach in the context of the impact dementia had upon a person's skills and abilities e.g., memory, temporal orientation. These were described primarily using the sub-themes "*Knowing Where*", "*Knowing What*", "*Knowing When*", "*Knowing How*", identified by Nygård and Johansson [112] and Nygård and Starkhammar [137] and the theme 'Awareness of Change' (Section 4.4.4.) However, causal factors not associated with dementia were also noted, including sensory and physical impairments and a person's physical and social environments. Unfamiliar or changed physical environments at home and in the community were reported as challenging, increasing the demand of an activity, as well as the

physical design of everyday technology. The impact of the social environment was described in detail in the theme 'Strategies Initiated by Others' (Section 4.4.3.), including the increased involvement of others in the performance of occupations, which can have both a positive and negative impact on performance. Feelings of stress and anxiety were also noted as a causal factor in a minority of studies.

The second theme 'Self-Initiated Adaptations and Strategies' (Section 4.4.2.) identified that the way in which occupations were performed had changed for some participants who had developed their own strategies to prevent or respond to problems. These were described in detail in Section 4.4.2. and included impacts or changes that were temporal in nature, including an increased amount of time spent planning and preparing for occupational performance, interruptions to the flow and continuity of an activity, and an increase in the duration of time and energy required to complete activities. Changes in the way the physical and social environments were used during occupational performance were also noted, for example sensory cues as a self-initiated strategy, confining performance to familiar locations and asking for help.

4.5.2. Strengths and Limitations

Strengths and limitations relating to the synthesis' methodology have been described in Chapter 3, this discussion will therefore focus on the limitations of the evidence included in this synthesis. Firstly, this body of evidence derives primarily from one research group, with 20 studies published from the Karolinska Institute in Sweden. Given this geographical bias, only one study was conducted in the UK [132] and this pertained to the occupation of work, as opposed to IADL, community access and everyday technology, which the remainder of the evidence pertained to. Whilst the limitations of generalising from qualitative studies is widely cited [152], the geographical and cultural bias in this synthesis may limit the transferability of findings to other contexts. A further limitation pertained to the tendency for studies from the Karolinska Institute to synthesise observational and interview data together, which made it difficult to determine if author summaries were based on their observations or were based on the expressed experiences of participants. The number of participants who experienced a particular difficulty, or the frequency or prevalence of these difficulties were also not routinely reported and therefore it is not possible to conclude if some difficulties were more prevalent than others. Whilst studies utilising a qualitative design included small numbers of participants, which raises concerns about generalisability, this permitted a detailed analysis and description of findings, which provided important insight into the lived experience of occupational performance. Aside from

studies included in this synthesis, the lived experiences of these difficulties during occupational performance have not been documented widely.

4.6. Synthesis Update

As described in Chapter 3, the evidence was searched again towards Thesis completion. No studies met eligibility criteria for the Population Synthesis and a PRSIMA flow diagram can be found in Chapter 3, Figure 7. It is important to acknowledge that 16 of the 22 publications meeting eligibility criteria for this synthesis in 2017 were identified from citation searching, which was not replicated in 2022, and this may account for these results on updating.

4.7. Chapter Conclusion

This synthesis has highlighted that there is an absence of studies from the UK examining the impact early-stage dementia has on occupational performance, and globally on the impact associated with activities beyond IADL and everyday technology. It has identified that impact on performance is highly individual, however, people living with early-stage dementia are likely to experience occupational performance difficulties due to dementia itself, as well as comorbid conditions, for example, physical and sensory impairments. Problems during performance are associated with risk, mistakes, non-completion of an activity and an increased duration of time and effort. Problems can lead to feelings of stress and anxiety in anticipation of performance, during performance, and after, which can compound the impact dementia and co-morbid conditions have on performance. Without occupational therapy intervention, people living with early-stage dementia do attempt to problem-solve with their own strategies, however these were reported to be highly individual and may or may not solve a problem and may make a problem worse. The social and physical environments influence the problems experienced and the problem-solving strategies utilised by people living with early-stage dementia and caregivers can provide support that is both supporting of a person's own doing and unsupportive.

Chapter 5: Intervention Synthesis

5.1. Introduction

In this Chapter, Study 1's second synthesis' findings are presented. This synthesis describes, quality appraises and synthesises studies relating to interventions delivered, managed, or designed by occupational therapists for people living in the community with early-stage dementia. It aimed to answer the following questions, in accordance with Thesis Objective 3:

1.3.1. What is the nature of occupational therapy intervention for people living with early-stage dementia in the community?

1.3.2. What outcomes are reported in relation to occupational therapy intervention for people living with early-stage dementia in the community?

1.3.3. What are people's views and experiences of occupational therapy intervention for people living with early-stage dementia in the community?

1.3.4. What barriers and facilitators are described in relation to occupational therapy intervention for people living with early-stage dementia in the community?

All study designs were eligible for inclusion, including experimental and quasi-experimental studies, case reports and case studies, process evaluations, and qualitative studies. Methods have been discussed in Chapter 3 and therefore included studies' methodological and substantive characteristics and quality appraisal will be described in this Chapter, followed by a thematic summary and discussion.

5.2. Included Studies

31 publications reporting on 25 studies met eligibility criteria, with Figure 6 (Chapter 3) depicting the review's PRISMA flow diagram, including the results of searching, screening, and final inclusion. Of the 25 studies included in this synthesis, study design was primarily experimental or quasi-experimental and comprised eight Randomised Controlled Trials (RCT's) [43, 48, 89, 153-157], three Controlled Trials (CT's) [95, 98, 158], two using a pre-post one group design [159, 160], and two retrospective cohort studies [161, 162]. Eight studies utilising a case-study design were included [94, 96, 97, 112, 163-166] as well as two studies using a qualitative design [167, 168]. An additional six publications reporting on secondary outcomes, process analyses and study protocols met inclusion criteria [44, 45, 169-172].

These pertained to three RCTs: Graff et al [43], Voigt-Radloff et al [48] and Clare et al [89] and are presented in Table 15.

Table 15: Studies with Multiple Publications

		Intervention		
		Community Occupational Therapy in Dementia (COTiD)		Goal Oriented Cognitive Rehabilitation
RCT Primary Outcomes		Graff et al [43]	Voigt-Radloff et al [48]	Clare et al [89]
Publications	Study Protocol		Voigt-Radloff et al [169]	
	Secondary Outcomes	Graff et al [44]		Van Paasschen et al [171]
	Economic Evaluation	Graff et al [45]		
	Process Evaluation		Voigt-Radloff et al [170]	Clare et al [172]

Of the 25 studies that met eligibility criteria, only two were conducted in the UK [89, 159], with an additional 11 [43, 48, 94, 96-98, 112, 162, 165, 166, 168] conducted in central and western Europe, including Sweden and Germany. One was carried out in the USA [95], four in South America [155, 158, 161, 163, 164], six in Asia [153, 154, 157, 160, 161, 167] and one in Australia [156]. Twenty-four studies included participants living with dementia, 13 studies additionally included family or caregivers [43, 48, 89, 94, 95, 98, 156, 158, 159, 163, 165-167], and one study included occupational therapists as participants [168]. Across studies involving participants living with dementia, sample sizes ranged from one [94, 165] to 206 [162]. Only studies reporting a mean MMSE of 18 or above were included in this synthesis and of the twenty-three studies that reported individual or mean MMSE for participants receiving the experimental intervention, a mean MMSE of 20.4 was reported, ranging from 18 to 25. Ten studies [89, 94, 98, 153, 155, 156, 158, 161, 165, 166] reported a mean MMSE of 21 or above, which is currently utilised as a benchmark for early-stage dementia by the Memory Services National Accreditation Programme (MSNAP) [26]. Sixteen studies reported dementia sub-type: Nine included participants with Alzheimer's Disease (AD) only [95, 153-155, 158, 161-163, 166], and aside from Graff et al [165], a case study of an individual living with dementia with sub-cortical features, a range of 72.7% to 100% of participants with AD was reported by the remaining six studies [89, 94, 96, 97, 112, 164]. Mean age ranged from 63 to 79.1 across studies reporting participant age. All participants were community dwelling, which was a synthesis inclusion criterion. Table 16 contains further details about included studies' methodological and substantive characteristics, including study aims, and participant demographics.

Table 16: Intervention Studies: Methodological and Substantive Characteristics

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Occupational Therapy								
Graff et al [43] RCT Single site *Graff et al* [44] *Secondary Outcomes* *Graff et al* [45] *Economic Analysis* Netherlands	To determine the effectiveness of COTiD on the daily functioning of patients with dementia and the sense of competence of their care givers.	Inc: 65 or over, mild-moderate dementia, living in community, caregiver. Exc: Above 12 GDS, severe behavioural or psychological symptoms, severe illness, not on stable treatment of a dementia drug.	n =	68	67	Caregiver Intervention: n = 68 Age: 66.0 (SD 15.3), Female: 67.65%; Spouse: 60.29%. Caregiver Control: n = 67; Age: 61.3 (SD 15.4) Female: 73.13%; Spouse: 56.72%.	COTiD	'Usual care'
			MMSE:	19 (SD 5.7)	19 (SD 4.0)			
			Age:	79.1 (SD 6.2)	77.1 (SD 6.3)			
			Education:	NR	NR			
			Female:	57.4%	53.7%			
			AD:	NR	NR			
Graff et al [165] Pre-post, single case Netherlands	To enhance insight into the process of occupational therapy and the changes after, in an older patient with mild dementia and his primary caregiver.	Inc: Mild – severe dementia, living at home, informal primary caregiver, motivated to participate in intervention. Exc: Behavioural or psychological symptoms of dementia.	n =	1		Caregiver: n = 1, Age: NR; Female: 100%; Spouse: 100%.	COTiD	
			MMSE:	24				
			Age:	71				
			Education:	NR				
			Female:	0%				
			AD:	0%				
Voigt-Radloff et al [48] RCT Multi Site (n = 7) *Voigt-Radloff et al* [169] *Study Protocol* *Voigt-Radloff et al* [170] *Process Analysis* Germany	To compare the benefits and harms of a Dutch 10 session COTiD programme for patients with AD with the impact of a one session consultation at home in German routine healthcare.	Inc: Mild-moderate dementia (MMSE 14-24), diagnosed AD or MD (ICD 10), living in community, caregiver. Exc: Above 12 GDS or major need for physical nursing care of more than 120 minutes per day, unstable medical conditions, severe behavioural disturbances.	n =	71	70	Caregiver Intervention: n = 71 Age: 64.9 (SD 15.7), Female: 66%; Spouse: 56%. Caregiver Control: n = 70; Age: 64.5 (SD 14.4) Female: 76%; Spouse: 57%.	COTiD	1hr Community Occupational Therapy Consultation (COTC)
			MMSE:	20.2 (SD 3.2)	20.7 (SD 2.7)			
			Age:	77.8 (SD 7.4)	78.5 (SD 6.3)			
			Education:	75% (9–10 years)	74% (9-10 years)			
			Female:	58%	57%			
			AD:	NR	NR			

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Josephsson et al [96] Pre-post single case design Sweden	To examine the effects of the intervention programme.	Inc: Dementia diagnosis DSM-III-R Exc: NR	n = MMSE: Age: Education: Female: AD:	1 18 65 NR 0% 100%			Supporting everyday activities in Dementia	
Josephsson et al [97] Pre-post single case design Sweden	To evaluate an intervention programme aimed at supporting occupation rather than improving cognitive abilities in dementia. To identify the quality and frequency of task performance.	Inc: Dementia diagnosis DSM-III-R Exc: NR	n = MMSE: Age: Education: Female: AD:	1 20 79 NR 100% 100%			Supporting everyday activities in Dementia	
Dooley and Hinojosa [95] CT USA	To examine the extent to which adherence to occupational therapy recommendations would increase the quality of life of persons with AD living in the community and decrease the burden felt by family members.	Inc: Living in own homes, caregiver, Possible or Probable AD, Mild – Moderate dementia – MMSE 10 – 30. Exc: Major Depression.	n = MMSE: Age: Education: Female: AD:	40 20.9* 77.08 (SD 8.86) High school = median 60% 100%		Caregiver Intervention & Control: n = 40; Female: 80%; Spouse: 50%.	Brief Occupational Therapy Intervention	No treatment
Cummings and Warren [168] Exploratory, Qualitative Ireland	To provide an in-depth understanding of occupational therapists' experiences of working with people with early-stage dementia and explore the type of interventions presently being employed in Ireland.	Inc: Occupational Therapists who work with people living with dementia, some of whom are in the early-stages of dementia, with experience of 6 months or more working in this clinical area. Exc: NR.	n = MMSE: Age: Education: Female: AD:			OTs: n = 6; Age: NR; Female: NR; Practice Setting: Ranged from acute in-patient to day hospital to community; Experience: Ranged from 9 months to 5 years.	N/A	

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Cognitive Rehabilitation								
Kim [153] RCT South Korea	To investigate the effect of cognitive rehabilitation including tasks of cognitive training on performance of everyday activities in elderly people with early-stage AD.	Inc: Possible / probable AD, early-stage dementia – MMSE 18 or above. Exc: Concurrent neurologic disorder or major psychiatric disorder.	n =	22	21		Cognitive Rehabilitation and Training	Unstructured conversation & health related videos. 1 hour each week for 8 weeks.
			MMSE:	23.1 (SD 2.1)	22.8 (SD 1.8)			
			Age:	70.4 (SD 7.9)	71.4 (SD 8.2)			
			Education:	8.7 (SD 3.8)	8.5 (SD 3.1)			
			Female:	63.6%	66.7%			
			AD:	100%	100%			
Clare et al [89] RCT Single Site *Van Paasschen et al* [171] *Secondary Outcomes* *Clare et al* [172] *Process Analysis* UK	To provide evidence regarding the clinical efficacy of cognitive rehabilitation in early-stage AD. To determine whether cognitive rehabilitation would produce improvement in performance in targeted areas of everyday activity.	Inc: Probable AD, early-stage dementia, MMSE 18 or above, stable dose of AChEI. Exc: Prior or current major psychiatric disorder, neurological disorder or if medication changed during study.	n =	22	G1: 24 G2: 22	Caregiver Intervention: n = 15; Spouse: 80%. Caregiver Control G1: n = 16; Spouse: 62.5%. Caregiver Control G2: n = 13; Spouse: 76.92%.	Goal-oriented Cognitive Rehabilitation	G1: Relaxation Therapy 1 hour per week for 8 weeks. G2: Control: No treatment
			MMSE:	23.14 (SD 3.12)	G1: 23.33 (SD 2.88) G2: 22.32 (SD 3.05)			
			Age:	76.32 (SD 6.39)	G1: 77.92 (SD 6.23) G2: 78.18 (SD 6.61)			
			Education:	11.41 (SD 2.81)	G1: 10.92 (SD 2.52) G2: 11.43 (SD 2.99)			
			Female:	59.1%	G1: 58.3% G2: 59.1%			
			Diagnosis AD:	72.7%	G1: 87.5% G2: 81.8%			

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Adam et al [94] Pre-post single case study design Belgium	To present the assessment and intervention programme which was conducted in a day centre.	NR	n =	1		Caregiver: n = 1, Age: 78; Female: 0%; Spouse: 100%.	Cognitive management of daily activities	
			MMSE:	25				
			Age:	70				
			Education:	3				
			Female:	100%				
			AD:	100%				
Cognitive Training								
Neely et al [98] CT Sweden	To examine the effectiveness of a collaborative memory intervention for persons with dementia and their spousal caregivers, where the couple acquired and practised memory supportive strategies to learn a face name association and to set a table for coffee / tea.	Inc: AD or VD diagnosis, mild-moderate severity. Exc: NR	n =	10	G1: 10 G2:10	Caregiver Intervention: n = 10; Age: 74.1 (SD 8.6). Caregiver Control G1: n = 10; Age: 72.1 (SD 5.9). Caregiver Control G2: n = 10; Age: 75.3 (SD 8.5).	Collaborative Cognitive Training	G1: Individual Cognitive Training I hour a week x 8 weeks & 1 psycho-education session 30mins / 40mins in length. G2: no treatment.
			MMSE:	21.0 (SD 3.3)	G1: 22.9 (SD 4.15) G2: 18.6 (SD 5.7)			
			Age:	74.4 (SD 6.0)	G1: 74.8 (SD 6.7) G2: 77 (SD 6.6)			
			Education:	NR	NR			
			Female:	70%	G1: 40% G2: 40%			
			AD:	NR	NR			

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Reminiscence								
Chung [160] Pre-post one group design Hong Kong	To examine the values of a reminiscence programme, adopting an intergenerational approach, on older persons with early dementia and youth volunteers.	Inc: 65 and above, medical diagnosis of dementia and CDR above 1. Exc: Major physical disability or psychiatric disorders.	n =	49		Youth volunteers: n = 117; Age: 91% between 16 and 25 years; Female: 76%.	Intergenerational Reminiscence	
			MMSE:	18.2 (SD 3.22)				
			Age:	79 (SD 6.05)				
			Education:	49% no formal education				
			Female:	80%				
			AD:	NR				
Self-Management and Peer Support								
Sprange et al [159] Pre-post one group design UK	To determine the feasibility of conducting a future population-based trial into a self-management intervention for community-living adults with early-stage dementia.	Inc: Early-stage dementia (MMSE 20 or above – however, clinical judgement was also utilised), recent diagnosis, able to give informed consent, able to understand and communicate verbally in English. Exc: Later stage dementia, MCI, unable to understand and communicate in English, individuals who may express aggressive or disruptive behaviour.	n =	10		Caregivers n = 7; Age 40's – 80's; Female: 85.71%.	Journeying through Dementia	
			MMSE:	NR				
			Age:	60's – 80's				
			Education:	NR				
			Female:	64.7%				
			AD:	NR				

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Chung [167] Exploratory, Qualitative Hong Kong, China	To discuss an early dementia programme developed for people living with dementia and family carers in a Chinese context.	Inc: People living with early-stage dementia and their families. Emphasis was placed on including all in a family who provide support / care, rather than one primary caregiver, reflecting Hong Kong and Chinese cultural values. Exc: NR.	n =	8		8 families.	Memory Training and Psychosocial Support	
			MMSE:	22.1 (20-26)				
			Age:	72.6 years (68-78)				
			Education:	NR				
			Female:	62.5%				
			AD:	NR				
Assistive Technology								
Nygård and Johansson [112] Case study design Sweden	To clinically evaluate and describe individual interventions using time aids.	Inc: Diagnosed with dementia, have experience of temporal problems, willing and motivated in study and able to participate in interviews. Exc: NR.	n =	5			Management of temporality using time aids	
			MMSE:	20.5 (14-27)				
			Age:	63 (54-69)				
			Education:	NR				
			Female:	60%				
			AD:	80%				
Lindqvist and Borell [166] Case study design Sweden	To describe how persons in the early stages of AD become users of assistive technology.	Inc: Diagnosed with AD, knew about their diagnosis, comfortable discussing experiences, interested in trying AT over 6 months, minimum score of 18 on the MMSE.	n =	10		Caregiver: n = 10, Female: 60%, Spouse = 90%.	Individually Chosen Assistive Technology	
			MMSE:	23.3 (15 – 28)				
			Age:	66.6 (54 – 79)				
			Education:	NR				
			Female:	50%				
			AD:	100%				
Navarro et al [163] Pre-post case study design Mexico	To evaluate the effectiveness of an assisted cognition system AnswerPad/AnswerBoard to support occupational therapy interventions.	Inc: 'Elderly', diagnosed with AD, mild – moderate cognitive impairment (MMSE 14 – 24), living in the community. Caregivers – must be living with the person. Exc: NR.	n =	2		Caregiver: n = 3; Age: Range 43 – 66; Spouse: 33.33%.	Personalised Ambient-Assisted Occupational Therapy	
			MMSE:	19				
			Age:	'Over 70'				
			Education:	NR				
			Female:	50%				
			AD:	100%				

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
de Oliveira Assis et al [164] Pre-post single case study design Brazil	To develop and evaluate low-cost technology for cognitive rehabilitation in older individuals with dementia.	NR.	n = MMSE: Age: Education: Female: AD	1 20 73 3 years 0% 100%			Cognitive Technologies in Geriatric Rehabilitation	
Multi-Modal Intervention								
Navarro et al [163] Pre-post case study design Mexico	To evaluate the effectiveness of an assisted cognition system AnswerPad/AnswerBoard to support occupational therapy interventions.	Inc: 'Elderly', diagnosed with AD, mild – moderate cognitive impairment (MMSE 14 – 24), living in the community. Caregivers – must be living with the person. Exc: NR.	n = MMSE: Age: Education: Female: AD:	2 19 'Over 70' NR 50% 100%		Caregiver: n = 3; Age: Range 43 – 66; Spouse: 33.33%.	Personalised Ambient-Assisted Occupational Therapy	
de Oliveira Assis et al [164] Pre-post single case study design Brazil	To develop and evaluate low-cost technology for cognitive rehabilitation in older individuals with dementia.	NR.	n = MMSE: Age: Education: Female: AD	1 20 73 3 years 0% 100%			Cognitive Technologies in Geriatric Rehabilitation	
Kumar et al [157] CT India	To study the effects of a novel occupational therapy programme on cognition, ADL, physical performance, depression, psychological and behavioural symptoms, and quality of life of people with mild to moderate dementia.	Inc: Diagnosed in accordance with DSM IV, <60 years old, MMSE 11-23. Exc: Severe dementia, depression (GDS <24), severe behavioural or psychological symptoms, requiring nursing care due to severe medical illness.	n = MMSE: Age: Education: Female: AD:	41 20.6 68.93 NR 10% NR	30 21.1 69.85 NR 21.9% NR		Novel Occupational Therapy Intervention	Medication only.

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Kim et al [154] RCT Korea	To evaluate the efficacy of a multidomain program in patients with AD.	Inc: CDR 1, probable AD. Exc: Illiteracy, brain tumours or encephalitis, psychiatric problems within last 2 years, severe depression – more than 18 on the Hamilton Depression rating scale, Parkinson's disease, Huntington's disease.	n =	32	21		Multi-domain Cognitive Stimulation	Medication only.
			MMSE:	18.75 (SD 4.7)	16.95 (SD 6.97)			
			Age:	78.44 (SD 1.00)	78.52 (SD 1.70)			
			Education:	4.34 (SD 0.72)	5.76 (SD 1.19)			
			Female:	75%	61.9%			
			AD:	100%	100%			
Santos et al [155] RCT Brazil	To evaluate the effects of a multidisciplinary rehabilitation program on cognitive ability, quality of life and depression symptoms in patients with AD.	Inc: <60 years old, standard pharmacological treatment, mild AD (MMSE 17 or more), and 0.5 – 1 on the CDR. Exc: NR.	n =	46	16		Multidisciplinary Rehabilitation Programme	Waiting List
			MMSE:	23.0 (SD 2.5)	23.3. (SD 3.9)			
			Age:	75.7 (SD 5.6)	74.8 (SD 4.7)			
			Education:	9.4 (SD 4.8)	11.0 (SD 5.1)			
			Female:	58.7%	62.5%			
			AD:	100%	100%			
Viola et al [158] Controlled trial Brazil	To evaluate the effects of a multidisciplinary rehabilitation program on cognition, quality of life and neuropsychiatric symptoms in patients with mild AD.	Inc: AD diagnosis, mild dementia (CDR 0.5 – 1 and MMSE 16 or more), stable medication for AD. Exc: NR.	n =	25	16	Caregiver intervention and control: n = NR; Age: 51.6 (SD 15.3); Spouse: 34.1%.	Multidisciplinary Rehabilitation Programme	Waiting list
			MMSE:	22.6 (SD 2.9)	23.3 (SD 3.9)			
			Age:	75				
			Education:	10				
			Female:	64%	62%			
			AD:	100%	100%			
Matsuzono et al [161] Retrospective Cohort Study Japan	To evaluate the add-on effect of cognitive rehabilitation for people living with AD taking donepezil.	Inc: Mild – moderate Dementia (MMSE 15-25), diagnosis AD, taking donepezil. Exc: NR.	n =	32	23		Ambulatory Cognitive Rehabilitation	Medication only.
			MMSE:	21.7 (SD 3.0)	21.7 (SD 2.2)			
			Age:	75.9 (SD 9.5)	77.4 (SD 7.6)			
			Education:	NR	NR			
			Female:	NR	NR			
			AD:	100%	100%			

Study, Design & Country	Study Aims	Inclusion and Exclusion Criteria	Sample at Baseline* (Reported as means unless otherwise stated)				Experimental Intervention	Control / Comparison Intervention
				PLWD		Other Participants		
				Intervention	Control			
Ibarria et al [162] Observational Cohort Study Spain	To describe the effects of an integrated psycho-stimulation program on patients with mild-moderate AD treated with acetylcholinesterase inhibitors and to identify factors related to greater benefit of the intervention.	Inc: Probable or possible AD, mild-moderate severity (CDR 1-2 and GDS 4 – 5), stable dose of AChEI's, caregiver. Exc: Illiterate, major depression, other psychiatric diagnoses, sensory loss.	n =	206			Integrated Psycho-stimulation Programme	
			MMSE:	19.6				
			Age:	75.88 (SD 8.97) 54-93				
			Education:	NR				
			Female:	72.8%				
			AD:	100%				
Falls Prevention								
Wesson et al [156] Pilot RCT Australia	To conduct a pilot randomised controlled trial exploring the design and feasibility of a novel approach to fall prevention for people with mild dementia living in the community.	Inc: Community dwelling, age over 65, diagnosis of dementia or an ACE-R score of ≤ 82, non-paid caregiver for at least 3.5 hours per week, English speaking. Exc: Delirium, acute medical condition, severe psychiatric disorder or other progressive neurological disorder, MMSE < 12, severe visual impairment.	n =	11	11	Caregiver intervention: n = 11; Female: 72.7%. Caregiver control: n = 11; Female: 72.7%.	Tailored Falls Prevention Programme	'Usual Care'
			MMSE:	24.5 (SD 3.1)	22.5 (SD 4.3)			
			Age:	78.7 (SD 4.2)	80.9 (SD 5.0)			
			Education:	10.6 (SD 2.4) years	12.0 (SD 4.3) years			
			Female:	45.5%	36.4%			
			AD:	NR	NR			

Abbreviations: Standard Deviation (SD), Not Applicable (NA), Not Reported (NR), Community Occupational Therapy in Dementia (COTiD) Person Living with Dementia (PLWD), Mild Cognitive Impairment (MCI), Alzheimer's Disease (AD), Vascular Dementia (VD), Mixed Dementia (MD), Assistive Technology (AT), Everyday Technology (ET), Activities of Daily Living (ADL), Mini Mental State Examination (MMSE), Geriatric Depression Scale (GDS), Clinical Dementia Rating (CDR), Acetylcholinesterase Inhibitor (AChEI), Addenbrooke's Cognitive Examination Revised (ACE-R).
*Some studies did not provide baseline data but reported the characteristics of participants who had completed the intervention and any follow ups, thereby excluding participants who dropped out after inclusion.

5.3. Quality Appraisal

Studies were appraised using four tools in accordance with their diverging methodologies (Section 3.3.2.5.) and a complete account of the results of this appraisal process can be found in Appendix F.

5.3.1. Randomised Controlled Trials (RCTs)

Studies using a RCT design were appraised using the Joanna Briggs Institute (JBI) Critical Appraisal Tool for Randomised Controlled Trials [117]. Of the eight studies utilising an RCT, five [43, 48, 89, 156, 157] reported sufficient details to determine if true randomisation occurred and four [43, 48, 89, 156] to determine whether allocation to treatment group was concealed. Across studies, participants and interventionists were not blinded to intervention group, since interventions were delivered face-to-face. Only three studies [43, 48, 156] reported that an Intention to Treat (ITT) analysis had been conducted, and only one study [48] provided sufficient information, for example number of raters and/or training received, to determine if outcomes were measured reliably and consistently.

5.3.2. Quasi-Experimental Studies

Seven studies [95, 98, 158-162] utilising a quasi-experimental design (controlled trials, pre-post one group designs and cohort studies) were appraised using the JBI Critical Appraisal Tool for Quasi-experimental Studies [117]. It was only possible to tell if follow up was complete for two [159, 160], with a lack of detail provided by the remaining five studies about which participants were included in the final analysis and whether anyone dropped out and why. Like studies using an RCT design, only two studies [95, 162] provided sufficient details to determine if outcomes were reliably captured. A particular weakness across the seven studies appraised using this tool, included the lack of reporting about whether a power calculation had been conducted to ensure that the studies were sufficiently powered.

5.3.3. Case Reports and Case Studies

The JBI Critical Appraisal Tool for Case Reports [118] was used to appraise eight studies [94, 96, 97, 112, 163-166] using a case study or case report design. All studies using these designs provided detailed information about the intervention received by participants and about participants'

demographic details. However, no studies provided details about whether any adverse or unanticipated events during the intervention period occurred.

5.3.4. Qualitative Studies

Two studies utilising a qualitative design were appraised using the CASP Qualitative Studies Checklist [113]. There was a clear difference between studies in terms of quality. Chung [167] was methodologically of low quality, with a lack of information provided about the methods used to recruit participants, generate data and analyse data, in contrast to Cummins and Warren [168] who were stronger in these areas. However, neither critically examined their role and personal bias in conducting and designing their studies.

5.4. Interventions

Eight broadly defined intervention modalities and 20 distinct intervention programmes were identified across studies (Table 17), with three programmes (COTiD, Supporting Everyday Activities in Dementia and Multidisciplinary Rehabilitation Programme) evaluated by multiple studies. Of the 20 intervention programmes, only three identified or were categorised as Occupational Therapy (Table 17), with one additional study exploring general views and experiences of occupational therapy intervention [168].

Specific details relating to the twenty intervention programmes can be found in Appendix G and a summary across studies is provided in Sections 5.4.1. – 5.4.5., structured using headings from the TIDieR Checklist [121]. Information extracted to populate Appendix G and to inform the summary below derives from narrative descriptions provided by authors themselves, which varied considerably in amount and quality. Unfortunately, no studies utilised the TIDieR Checklist or other similar tool to describe their interventions and only one programme (COTiD) referred to a published intervention manual. This manual was in Dutch and therefore was not included in this synthesis [128]. Only two studies generated qualitative data on views and experiences relating to intervention format, delivery and content and are summarised in Section 5.4.6.

Table 17: Intervention Modalities and Programmes

Intervention Modality	Intervention Programme[5]	Publication(s)
Occupational Therapy	Community Occupational Therapy in Dementia (COTiD)	[43-45, 48, 165, 169, 170]
	Brief Occupational Therapy Intervention	[95]
	Supporting Everyday Activities in Dementia	[96, 97]
	Views of occupational therapy intervention in Ireland[6]	[168]
Cognitive Rehabilitation	Goal-oriented Cognitive Rehabilitation	[89, 171, 172]
	Cognitive Rehabilitation and Training	[153]
	Cognitive Management of Daily Activities	[94]
Cognitive Training	Collaborative Cognitive Training	[98]
Reminiscence	Intergenerational Reminiscence	[160]
Self-Management and Peer Support	Journeying through Dementia	[159]
	Memory Training and Psychosocial Support	[167]
Assistive Technology	Personalised-Ambient Assisted Occupational Therapy	[163]
	Cognitive Technologies in Geriatric Rehabilitation	[164]
	Management of Temporality using Time Aids	[112]
	Individually chosen Assistive Technology	[166]
Multi-modal Intervention[7]	Novel Occupational Therapy Intervention	[157]
	Multi-domain cognitive stimulation	[154]
	Multidisciplinary rehabilitation programme	[155, 158]
	Ambulatory Cognitive Rehabilitation	[161]
	Integrated Psycho-stimulation Programme	[162]
Falls Prevention	Tailored Falls Prevention Programme	[156]

5.4.1. Intervention Rationale, Theory or Goal

Six programmes [95, 154-158, 161] did not describe an intervention aim or goal, however, ten [43, 48, 89, 94, 96-98, 153, 159, 162, 164-166] specified goals that related to improving or maximising the performance, functioning, participation or independence of people living with dementia in relation to their occupations or activities. Two programmes [43, 48, 165, 167] aimed to improve the relationship or dynamic between the person living with dementia and their family / caregivers. Other aims or

[5] Where provided by authors, intervention programme names have been used. In the absence of a programme name, words used by authors to describe the programme or study have been used.

[6] Cummins and Warren's [168] study has been included in Table 16, since it relates to the modality of Occupational Therapy, however, does not describe or report on a specific intervention programme, rather general views and experiences on occupational therapy intervention for people living with early-stage dementia in Ireland.

[7] An intervention was deemed multi-modal if it comprised multiple distinct intervention modalities e.g., reminiscence, exercise therapy, pet therapy, speech and language therapy, which could be delivered independently as an intervention in its own right.

goals included reducing behavioural and psychological symptoms associated with dementia [163], addressing temporal difficulties [112] and increasing self-efficacy [159].

A lack of information was reported about the theoretical underpinnings of intervention programmes, with six programmes [94, 112, 154, 161, 163, 167] providing no information about theoretical influences. The Model of Human Occupation (MOHO) was cited by three programmes [43, 48, 96, 97, 157, 165] and 'cognitive rehabilitation' by another three [89, 153, 164]. A variety of other theories were also referenced, including the Theory of Learning [98], Social Cognitive Theory [159], reality orientation [164], errorless learning [164], Task Analysis [43, 48, 165], cognitive neuroplasticity [162] and the Environmental-Press Competence model [95]. Whilst articulating a complex intervention's programme theory has been emphasised by successive MRC Frameworks [64, 65] and guidelines [173], no programmes provided information about their intervention's programme theory.

5.4.2. Content and Components

Disparity in the details reported by studies in relation to specific intervention contents and components was evident, with studies using a case study methodology providing greater detail than those using experimental or quasi experimental designs. Table 18 synthesises the content or components across intervention programmes, which are summarised below and described in further detail in Appendix G.

Assessment and Goal Setting

Seven programmes, including all from the modality of Occupational Therapy, reported a pre-intervention assessment process. This varied between programmes but included activities ranging from observational assessments, interviews with the person living with dementia and caregivers, and standardised assessments. Goal setting was also described as a pre-intervention activity by seven programmes, namely those from the modalities of Occupational Therapy and Cognitive Rehabilitation, with the Canadian Occupational Performance Measure (COPM) [174] used by 4 programmes (Table 18). Clare et al [172] conducted a process analysis of goal setting using the COPM during their RCT [89], and identified that goals amongst their participants were in nine broad domains: memory, practical skills and activities, word finding and naming, concentration, organisation, social interaction, visual recognition, orientation and general well-being.

Intervention

Eleven programmes emphasised that their intervention was individualised or personally tailored, although there was a lack of detail reported about how tailoring was enacted during the intervention programme. 'Strategies' to support the performance of activities or occupations were the most widely reported intervention content, reported by 14 programmes (Table 18). Studies varied in the level of detail provided about the nature of strategies, with some studies referring to blanket 'memory' or 'compensatory' strategies. Some studies provided brief examples, which are detailed in Table 18 and primarily comprised adaptations to the physical environment, including aids and equipment and adaptations to the social environment including providing advice and training to caregivers about cueing, prompting and problem-solving. Strategies based on the principles of cognitive training were also described in the context of strategies, particularly by studies from the modalities of Cognitive Rehabilitation and Cognitive Training. Stress and anxiety management as well as adapting occupations or activities were less frequently reported strategies. Whilst strategies featured prominently as an intervention component, less detail was reported about activities or methods of change associated with enabling people to be able to use strategies. Eleven programmes shed some light on these activities, to varying degrees, which included providing information about strategies, teaching or training people living with dementia or their caregivers in using strategies through demonstration, active experimentation, role modelling and encouragement (Table 18). In addition to content associated with strategies, providing information about topics including dementia and community support was reported by six programmes, peer support by two programmes, and participating in a group recreational occupation or activity by seven (Table 18).

5.4.3. Mode and Location of Delivery

Intervention programmes were delivered face-to-face on a dyad or individual basis [43, 48, 89, 94-98, 112, 156, 160, 163, 164, 166], and on a group basis [154, 155, 157, 158, 161, 167], with two interventions delivered in both a group and on an individual or dyad basis [153, 159]. Multi-modal programmes of intervention were typically delivered in a group format and in an outpatient or clinic setting. In contrast, individual or dyad programmes were typically delivered within the home environment, with one delivered at a non-clinical community venue [160] and another in a clinical setting [96, 97]. Wesson et al [156] and Lindqvist et al [166] additionally provided telephone contact alongside face-to-face appointments.

5.4.4. Duration and Intensity

Heterogeneity was evident regarding the duration and frequency of intervention programmes, with the former ranging from five weeks to a year and the majority reporting intervention length between five and twelve weeks [43, 48, 89, 94, 153, 155-160, 165]. Frequency of contact ranged from one contact per week, to up to five per week, with the majority delivered once [89, 153, 159-161] or twice per week [43, 48, 94, 155, 157, 158, 165]. Dooley and Hinojosa [95] and Nygård et al [112], were outliers in terms of duration and frequency, only two in person contacts were provided by both intervention programmes. There was sometimes a lack of detail about length of intervention sessions, with eight studies not reporting this or providing ambiguous information [94, 95, 112, 156, 161, 163, 166, 167]. Of the studies that did report length of intervention sessions, a range of 5 minutes [96, 97] to 8 hours [162] was reported, with the majority of programmes providing between 1 and 2 hours duration per contact [43, 48, 89, 98, 159, 165].

5.4.5. Interventionist

Ten programmes [43, 48, 89, 95-97, 112, 154, 159, 163, 165-167] utilised occupational therapists as experimental interventionists, three [157, 162, 164] described their intervention programme as 'occupational therapy', although did not specify an interventionist and five programmes utilised occupational therapists and interventionists from other professional disciplines, including physiotherapists and speech and language therapists [94, 98, 155, 156, 158, 161]. One programme utilised youth volunteers as interventionists and was included within this review as the intervention was designed, managed and supervised by an occupational therapist [160]. Another programme was published by a sole author, who is a registered occupational therapist, and therefore was included on the basis that, as the sole author, an occupational therapist was involved in the overall design and conduct of the study [153].

Table 18: Intervention Programme Contents, Components and Activities

Intervention Content / Component / Activity		Number of Programmes	Programmes
Assessment		n = 7	Occupational Therapy (n=3) [43, 48, 95-97, 165] Assistive Technology (n = 2) [112, 166] Cognitive Rehabilitation (n = 1) [94] Falls Prevention (n = 1) [156]
Goal Setting		n = 7	Cognitive Rehabilitation (n = 3) [89, 94, 153] Occupational Therapy (n=2) [43, 48, 96, 97, 165] Assistive Technology (n = 2) [112, 166]
Establishing a Relationship		n = 1	Self-Management and Peer Support (n = 1) [159]
Individually Tailored		n = 11	Occupational Therapy (n=3) [43, 48, 95-97, 165] Cognitive Rehabilitation (n = 3) [89, 94, 153] Assistive Technology (n = 4) [112, 163, 164, 166] Falls Prevention (n = 1) [156]
Problem-Solving 'strategies' to Support Occupational or Activity Performance		n = 14	Occupational Therapy (n=3) [43, 48, 95-97, 165] Falls Prevention (n = 1) [156] Cognitive Rehabilitation (n = 3) [89, 94, 153] Assistive Technology (n = 3) [112, 163, 164] Self-Management and Peer Support (n = 2) [159, 167] Multi-Modal Intervention (n = 1) [155, 158] Cognitive Training (n = 1) [98]
Strategy Type	**Adapting Physical Environment**	n = 6	Occupational Therapy (n=3) [43, 48, 95-97, 165] Assistive Technology (n = 1) [164], Falls Prevention (n = 1) [156] Multi-Modal Intervention (n = 1) [155, 158]
	Adapting Social Environment (e.g., verbal prompts, physical demonstration, hierarchical cueing, advice, training to caregiver in using problem solving, coping strategies, and effective use of supervision).	n = 7	Occupational Therapy (n=3) [43, 48, 95-97, 165] Assistive Technology (n = 2) [163, 164] Cognitive Training (n = 1) [98] Cognitive Rehabilitation (n = 1) [94]

Intervention Content / Component / Activity		Number of Programmes	Programmes
Strategy Type (Continued)	**Aids and Equipment** (e.g., diaries, calendars, digital assistive technology, digital prompts, and reminders (e.g., for medication).	n = 10	Occupational Therapy (n=1) [43, 48, 165] Self-Management and Peer Support (n = 1) [159] Cognitive Rehabilitation (n = 2) [89, 153] Assistive Technology (n = 4) [112, 163, 164, 166] Cognitive Training (n = 1) [98] Falls Prevention (n = 1) [156]
	Adapting Occupation (e.g., simplifying occupation).	n = 1	Cognitive Training (n = 1) [98]
	Cognitive Training (e.g., face name learning, spaced retrieval, letter cues, practicing maintaining attention and concentration).	n = 7	Cognitive Rehabilitation (n = 2) [89, 153] Cognitive Training (n = 1) [98] Assistive Technology (n = 2) [163, 164] Multi-Modal Intervention (n = 2) [154, 157]
	Stress and / or Anxiety Management	n = 2	Cognitive Rehabilitation (n = 1) [89] Self-Management and Peer Support (n = 1) [159]
Activities associated with Strategies	**Providing Information about Strategies**	n = 2	Occupational Therapy (n = 1) [43, 48, 165] Assistive Technology (n = 1) [166]
	Enabling Decision Making about Strategies	n = 1	Assistive Technology (n = 1) [166]
	Teaching / Training (e.g., role modelling, supporting practice of strategies, active experimentation, errorless learning, encouragement, demonstration, practice in between sessions)	n = 11	Occupational Therapy (n = 1) [43, 48, 165] Self-Management and Peer Support (n = 2) [159, 167] Assistive Technology (n = 3) [112, 164, 166] Cognitive Rehabilitation (n = 2) [89, 94] Cognitive Training (n = 1) [98] Multi-Modal Intervention (n = 2) [155, 158, 161]
	Providing Materials (e.g., aids / equipment / strategies)	n = 1	Assistive Technology (n = 1) [166]
	Evaluating and Monitoring Progress	n = 2	Assistive Technology (n = 1) [166] Cognitive Rehabilitation (n = 1) [94]
Providing Information		n = 6	Occupational Therapy (n = 1) [95] Self-Management and Peer Support (n = 2) [159, 167] Falls Prevention (n = 1) [156] Cognitive Training (n = 1) [98]

Intervention Content / Component / Activity		Number of Programmes	Programmes
Information Provision About	**Community Resources / Assistance / Support**	n = 2	Occupational Therapy (n = 1) [95] Self-Management and Peer Support (n = 1) [167]
	Dementia and its Impact on Occupations	n = 3	Cognitive Training (n = 1) [98] Self-Management and Peer Support (n = 2) [159, 167]
	Physical Activity / Active Lifestyle	n = 1	Self-Management and Peer Support (n = 1) [159]
	Home Hazards	n = 1	Falls Prevention (n = 1) [156]
Group Occupation / Activity (typically enjoyable, recreational)		n = 7	Multi-modal Intervention (n = 4) [154, 157, 161, 162] Assistive Technology (n = 1) [164] Self-Management and Peer Support (n = 2) [159, 167]
Peer Support (e.g., peer group discussions, engaging in activities together, sharing experiences)		n = 2	Self-Management and Peer Support (n = 2) [159, 167]
Cognitive Stimulation (e.g., cognitive games)		n = 2	Assistive Technology (n = 1) [163, 164]
Relaxation		n = 1	Multi-Modal Intervention (n = 1) [157]
Physical Exercises		n = 1	Multi-Modal Intervention (n = 1) [157]
Reminiscence		n = 1	Reminiscence (n = 1) [157]

5.4.6. Intervention: Views and Experiences

Cummins and Warren [168] and Sprange et al [159] generated qualitative data which captured views and experiences about intervention content and format, however, both differed in their focus and participants. Using semi-structured interviews with occupational therapists in Ireland, Cummins and Warren [168] explored views and experiences of occupational therapy interventions for people living with early-stage dementia. Interviews were thematically analysed, with five primary themes identified; four pertained to interventions delivered, which have been presented in Appendix H, alongside data extracts from participants and author summaries. Reflecting intervention programme aims, goals and theory described in Section 5.4.1., Cummins and Warren's [168] participants emphasised the importance of facilitating independence and occupational performance and also utilised the MOHO as an underpinning theory. Interventions associated with facilitating occupational performance were also similar to those presented in Table 18, including strategies involving adapting the physical and social environment, providing anxiety management and information about community resources. However, participants additionally spoke about enabling people to come to terms with their diagnosis in the theme "*Looking beyond the diagnosis*", and re-introducing and exploring new occupations in the theme "*Enabling occupational identity*".

Sprange et al [159] conducted interviews with participants living with dementia and caregivers pre- and post their Journeying through Dementia group intervention programme, as well as a focus group with interventionists post intervention, which were analysed using Framework Analysis. Key themes identified by Sprange et al [159] pertaining to views on intervention content and mode of delivery are presented in Appendix H, alongside data extracts from participants and author summaries. Overall, views were positive; participants valued the flexibility afforded by the programme to explore topics of their choosing and enjoyed learning about strategies, however caregivers wanted more information about how to support learning outside group sessions. There was a disparity between interventionist and participants' views on length of delivery, with participants eager to continue sessions beyond the 12 weeks, whilst facilitators deemed this an adequate amount of time to learn new skills whilst avoiding what they called "*dependency*" (p9). Interventionists were viewed positively, described as "*fun*" and "*imaginative*" (p7) and comments indicated that their manner and skill encouraged group attendance. An accessible centrally located venue was also perceived as important by participants, and interventionists valued weekly supervision after group delivery.

5.5. Outcomes

Quantitative outcomes for participants living with dementia were reported by 21 studies in relation to 17 intervention programmes, with outcomes for caregivers reported by 13 studies in relation to 10 intervention programmes (Appendix I). Qualitative impacts or outcomes were reported by three studies [159, 166, 167]. This section will commence by summarising quantitative outcomes and will conclude with a description of qualitative impacts or outcomes.

5.5.1. Quantitative Outcomes

Reflecting the diversity in study designs, quantitative outcomes were reported on a between group basis (intervention vs control or comparison) by 10 studies, on a within group basis by five studies (intervention group only) and on an individual participant basis by six studies. Outcomes were measured primarily pre and post-intervention, with only five studies additionally conducting a follow up. All quantitative outcomes are presented in Appendix I and outcomes relating to people living with dementia are summarised below.

5.5.1.1. Occupational Performance / Functioning

Fifteen studies reported outcomes pertaining to participants living with dementia's occupational performance, using 12 different outcome measures. All studies from the modalities of Occupational Therapy and Cognitive Rehabilitation captured this outcome, although there were differences in measures used.

Occupational Therapy

At post intervention and at twelve weeks follow up, Graff et al's [43] RCT reported statistically and clinically significant differences, with very large effect sizes, attesting to the superiority of COTiD compared to 'usual care' on the Assessment of Motor and Process Skills (AMPS) and the Interview of Deterioration in Daily activities in Dementia (IDDD). Graff et al's [165] case report of a dyad, like Graff et al [43], reported an improvement on the AMPS and the IDDD. In contrast, no statistically significant outcomes were observed post intervention or at follow up on the IDDD[8] by Voigt-Radloff et al's [48]

[8] The AMPS was not utilised by Voigt-Radloff et al [48] as it was not possible to acquire a German translation of the measure prior to study commencement.

RCT when COTiD was compared with a 1 hour Community Occupational Therapy Consultation (COTC). Two single case studies investigating the intervention programme Supporting Everyday Activities in Dementia captured occupational performance outcomes using the AMPS, with both participants demonstrating statistically significant improvements on items measured on the AMPS process scale post intervention and at follow up [96, 97]. Post intervention, Dooley and Hinojosa's [95] CT reported statistically significant improvements on the Physical Self-maintenance Scale (PSMS) in favour of their Brief Occupational Therapy Intervention compared to control.

Cognitive Rehabilitation

Clare et al [89] and Kim [153] utilised the Canadian Occupational Performance Measure (COPM) to measure occupational performance outcomes pre and post their Cognitive Rehabilitation programmes. Both reported statistically significant between-group differences in performance and satisfaction as measured on the COPM, favouring cognitive rehabilitation. However, whilst Kim [153] did not report effect sizes, Clare et al [89] reported large confidence intervals, ranging from small or medium to very large on all analyses utilising the COPM. In addition to the COPM, Clare et al [89] utilised the Independent Living Scale (ILS): Health and Safety Subscale post intervention and at follow up and Kim [153] utilised the Modified Barthel Index (MBI) post intervention. No statistically significant between group differences were noted on these outcome measures. Adam et al [94] utilising a case study design, reported no change in outcomes related to occupational performance as measured on the Teunisse's Scale and Gelinas' Scale.

Other Modalities

Kumar et al's [157] RCT investigating the multi-modal intervention programme Novel Occupational Therapy Intervention, reported a significant between-group difference in favour of their intervention post intervention on the Bristol Activities of Daily Living Scale (BADLS), however, Ibarria et al's [162] retrospective cohort study investigating their multi-modal intervention, reported a statistically significant decline in performance at 6 and 12 months as measured on the Rapid Disability Assessment Scale-2 (RDRS-2). Wesson et al's [156] falls prevention intervention and Chung's [160] Reminiscence intervention did not report a statistically significant improvement post intervention on this outcome as measured on the IDDD and MBI, and the Instrumental Activities of Daily Living Scale-Chinese Version (IADL-CV), respectively.

5.5.1.2. Affect

Five outcome measures were used by 12 studies to capture outcomes in relation to participants living with dementia's affect, including depression, anxiety, and apathy. The Cornell Scale for Depression (CSD) was utilised by all three studies investigating COTiD, however there was a disparity in results reported. Graff et al [44] reported statistically significant differences post intervention and at twelve weeks follow up, and Graff et al's [165] case report of a dyad reported an improvement. In contrast, no statistically or clinically significant outcomes were observed post intervention or at follow up by Voigt-Radloff et al [48]. The CSD was additionally used by Wesson et al [156] however, no significant outcomes were reported between their Falls Prevention Intervention programme, and control.

Five studies utilised the Geriatric Depression Scale (GDS), including three studies investigating multi-modal interventions [155, 157, 158]. Kumar et al's [157] RCT reported a statistically significant improvement in favour of their intervention compared to control post intervention and Viola et al [158] and Santos et al [155] who investigated the same Multidisciplinary Rehabilitation Programme both reported a significant within-group improvement post intervention. Chung [160] also reported a significant within group difference post-intervention in relation to their reminiscence programme on the GDS. The Hospital Anxiety and Depression Scale (HADS) was utilised by Clare et al [89] to evaluate their Goal-Oriented Cognitive Rehabilitation at post intervention and follow up, however, no significant outcomes were reported.

5.5.1.3. Quality of Life and General Health Status

Eleven studies captured outcomes about participants living with dementia's quality of life and general health status using five outcome measures. Five studies utilised the Quality of Life in Alzheimer's Disease (QoL-AD) assessment, including Clare et al's [89] and Kim's [153] Cognitive Rehabilitation programmes. However, whilst Clare et al [89] reported no significant differences between those receiving Goal-oriented Cognitive Rehabilitation, control and attention control, post intervention and at follow up, Kim [153] reported a statistically significant difference between their Cognitive Rehabilitation and Training programme and control post intervention. Both Viola et al [158] and Santos et al [155] reported a statistically significant within group improvement post their multi-modal Multidisciplinary Rehabilitation Programme as did Chung [160] following their Intergenerational Reminiscence programme on the QoL-AD.

The Dementia Quality of Life Instrument (DEMQOL) was utilised to measure quality of life by all three studies investigating COTiD. However, divergences between COTiD studies were again reported in relation to this outcome, with Graff et al [44] reporting statistically significant differences, with very large effect sizes at post intervention and at twelve weeks follow up, and Graff et al's [165] case report of a dyad reporting an improvement. No statistically or clinically significant outcomes were observed post intervention or at follow up by Voigt-Radloff et al [48]. The DEMQOL was also utilised by Sprange et al [159] on a within group basis following their Journeying through Dementia Programme with a trend towards improvement noted post intervention.

5.5.1.4. Cognition and Dementia Severity

Outcomes relating to participants living with dementia's cognition and dementia severity were captured by 13 studies using 11 outcome measures, and one study [98] utilised a researcher developed tool. The MMSE was utilised by all studies evaluating multi-modal interventions. Kumar et al [157] and Kim et al [154] reported no between group differences following their multi-modal programmes, whilst Matsuzono et al [161] did. There was a disparity between Viola et al [158] and Santos et al's [155] outcomes in relation to their Multidisciplinary Rehabilitation Programme: Santos et al [155] reported a statistically significant improvement on the MMSE post intervention, whilst Viola et al [158] did not. Ibarria et al [162] reported no significant within group differences at 3 and 6 months during the intervention period, however, noted a statistically significant deterioration at 9 and 12 months. Chung [160] also utilised the MMSE, however reported no significant within group differences post their Intergenerational Reminiscence programme.

All studies investigating Cognitive Rehabilitation programmes of intervention captured outcomes relating to cognition, however, different measures were used by Clare et al [89], Kim [153] and Adam et al [94]. Clare et al [89] reported no between group differences post intervention and at follow up on the Memory Awareness Rating Scale (MARS), Test of Everyday Attention (TEA) and Verbal Fluency Test, and no significant differences between groups were also reported by Kim [153] on the Lowenstein Occupational Therapy Cognitive Assessment - Geriatric (LOTCA-G) and the MMSE. Adam et al [94] reported no change on the MMSE for their participants but noted a deterioration on the Mattis Dementia Rating Scale.

5.5.1.5. Other Outcomes

Five studies measured outcomes capturing data about participants living with dementia's behaviour using four outcome measures, however, only Adam et al [94], a case study of one individual reported an improvement on this outcome. Wesson et al [156], who investigated the outcomes of a Tailored Falls Prevention Programme utilised additional outcome measures to capture the interventions impact on falls, however, no outcomes were statistically significant. Sprange et al [159] utilised the General Self-efficacy Scale (GSE) to measure self-efficacy, however concluded that results were inconclusive owing to the low numbers of participants.

In addition to clinical outcome measures, to evaluate Clare et al's [89] Goal Oriented Cognitive Rehabilitation, van Paasschen et al [171] utilised fMRI to examine brain activation during encoding and recognition tasks pre and post intervention. During an encoding task, van Paasschen et al [171] reported no significant changes in brain activations, apart from a decrease in activity in the right insula for the Cognitive Rehabilitation group and left inferior frontal gyrus for the control groups post intervention. However, during a recognition task, significant increase in brain activation was noted in three areas in the Cognitive Rehabilitation group post intervention, whilst the control groups showed a significant decrease in seven areas.

Only one economic evaluation was conducted in relation to intervention programmes contained in this synthesis. Graff et al [45] demonstrated that average savings per couple receiving COTiD [43], compared to those in the control group was €1748, however, the main cost saving was from reduced informal care.

5.5.2. Qualitative Outcomes: Views and Experiences

Sprange et al [159], Chung [167] and Lindqvist et al [166] generated qualitative data which captured the impact or outcomes associated with their intervention programmes. Data was generated by all three studies using semi-structured interviews post-intervention, with Chung [167] additionally utilising observation and Lindqvist et al [166] field notes. Qualitative impacts or outcomes identified across studies have been presented in Table 19 alongside quotes from participants and author summaries.

Both Chung [167] and Sprange et al [159] investigated intervention programmes from the modality Self-Management and Peer Support, with programmes delivered in a group setting. They reported a positive impact on participants' affect from engaging with other group members and participating in shared activities. However, Chung [167] identified that despite their intervention programme, caregivers and participants living with dementia remained anxious about their ability to manage in the future, which was associated with caregivers' concerns about their limited knowledge and skills. Lindqvist et al's [166] intervention programme was delivered on an individual or dyad basis and pertained to Assistive Technology. They reported a reduction in negative affect, namely feelings of stress and anxiety after the intervention period. Whilst not noted as an outcome or impact by Lindqvist et al [166] or Chung [167], Sprange et al [159] identified a change in the attitude or beliefs of participants post intervention, including a positive change in attitude in relation to their own ability, and a change from thinking about the past, to looking forwards to the future. An increase in confidence and independence was reported by both Sprange et al [159] and Lindqvist et al [166], and increased feelings of safety were reported by one of Lindqvist et al's [166] participants, and a decrease in time and effort required to carry out activities was reported by another. Chung [167] additionally reported improved communication and relationships between caregivers and the person living with dementia.

Table 19: Qualitative Intervention Impacts / Outcomes Identified Across Studies

Intervention Impact / Outcome Identified		Studies and Examples
Affect	Feelings of enjoyment, fun, pleasure	Sprange et al [159]: "*They were fun and they were, you felt confident in them. They were imaginative. they made things fun and I think that was a big part of it*" (Participant) (p7) Chung (2001): "*Enjoyable and pleasurable feelings were noted in most participants, particularly when they engaged in the task-oriented activity*" (p87)
	Decreased feelings of anxiety and stress.	Lindqvist et al [166]: *"It [day planner and talking clock] enabled her to take control of her morning hours and thereby plan and perform her morning routines free from stress, which was of great significance to her since stress otherwise could "ruin the whole day"" (p393)*
	Anxiety about the future	Chung [167]: *"…most sufferers…expressed anxiety about coping with further deterioration, while carers generally worried about their inadequate knowledge and caregiving techniques to handle their relatives' increasing disabilities and behavioural problems."* (p87)
Attitude	Change in attitude from dwelling on the past to looking towards the future	Sprange et al [159]: "*They made us realise….it wasn't the end of the world, that there was still life to live…"*
	Change in attitude in relation to own ability	Sprange et al [159]: *"…we all realised that we were still capable of…going out and about er which is something I must admit I had stopped doing*." (participants)
Confidence	Increased confidence	Sprange et al [159]: "*Tools, techniques, for example daily diaries, memory cards and re-usable activity cards, explored as part of the programme appeared to increase self-efficacy*" (p10)
		Lindqvist et al [166]: "*After a period of usage [mobile phone / GPS] she felt more confident taking walks on her own in the woods near her house once again. She described it like this: "This summer, I dared to go exactly everywhere… in the woods, even places I'd never been to""* (p393-394).
Independence	Increased independence	Lindqvist et al [166]: "*Gunnar, who had previously been reminded by his wife when it was time for medication, was now reminded by the AT (Alarm watch) instead. …He was in charge of his medication and they both worried less about it."* (p393)
Safety		Lindqvist et al [166]: *"…thanks to the mobile phone…they both also felt safer when they went out together for various activities. They knew they could get in touch with each other…"* (p394)
Time and Effort	Decreased time and effort associated with activities	Lindqvist et al [166]: "*Before the provision of the AT (info panel), she seldom forgot to turn off the home appliances at home, but, to be on the safe side, she checked them repeatedly and she also went home and checked them again. With the AT she did not have to do any of these tasks*." (p393)
Relationships	Improved communication and relationships	Chung [167]: *"…the carers established a closer relationship with their relatives with dementia. An interviewee said she felt more comfortable to relate with her husband after joining the program."* (p87)

5.6. Barriers and Facilitators

Barriers and facilitators relating to the delivery or implementation of interventions were identified in data reported by five studies [112, 159, 166, 168, 170]. Whilst these studies differed in aims and intervention programmes, barriers and facilitators across studies were described in relation to the intervention context, the interventionist, and intervention recipients.

5.6.1. Intervention Context

Cummins and Warren [168], who conducted semi-structured interviews with occupational therapists working with people living with early-stage dementia in Ireland, identified barriers in the service / setting and economic context as described in their theme 'Inaccessible and Inadequate Resources'. Barriers identified in this theme are presented in Table 20 and included difficulties people living with dementia have in accessing services due to waiting lists, disjointed services and a lack of financial resources which delay service developments to meet current needs.

Table 20: Themes Identified by Cummins and Warren [168] Concerning Barriers

Theme Identified by Cummins and Warren [168]	Barriers Identified from Data Extracts and Author Summary
Inaccessible and Inadequate Resources	• Service developments not quick enough to meet needs: "*developments are so behind relative to the needs of an aging population*" (p8) • Lack of community services: "*community services are so scarce*" (p8) • Inaccessible services: "*services are very disjointed*", resulting in delays, which means "*by the time they get off the waiting list the person is slipping into moderate, and I think that is a tragedy*". (p8) • Lack of resources to be able to evaluate interventions.

In contrast to Cummins and Warren [168], barriers and facilitators associated with the intervention context identified in Sprange et al's [159] qualitative data comprised the physical location where their group intervention Journeying through Dementia was delivered. Group sessions were conducted at a community venue and the accessibility and ambience of the venue was deemed important by group facilitators, caregivers and people living with dementia. Having the flexibility to access the community during venue-based activities was also valued to enable the practicing of skills learnt in the group. However, noisy, and busy venues were perceived as barriers to the delivery of the intervention by participants and facilitators.

5.6.2. Intervention Recipients

COTiD

Due to the inconsistency in outcomes reported in relation to COTiD by Graff et al [43] and Voigt-Radloff et al's [48] RCTs, as described in Section 5.5., a process evaluation was conducted by Voigt-Radloff et al [170] to explore potential contributing factors. This reported the results of a questionnaire generating qualitative and quantitative data on the implementation of pre-defined COTiD sub-processes from the perspective of interventionists [170]. The questionnaire highlighted that a number of subprocesses deemed key to the quality of COTiD were perceived by occupational therapists to have been implemented 'poorly', and Appendix J provides examples of some subprocesses and qualitative data extracts from Voigt-Radloff et al [170]. Barriers were solely reported in relation to the person living with dementia or their caregiver and included dementia severity, caregiver burden and preferences about having physical adaptations made to the home environment. Graff et al [43] did not conduct a process analysis, therefore direct comparisons between studies cannot be made. Like Voigt-Radloff et al [170], Graff et al [165] noted an initial barrier to the implementation of COTiD, namely the ambivalence of the dyad to receive 'training' from their occupational therapist, however, the dyad were happy to accept 'advice' and did receive 'training' as the study progressed.

Assistive Technology (AT)

Lindqvist et al [166] and Nygård et al [112] both generated qualitative data about intervention recipients in relation to their AT programmes. Nygård et al [112] utilised a descriptive case-study design to find possible solutions to temporal difficulties using time aids with five participants. No formal qualitative analysis was conducted; however, comments provided by authors about how time aids were used and their success in addressing temporal difficulties provides insight into the barriers and facilitators associated with interventions using assistive technology. These have been summarised in Appendix J and include a person's perceptions of the device, including its technicality and its appearance, its weight and size as well as the persons motivation to use it.

Lindqvist et al [166] also utilised a descriptive case study design to explore how ten people living with early-stage dementia become users of AT. Qualitative data was generated during two interviews with participants pre- and post-intervention, in addition to researcher field notes. These were analysed using a constant comparative approach, with five themes identified. Four themes pertained to key

'junctures' or stages in the process of becoming a user of AT, which included an initial decision to use AT, making adjustments to daily routines to incorporate AT, trusting that the AT can support appropriately and be relied upon, and finally feeling confident and able to use the AT. Appendix J provides further details pertaining to the barriers and facilitators identified from authors' summaries relating to these 'junctures'.

5.6.3. Interventionists

In their process analysis, Voigt-Radloff et al [170] additionally explored other potential factors that may account for the disparity in outcomes they reported compared to Graff et al [43], including study design and interventionists themselves. Whilst COTiD in Graff et al's [43] RCT was delivered from one site by two highly experienced therapists in the Netherlands, Voigt-Radloff et al [48] recruited pragmatically from seven sites in Germany, with COTiD delivered by eleven therapists with less experience, which may have influenced outcomes reported.

Whilst Sprange et al [159] did not conduct a process analysis akin to Voigt-Radloff et al [170], qualitative data generated post their Journeying through Dementia group intervention programme highlighted that participant perceptions about interventionists were significant in encouraging group attendance, as described in their theme 'Facilitator training and programme facilitation' and discussed in Sections 5.4.6. and 5.6. Facilitators identified by Sprange et al [159] included perceived weekly supervision helpful in planning and tailoring the programme, however the degree of supervision was dependent upon the experience of the facilitator. A greater need for supervision was required at the start of the intervention programme and was perceived to be most effective when conducted straight after an intervention session.

5.7. Discussion

This synthesis aimed to describe, quality appraise and synthesise, using a thematic summary, studies relating to interventions for people living in the community with early-stage dementia that were delivered, designed or managed by occupational therapists. 31 publications reporting on 25 studies were included, which utilised a range of designs and methods, including 15 RCT's and quasi-experimental studies [43, 48, 89, 95, 98, 153-162], eight case reports or studies [94, 96, 97, 112, 163-166] and two studies utilising a qualitative design [167, 168]. Whilst studies were distributed globally, only two studies were conducted in the UK [89, 159], both of which were delivered by occupational

therapists, however, were not described as an occupational therapy intervention. To enable the synthesis of data across diverse study designs, four questions (Section 5.1.) were utilised to structure this synthesis to meet Thesis Objective 3, which will now be used to guide this discussion.

5.7.1. Interventions

1.3.1. What is the nature of occupational therapy intervention for people living with early-stage dementia in the community?

20 distinct intervention programmes were identified across studies from eight broadly defined intervention modalities: Occupational Therapy, Cognitive Rehabilitation, Cognitive Training, Reminiscence, Self-Management and Peer Support, Assistive Technology, Multi-Modal Interventions and Falls Prevention.

The heterogeneity of intervention modalities identified is consistent with prior evidence syntheses reporting on interventions involving occupational therapists for people living with dementia of all stages [84, 175]. Three modalities identified in this synthesis: Reminiscence, Cognitive Rehabilitation and Occupational Therapy, are those which NICE [2] advises clinicians to 'consider' for people living with early to middle stage dementia. Of notable absence were intervention programmes described as Cognitive Stimulation, which NICE [2] state that people living with early and middle-stage dementia 'should' be offered. However, intervention programmes from the Multi-Modal modality often included components which authors described as Cognitive Stimulation, alongside multiple other modalities, however no standardised programme was referenced as being used.

Within and across intervention modalities, heterogeneity was evident with regards to the overall duration of intervention programmes, the duration of individual sessions, as well as the location of delivery. However, interventions delivered on an individual or dyad basis were typically delivered in the home environment over approximately 1 hour sessions, whilst group interventions, which were typically those that were multi-modal or those with an additional emphasis on peer support, were delivered in a clinic, day centre or community venue and were delivered during sessions of 90 minutes or more.

Whilst studies using a case study or case report design typically provided detailed information about intervention contents or components, a lack of detail was notably provided by study's using an RCT or

quasi-experimental design. From the information available, some commonalities in contents and components were noted. Strategies to support occupational or activity performance, participation, functioning, and independence were the most widely reported intervention components, particularly interventions from the modalities of Occupational Therapy, Cognitive Rehabilitation, Cognitive Training, and Assistive Technology (Table 18), and to a lesser degree Self-Management and Peer Support. The use of strategies to problem-solve difficulties experienced during occupational performance is a widely described intervention component in occupational therapy interventions for people living with middle and later stage dementia [85] and indeed occupational therapy interventions in general [66]. Outliers in terms of intervention content were interventions from the Multi-Modal, Falls Prevention and Reminiscence modalities, which placed less or no emphasis on 'strategies'.

Three distinct intervention programmes were identified or self-identified as Occupational Therapy: COTiD [43, 48, 165], Brief Occupational Therapy Intervention [95] and Supporting Everyday Activities in Dementia [96, 97]. Whilst all reported similar aims associated with occupational performance and the primary intervention content consisted of strategies, divergences in the duration and intensity of programmes were noted. In particular, Dooley and Hinojosa's [95] Brief Intervention consisted of two contacts only, whilst COTiD and Supporting Everyday Activities in Dementia were of longer duration and intensity. Furthermore, Dooley and Hinojosa's [95] programme provided strategy recommendations only and did not involve implementing strategies through practice or the provision of aids and equipment, akin to COTiD and Supporting Everyday Activities in Dementia.

5.7.2. Outcomes

1.3.2. What outcomes are reported in relation to occupational therapy intervention for people affected by early-stage dementia in the community?

Quantitative outcomes were primarily generated by studies included in this synthesis, with 20 using clinical outcome measures for participants living with dementia or their caregivers. Heterogeneity again was evident in terms of outcome measures used, with over 50 distinct outcome measures capturing data in relation to participants living with dementia alone. Despite the heterogeneity, outcomes were typically clustered in five domains: occupational performance or functioning, affect, quality of life and general health status, cognition and dementia severity, and behaviour.

Heterogeneity in terms of interventions, outcomes, population, and quality, prevented an aggregative or meta-analysis by pooling quantitative data across studies [122]. However, outcomes reported by intervention programmes identified as Occupational Therapy will be briefly discussed. Despite being RCT's which were of high quality (Appendix F), Voigt-Radhloff et al [48] who evaluated COTiD compared to a Community Occupational Therapy Consultation (COTC), failed to replicate the large effect sizes observed on all outcome measures by Graff et al [43] post intervention and at follow up. Evidence to support COTiD was therefore inconclusive, and towards Thesis completion, the results of COTiD UK were also published, which like Voigt-Radhloff et al [48], did not report any differences on outcomes between COTiD and usual care [49]. Only one study, a Controlled Trial, was identified evaluating Brief Occupational Therapy Intervention [95]. Statistically significant outcomes were reported on measures of occupational performance, quality of life and caregiver burden post-intervention, however no effect sizes were reported, randomisation was not conducted and no further studies corroborating these findings were identified. Josephsson et al [96] and Josephsson et al [97] utilised a case study design to evaluate their intervention Supporting Everyday Activities in Dementia, with data from only two participants included in this synthesis. Both participants demonstrated an improvement on the AMPS process scale, however, given the study design, there is insufficient high-quality evidence currently in relation to this intervention.

Outcomes from only one economic evaluation, pertaining to COTiD [45], were reported in relation to the 20 intervention programmes included in this synthesis. This highlights a gap in the existing knowledge base about the cost-effectiveness of occupational therapy interventions for people living with early-stage dementia, and the cost-effectiveness of occupational therapy has been recognised in the RCOT's top 10 research priorities for the profession [176].

Qualitative outcomes were captured by three studies [159, 166, 167]. Two out of the five outcome domains identified from studies generating quantitative data (occupational performance and affect), were also captured by studies generating qualitative data. Firstly, an increase in independence was reported by both Sprange et al [159] and Lindqvist et al [166]. Secondly, participants receiving Sprange et al [159] and Chung's [167] group self-management and peer support interventions, reported positive impacts in relation to affect from engaging with other group members and participating in shared activities. The positive impact of peer support on affect and emotional wellbeing has been previously recognised, for example by Keyes et al [177] and Hicks et al [178]. Whilst Lindqvist et al [166] reported a reduction in negative affect, namely feelings of stress and anxiety after their Assistive Technology intervention, Chung [167] reported that feelings of anxiety were still present amongst

caregivers, regarding their skills and ability to support the person living with dementia in the future. Caregivers' concerns and worries about their 'performance' as a caregiver were first recognised by Lawton et al [179, 180] and have since received wider attention, more recently by Lim et al [181], who highlight that concerns about performance are most notable in the early-stages.

Whilst not captured by quantitative outcome measures, Sprange et al [159] identified a positive change in participants' attitude and confidence post intervention, about their own ability, and a change from thinking about the past, to looking forwards to the future. Attitudes and thoughts and feelings related to self-efficacy have been identified as determinants or mediators of change in complex interventions [68]. These qualitative outcomes indicate the possibility that a change in attitudes about ability to 'do' and thoughts and feelings about 'doing' are a potential determinant or mechanism of change in interventions delivered or designed by occupational therapists.

5.7.3. Barriers and Facilitators

1.3.3. What barriers and facilitators are described in relation to occupational therapy intervention for people affected by early-stage dementia in the community?

Barriers and facilitators were identified concerning the intervention context, interventionist, and intervention recipients. Service and economic contextual barriers were identified by Cummins and Warren [168] in Ireland, including a lack of resources, with demand outstripping need, leading to waiting lists and people progressing to the middle-stages prior to contact with services. These barriers were also identified in Edwards' [39] survey of occupational therapy practice in Wales and the chronic lack of funding for statutory services for dementia in the UK has been consistently highlighted the Alzheimer's Society [182]. In contrast to Cummins and Warren [168], Sprange et al's [159] contextual barriers and facilitators pertained to the immediate social and physical environment within which the intervention was delivered. The views and experiences expressed by participants are in congruence with literature about accessible environments for people living with dementia, including minimising demands in the social and physical environment, for example noise and distractions [183].

Voigt-Radloff et al [170] and Sprange et al [159] provided insight into barriers and facilitators related to the competence of interventionists, including their experience, training and supervision. Van't Leven's [184] qualitative study investigating the barriers and facilitators associated with implementing COTiD in clinical practice in Germany did not meet eligibility criteria for this synthesis, however, it

identified that feelings of incompetence amongst occupational therapists due to lack of experience and skills was perceived as a barrier to implementation. However, they also noted that detailed COTiD guidelines, its evidence base, and support from management as facilitators. Voigt-Radloff et al's [170] process analysis additionally reported interventionist's perceived barriers to the delivery of COTiD, which pertained to intervention recipients, including dementia severity, the attitudes and preferences of caregivers and caregiver burden. In relation to dementia severity, Voigt-Radloff et al [170] noted that there were differences between theirs and Graff et al's [43] samples regarding the need for assistance with instrumental activities of daily living (IADL), with the latter reporting an increased need for assistance, with mean IDDD scores at the end of intervention comparable to Voigt-Radloff et al's [48] sample at baseline. Voigt-Radloff et al [170] suggests that there was a limited room for improvement for their participants on this measure. In relation to attitudes and preferences, the acceptability of an intervention to intervention recipients, is widely considered key to the development and evaluation of complex interventions [185]. Sekhon et al [185], in their systematic development of a theoretical framework of intervention acceptability, identify affect, attitude, perceived burden of an intervention, and self-efficacy as key components of acceptability. Lindqvist et al [166] and Nygård et al's [112] studies included in this review attested to the importance of these aspects of acceptability in regards to their assistive technology interventions. This included the physical attributes and design of an assistive device and the persons perceptions of the device, including its technicality and appearance as an assistive device.

5.7.4. Views and Experiences

1.3.4. What are people's views and experiences of occupational therapy intervention for early-stage dementia in the community?

There was a notable lack of studies eligible for this synthesis generating data on the views and experiences of occupational therapy intervention for people living in the community with early-stage dementia. Only two studies utilised a qualitative design [167, 168], although qualitative data was generated by Sprange et al [159] during their feasibility study and Lindqvist et al [166] during their multiple case-study. Views were gathered from occupational therapists by Sprange et al [159] and Cummins and Warren [168], and from people affected by dementia and caregivers by Sprange et al [159], Lindqvist et al [166] and Chung [167]. Given the lack of studies, and the differing aims and participants, qualitative data generated was synthesised in this Chapter in accordance with the preceding three questions.

5.7.5. Strengths and Limitations

This is the first study to synthesise studies generating quantitative and / or qualitative data relating to interventions involving occupational therapists for people living with early-stage dementia. It has therefore gleaned new insights into this existing body of research. However, a number of limitations must be noted, including the overall quality of studies: only eight RCTs were identified and a number of these were described as pilot or feasibility studies [156]. There was a considerable lack of reporting about intervention programme theory and contents, namely what constitutes a 'strategy', with only one programme, COTiD, having a published or publicly available intervention manual which was not published in English [128]. As Hoffman et al [121] note, interventions have historically been "*remarkably poor[ly]"* (p1) described, particularly those considered 'complex', which restricts the ability to replicate useful interventions and build upon existing research. Furthermore, there was a considerable lack of studies utilising a qualitative approach, which means that there was a lack of studies to synthesise pertaining to views and experience of occupational therapy interventions. It is also important to acknowledge limitations relating to the search strategy utilised (Table 5), particularly search strategy keywords utilised in relation to the intervention. These were restricted to identify interventions delivered, designed, or managed by occupational therapists, as opposed to all interventions of potential relevance to this programme of research and occupational therapy. This may have resulted in publications being omitted in 2017 and on updating in 2022 (Section 5.8.), for example Orget et al [186].

5.8. Synthesis Update

Chapter 3 explained that the evidence was searched again towards Thesis completion to inform the Thesis' overall conclusion. Methods have been described in Section 3.4. and a summary of studies meeting inclusion criteria will be provided briefly in this section and a PRSIMA flow diagram can be found in Chapter 3, Figure 7. Fifteen publications reporting on ten studies met inclusion criteria and again primarily consisted of experimental and quasi-experimental studies (Table 21). No economic evaluations were identified and only two studies generated qualitative data alongside multi-site RCTs [187, 188]. Six intervention modalities and nine distinct intervention programmes were described (two were also identified in 2017) (Table 21). Heterogeneity in terms of modality and intervention duration and intensity was congruent with the findings of the original search in 2017. Three intervention programmes were identified as Occupational Therapy, whilst six programmes were interventions delivered by occupational therapists. Given the aim of this Thesis, this summary will

focus on the former. Akin to 2017, no programme theories or intervention manuals in English were identified.

Table 21: Intervention Modalities and Programmes identified in 2022

Intervention Modality	Intervention Programme	Country, Publication(s) and Design
Occupational Therapy	Community Occupational Therapy in Dementia (COTiD)	UK: Multi-site RCT [49]; Fidelity Evaluation [189]; Qualitative Interviews [187] Italy: One group pre-post design [190]
	Occupational Therapy Memory Strategy Education Group	Ireland: One group pre-post design [191]
	Home-Based Occupational Therapy Intervention	Spain: One group pre-post design [192]
Cognitive Rehabilitation	Goal-oriented Cognitive Rehabilitation	UK: Multi-site RCT [193]; Implementation Process Evaluation [188]
Cognitive Stimulation	Cognitive Stimulation Therapy	Taiwan: CT [194]
Falls Prevention	Promoting Activity, Independence and Stability in Early Dementia (PrAISED)	UK: Feasibility RCT [195]; Intervention Development [196]; Feasibility RCT Protocol [197].
Reminiscence	Recollection-Based Occupational Therapy Programme	Republic of Korea: RCT [198]
Multi-modal Intervention	Interdisciplinary Home-Based Reablement Programme (I-HARP)	Australia: Feasibility RCT [199]
	Multi-Component Rehabilitation Programme	Belgium: Retrospective Cohort Study [200]

COTiD

COTiD has been described in this Chapter in relation to RCT's in the Netherlands [43] and Germany [48]. Three publications deriving from the UK met inclusion criteria on updating, comprising the results of a multi-site RCT [49], an evaluation of COTiD's implementation fidelity [189] and qualitative interviews with participants and interventionists [187]. A fourth publication pertained to a one group pre-post pilot study in Italy [190].

Mirroring Voigt-Radloff et al [48], Wenborn et al [49] reported no differences between COTiD and treatment as usual (TAU) on any outcomes for people living with dementia and their caregivers in the UK. In Italy, significant pre-post improvements were reported on the COPM only, which was not utilised as an outcome measure by Voigt-Radloff et al [48], Wenborn et al [49] nor Graff et al [43]. Walton et al [189] reported that COTiD was implemented with moderate fidelity in the UK, and poorly at some sites, which again mirrors results reported in Germany [170]. Qualitative interviews with purposively sampled occupational therapists and COTiD recipients in the UK identified barriers relating

to implementation [187]. These included a lack of local resources and services, for example the availability of equipment, as well as individual factors for example negative dynamics between the person living with dementia and their caregiver and physical health conditions. Views and experiences were also captured during qualitative interviews, with occupational therapists valuing the opportunity COTiD provided to use their core occupational therapy skills in the face of an increased emphasis on working generically, as well as the emphasis it placed on getting to know the intervention recipients and building a therapeutic relationship, which was also relayed by intervention recipients.

Home-Based Occupational Therapy Intervention

A one group pre-post study consisting of 21 participants living with mild AD, conducted in Spain met inclusion criteria on updating [192]. The intervention was delivered at home, akin to other interventions from this modality, however, was significantly longer in duration and intensity: 20 weeks' duration, delivered for 1.5 hours, twice a week. Whilst not described in detail, intervention contents also reflected other interventions from this modality, and it also aimed to optimise daily functioning. Outcomes reported after 20 weeks' duration included a significant improvement on the total score of the Barthel Index (BI), a measure of occupational functioning, with a large effect size, however confidence intervals were not reported.

Occupational Therapy Memory Strategy Education Group

Coe et al [191] also utilised a one group pre-post design in Ireland to evaluate their occupational therapy memory strategy group amongst 47 participants, delivered for an hour a week over 6 weeks. This was the only occupational therapy intervention identified in 2017 and 2022 which was delivered in a group setting, with all other programmes from this modality delivered on a dyad or individual basis. Intervention contents and components consisted of goal setting using the COPM as well as strategy-based information, homework, discussion, and practice to support performance or functioning in daily life, consistent with other individual and dyad based interventions from this modality. Intervention recipients were individuals who had Mild Cognitive Impairment (MCI), early-stage dementia as well as people with subjective memory concerns (SMC). Outcomes inclusive of all participants were statistically significant on the Rivermead Behavioural Memory Test II (RBMT-II), the COPM and DEMQOL. Median scores for participants living with dementia on the RBMT-II and COPM increased post intervention, however, subgroup analysis highlighted that participants with SMC and MCI showed greater improvements compared to those with early-stage dementia.

5.9. Chapter Conclusion

Evidence about interventions delivered, designed, or managed by occupational therapists for people living with early-stage dementia primarily derives from studies generating quantitative data on clinical outcomes. There is a notable absence of studies using a qualitative methodology generating data on views and experiences as well as studies on cost-effectiveness. Interventions identified were heterogenous, with eight broad modalities identified, one of which consisted of interventions identified as occupational therapy. Five distinct occupational therapy intervention programmes were reported upon: in 2017 this comprised COTiD, Brief Occupational Therapy Intervention and Supporting Everyday Activities in Dementia; and in 2022, COTiD, Occupational Therapy Memory Strategy Education Group and Home-Based Occupational Therapy Intervention. These intervention programmes varied considerably in length and duration, although all aimed to improve, optimise, or maintain functioning or occupational performance in ADL, and included strategies as the primary intervention content. Of these five programmes, only three RCT's were identified in relation to COTiD (two in 2017 and one in 2022). However, there were inconsistencies in outcomes reported by these studies, with multi-site RCT's in Germany and the UK failing to report any significant outcomes, despite the very large effect sizes reported on all outcomes in the Netherlands. In light of the findings of COTiD UK's RCT, and in the absence of other RCT's deriving from the UK reporting on interventions identified as occupational therapy, there is an absence of evidence deemed 'high quality' to support the specific practice and core skills of occupational therapists in the UK. Furthermore, no pilot, feasibility, quasi-experimental or intervention development studies were identified in the UK from this modality, suggesting that there are no current intervention programmes progressing through the MRC's four stages.

Study 2: Semi-structured Interviews

Chapter 6: Methods

6.1. Introduction

This Chapter is the first reporting on Study 2, which constituted semi-structured interviews with people affected by dementia and occupational therapy practitioners. In this Chapter, Study 2's aims, objectives and methods will be outlined, with Study 2's findings and a discussion contained in Chapters 7, 8, and 9. In Study 2, pseudonyms have been used for study sites and participants to maintain anonymity.

6.2. Aims, Objectives and Research Questions

As outlined in Chapter 1, this Thesis' overall aim, is to describe and develop an occupational therapy intervention for people living in the community with early-stage dementia. As is common practice when developing complex interventions, multiple methods were used, with Study 1 (Chapters 3, 4 and 5) reporting on one method: an evidence synthesis. In addition to identifying existing evidence, Intervention Mapping [68] and the MRC Frameworks [64, 65] highlight the importance of conducting primary research when developing a complex intervention. In this context, semi-structured interviews were used to further inform this programme of work's needs assessment (Section 2.3.1.). Needs assessment objectives for this Thesis were outlined in Chapter 2 and were utilised to develop research questions for Study 2, which are presented below:

- **Thesis Objective 1:** Understand the intervention population.

  Study 2 Research Questions:

  2.1.1. What does the term 'early-stage' dementia mean to occupational therapy practitioners and people affected by dementia?

  2.1.2. What impact, if any, does early-stage dementia have on the occupational (activity) performance of people living in the community?

- **Thesis Objective 2:** Understand the intervention setting and context.

Study 2 Research Questions:

2.2.1. In what services / settings are occupational therapy practitioners currently working with people affected by early-stage dementia living in the community?

2.2.2. *In what services / settings could occupational therapy practitioners work with people affected by early-stage dementia living in the community?*

2.2.3. What barriers and facilitators do they / could they face?

- **Thesis Objective 3:** Identify existing clinical and research-based occupational therapy interventions.

Study 2 Research Questions:

2.3.1. What interventions are occupational therapy practitioners currently delivering to meet the needs of people affected by early-stage dementia living in the community?

2.3.2. What interventions could occupational therapy practitioners deliver to meet the needs of people affected by early-stage dementia living in the community?

2.3.3. What barriers and facilitators do they / could they face?

6.3. Methods

6.3.1 Data generation

6.3.1.1. Semi-structured Interviews

Semi-structured interviews were utilised to generate a detailed and flexible exploration of the population, context, and intervention, from the perspective of occupational therapy practitioners and people affected by dementia [201]. In line with a pragmatic approach, a decision to use interviews as a method was informed by prior research undertaken with this population (Section 1.5.1.), which included a cross-sectional survey of the practice of occupational therapists working with people affected by dementia in the Welsh NHS [39]. Scant detail was provided by participants about the nature of occupational therapy interventions, therefore a method that captured this information in detail was deemed more appropriate for this study. Interviews have also been identified as an

accessible way to involve people affected by dementia, particularly given their flexibility to accommodate difficulties concentrating or comprehending [202, 203]. The proposal to use semi-structured interviews was discussed early on in the design of this programme of work with the study's LEAG (Appendix B). Members welcomed the use of semi-structured interviews as it provided an opportunity to describe in detail day-to-day experiences of living with dementia.

Interview Schedule Development

Separate schedules were developed for occupational therapy practitioners and for people affected by dementia to account for their differing perspectives (Appendix K and L). These were developed based on Study 2's objectives and research questions, and were informed by a number of different sources, which included the following: -

- Literature about complex intervention research: Intervention Mapping [68], the Medical Research Council's (MRC) Guidance on conducting process evaluations [173] and the TIDieR Checklist [121].
- Study 1: Research Question 2.1.1. and corresponding interview schedule questions were included in response to the lack of clarity identified in Study 1 about what constitutes early-stage dementia, particularly in relation to cognitive assessments.
- Prior experience of conducting research interviews with people affected by dementia [39]: Questions for people affected by dementia did not include the word 'occupation', as prior experience suggested that this word is often interpreted differently by people who are not occupational therapists. The word 'doing' was used during interviews with people affected by dementia and probes used flexibly as appropriate.
- Stakeholder engagement: Provisional interview schedules were developed following consultation with the study's Lived Experience Advisory Group (LEAG). These were reviewed on completion by the group, who offered positive feedback and made no recommendations for improvement.

Demographic Questionnaire

A demographic questionnaire was utilised to capture participants' demographic details, including gender, age, education, and ethnicity. Additional questions were included to capture practice setting and banding for occupational therapy practitioners and diagnosis for people affected by dementia.

Personnel and Procedures

Interviews were conducted on one occasion and in accordance with participant preference were primarily conducted on an individual (n = 14) and dyad basis (n = 7), with one interview conducted with three participants. All interviews with occupational therapists were conducted on NHS premises, with interviews with people affected by dementia occurring at their home or on NHS premises, determined by participant preference. Interviews with all participants were carried out in English, although the opportunity to participate in Welsh was provided. All interviews were audio recorded and only the interviewer and participants were present during interviews. In total 22 interviews were conducted with 31 participants (Tables 22 and 25).

I conducted all interviews, and as a researcher in residence had a prior established relationship with occupational therapy practitioners at one participating site. I had also met three people affected by dementia who participated in interviews through my engagement with third sector organisations. I had prior experience of conducting semi-structured interviews through earlier work in this area (Section 1.5.1.) and had also worked on two NIHR funded multi-site, cross national studies interviewing people living with a mental health condition. I also approached these interviews as someone who had no experience working clinically with people affected by dementia, and therefore had no concrete pre-conceived ideas of what an intervention for this population would look like or entail.

6.3.2. Sampling and Recruitment Strategy

6.3.2.1. Occupational Therapy Practitioners

Taliesin Health Board

The revised MRC Framework [65], drawing on O'Cathain et al [69], highlight that real world implementation must be considered from the outset of the intervention development process. Accordingly, at the time of data generation and in preparation for a future feasibility study of the developed intervention, Taliesin Health Board was identified as the initial implementation context. Taliesin was selected, as a funding application had been successfully made for a new Memory Assessment Service (MAS) occupational therapy team through funding associated with the WG's Dementia Action Plan [51], and therefore resources were available to support implementation.

A purposive sampling strategy was used to recruit occupational therapy practitioners (occupational therapists and occupational therapy support workers or technicians) working in Taliesin Health Board's Older Persons Mental Service[9] [201]. All occupational therapy practitioners within the team were invited to participate to ensure that people with expert knowledge about the context the intervention would be implemented in, and the intervention population, were central to the data generation process. Invitation emails were sent to all team members and an invitation was provided verbally during a routine team meeting. As presented in Table 22, nine occupational therapy practitioners participated from Taliesin between 21.3.2018 and 27.7.2018, which included two occupational therapy support workers and seven occupational therapists. Participants from Taliesin were working in secondary, inpatient, and intermediate care Older Persons Mental Health Services, including Older Persons Community Mental Health Teams (OP-CMHT) and mental health liaison services.

Hergest, Rhydderch, Arberth and Dyfed Health Boards

Whilst Taliesin was identified as the initial implementation site for feasibility testing, the updated MRC Framework [65] and O'Cathain et al [69] additionally emphasise that implementation in the future as well as 'scaling up' should also be considered at the start of the development process. The Welsh NHS was therefore identified as a future 'scaling up' implementation context, given the shared political and policy context across Welsh Health Boards. Accordingly, attempts were made to recruit occupational therapists in all six remaining Health Boards, however, given study timescales, recruitment was confined to four additional Health Boards (Hergest, Rhydderch, Arberth and Dyfed). A purposive sampling strategy was used to recruit participants who had current experience of working with people living with early-stage dementia as an occupational therapist (Table 23). Gatekeepers, who were senior occupational therapists or occupational therapy managers for Older Persons Mental Health Services, distributed an invitation to participate email to all eligible occupational therapists within their service. The number of participants per Health Board was limited to five, owing to study timescales and capacity, therefore the first five volunteers per Health Board were recruited to participate between 8.8.2018 and the 1.11.2018. Twelve occupational therapists participated from Hergest (n = 3), Rhydderch (n = 3), Arberth (n = 5) and Dyfed (n = 1).

[9] Taliesin did not have a service specifically for young-onset dementia, with OPCMHT's working with people living with dementia of all ages within the Health Board.

Table 22: Demographic Data: Occupational Therapy Practitioners

Health Board	Number of Interviews	Number of Participants	Gender	Age	Ethnicity	Highest Educational Qualification	Band	Primary Practice Setting
Taliesin	n = 8	n = 9	Female: n = 9	25-29: n = 2 35-39: n = 1 40-44: n = 3 50-54: n = 1 55-59: n = 2	White British / European: n = 9	Degree / Diploma: n = 9	3: n = 2 6: n = 5 7: n = 2	MH Liaison: n = 2 OP-CMHT: n = 2 Inpatient OPMH: n = 3 Reablement: n = 1 Specialist Intervention Team: n = 1
Hergest	n = 2	n = 3	Female: n = 3	30-34: n = 1 40-44: n = 1 45-49: n = 1	White British / European: n = 3	Degree / Diploma: n = 3	6: n = 2 7: n = 1	OP-CMHT: 3
Rhydderch	n = 3	n = 3	Female: n = 3	30-34: n = 1 35-39: n = 1 40-44: n = 1	White British / European: n = 3	Degree / Diploma: n = 2 Post Grad Cert / Diploma: n = 1	6: n = 2 7: n = 1	MAS: n = 2 OP-CMHT: n = 1
Dyfed	n = 1	n = 1	Female: n = 1	50-54: n = 1	White British / European: n = 1	Degree / Diploma: n = 1	7: n = 1	OP-CMHT: n = 1
Arberth	n = 3	n = 5	Female: n = 4 Male: n = 1	25-29: n = 2 30-34: n = 1 45-49: n = 1 50-54: n = 1	White British / European: n = 5	Degree / Diploma: n = 3 Post Grad Diploma: n = 2	5: n = 1 6: n = 3 7: n = 1	Admissions Prevention: n = 2 Inpatient OPMH: n = 1 MH Liaison: n = 1 Young Onset Team: n = 1

Abbreviations: MAS: Memory Assessment Service; OP-CMHT: Older Persons Community Mental Health Team; OPMH: Older Persons Mental Health

Table 23: Inclusion / Exclusion Criteria: Hergest, Rhydderch, Arberth and Dyfed

Inclusion Criteria	Exclusion Criteria
• Works as a clinical occupational therapist with people affected by early-stage dementia. • Willing to participate and able to provide informed consent. • Employed by: Hergest, Rhydderch, Arberth or Dyfed Health Boards	• Does not work as an occupational therapy clinician with people affected by early-stage dementia. • Unable to provide informed consent. • Does not wish to participate.

In total, 21 occupational therapy practitioners participated in this study across five Health Boards: 19 were occupational therapists and two were occupational therapy support workers. Table 22 reports upon occupational therapy practitioners' demographic details. Only one was male, all were white British or European, 60% were working at a band 6, with banding ranging from 3 to 7. Seven participants reported working in MAS, however, only two participants identified MAS as their primary practice setting and no participants identified other primary care services as their primary or secondary practice setting.

6.3.2.2. People Affected by Dementia

Purposive and snowball sampling strategies were utilised to invite people affected by dementia to participate who were living in Taliesin Health Board, as the initial anticipated implementation context (Section 6.3.2.1.). Inclusion criteria were broad and included having lived experience of early-stage dementia as a person living with dementia or as a family member or supporter (Table 24). There was no need for participants to have experience of occupational therapy, owing to the absence at the time of recruitment, of an occupational therapy service for early-stage dementia in Taliesin.

The initial recruitment strategy for which ethical and NHS Research and Development (R&D) approval was received consisted of recruiting participants through occupational therapy practitioners, members of the multi-disciplinary team and posters in Taliesin. However, at the time of recruitment, to maintain interdepartmental relationships, this approach was not supported by departmental leads, and therefore alternative recruitment strategies outside Health Board settings were developed. This included snowball sampling through the study's Lived Experience Advisory Group (LEAG) who distributed invitations to participate, and by utilising social media. Given the limited response received from these recruitment methods (n = 4), recruitment was initiated through the Join Dementia Research (JDR) database [204]. JDR bases its recruitment on distance from a District General Hospital

(DGH) and given the DGH and 7-mile radius utilised by JDR for this study, recruitment occurred within Taliesin and Arberth Health Boards. Unfortunately, recruitment was halted prematurely due to the COVID-19 pandemic and therefore, only 10 participants affected by dementia were able to participate in the study. Recruitment commenced on 10.9.18 and the last person was recruited on the 23.1.2020.

Table 24: Inclusion / Exclusion Criteria: People Affected by Dementia

Inclusion Criteria	Exclusion Criteria
• Has a diagnosis of dementia, which could include (but not limited to) Alzheimer's Disease, Vascular Dementia or Frontotemporal Dementia. OR • A carer / family member / significant other over the age of 18. AND • Comfortable talking about their experiences of occupational therapy and diagnosis. • Able to understand written or verbal information in English or Welsh. • Able to converse in English or Welsh. • Willing to participate and able to provide informed consent. • Aware of their diagnosis.	• Does not have a diagnosis of dementia. OR • Is not a carer / family member / significant other over the age of 18. • Unable to provide informed consent. • Participation is likely to cause distress. • Does not wish to participate. • Participation in the study would pose an unacceptable risk to the person with dementia themselves, carers, researchers or anyone else.

Of the 10 participants affected by dementia who participated in this study, five were living with dementia and five were family members (Table 25). Three participants living with dementia had been diagnosed with early-onset Alzheimer's Disease (AD) and two with late-onset AD. Two supporters had experience of supporting a family member living with Lewy Body Dementia, with the remaining three having experience of supporting someone living with a family member with AD. All participants were white British, and only one male participated. Four participants living with dementia had received a diagnosis between 1 and 5 years prior to interviews, with one diagnosed less than a year before participating.

Table 25: Demographic Data: People Affected by Dementia

	Gender	Age	Ethnicity	Diagnosis / Diagnosis of Person Caregiver Supports	Time Since Diagnosis	Relationship with Person Living with Dementia
Person Living with Dementia	Female: n = 4 Male: n = 1	50-54: n = 2 60-64: n = 1 75-79: n = 1 80-84: n = 1	White British / European: n = 5	AD: n = 5	Less than 1 year: n = 1 1 – 5 years: n = 4	
Caregiver	Female: n = 5	18-24: n = 1 40-44: n = 1 45-49: n = 1 70-74: n = 1 80-84: n = 1	White British / European: n = 5	AD: n = 3 Lewy Body Dementia: n = 2		Child: n = 3 Spouse: n = 2
Abbreviations: AD: Alzheimer's Disease.						

6.3.3. Data Processing and Analysis

Miles et al's [120] methods sourcebook for qualitative data analysis was utilised to guide a thematic analysis of data generated during Study 2. They provide an explicit and extremely detailed account of the "*doing*" (p6) during qualitative data analysis, and taking a pragmatic approach argue for the use of data analysis techniques on an *"as needed basis*" (p9), in a systematic, transparent, "*deliberate and diligent*" (p9) way. This approach was adopted during this study and is described below in four key stages.

Stage 1: Processing and Preparing

Interview audio recordings were transcribed by an external contractor specialising in the transcription of health-related interviews [205]. Once returned, transcriptions' accuracy were evaluated against audio recordings, with modifications made as necessary. All identifying data was anonymised, with pseudonyms used for participant names, Health Boards and other identifying names and locations. Anonymised transcripts were finally uploaded to NVivo, which was used to manage and store data during analysis.

Stage 2: Familiarising and Categorising

To enable the analysis of data in accordance with Thesis Objectives 1 – 3 and their corresponding research questions (Section 6.2.), the entire data set was categorised using Nvivo. Three categories were used which mirror Thesis Objectives 1 – 3, with large data chunks categorised accordingly, and where relevant data could appear in multiple categories. Data was read and re-read in accordance with category, with amendments made to data categorisation as necessary. Provisional coding memos were made in preparation for Stage 3.

Stage 3: Coding and Sub-coding

Coding was conducted on a category / Thesis Objective basis. Data pertaining to Thesis Objectives 1 and 2 was coded using an inductive approach, to ensure codes were "*grounded empirically*" in the data [120] p81. Data was read and re-read, with provisional codes developed during stage 2 revised iteratively. Descriptive and process codes were used (Table 26), which are described by Miles et al [120] as "*elemental*" and "*foundational*" coding methods (p74).

Table 26: Elemental Coding Methods (Adapted from Miles et al [120])

Coding Method	Description	Examples from this Study
Descriptive Coding	A word (most typically a noun) or short phrase that summarises data	Complexity and Variability Skills and Abilities
In Vivo Coding	Words or short phrases from participants' own language	*"I'm still who I am, I can still do things"* An Awareness of Change: "S*omething's not quite right"* Primary Care: *"We're missing people"*

A priori, codes informed by the TIDieR Checklist [121] were used to code data generated to meet Thesis Objective 3 (Table 27). TIDieR was used to inform the synthesis of data about the nature of interventions identified in Study 1's Intervention Synthesis studies (Chapter 5) and is a world-renowned checklist to facilitate a "*complete published description of interventions"* (no page number). Its use in Studies 1 and 2 was strategic, to enable the synthesis of data about interventions deriving from both research (Study 1) and practice (Study 2) to inform intervention development. These a priori codes were held lightly, however, proved to be a suitable way of coding larger chunks of data relating to Thesis Objective 3. Inductively developed descriptive and in vivo sub-codes were developed as necessary [120].

Table 27: Codes Informed by TIDieR Used in Study 2

• Intervention Rationale, Theory, or Goal.
• Content and Components
• Mode and Location of Delivery
• Interventionist
• Duration and Intensity

Stage 4: Narrative Description

A formal description of 'themes' (codes) and 'sub-themes' (sub-codes) was written per category / Thesis Objective and is reported in Chapters 7, 8 and 9. Differences in views between Health Boards and between participants affected by dementia and occupational therapy practitioners have been highlighted. Data deriving from occupational therapy practitioners in Taliesin Health Board pertaining to Thesis Objective 3 were initially coded (Stage 3) and described (Stage 4) separately from

participants in Hergest, Rhydderch, Arberth and Dyfed Health Boards, owing to the minor difference in interview question focus (in Taliesin participants were asked about a new intervention, whereas participants in other Health Boards were asked about interventions currently delivered). However, given the striking similarities, they are presented in this Thesis together to avoid repetition in Chapter 9.

6.3.4. Ethical Approval and Conduct

Ethical approval was received for this study from an NHS Research Ethics Committee, Wales REC 2, REC Reference: 18/WA/0107 (Section 2.6.1.). Research and Development (R&D) Risk Review approval was also received from all five NHS research sites.

Consent Procedures

Interviews were carried out on an opt-in basis, with a signed record of consent obtained in person. Only participants who were able to provide freely given informed consent were recruited to the study, consultees were not utilised. As potential participants included people affected by dementia, the provisions of the Mental Capacity Act [206] and the Code of Practice [207] were adhered to, when assessing capacity to consent, including the two-stage test of capacity. In accordance with the Code of Practice, all practical and reasonable steps to enable a person with dementia to participate were taken. This included communicating information about the study in in an accessible manner. Two Participant Information Sheets and two Consent Forms were developed, one in accordance with the standard HRA Participant Information Sheet template and one that was accessible, which was shorter, used bullet points and accessible language. The study was also explained verbally to participants, drawing upon recommendations in the Code of Practice, including utilising appropriate wording, breaking down difficult information and explaining information. No participants withdrew from the study after providing informed consent.

Confidentiality and Information Governance

Throughout the duration of this study, the principles of the Data Protection Act [208] and subsequently the UK General Data Protection Regulations (UK GDPR) [209], and organisational policies were adhered to. Audio recordings were uploaded and stored on NHS password protected computers before being securely transferred through an encrypted and password protected portal to an external

transcription agency. An information governance agreement was additionally prepared between the Health Board and the transcription agency. Transcripts were transferred back through the portal and all identifying data was anonymised by using pseudonyms on their return. Following anonymisation, data was stored on password protected laptop computers for analysis. The study's site file and all hard copy data, for example demographic questionnaires and consent forms, were stored in a locked filling cabinet at a Health Board site. Permission for direct quotations was obtained from all participants.

Risks and Burdens

The primary burden for occupational therapy practitioners was upon their time. Therefore, every effort was taken to ensure participation did not impact upon the delivery of care or services, this included arranging semi-structured interviews flexibly around clinical work. People affected by dementia also experienced a burden upon their time and therefore, interviews were arranged flexibly in accordance with preferences. Interview schedules were reviewed by the study's LEAG to ensure all questions were sensitive to the feelings and needs of people affected by dementia. Participant Information Sheets also emphasised that some people may become distressed whilst talking about their experiences, this was discussed with participants prior to gaining consent, to ensure that they are fully informed of this unlikely consequence.

6.3.5. Strengths and Limitations

To my knowledge this is the first study to explore views and experiences of occupational therapy intervention for people living in the community with early-stage dementia in Wales. However, limitations must be acknowledged, particularly the absence of multiple coders, which may undermine the study's credibility. Data was also analysed in the context of a programme of work seeking to develop an occupational therapy intervention, and as described in Section 6.3.3., data was categorised and analysed in accordance with Thesis Objectives 1, 2 and 3. Therefore a secondary analysis of the data set may glean new insights into the views and experiences of participants that do not pertain to these objectives. Recruitment of participants affected by early-stage dementia was halted due to the COVID-19 pandemic, resulting in only 10 participants affected by dementia, whilst 21 occupational therapy practitioners participated. Additional, alternative methods of generating data from people affected by dementia were recommended by the studies LEAG, for example video diaries, however given the confines of time and resources this was not possible.

6.4. Chapter Conclusion

In this Chapter, Study 2's methods have been described, including semi-structured interviews with people affected by dementia and occupational therapy practitioners, and a thematic analysis using Miles et al's [120] pragmatic approach. Study 2's research questions based on Thesis Objectives 1 - 3 have also been described. Study 2's findings will now be reported in Chapters 6 – 8 as follows: -

- Chapter 6: Thematic Analysis: Population, Thesis Objective 1
- Chapter 7: Thematic Analysis: Context, Thesis Objective 2
- Chapter 8: Thematic Analysis: Intervention, Thesis Objective 3.

Chapter 7: Thematic Analysis: Population

7.1. Introduction

Findings deriving from Study 2 that aimed to meet Thesis Objective 1, to understand the intervention population, will be presented in this Chapter. Research questions associated with this objective were described in Chapter 6 and comprised:

> 2.1.1. *What does the term 'early-stage' dementia mean to occupational therapy practitioners and people affected by dementia?*
> 2.1.2. *What impact, if any, does early-stage dementia have on the occupational (activity) performance of people living in the community?*

An inductive thematic analysis was conducted on data generated during semi-structured interviews to meet these research questions, as described in Section 6.3.3. Table 28 provides an overview of themes identified, which will be described in detail in the remainder of this Chapter.

Table 28: Themes: Intervention Population

Research Question	Codes / Themes
2.1.1. Defining Early-Stage Dementia	• An Individual yet Similar Experience?
	• An Awareness of Change: "*Something's not quite right"*
	• A Service Perspective: Assessment and Diagnosis
	• An Occupational and Functional Perspective
2.1.2. Impact on Occupational Performance	• Skills and Abilities
	• Motivation and Mental Health
	• Occupations and Environments
	• *"I'm still who I am, I can still do things"*

7.2. Findings

7.2.1. Defining Early-stage Dementia

Multiple perspectives were evident in response to questions about the meaning of the term 'early-stage' dementia. Four themes were identified (Table 28) which reflect these multiple perspectives.

7.2.1.1. An Individual yet Similar Experience?

Across interviews, an overarching recurring theme was the emphasis placed by participants on the very individual way in which early-stage dementia is experienced and impacts on occupational performance. Multiple reasons were provided to underpin this view, including the way different forms of dementia can manifest themselves differently during the early stages. For example, participants advocated that people living with Alzheimer's disease (AD) may experience changes to their short-term memory, whilst people living with vascular dementia may experience depression and apathy, whereas people living with fronto-temporal dementia may experience personality changes. Further references were made to aspects of a person's life that can influence individual experiences and impacts, including age, education, living and relationship status, level of functioning prior to dementia, and personal interests. Anita illustrated the difference age can make:

> *"I think it would depend on the person and the individual. I think it would also depend on what their background is to a large extent, but generally if people are still of working age, they're likely to have difficulties with working and I think somebody with an early dementia perhaps who's retired is likely to have problems with forgetting possibly appointments."*
>
> Anita, Occupational therapist

Participants affected by dementia additionally highlighted that even on an individual basis, variability was experienced. They spoke about the adverse impact being tired and having a busy day or week could have upon them:

> *"If I do too much, I will have a bad day. And I feel very emotional, my head can be really pounding, exhaustion and all I will do then all day is sleep. Don't want to talk*

to anyone, I just want to be left alone. I don't want to eat, I don't want to drink, I just want to be left and I want to curl up into a ball and just stay there."

Carla, Person living with dementia

Despite individual differences, occupational therapy practitioners reflected that whilst no two people living with early-stage dementia are the same, they often have similar needs and share similar experiences, as Gemma reflects:

"Everybody seems to be different, [but] there are similar traits…. It isn't a clear area and everybody is, as I say, everybody is very individual, [but] there are certain traits and you can see certain…paths that people go down, but not every person is identical. You'll say, oh so and so is like so and so or Mrs Jones is like, oh remember Mrs Thomas? But they're never identical."

Gemma, Occupational therapist

7.2.1.2. An Awareness of Change: "*Something's not quite right*"

Frequent references were made to the lived experience of early-stage dementia as an awareness that something has changed or that something is "*not quite right*". Emphasis was placed on people themselves, or their support network, noticing changes in ability to complete day-to-day activities from the persons previous norm or standard, as described by Angharad:

"…individuals are usually still functioning…to a good level but people might be noticing some difficulties. Often close family may notice whereas passers-by or friends may not because people can often cover and mask things quite well, or it just doesn't show in that social type setting."

Angharad, Occupational therapy practitioner

Some participants living with dementia described becoming aware that they shared similar symptoms or difficulties to people they knew who had dementia. Eleanor recognised that she had similar experiences to her mother and grandmother, who both had dementia, whilst Geraint noticed a similarity between himself and a friend:

"…And it sounds odd, we had two lovely friends…one's died now, but they went to live near their daughter…and when they went…he [Geraint] said to me, I'm going to, I'm like, [name redacted], that was our friend, I'm like [name redacted]..."

Carol, Family member / carer

An awareness of change was sometimes associated with attempts by people living with dementia to understand and make sense of changes, as expressed by Elin:

"It's a bit of a shock, trying to get your head around it, trying to understand why you feel different. Why you're not doing the same things that you used to do, why things feel strange, by that I mean the things that you used to do every day, and places you used to go every day, they don't seem familiar. Trying to understand the mood swings although I don't realise I'm doing them and everybody else is telling me that I am. Trying to understand my fear of going out, I feel safer in the house… I'm happier in my little cocoon so to speak."

Elin, Person living with dementia

Occupational therapy practitioners highlighted that some people affected by dementia may not notice that changes have happened themselves. They also emphasised that the person themselves or their family may not be ready to acknowledge that they are experiencing difficulties or feel that any changes are significant enough to seek support or advice during the early stages.

7.2.1.3. A Service Perspective: Assessment and Diagnosis

A disparity between the lived experience of change as outlined in the preceding theme and defining early-stage dementia from a service perspective was described by some occupational therapy practitioners. They spoke about the role diagnosis, contact with services and assessments often play in shaping clinical perceptions about whether someone has early-stage dementia. Some occupational therapy practitioners associated 'early-stage' dementia with someone who was undergoing diagnostic procedures or someone who had recently received a diagnosis. However, participants also noted that people affected by dementia often enter services in the middle to severe stages or in a crisis, rather than in the earlier stages. Hannah, like participants living with dementia, emphasised that even in the

early stages, contact with services may not reflect the onset of symptoms, which may occur months or years before:

> *"From a service point of view that stage we might refer to it, because that's the point of contact, but it's not always a reflection of, they might have had some problems for some time so…in terms of classification of stages, so where people use cognitive assessments that then indicates this is this stage so there are, there's some classification to it. But I think…there's a lived experience, what we call they've just got in contact, they've just got diagnosed, but they might have had experience for some time …"*
>
> Hannah, Occupational Therapist

As mentioned by Hannah, occupational therapy practitioners reported that standardised cognitive assessments, primarily the Montreal Cognitive Assessment (MOCA) and the Addenbrooke's Cognitive Examination (ACE) were typically used by members of the Multi-Disciplinary Team (MDT) during the assessment and diagnostic process. However, there was a lack of clarity among occupational therapy practitioners about what scores on these assessments were indicative of early-stage dementia. Participants were critical of using cognitive assessments alone to determine dementia severity, emphasising that scores on such assessments would typically be considered on an individual basis following further assessments, including MRI scans, blood tests, occupational or functional assessments and additional psychometric testing. Carol and Geraint also reflected on the limitations of cognitive assessments in the early stages from a lived experience perspective:

> *Carol:* *"I had noticed he was forgetting things, but wasn't that bad. So, the Doctor did refer him about a year later and so they just said, well he's not bad enough, and any tests they gave him were things that we did in our 11 plus, so he knew the answers to them all before –"*
>
> *Geraint:* *(indicates understanding)*
>
> *Carol:* *"That were in your brain, you don't –"*
>
> *Geraint:* *"As I said, they're just in built with you now."*
>
> Carol, Family member and Geraint, Person living with dementia

7.2.1.4. An Occupational Perspective

Throughout interviews, occupational therapy practitioners emphasised the occupational and functional focus of their work. Reflecting this focus, dementia severity or stage was associated by occupational therapy practitioners with its impact on a person's ability to function in their day-to-day life. In particular, emphasis was placed when considering severity on the impact dementia has on a person's independence, including the amount of support required from another person, as well as their ability to learn, as Gemma describes:

> *"In the early stages the difficulty with their memory just tends to make things a little bit more difficult because as I said, things take, might take three times as long to do, forgetting important things. But they're still able to generally learn and we can help them with their routines and help them maintain their routines so they can stay as independent as possible. Going into the more moderate stage, again they still have a learning potential, however it may be that somebody else has to initiate the task or prompt them with a task because they wouldn't do that themselves. Towards the end stage it's generally someone is actually beginning to do for or totally doing for…"*
>
> Gemma, Occupational therapist

Given their emphasis on occupational performance and functioning, occupational therapists advocated the need to use observational functional assessments in determining dementia severity, whilst emphasising that a person's performance on routinely utilised standardised cognitive assessments may not necessarily reflect ability to perform occupations day-to-day:

> *"It's just that some people can score really poorly on all the psychometric testing, but their routines are so entrenched from an early age that they might actually function marvellously because their routines are so tight. Other people especially if they live with others, because other people will compensate for them, they tend to lose their skills quicker therefore sometimes you think somebody's at an early-stage but actually they're much more moderate when you do the functional testing."*
>
> Gemma, Occupational Therapist

Whilst observational non-standardised functional assessments were primarily utilised by occupational therapists, some participants spoke about using the Large Allen Cognitive Level Screen (LACLS), which provides a score using the Cognitive Disabilities Model's (CDM) six functional levels. Level 5 and upper level 4 were associated with earlier, milder difficulties in ability to carry out activities. However, like cognitive assessments which produce a score, the LACLS as a screening tool and not an everyday functional assessment was criticised by some practitioners.

7.2.2. Impact on Occupational Performance

Reflecting conceptual models of occupational therapy practice [37, 79, 210] participants' descriptions of the impact early-stage dementia can have upon occupational performance pertained to the person (their skills and abilities, motivation, and mental health) and their environment (social, occupational, and physical). Four themes were identified as presented in Table 28, which will be described in this section.

7.2.2.1. Skills and Abilities

Memory and Forgetting

The impact changes in short-term memory can have on occupational performance were widely recounted by both occupational therapy practitioners and participants affected by dementia, who spoke about their experiences of "*forgetting*". Remembering to do something, for example taking medication, attending appointments or events, and turning off the cooker or tap were expressed as prevalent difficulties. Remembering to do was often associated with difficulties remembering or knowing the time and date. Being unable to remember or know what's behind a cupboard door in the kitchen or bedroom was described, which could prevent the initiation and completion of occupations in these environments. Further difficulties were expressed in relation to remembering or knowing how to do something, for example how to cook or how to use the TV remote control. Problems recalling events or activities were also noted, including remembering what happened yesterday, whether lunch had been eaten or if medication has been taken. Forgetting whether a task had been completed could result in an activity being repeated, as Elin describes:

Elin: *"Because I forget my tablets, I'll take my tablets and then I think, have I taken my tablets, and then I'll take them again, so I overdose myself."*

Sian: *"Or you don't take your tablets."*

Elin: *"And I don't take my tablets, and it's like, have I taken my tablets?"*

Elin, Person living with dementia and Sian, Family member

Given the nature of the occupation or activity involved, forgetting to do something, or not knowing whether an activity had been completed could compromise a person's safety as indicated by Elin in relation to her medication. Others, including Gemma reported that it could lead to an activity taking longer than before, due to multiple repetitions:

"It's generally going upstairs to do something, and you've got upstairs and you've actually forgotten what you went up there for and you go downstairs and then they'll see something that prompts them and they'll think, oh yes, I was going to do that. And they go upstairs again, so it's, it's generally it takes you perhaps twice or three times as long to do something that you would normally have done straightaway."

Gemma, Occupational therapist

Difficulties orientating to place were often described by participants affected by dementia in the context of memory and forgetting. Getting lost and not being able to recall journeys or directions, particularly when driving was spoken about by Geraint and Carol:

Carol: *"I'm the chauffeur."*

Geraint: *"As I say, I don't drive now because I wouldn't, I would be lost really quickly if I was driving, so Carol always drives for me if I do that."*

Carol: *"…if we take you out of [name redacted] area, the park and around, you've completely no idea where you are –"*

Geraint: *(indicates agreement, yes)*

Carol, Family member and Geraint, Person living with dementia

Despite the prevalence of memory or forgetting related impacts on occupational performance, occupational therapy practitioners highlighted that procedural memory was typically less affected in the earlier stages. They reported that this enables the functional performance of more automatic or routine activities. In addition, occupational therapy practitioners emphasised that people affected by early-stage dementia can still retain and learn new information, which enables them to adapt and learn new ways of doing. There was ample evidence from participants affected by dementia that they had the ability to adapt and learn new ways of doing activities. Some adaptations were initiated by the person themselves, others by their support network and some by an occupational therapist. Elin spoke about the strategies she was taught by her occupational therapist from intermediate care services, which she was referred to after a physical illness:

> *"They taught me to have timers everywhere in the kitchen because I kept burning things and forgetting about it and leaving stuff on so I've got a multitude of timers. And the other big thing, this is really, really important this was, all my stuff was in cupboards, so everything's come out of cupboards like my food mixer is on top of my cupboard, my soap mixer is there… everything is on worktops or on top of my cupboards so when I go in the kitchen, if I can't quite remember why I'm in the kitchen I can look up or look around and think, oh I'll bake a cake. It just helps me to remember, so it's visualisation, they taught me visualisation was a big key thing…"*
>
> Carla, Person living with dementia

Executive Functioning

The impact early-stage dementia can have on executive functions was highlighted frequently by occupational therapists. Yet, beyond naming "*executive functions"* as a collective or naming individual executive functions, for example "*attention and concentration*", "*problem solving*" and "*organising and planning*", scant detail was provided about the impact these changes can have on activities. However, difficulties associated with executive functions were noted to be more prevalent when performing "*complex"* occupations in unfamiliar or busy environments that place greater demands on a person's ability to concentrate, attend to multiple things, and problem-solve in the moment.

Mobility and Physical Abilities

Participants affected by rarer forms of dementia (Lewy body and early-onset AD), recounted how their ability to mobilise had deteriorated in the early-stages. They described stumbling or falling, being unable to maintain balance whilst standing or sitting and being unable to get into the bath or shower safely, as described by Carla:

> *"…I lose grip, I drop things, and they're in my hand and the next minute they're not, but I don't understand why because I don't feel the grip going…, I could get in the bath but I couldn't get out of the bath I used to struggle and sometimes I'd fall. So, unless [name redacted] was in there or somebody was there with me, I wouldn't be able to use the bath….I was struggling getting up and down the stairs and they were, because it's quite steep stairs they were worried that, I was just stumbling and I was going to fall down the stairs..."*
>
> Carla, Person living with dementia

Nia and Linda expressed concerns that rarer symptoms of early-stage dementia for people living with Lewy Body dementia, in particular mobility, had resulted in an absence of support and delayed treatment for their relative due to a lack of awareness amongst professionals:

> *Linda:* *"It was, basically we waited a long, long time, and even though there were mobility issues it was slightly delayed, a considerable amount of time after we noticed these things were happening with him…."*
>
> *Nia:* *"Yes, I agree entirely."*
>
> *Int:* *"Why do you think there was that delay?"*
>
> *Linda:* *"Lack of understanding of his condition, without a shadow of a doubt, no two ways about it…. So, it was I think a lack of understanding of how the condition affected him differently to anybody else."*
>
> Linda and Nia, Family members

Significantly, participants who had late-onset dementia, spoke about difficulties mobilising and carrying out physical activities, which were unrelated to their dementia diagnosis. Eleanor described

how her decreased ability to mobilise outside for physical reasons had impacted on her ability to access dementia related groups and activities that were held in inaccessible buildings:

> *Eleanor:* *"…there's those big pebbles to go up. Well taking the walker up there it wasn't on, I just couldn't cope with it."*
>
> *Maria:* *"Yeah, and the steps afterwards."*
>
> *Eleanor:* *"And then the steps going into the church hall you see. When [name redacted] was well, when he was well enough, we'd both used to go up there and of course he used to help me, but I didn't have, need a walker then."*
>
> *Maria:* *"But you were a lot better then, a lot more mobile."*
>
> Eleanor, Person living with dementia and Maria, Family member

Sensory Perception: "I'm walking onto a black hole some days"

Whilst not a prevalent impact across the data as a whole, changes associated with sensory-perception, primarily visual, were evident in data deriving from participants who had experience of rarer forms of dementia. Being unable to determine distance or depth was reported in addition to difficulties distinguishing or identifying objects or aspects of the environment of a similar colour. Elin describes how these difficulties can impact her safety, for example by falling when walking and climbing the stairs:

> *"Yeah, it's like I can sit on the couch and I can look at the floor, and I've got a laminate floor a little bit darker than this, and it looks like it's just going down, and down, and down, and down and I don't feel, if I put my foot down I feel like I'm going to go through, I feel like it's a hole then and I feel like I'm going to fall and I can stand up to go to walk and I will stumble because I'm convinced I'm falling because I'm convinced I'm going in a hole and I don't see doors, or handles, or door frames, and I'm walking into everything because I can't see them."*
>
> Elin, Person living with dementia

Language and Communication

Changes in ability to communicate verbally were noted by some occupational therapists. This included repeating conversations and 'word finding' difficulties, which were often associated with memory problems and forgetting. Difficulties associated with dysphasia were described by one occupational therapist, in relation to rarer forms of dementia, including fronto-temporal dementia.

7.2.2.2. Mental Health and Motivation

Occupational therapy practitioners identified that for some people, depression, anxiety, and apathy can be experienced as a symptom of early-stage dementia, particularly those living with vascular dementia. Whilst participants affected by dementia did not mention 'depression' or 'anxiety' specifically, they spoke about "*feeling emotional*" and described experiencing "*mood swings*". Reduced motivation to engage in activities was often described in the context of the emotional and mental health impact of early-stage dementia, although some occupational therapy participants highlighted that it can occur following personality changes. Three out of five participants affected by dementia who participated in this study reported low motivation which impacted upon their ability to carry out a range of day-to-day activities. Elin spoke about her lack of motivation to engage in previous hobbies: "*I used to do a lot of cross stitch, now I struggle, I haven't got the motivation*." For Anna, low motivation had an impact on her ability to complete domestic tasks, which she received support to complete from support workers:

> *"They work with me. Well else they'll do it with me, I don't want them doing it for me but with me is a help. It motivates me, gets me, so now I can, actually I did put the hoover round and washed the floor because the mop's upstairs, but I'll do a bit out there now…see how that's motivating me, making me understand... Because when they come out then, we can go up and, maybe do my bedroom, polish, hoover and mop the floor. Something to do isn't it? But if I had my own way, I wouldn't even do it."*
>
> Anna, Person living with dementia.

In addition to the direct impact early-stage dementia can have upon mental health and motivation, Carla spoke about the impact receiving a diagnosis as a younger person had on her:

Carla: *"…I did go in a dark place."*

Elin: *"You did, yes."*

Carla: *"For I think for about six to eight months,"*

Elin: *"Very, very dark."*

Carla: *"I didn't get out of bed, I wouldn't get out of bed, I didn't do any cooking, cleaning, I wouldn't get out of bed. [Name redacted], how he describes it, he needed body armour to come into the room with me, I was that bad. I didn't think I was."*

Carla, Person living with dementia and Elin, Person living with dementia

In contrast to Carla, not all participants reported experiencing adverse impacts to their mental health after receiving a diagnosis, in particular, participants who had received support immediately after diagnosis and those who were older. Anna recalls: "*I took it on the chin right, but then I did get all the correct help that I needed*", whilst Eleanor stated *"…I more or less accepted…I was upset, but I was expecting it… I think because of the family history as well."*

Another impact on mental health identified during interviews with some participants living with dementia included increased feelings of anxiety, stress, and fright whilst engaging in activities:

"And I can't remember how to cook but I forget what's in my cupboards and I've got to the point where I'm afraid to open them, because I'm afraid of what's there, and it's the same in the bedroom my wardrobe and drawers and it's, I sit on the bed, on my ottoman, bottom of the bed, and I look at the wardrobe and I think, I don't want to open that because I don't know what's in there. Or I'll think, am I meant to go in there?"

Elin, Person Living with Dementia

For Carla, the distress experienced whilst trying to engage in previous hobbies and interests had led to her stopping these activities:

"I don't read because my degree was in literature and I was passionate about it, and because I forget things it's something that I wanted to put, it's something I

closed the door on because I, that was too upsetting, so I don't do that. But that's fine because I've adapted in other ways."

Carla, Person Living with Dementia

7.2.2.3. Occupations and Environments

"Complex" Activities

Occupational therapy practitioners identified what they called "*complex*" occupations or activities as those that people living with early-stage dementia may experience difficulties doing. Whilst detailed information about what constituted "*complex*" was not provided during interviews, it appeared that activities were deemed "*complex*" if they relied on higher order executive functions. Examples were given by practitioners which were also reflected in the accounts of people affected by dementia, and primarily included work and instrumental activities of daily living (IADL). The latter included using public transport, driving, shopping, managing finances, managing medication, cooking, and using everyday technology:

"I see people just not being able to keep on top of perhaps things like what appointments, things to do, what, what's going on in life, medication, perhaps those, cooking, the more complex thing starts to become a little bit more difficult."

Catrin, Occupational therapist

As mentioned by Catrin, across all participants, managing medication was the most frequently reported activity that people affected by early-stage dementia may experience changes doing. Angharad provided some information about the challenges medication can pose:

"…difficulty with medication, that's often when you start to see some problems understanding the complexity of the medication, forgetting to take the medication and then if, if something new is introduced, they are struggling."

Angharad, Occupational therapist

Community access and driving were also frequently acknowledged across participants as "*complex*" activities that are likely to be impacted during the earlier stages of dementia, and Eleanor stated that

she had first noticed symptoms of dementia whilst driving. However, despite noticing changes, three participants living with dementia spoke about being able to continue driving after receiving their diagnosis. Geraint had continued to drive for three years after diagnosis and Eleanor had stopped driving a year prior to her interview after a deterioration in her eyesight. Carla continued to drive at the time of interview on a one-year licence: *"I'm still able to drive on a yearly license which is fantastic".* For people still in employment, the complexities of work and the work environment were also noted as potentially challenging. Angharad talked about her work enabling someone to stay in employment:

> *" I had one lady…and she was having difficulty, she was forgetting to give people change, so she'd do half the task and not all of it. She… had a lot of things going on, it was very busy, and she would forget to turn the fryers off, and different things, and we had to provide lots of memory prompts around what to turn off and things. But she had a lot of complex things going on. So, I think complex things, and I think when…people are very busy and have got a lot going on, you might notice the memory problems more than if they're calm and things are in a routine way. Because they're trying to, the brain can only hold so many things and, so with the dementia, you can hold a little bit less each time..."*
>
> Angharad, Occupational therapist

In contrast to the support provided by Angharad, Carla and Elin spoke about having to leave work after experiencing difficulties related to early-stage dementia. However, both highlighted that they could have remained in employment with the right support and job role:

> *"…they forced me into early retirement which I didn't want to do and in reality now, in hindsight they should have, HR should have given me another position, OK, I worked in pharmacy I understand I can't do people's medication anymore, not a good idea but…they could have put me in a different position and kept me earning and all they wanted to do was get rid of me because I was dead wood…"*
>
> Carla, Person living with dementia.

New, Unfamiliar, Activities and Environments

New, unfamiliar, and non-routine activities were also described by occupational therapy practitioners as activities that people living with early-stage dementia may experience difficulties completing. Examples included going on holiday and missing, or forgetting appointments, events, and birthdays:

> *"I remember I'm having couple of people that they went abroad to America and they described the person with dementia as needy because they couldn't remember the location of the bathrooms or, because it's a new environment they couldn't remember where the toiletries are, where they put their clothes, but it was classed as being needy …but perhaps that's the first signs people will recognise that, being outside a familiar environment or, yeah it's more about the task that you do perform daily. Perhaps if you go to work day-to-day that's fine but if your routine at work is all the same you may be OK for much longer, but if it changes every day you might notice, well actually I'm not managing as well as I used to..."*
>
> Gwen, Occupational therapist

Whilst some participants affected by dementia also reported difficulties carrying out new and unfamiliar activities, Anna's experience highlighted that with the right social support, including an understanding attitude, holidays are an activity which she can continue to enjoy:

> *"…our friends, a couple we've known years now, we go on holidays with them and they understand that, we just went on a fortnight's cruise. Come back about three weeks or so ago. But…they know that if I want to go bed in the day, I can go, they, I got no pressure, and they watch over me as well. So I'm lucky, there's some people haven't got anyone, and my heart do go out to them…"*
>
> Anna, Person living with dementia

As Gwen highlighted, changes imposed to the way previously familiar activities and routines are performed were perceived by occupational therapists to be potentially problematic, for example if someone had to change from washing in a shower to strip-washing or taking a bath, this could cause difficulties in maintaining personal care. New activities, particularly those considered "*complex*", that required new learning, were also identified as potentially difficult, for example being able to use a new

item of technology. Maria and Eleanor spoke about the difficulties Eleanor had in using technology and managing finances, activities that her late husband had previously carried out:

Maria: *"…Something that I have to do is sort her bills and things."*

Eleanor: *"Yes."*

Maria: *"Because that's something that she can get confused but reading bills and knowing how much to pay and …Well see my Dad always did the bills again, so anything to do with money, anything new and she gets confused."*

Eleanor: *"The television I get confused with."*

Maria: *"Because again Dad did the recordings and, yeah… Another thing is central heating timer. Now, if it needs to be changed, like when the clocks change..."*

Eleanor, Person living with dementia and Maria, Family member

Difficulties in new, unfamiliar, and 'busy' physical and social environments, were additionally reported. Orientation when following a journey was described as challenging for some and getting lost outside the home environment was a commonly reported experience. Geraint spoke about stopping driving due to difficulties being able to follow journeys in unfamiliar environments, however, was able to continue walking around his local area independently, which was familiar to him. Carol spoke about the challenges that she and Geraint face when trying to attend non-routine medical appointments in unfamiliar and busy environments:

Carol: *"I applied for a Blue Badge…if the getting lost gets worse and it isn't going to get better, there will be times when I need to be able to park nearer. …I went to take him to the dentist…and I couldn't park, so I had to stop, because he didn't know where the dentist was I had to literally stop outside, it's a busy road…Let him get out and then I had to go and find somewhere to park, but at least I knew then he was going in there…"*

Int: *"How do you feel when you're dropped off and you don't recognise what's around you?"*

Geraint: *"As long as I know where I'm going it's OK."*

Carol: *"You couldn't have found it yourself and it's not that difficult. I parked one day and because we were pushed for time you went across the road and you were looking at every house as you went past and I thought, he's no idea where he's going. Fortunately, I was behind you, but I thought then, you didn't know which side of, there's a side road, you didn't know which side of that side road we were going to..."*

Carol, Family member and Geraint, Person living with dementia

Social Activities and Relationships

Occupational therapy practitioners additionally described the impact dementia can have on social activities and relationships. In addition to potential barriers related to community access, being unable to remember names, repeating conversations, and withdrawing from social engagements and events were noted as prevalent changes:

"…we might have expected them to maybe withdraw a little bit from maybe some kind of social situations or groups that they have. Maybe they're not keeping up with the conversation or they're feeling a bit embarrassed because they're having trouble remembering people's names or topics or dates of groups and things. So we'd expect maybe a little bit of withdrawal from social activities as well."

Angharad, Occupational Therapist

Conversely, all five participants affected by dementia who participated in this study spoke frequently about their attendance at peer support groups, community groups and social events. For some, their social activities had increased since being diagnosed with dementia. Anna spoke at length about the peer support group which she established and the creative activities that they engaged in together:

"…you get to know them, and we understand one another. I've even had them making their own, learnt one of them to crochet. She crocheted slippers. Honestly now…and she's crocheted a blanket for her mother, shawl. But that's something that's in me, I like to help others, and I suppose that's not going to go away easily. Well you've met me, and I am sociable…"

Anna, Person living with dementia

Whilst participants living with dementia were currently actively engaging in social activities, some spoke at length about the impact early-stage dementia had had on their relationships with family and friends and the loss of previously held roles. A decreasing social circle was described after diagnosis by participants living with young-onset dementia, which Elin and Carla associated with a loss of work roles:

Elin:	*"All my work colleagues gone."*
Carla:	*"Because they didn't know how to cope, or how to deal, or how to speak to me."*
Elin:	*"The only friend I've got is Carla, everyone else is gone."*
Carla:	*"Yeah, same with me, I've only got Elin."*
Elin:	*"And other than yourself and [name redacted], the groups that I'm with, they now are my friendships".*
Carla:	*"Yeah, same with me, but we're the only –"*
Sian:	*"So you need more friends that can understand you."*
Carla:	*"Like me and Elin, we know everything about each other, but everybody else has backed off because they don't want to know…"*
Elin	*"I've felt like I was a leper."*

Elin, Person living with dementia, Carla, Person living with dementia and Sian, Family member

In addition to changes in friendships, participants affected by dementia additionally described how roles and responsibilities within a family had changed, for example a daughter providing care for a parent:

> *"…my daughter has to hold my hand and she said to me, mum I feel like I'm treating you like a child, because you don't know when you're safe to cross the road."*
>
> Carla, Person living with dementia

Some participants affected by dementia described experiencing greater conflict in their relationships with family, which was attributed to a lack of information and support for families and emotional symptoms related to their condition. Others spoke about the cumulative impact that their declining

functional ability had upon how they viewed themselves and the impact they were having on others. Anna spoke about her concerns of becoming a 'burden' to her family:

> *"I can see me going downhill. I can't afford to, not yet. I know it's going to happen, and I know, this is the only thing that cripples me is that I'm going to be a burden to the family, who do…dearly for me, all of them, mother, father, sisters. I think that's the worst thing with anyone with dementia, knowing they're going to become that burden."*
>
> Anna, Person living with dementia

7.2.2.4. "*I'm still who I am, I can still do things*"

Whilst all participants living with dementia reported experiencing changes in their ability to carry out their activities, they expressed a determination and ability to remain active, engaged, and independent. A process of adaptation to these changes was evident across participants. Despite experiencing a loss of roles and activities, Elin expressed that she had adapted to her situation over time, which had led to the development of new roles and activities. After talking about what she had lost, including her employment, Elin stated:

> *"But that's fine, because I've adapted in other ways. …four years ago I was fortunate to be, to meet up with [name redacted] and [name redacted] on the theatre group and they asked me to become part of their little gathering. It's a theatre group with lived experiences, and we portray our lived experience whether they're negative or positive in an enactment of a play and roles, and we then show it to conferences, lectures, we even had a three day in [name redacted] Theatre where it went viral, fantastic. …I used to go on the panels to interview people who would going to be working with the Alzheimer's etc. And then I met up with [name redacted] from DEEP, and she is, well she turned my life around really I think, more than anyone else...Yeah, and all these groups and all these conferences and everything else, I haven't got time to work anyway because I'm still busy so it's like having a career now but it's like my career path now is, give my name, give my word and speak…"-*
>
> Elin, Person living with dementia

Like Elin, Sian and Anna, also participants living with early-onset dementia, spoke at length about the new roles and activities they had started, including setting up and facilitating peer support groups, as described in the preceding theme.

Further adaptations in response to the impact early-stage dementia had upon activities was evident across interviews. Geraint described how he continued to engage in his two life-long interests: woodwork, and walking, however, the way in which he carried out these activities had changed. Carol described how they had adapted the way these activities occurred together, with Carol being present when Geraint engaged in his woodwork, thereby making herself available to answer questions about the activity as necessary:

Carol:	*"…we discuss it more which we never used to do, yeah, because he would get on with it and do it, where now. "*
Geraint:	*(indicates agreement, yes)*
Carol:	*"We, because I'm there we discuss it don't we?"*
Geraint:	*(indicates agreement, yes)*
Carol:	*"Yeah."*
Int:	*"What type of things do you say, things like maybe prompting or?"*
Carol:	*"No, sometimes he'll ask me, at the moment he's doing a love spoon… And he'll say, well do you think I need to hollow this out or shall we go through here or, you know, yeah."*

Carol, Family member and Geraint, Person living with dementia

Other participants affected by dementia also described how they had initiated their own adaptations and strategies to manage day-to-day occupational difficulties. For example, to manage medication, participants received prompting from family members, used Dossett boxes and set electronic reminders on a key ring or phone as prompts. Eleanor had initiated a strategy of her own accord to manage appointments by using a calendar:

Int:	*"So, have you missed appointments before or are you good at keeping them?"*
Eleanor:	*"No."*
Maria:	*"No, because they're written down there and I write it straight on my calendar."*

Eleanor: *"No, we haven't missed any appointments at all."*

Maria: *"No."*

Int: *"So, you just adapted yourself and you've got your own way of working it out?"*

Maria: *"Yes, that's it. Yes, she's pretty good at writing things down when she gets a phone call."*

Eleanor: *"I've always done that. You see I, the thing is when I was a health visitor I worked with the elderly. So, these are the things that I used to tell them to do. So, it's a job that has helped me I think, as well."*

Eleanor, Person living with dementia and Maria, Family member

Occupational therapy practitioners also spoke about changes or adaptations that people with early-stage dementia may make themselves to the way an activity is completed. Examples were provided, including making less complex meals using the microwave, using diaries, timers and receiving support from others. However, occupational therapists noted that these adaptations and compensations did not always enable occupational performance and could fail:

"Yeah, so like you say, it's like the diary but then you might find that they have started but they'll lose it or they won't start using it again. And so they might have three different diaries on the go at the same time and different information and different things because they've perhaps started one, lost it, think I need a diary, buy another one. And then they're using two or three."

Ffion, Occupational therapist

7.3. Discussion

In this Chapter, eight themes deriving inductively from semi-structured interviews with occupational therapy practitioners and people affected by dementia pertaining to Thesis Objective 1, to understand the intervention population, have been described. These themes sought to answer two exploratory research questions, which were outlined in Section 7.1, and will be discussed accordingly.

7.3.1. Defining Early-stage Dementia

Four themes were identified and described in Section 7.2.1. based on data generated to answer Study 2's research question:

> 2.1.1. *What does the term 'early-stage' dementia mean to occupational therapy practitioners and people affected by dementia?*

This question was developed in response to the multiple ways in which early-stage dementia is defined and understood, as identified in the wider literature (Chapter 1) and in Study 1. In Study 2, the four themes identified attest that there were also multiple perspectives amongst participants in this study. The initial theme, 'An Individual yet Similar Experience?' (Section 7.2.1.1.), described the view that each person is likely to have an individual experience of early-stage dementia which is unique to them, yet also broadly similar to others. As well as the influence dementia sub-type has on how early-stage dementia presents or is experienced, in this study, occupational therapy practitioners additionally spoke about the influence socio-cultural-economic factors can have. Low educational attainment and occupational class [211], deprivation [212], ethnicity [213] and age [19] are known factors that can impact on someone's experience of dementia, and their access to services.

A new perspective in the context of this Thesis, about how early-stage dementia is sometimes perceived by occupational therapy practitioners, was described in the theme 'A Service Perspective: Assessment and Diagnosis' (Section 7.2.1.3.). Some practitioners associated early-stage dementia with someone who was undergoing diagnostic procedures or had recently received a diagnosis. However, they also noted that people affected by dementia often enter services in the middle to late stages or in a crisis, rather than in the earlier stages. This inconsistency may reflect the current emphasis in UK policy on early diagnosis and intervention [26, 39, 51], yet the reality on the ground where diagnostic rates are low and there are lengthy waits for assessment, diagnosis, and intervention where it exists [39, 182].

In contrast to the emphasis placed by studies included in Study 1 on the MMSE as an assessment to stage dementia, occupational therapy practitioners in this study did not speak about the routine use of the MMSE in practice. This may be accounted for by the MMSE's current copyright restrictions [28], and participants described the routine use of the MoCA , a tool developed to identify mild cognitive impairment (MCI) [214], and the Addenbrookes Cognitive Examination (ACE) [215]. Whilst there was

a lack of clarity among occupational therapy practitioners about what scores on these assessments were indicative of early-stage dementia, neither the MoCA nor the ACE provide clarity on this, however, a score of 61 as a cut off between early and middle stage dementia has been proposed on the ACE-III [216]. The theme, 'An Occupational Perspective' (Section 7.2.1.4.) highlighted the importance occupational therapy practitioners placed on observational functional assessments to determine severity, emphasising that a person's performance on routinely utilised standardised cognitive assessments may not necessarily reflect ability to carry out activities day-to-day. Carol and Geraint, from a lived experience perspective, additionally highlighted the limitations of basing a diagnosis on cognitive assessments alone, particularly in the early-stages for those who have remained in education longer, something that is noted prevalently in the literature [217]. Practitioners associated the ability to learn and greater independence in non-complex and familiar activities with early-stage dementia.

Finally, the lived experience of change experienced during the early-stages of dementia was highlighted in the theme 'An Awareness of Change: "*Something's not quite right*"' (Section 7.2.1.2.), which echoed the theme 'Awareness of Change' identified during Study 1's Population Synthesis, particularly by Öhman et al [141] and Öhman et al [150]. Participants described how people living with early-stage dementia and / or their support network often experience a growing awareness that "*something's not quite right*", often before a diagnosis is made or contact with services has been initiated. Like Öhman et al's [141] and Öhman et al's [150] participants, Elin described a process of trying to understand and make sense of changes as a younger person, and at the time of her interview, appeared to be still making sense of her experiences. In contrast, the two participants living with late-onset dementia who participated in this study, described becoming aware that they shared similar symptoms or difficulties to people they knew who had dementia, which they explained was helpful in making sense of changes. Whilst normalising or identifying with others was also described as helpful for some of Öhman et al's [141] participants, others found identifying with others to be a distressing experience. Robinson et al [218] and Yuile [219] discuss the process of noticing changes, coming to terms with an eventual diagnosis, and adapting to this in the context of theoretical models of loss and the grieving process, respectively. This process may be more profound for those living with young-onset dementia, like Elin, who may have dependent children, be in employment and typically experience greater difficulties in obtaining a diagnosis [219].

7.3.2. Impact on Occupational Performance

Four themes described in Section 7.2.2. sought to answer Study 2's research question:

> 2.1.2. *What impact, if any, does early-stage dementia have on the occupational (activity) performance or people living in the community?*

This question was utilised during Study 1's Population Synthesis and its use in this study aimed to triangulate and build upon this knowledge. Akin to Study 1, impact on occupational performance was highlighted as individual and dependent upon personal and environmental factors, and therefore impacts described may not apply to all living with dementia. In this Chapter, frequent references to occupational performance difficulties, problems, and changes were also identified, reflecting Study 1. Changes and difficulties were associated with occupations becoming riskier, temporally different (e.g., taking longer, not completed at the right time or in the right sequence), mistakes, and not completing or initiating the activity. Some participants spoke about others taking over the performance of certain occupations including driving or being excluded from occupations for example work. Self-initiated adaptations were described, albeit less frequently, including the cessation of occupations, the use of prompts, cues and reminders and a normalising strategy associated with accepting or coming to terms with changes akin to Öhman et al's [141] participants.

Impact on occupational performance was typically described in relation to causal factors or determinants pertaining to the person and their environments (occupational, social, and physical), like Study 1. The theme 'Skills and Abilities' (Section 7.2.2.1.) described early-stage dementia's impact on a person's skills or abilities, with impacts pertaining to memory the most frequently reported. Difficulties relating to executive functioning, sensory perception, language and mobility were also identified akin to Study 1's Population Synthesis, reflecting the wider literature about early-stage dementia's impact [1, 4]. The second theme, 'Mental Health and Motivation' (Section 7.2.2.2.) parallels, but also builds upon, the consequences difficulties during occupational performance have on a person's thoughts, feelings and confidence noted in Study 1's Population Synthesis. In this study, participants living with dementia additionally noted the negative impact receiving a diagnosis can have, which in and of itself could impact on motivation to carry out occupations. This was not experienced by all participants living with dementia, notably participants who were older and / or had received appropriate support following diagnosis, with the variability in terms of emotional responses to a dementia diagnosis attested by Aminzadeh et al [220]. They identified three immediate responses

in their study, which they hypothesised people can move through over time: Denial or a lack of insight; grief reaction / emotional crisis and positive coping.

Significantly, occupational therapy practitioners were eager to emphasise that people living with early-stage dementia still have remaining skills and abilities, which includes procedural memory for people living with AD. Procedural memory enables pattern, habit and skill learning and is considered a subtype of what is known as implicit memory [221]. Rehabilitation programmes with an emphasis on procedural learning by practicing the performance of day-to-day activities report promising results [222]. The theme*, "I'm still who I am, I can still do things"* (Section 2.2.2.4.), accentuates this emphasis on remaining skills and abilities from a lived experience perspective, highlighting the continued determination and motivation expressed by all participants living with dementia to remain active and independent. It must be noted that participants in this study were not newly diagnosed; as outlined in the theme 'Mental Health and Motivation' (Section 2.2.2.2.), two participants' motivation and mental health was adversely impacted on receiving their diagnosis. However, it appears that over time, their motivation to remain active, albeit in a different way had returned, suggesting they had moved to Aminzadeh et al's [220] third response following diagnosis (positive coping responses), paralleling Study 1's self-initiated strategies sub-theme 'Accepting Changing Occupational Conditions'.

Causal factors and determinants associated with the occupational, social, and physical environments were described in the theme 'Occupations and Environments' (Section 2.2.2.3.). Impact on occupational performance was typically expressed in relation to IADL (e.g., cooking, managing medication and community access), akin to Study 1, which were frequently described by occupational therapists as 'complex'. Work was specifically identified by participants living with early-onset dementia, and themes identified by Chaplin and Davidson [132], included in Study 1, for example a lack of support to remain in employment were also reported in this study. Driving was identified by all participants living with dementia, however, occupational therapy practitioners did not discuss driving frequently, despite driving assessments being an area of practice for occupational therapists [223]. Whilst not identified as a prominent difficulty in Study 1's Population Synthesis, social activities were specifically identified by occupational therapy practitioners, who described how people withdraw from social engagements due to feelings of embarrassment, which was also reported by Clarke and Bailey [224]. Nevertheless, at the time of interview, only one participant living with dementia expressed a reduction in social activities, with the remaining four describing an increase, with a significant emphasis on attending peer support groups. However, participants with young onset dementia spoke about how they had lost friends and work colleagues as well as the changes

and negative impact it had had on their relationships and family caregivers, echoed by Tatangelo et al [225, 226]. Akin to Study 1's Population Synthesis, occupations and environments that were unfamiliar and non-routine to the person living with dementia were also described as potentially difficult, with examples provided including appointments, birthdays and holidays, technology, managing finances or occupations that had changed, making them new or unfamiliar.

7.4. Chapter Conclusion

Findings deriving from Study 2 generated to meet Thesis Objective 1, to understand the intervention population and it's two corresponding research questions have been presented in this Chapter. Multiple perspectives were identified about what constitutes early-stage dementia, which parallel and build upon the findings of Study 1 and the broader literature. Significantly, this analysis identified that the MMSE, the most prevalent tool utilised to stage dementia in Study 1, was not utilised in clinical practice at participating sites. The disadvantages of utilising cognitive assessments to stage dementia were also highlighted, including the disparity seen between actual occupational performance and an assessment score. Given the themes identified in this Chapter, as well as Study 1, it is likely that people affected by dementia, occupational therapy practitioners as well as clinicians from other professions will have differing experiences and understandings about what constitutes early-stage dementia.

Impacts on occupational performance were again described in the context of dementia's impact on personal factors or determinants, namely skills and abilities (e.g., memory, executive functioning), and were also associated with making mistakes, increased risk, temporal changes, non-completion, and cessation. However, analysis in this Chapter additionally identified that the negative impact on mental health and wellbeing associated with receiving a diagnosis can decrease motivation and interest in occupational performance. People living with early-onset dementia may be more likely to experience these negative effects, as well as those who have difficulties accepting or coming to terms with a diagnosis. Emphasis was again placed on environmental risk factors relating to the social, physical and occupational environments including those that were experienced as unfamiliar or non-routine and complex or demanding.

Chapter 8: Thematic Analysis: Setting / Context

8.1. Introduction

In this Chapter, findings deriving from Study 2 generated to meet Thesis Objective 2, to understand the intervention setting and context, will be presented. Research questions to meet this objective, described in Chapter 6, Section 6.2., comprised:

2.2.1. *In what services / settings are occupational therapy practitioners currently working with people affected by early-stage dementia living in the community?*
2.2.2. *In what services / settings could occupational therapy practitioners work with people affected by early-stage dementia living in the community?*
2.2.3. *What barriers and facilitators do they / could they face?*

As described in Chapter 6, an inductive thematic analysis was conducted on data generated during semi-structured interviews to answer these research questions. Table 29 provides an overview of themes identified, which will be presented in detail in this Chapter.

Table 29: Research Questions and Themes: Intervention Setting / Context

Research Question	Themes
2.2.1. & 2.2.2. Setting / Service Context	• Primary Care: "*We're missing people"*
	• Complexity and Variability
	• Change
2.2.3. Barriers and Facilitators	• A Small and Stretched Resource
	• Control and Influence
	• Awareness and Understanding of Occupational Therapy
	• Access: Demographic and Individual Factors

8.2. Findings

8.2.1. Setting / Service Context

Three themes were identified concerning the service context or setting (Table 29). The initial, 'Primary Care: We're Missing People', relates to the current service context in Taliesin, and the services from which an intervention could be delivered in the Health Board, as the anticipated context for an initial feasibility study. The latter two themes, 'Complexity and Variability' and 'Change', were themes identified across Health Boards.

8.2.1.1. Primary Care: **"***We're missing people***"**

As outlined in Chapter 1, at the time of data collection, occupational therapy practitioners in Taliesin were not working in dementia specialist primary care mental health services, namely Memory Assessment Services (MAS). Historically, occupational therapy practitioners had been working in MAS until approximately two years prior to interviews, with occupational therapists working in Older Persons Community Mental Health Teams (OP-CMHTs) dedicating one day a week to MAS for assessment purposes only. This involvement had ceased to ensure occupational therapists working in OP-CMHTs had adequate resources to meet the Welsh Government's referral to treatment targets. Whilst Taliesin had recently commissioned an occupational therapist to work across one GP cluster in the Health Board, at the time of data collection, this practitioner was not working as a mental health or dementia specialist. Reflecting on the current lack of presence within primary care and services that typically work with people in the early stages of dementia, Sara stated:

> *"…we're missing people…memory clinic and GPs, we're not sitting in them and we're missing people. And then we're not getting them until they're further on down the line."*
>
> Sara, Occupational therapy practitioner

In line with Sara's concern, when occupational therapy practitioners were asked what service they could be working within to meet the specific needs of people living with early-stage dementia, primary care, specifically GP surgeries and MAS, were the most frequently advocated settings as articulated by Angharad:

"…I think the first thing is we need to be at the right place, we need to be in that early stage, whether that's almost as early as a GP surgery or whether it is at the point… the GP refers to memory clinic. So, at one of those stages, we would need to be involved so we get individuals early."

Angharad, Occupational therapist

Overall, GP surgeries were occupational therapy practitioners' preferred service in Taliesin for a new intervention, with participants highlighting that it is here that the first approach is made to a healthcare professional about symptoms indicative of dementia. Given this, they felt it would provide the greatest opportunity for people to benefit from the preventative impact of occupational therapy when delivered early. Participants were critical of the barriers to early intervention in MAS, including the time delay from initial approach to the GP to receiving input from MAS, and the requirement for a specific score on a cognitive assessment before acceptance to MAS. Others felt that the benefits of occupational therapy had not previously been understood by staff within Taliesin's MAS. Carys explains some of the barriers relating to early intervention in MAS:

"GP…because I think, if you said leave it to memory clinic, you're looking at a later stage or later diagnosis. I think by the time things have hit the point where people ask for help, that's when it needs to be delivered…I'm a big believer in prevention being better than cure…Because sometimes people are too advanced with their symptoms before they're referred to some …memory assessment services…I know there's a requirement on the MoCA score, but I don't know what it is…"

Carys, Occupational therapist

Despite the benefits of facilitating early intervention, some potential barriers were raised about GP surgeries by Alys and Sara. They hypothesised that as private businesses, a decision to employ an occupational therapist would need to be made on a GP surgery or GP cluster basis. Further considerations were noted, particularly given that a dementia diagnosis is typically given by MAS and not by a GP, although Delyth argued that a diagnosis was not necessary for occupational therapy intervention:

"…sometimes the diagnosis actually comes quite late in, but they've been struggling for a good few years beforehand, so I think it shouldn't necessarily be based on, you've got the diagnosis of dementia, because the issues have started before that, and obviously the pattern of interaction between the caregiver and the person with dementia has established, so it's going to be harder to then change that. Whereas if you can go in right at the beginning, then you can advise carers, well I know this is what is the struggle at the moment, but what if we said this or laid out the bedroom that way or? So I think you've got to go in as early as you can whether there's a diagnosis of dementia or not, I think as long as there's some cognitive impairment that is hindering people to carry out their function, day to day function…and not just relying on what the diagnosis is..."

Delyth, Occupational therapist

8.2.1.2. Complexity and Variability

A complex and variable picture of occupational therapy service provision for people living in the community with early-stage dementia was apparent from data generated across Health Boards (Table 30). At the time of data generation, a standardised occupational therapy role or service was not apparent. No participants reported that occupational therapists from their service were working in GP surgeries and only three out of five Health Boards had occupational therapists working within their MAS (Hergest, Rhydderch and Dyfed, Table 30). All three Health Boards reported internal divergences in service set-up, service provision and the occupational therapy role (Table 30). These divergences were typically associated with local county borough council boundaries or 'localities' (between three and six within each Health Board). In Hergest, occupational therapists were primarily located in OP-CMHT's in secondary care, with a small minority of their work being conducted in MAS for assessment and diagnostic purposes only. However, prior to recent services changes, occupational therapy assessment and intervention had been routinely available in MAS in Hergest. Rhydderch had occupational therapy posts sitting exclusively in some of their six MAS teams, whilst in other teams, spilt posts existed between MAS and OP-CMHT's, with assessment and intervention provided by all occupational therapists. In Dyfed, a different service configuration existed in each of its three localities, with the functions of MAS (assessment and intervention) being delivered by multiple teams, including primary care mental health services, teams that prescribed acetylcholinesterase (AChE) inhibitors, and OP-CMHT's.

Table 30: MAS Service Context and Occupational Therapy (OT) Role

Health Board	Type of MAS	Occupational Therapy Role in MAS				
		OT in MAS?	OT Assessment	OT Intervention	Generic Duties	Comments
Taliesin	Locality Teams	No	n/a	n/a	n/a	Historically, occupational therapists working in CMHT's dedicated one day per week to MAS, which was limited to the assessment and diagnostic process only.
Hergest	Locality Teams	Yes	Variable. In most localities at a consultant's request, an OT assessment would be conducted if there were queries regarding diagnosis.	Variable. In most localities, no OT intervention was being provided, although in some areas OT intervention was being provided on an individual and group basis.	Variable. In a minority of localities generic working was occurring during clinic assessments and follow up.	n/a
Rhydderch	Locality Teams	Yes	Yes	Yes (short-term)	Variable. In some localities generic working was occurring in clinic assessments and follow up.	OT role standardised across localities with minor variability in relation to generic duties.
Dyfed	Locality Teams	Yes	Variable	Variable	Variable. In some localities generic working including Part 1 MH Measure assessments.	Multiple teams (primary care services, teams prescribing acetylcholinesterase inhibitors and OP-CMHT's) were reportedly providing the service of a MAS.
Arberth	Health Board Team	No	n/a	n/a	n/a	No historic presence in MAS.

8.2.1.3. Change

Across Health Boards participants reported that they had or were about to experience changes which would impact on occupational therapy service provision for people living with early-stage dementia. Arberth and Taliesin were due to receive additional investment from the Welsh Government's Dementia Action Plan, to create new occupational therapy posts in MAS. In Arberth this amounted to one occupational therapy post within its Health Board wide MAS, and in Taliesin this comprised a team of occupational therapists and assistants that would work across the Health Board's four MAS. Dyfed was undergoing changes in one locality, which would result in shifting OP-CMHT resources, including occupational therapists from secondary care to primary care. Significantly, Hergest was the only Health Board where occupational therapists reported that recent changes to their operational policies had resulted in a decrease in occupational therapy service provision, namely routine occupational therapy intervention and assessment in MAS. Whilst Rhydderch did not report an increase or decrease in service provision, recent changes were reported, including being professionally managed by an occupational therapist, which had resulted in control over their own budget.

8.2.2. Contextual Barriers and Facilitators

Multiple contextual barriers were evident in the data, with three themes identified across Health Boards relating to the service context / setting: 'A Small and Stretched Resource', 'Control and Influence' and 'Awareness and Understanding of Occupational Therapy'. These themes centred around a common barrier: the availability of, and access to, occupational therapy intervention for people affected by early-stage dementia. Given this commonality, a fourth theme has been reported in this section, which pertained to demographic and individual factors that appeared to influence access to services.

8.2.2.1. A Small and Stretched Resource

Across Health Boards, human resources were perceived to be a significant contextual barrier. As presented in Table 30, Taliesin and Arberth had no occupational therapists working in MAS at the time of interview, and in Hergest, occupational therapy resources were being moved from MAS to secondary care. Participants who were currently working in MAS expressed that confined resources were impacting the way they were able to work with people, for example pressures to deliver

interventions in a group rather than on an individual basis, and basing decisions about who to work with, and for how long, on risk:

> *"…we're mostly working on risk, so… we're not able to do long pieces of work with people that are just for interventions sake, just for enabling sake. That sounds really, where you have in terms of prioritisation we're listening out and responding and being asked to look at risk to do with occupation. So it often is around risks to do with functioning at home, so I wonder again how long people are starting to struggle for some time but it's not becoming something that's presenting as risky or if anyone is doing anything about it significantly…"*
>
> Hannah, Occupational therapist

Access to occupational therapy technicians and support workers was variable between and within Health Boards, with the ability to deliver longer term interventions, for example community integration, dependent upon their availability. Some occupational therapists spoke about the lack of local services and resources, which restricted the type of intervention that they could provide, for example a lack of access to telecare or social care services to support medication management. Carol expressed that given confined resources, occupational therapists were currently unable to fulfil their potential as a profession, particularly in relation to meeting Welsh Government policy initiatives including enabling people to remain independent, and integration across the health and social care interface.

In some Health Boards, occupational therapy practitioners were eager to emphasise that all staff members in MAS were under-resourced. This was often attributed to the way in which MAS services were created following the introduction of the Mental Health (Wales) Measure (2010) [227], out of existing resources and facilitated by the "*goodwill*" of existing staff. One participant highlighted that whilst the number of people living with dementia is increasing, no additional resources were being provided to meet demand. Due to general service pressures, some occupational therapists in Hergest and Rhydderch spoke about being asked to conduct clinics that were typically conducted by nursing staff. Whilst some participants felt that this was beneficial as it enabled them to identify people with occupational needs who require occupational therapy intervention, others queried whether this was a wise use of a small resource. In Taliesin, reference was made to MAS waiting lists, which was deemed to be a key barrier to the delivery of occupational therapy to people living with early-stage

dementia. Three participants living with dementia also reported a lack of support post-diagnosis, with the following short extract highlighting the absence of support experienced by Carol and Geraint:

Int *"Tell me a bit about the support that you've had from services?"*

Carol: *"None."*

Int: *"None?"*

Gareth: *(indicates agreement, had no services)*

Carol, Family member and Geraint, Person living with dementia

8.2.2.2. Control and Influence

A number of inter-related sub-themes were evident relating to the lack of control and influence occupational therapists perceived they had over their role, service, and ability to provide intervention to people living with early-stage dementia. The influence of psychology as a profession in leading and influencing service developments and transformations was spoken about by participants in two Health Boards. Emphasis was placed on services prioritising Cognitive Stimulation Therapy (CST) and other psychological interventions, above other possible interventions, including occupational therapy. In Hergest, concerns were raised that this had resulted in a service "*gap*" since the removal of occupational therapy intervention from MAS:

Ffion: ***"…****I'm very concerned there's this gap that's been created…Obviously I know that we can't see everybody that comes through the memory clinic, from an OT point of view…there is this gap and the memory clinic nurses are now having to refer onto the social services OTs. But predominantly they're only going to be looking at the equipment side of things."*

Ava: ***"****Yeah, whereas we would tend to go in quite holistically and do an information gathering assessment stage first and look to see if the, where the needs are, whether it is within socialisation, whether it is in adapting the environment or adapting some memory strategies or to look at their cognition, we would just go in and see…where the needs lie."*

Ffion and Ava, Occupational therapists

Carol highlighted that the influence of psychology and interventions developed by psychologists may be due to a lack of robust research and evidence to support occupational therapy intervention:

> *"And I would say our other biggest challenge is what we've already talked is that lack of research that has been done in that we are getting leapfrogged with certain, like we talked about psychology because we aren't very good at articulating it, we're not…we haven't got our evidence to…put to commissioners to say well, this is what we do, this is the outcome of what we do and then be able to get our resources and we're not very good at that….I've seen that quite a lot over my career… we've been leapfrogged over and then we get stuck with bits that perhaps people don't want to do, yeah the glamorous bits like toilet seats."*
>
> Carol, Occupational therapist

Again, in two Health Boards occupational therapists referred to the dominance of the medical model in MAS, which they felt had resulted in an over-emphasis on assessment, diagnosis and prescribing, as opposed to support and intervention to live well after diagnosis, as Hannah articulated:

> *"The biggest barrier is that it's still framed as a very medical model area, so our Memory Clinics are based on…could this person then take a memory drug, the titration of the memory drug, there is no cure or treatment for dementia. The memory drugs, I've seen them be extremely effective, they do not, it's, I feel it's a distraction really from living with dementia… But…if we stripped away the medical model, if we owned it for the fact that it does nothing for dementia other than last resort stuff, so it was treated like a minority in terms of what we look at, then I think occupational therapy would lead the way in dementia care. …I think we'd absolutely take the lead in it.."*
>
> Hannah, Occupational therapist

Hannah went on to highlight that Welsh Government targets and a lack of evidence to support occupational therapy interventions were also contributing to an emphasis on assessment and diagnosis as opposed to therapy:

"…the pressure is on Memory Clinics in terms of the timescale, in terms of from when they've been referred and the point of diagnosis, that's where the specific targets [are], it's not on what happens next. But what is that from a point of someone living with dementia and their carer, what's the point of being seen if there's nothing to offer or you're on a long waiting list or you don't know what happens next. It's a bit like, great you've been diagnosed with cancer but there's no treatment or help afterwards… and I can't blame senior managers because that is, they haven't created those targets and we haven't got targets that are about other things. But maybe we haven't got targets for other things because we haven't got the evidence base to, so all of these things inter-relate don't they."

Hannah, Occupational therapist

In Rhydderch, occupational therapy participants also reflected on the lack of control they had over how resources were spent in MAS, as many were managed by non-occupational therapists, with funding for occupational therapy coming from a centralised service budget. Being managed by non-occupational therapists was also perceived to be a barrier to standardising practice across a Health Board:

"I think one of the biggest challenges within all that is that we've been managed by nurses who have been dictating our practice quite a lot, and I'm very fortunate that our Band 7 at the moment is very pro OT…and I think she's had good influence with OT, so gets it, understands it and gives me autonomy within my practice but that's not always the case and it hasn't always been the case in the past..."

Carol, Occupational therapist

8.2.2.3. Awareness and Understanding of Occupational Therapy

A lack of awareness and understanding about occupational therapy was sometimes utilised by participants to explain the reduced influence or control they felt they had over their role and service provision, particularly by senior management. Catrin spoke about the recent service changes in Hergest, where occupational therapy intervention was being withdrawn from MAS:

> *"There seems to be a bit of a drive about dementia's everyone's business, refer it to the general OTs, refer it to social services OTs. So that's, that seems to be a barrier, this sort of belief really that it's everyone's business which I don't disagree with, but…is there not a place for a specialist service, so I suppose the barriers that I see is actually the viewpoint of our management, that they don't seem to understand what we do as OTs, possibly… I think it's going to be quite a challenging time. I really don't know what they do see as our role..."*
>
> Catrin, Occupational therapist

In addition to senior management, participants across Health Boards highlighted that they were often not involved in decisions about who was referred to occupational therapy. Since people typically receive occupational therapy on referral, one occupational therapist stated that they were at the "*mercy of our referrers*" and their knowledge and views about occupational therapy. Participants highlighted that there may be a misconception that occupational therapy is about the provision of equipment as well as a lack of knowledge about the rehabilitative interventions occupational therapists can provide for people living with early-stage dementia. As mentioned by Catrin, some highlighted that this could cause confusion about when to refer to occupational therapy and which occupational therapy team to refer to, for example a generic community equipment team or an OP-CMHT. Gemma also reflected on the perception that occupational therapy is for people living with moderate to severe dementia:

> *"…the subjective opinion of certain professionals may be a barrier because they wouldn't think that people need to be referred on because, oh they're OK or they don't need occupational therapy yet. I think it's really important that it actually starts at the beginning, and we can always add to, but I feel that at the beginning of their journey is where we should start."*
>
> Gemma, Occupational therapist

However, not all occupational therapists felt that other members of staff lacked an understanding of their role, with one highlighting that their long-term relationships with nursing staff meant that their referrals were primarily appropriate. In Taliesin, whilst all other participants raised concerns about the support they would receive from other professionals and senior management if they were to introduce and deliver a new intervention in MAS, Juliette expressed that now was the opportune time:

"I think as a Health Board, we're definitely more proactive in terms of trying to change things, with…the programme that's running where mental health services for older persons is being changed, that change should be able to support this intervention. Because there's a shift in culture within the older person's service anyway, so you're not going against the norm, when actually the norm is now changing. So now would be the right time in order to fit this."

Juliette, Occupational therapist

To overcome the impact of a lack of awareness and understanding, several participants spoke about the ways in which they have previously increased the awareness and understanding of others about their role. This included attending team meetings, proactively engaging in discussion with other members of the team about people who were attending clinic and holding promotional events. Drawing on their experiences of working as lone practitioners in a new service, Alys and Sara spoke about the importance of team working, including having an opportunity to learn about team members' roles:

Alys: *"I think that one's definitely a barrier that we might hit. Of people really need to be educated on what OT is."*

Sara: *"Yeah but also other professionals accepting us and recognising we play a part in –"*

Alys: *"A team… and being a part of a team rather than individuals. Like oh it's OTs –"-*

Sara: *"Yeah or there's therapies over there, we're nurses here and there's doctors and consultants. Yeah I think…if you're going to join a team I think it's quite important that, not just for OTs but everyone explains their role and what they bring to the table and how we can help. Because just from experience, I don't know if you felt the same, experience when going onto a ward it's like, well we've never had OT before so what do you do? What can you bring? Why are you doing this? What's your reasoning for doing these things? So just to get a better understanding of us as well. So I think it would be nice if we did become part of a team and went into, say you went into GP services that you had a morning where you all sat and was like, my role's this, my role's that, and I can provide this and I can*

provide this. So you're all, yeah you work as a team and you're all aware of each other and what each other can do and how you can work with each other rather than, oh just pass that to OT. …Or no we don't need OTs CPNs can do that."

Alys and Sara, Occupational therapy practitioners

In addition to members of staff, some occupational therapists highlighted that the general public may not be aware or understand the interventions that occupational therapists can provide, and typically do not approach services asking for occupational therapy, as Carol articulated:

"…the person with dementia isn't…saying I really want an occupational therapist to help me do this. Sometimes the carers aren't, sometimes the carers are in equally a distressing place and thinking right I've got to think about this and oh my goodness mum's left the cooker on so we'll switch the cooker off and we'll never have a cooker again…So it's not that they're going help I can't do this, it's more that, I don't think people with dementia and the carers always know what they need, so we're relying on other professionals, the person with dementia and the carer to say we need this help. But I guess who knows what they need if you don't know what could be on offer…"

Carol, Occupational therapist

8.2.2.4. Access: Demographic and Individual Factors

Whilst the preceding three themes have been described in relation to the service context and its impact upon the availability of, and access to occupational therapy, individual factors were also noted, although less frequently. In Taliesin Carys stated that some people may be reluctant to access or engage with services, due to fears of receiving a diagnosis:

"Some have said, I don't want to be labelled with dementia, I'm scared, I wouldn't want that, because they see dementia as, on TV, as like the full blown quite unwell, whereas we know people can live in the community well with dementia for many, many years so…"

Carys, Occupational therapist

In Taliesin and Rhydderch participants spoke about the differences in early access to services between Health Board localities, which they associated with socio-demographic differences. Carol spoke about her experiences in Rhydderch, where people living in the locality with the lowest levels of multiple deprivation approached and accessed services earlier than the locality with greater levels of deprivation:

> *"Yeah, so I am based within the Memory Assessment Service within Locality A although I do still cover some of the community mental health team as and when but primarily it's within MAS so our, the challenge that we have in within Locality A is that we're seeing people who are more advanced, so they're not even touching our service before they get more advanced whereas… as far as I'm aware the research that has been done within our statistics say that Locality B have the early, the earliest diagnosis and we have the latest diagnosis so by the time they touch our service they are already moderate... So because of that, that obviously affects the kind of work that I'm doing a lot so whereas I think I would love to be doing things around memory strategies…I don't do a huge amount of that work just by the nature of how our service is so a lot of my work is around people who are challenging they, often they're wondering so they want me to do road safety assessments, so I do a lot of road safety, they're having problems in the kitchen, they're leaving their gas on, they're doing those kind of things that people end up getting very twitchy about."*
>
> Carol, Occupational therapist

8.3. Discussion

Seven themes deriving from semi-structured interviews with occupational therapy practitioners and people living with dementia, to meet Thesis Objective 2, to understand the intervention service ontext / setting and associated barriers and facilitators, have been presented in this Chapter. These themes were generated to answer three research questions, which will now be discussed.

8.3.1. Setting / Service Context

Three themes were described in Section 8.2.1, which sought to answer the research questions:

2.2.1. *In what services / settings are occupational therapy practitioners currently working with people affected by early-stage dementia living in the community?*

2.2.2. *In what services / settings could occupational therapy practitioners work with people affected by early-stage dementia living in the community?*

The theme 'Complexity and Variability' (Section 8.2.1.2.) derives from interviews with occupational therapy practitioners across all research sites and suggests, akin to Edwards [39] that there is no standardised occupational therapy service provision for people living with early-stage dementia across or within the five Health Boards that participated in this study. Two Health Boards did not have an occupational therapy presence within their MAS teams and the remaining three had different set ups across their organisations. The variability in MAS service provision and composition was highlighted in the last publicly published audit of MAS in Wales in 2014 [59], however, data on occupational therapy was not generated or reported. Data generated during this study suggests that the variability reported in 2014, continues to exist and perhaps is more pronounced when it comes to occupational therapy. In the context of complex intervention research, this theme underscores the importance of understanding local implementation contexts when developing an intervention, which as demonstrated, can vary significantly even within the same country [65, 228].

The theme 'Primary Care: "*We're missing people*"' (Section 8.2.1.1.) reflected practitioner views in Taliesin Health Board, as the anticipated initial feasibility evaluation context. This theme highlighted the absence of occupational therapists within services for people living with early-stage dementia at the time of interview, with primary care, comprising MAS and GP surgeries identified as potentially suitable services for feasibility testing. Whilst the former is primarily associated with early-intervention and diagnosis [26], GP surgeries have received less attention as a setting for early-intervention, although have relating to diagnosis [229]. Occupational therapy practitioners in this study emphasised the benefits of such a setting, primarily in overcoming the delay from GP to receiving input from MAS. The Wales MAS audit [59] reported an estimated mean 9.6 weeks (median 8) between first assessment and receiving a diagnosis, however, a range of 4 to 39 weeks was reported, indicating variability across Health Boards. The time from first contact with a GP to receiving occupational therapy intervention has not been formally captured and may be longer if a diagnosis is required.

The theme 'Change' (Section 8.2.1.3.) represented the changes underway in relation to occupational therapy for early-stage dementia across all participating sites. Two sites, Taliesin and Arberth were

due to experience changes in the context of the Dementia Action Plan for Wales [51] which made an additional £50 million available for dementia services. Both Health Boards, who did not have an occupational therapy presence in MAS at the time of interview, were due to see an increase in service capacity to address this gap in service provision. Whilst this was an external influence at the macro (national) level instigating change locally, the other three Health Boards reported internal influences at the meso (Health Board) level, including local policy and budget changes leading to service change [228]. Again, in the context of complex intervention research, this theme highlights the importance of viewing an intervention context as an open and dynamic system, with future changes at macro, meso and micro levels potentially impacting upon the feasibility of implementing an intervention [230].

8.3.2. Contextual Barriers and Facilitators

In Section 8.2.2, data analysed and presented sought to answer the research question:

2.2.3. *What barriers and facilitators do they / could they face?*

Four themes were described across Health Boards, centering around a common barrier: the confined availability of, and access to, occupational therapy intervention for people affected by early-stage dementia. The three initial themes described related to the intervention setting or service context and the latter to individual factors.

'A Small and Stretched Resource', (Section 8.2.2.1.) highlighted the impact confined human resources had on service provision; where no human resources were available, no service was available as described in Sections 8.2.1. and 8.3.1. However, where resources were available, the confined amount influenced the way occupational therapy was made available, for example in groups as opposed to on an individual basis, prioritising individuals for intervention based on risk, and being unable to deliver longer-term interventions. In the financial year 2019-2020, NHS Wales spent only 3.3% of its budget on mental health services for older people, which includes dementia [231]. The lack of available resources to ensure occupational therapy services across NHS Wales can meet demand was also a reoccurring barrier identified by Edwards [39] and was additionally identified by Cummins and Warren [168] in Study 1's intervention synthesis as a barrier in Ireland.

Secondly, the theme 'Control and Influence' (Section 8.2.2.2.) described how the professions of psychology and medicine were perceived to have greater control and influence organisationally and nationally, which some participants felt negatively impacted on the availability of occupational therapy intervention. On a national level, policy, for example the Dementia Action Plan for Wales' High Level Performance Measures [51], which focus on assessment, diagnosis and prescribing, as opposed to therapeutic interventions, was associated with the dominance of the medical model by practitioners in this study. An absence of evidence to support occupational therapy intervention was deemed by some to contribute to the professions limited control and influence compared to the psychology profession. Despite occupational therapy's emerging international evidence base as demonstrated in Study 1, some interventions developed and researched by psychologists in a UK context, for example Cognitive Stimulation and Goal-Orientated Cognitive Rehabilitation, currently have a more robust evidence base [2, 193]. Given the continued development and evaluation of new interventions by psychologists for people living with early-stage dementia, including Behavioural Activation [186], and in the absence of a UK evidence base for occupational therapy intervention for this population, the limited control and influence experienced by practitioners in this study is likely to continue.

A lack of awareness and understanding about occupational therapy, described in the theme 'Awareness and Understanding of Occupational Therapy' (Section 8.2.2.3.) was also considered a potential contributing factor to the limited control and influence reported. In addition to medical professionals and psychologists, senior manager, referrers, and members of the public were also described as potentially unaware of the types of interventions occupational therapists can provide to people living with early-stage dementia, thereby limiting the availability and accessibility of occupational therapy. A limited and variable level of knowledge and understanding of the role of occupational therapy across multiple practice settings has been reported internationally, including amongst psychiatrists [232], nurse practitioners [233], healthcare professionals [234] and the general public [235].

The final theme, 'Access: Demographic and Individual Factors' (Section 8.2.2.4.) described the view expressed by occupational therapy practitioners that an individual's socio-economic circumstances and fears about receiving a diagnosis can also be barriers to accessing help for dementia related symptoms. In their cross-national study utilising focus groups with people living with dementia, their supporters, and health and social care professionals, Stephan et al [236] also noted multiple potential barriers to accessing support which pertained to health systems, professionals and people affected by

dementia themselves. This included the attitudes and beliefs of people living with dementia and their supporters, for example difficulties acknowledging that there is a problem or accepting a diagnosis, as well as a lack of information and understanding about dementia or the availability of services.

8.4. Chapter Conclusion

In this Chapter findings deriving from Study 2 to meet Thesis Objective 2, to understand the intervention setting and context, have been presented and discussed. Significant diversity was identified in the availability and provision of occupational therapy for early-stage dementia across, and within, sites. A considerable barrier identified included a lack of funding and resources, which in some sites resulted in no occupational therapy provision, whilst in others, confined resources placed limits and restrictions on how and what intervention was provided. A perceived lack of influence organisationally and nationally, and a lack of understanding about occupational therapy amongst other professions was also considered a contributory factor. Changes at the macro (national) and meso (Health Board) levels, including policy decisions and resource allocation were at the time of interview due to impact service provision, highlighting the need to view the intervention context as dynamic and in flux.

Chapter 9: Thematic Analysis: Intervention

9.1. Introduction

In this Chapter, Study 2's findings generated to meet Thesis Objective 3, to identify practice or research-based occupational therapy interventions, will be presented. Research questions to meet this objective were as follows:

2.3.1. *What interventions are occupational therapy practitioners currently delivering to meet the needs of people affected by early-stage dementia living in the community?*

2.3.2. *What interventions could occupational therapy practitioners deliver to meet the needs of people affected by early-stage dementia living in the community?*

2.3.3. *What barriers and facilitators do they / could they face?*

Chapter 6 described that data was thematically analysed using an a priori framework, informed by the TIDieR Checklist [121], with subthemes identified inductively (Table 31). Chapter 6 also outlined that this Chapter synthesises data about occupational therapy practitioners' current practice with people living with early-stage dementia (Research Question 2.3.1.) as well as data about views on a new intervention in Taliesin, as the identified feasibility context (Research Question 2.3.2.). Whilst data was analysed separately, it has been synthesised together in this Chapter given the similarities to avoid repetition.

Table 31: Intervention: Themes and Sub-Themes

Codes / Themes	Sub-Themes
Intervention Rationale, Theory or Goal	Theory
	Research
	Aims and Goals
Content and Components	Personalising and Tailoring
	Establishing a Therapeutic Relationship
	Identifying Occupational (Functional) Needs and Goals
	"It's all about those strategies"
	Advice, Information and Education
Mode of Delivery	Face to Face
	Individual and Dyad Formats
	Group Formats
Location of Delivery	Home
	Community Settings
Duration and Intensity	
Interventionist	

9.2. Findings

9.2.1. Intervention Rationale, Theory or Goal

9.2.1.1. Theory

In accordance with occupational therapy philosophy, theory, and conceptual models of practice, participants across Health Boards frequently spoke in broad terms about interventions being person-centred, holistic and occupationally or functionally focused [37, 79, 210]. Six out of seven occupational therapists from Taliesin identified the Canadian Model of Occupational Performance and Engagement (CMOP-E) as their preferred occupational therapy model for a new intervention. In addition to its existing use within the service, participants felt that compared to the Model of Human Occupation (MOHO), the CMOP-E was less complicated, was visual in nature and had a strong emphasis on physical and occupational needs. Despite the clear preference for CMOP-E in Taliesin, some participants highlighted that the MOHO offered additional theoretical concepts, not apparent in the CMOP-E, for example volition (motivation) and roles:

> *"I like MOHO because it does focus on the volition of the person and sometimes if they're depressed, that's the first thing to go. So you could look at what is it, what is actually going on? Some of the patients we see have lost a family member, particularly a spouse and then you see the massive difference in their motivation… particularly with the gentlemen who've lost their wives at whatever age because often the wives have done lots of things for them, and they're suddenly finding themselves on their own two feet. So I like MOHO because that really looks at that whereas the others don't."*
>
> Angharad, Occupational therapist

In contrast to Taliesin, all participants from other Health Boards reported that their service used the MOHO. A common critique in Taliesin, Hergest and Dyfed Health Boards concerning all occupational therapy models, was the lack of focus on memory or cognition. Given this, Gwen and Delyth from Taliesin advocated taking an "*eclectic*" approach, by using multiple theories, models or approaches when working with people living with early-stage dementia. In this vein, participants from Taliesin, Hergest and Dyfed discussed their use of the Cognitive Disabilities Model (CDM), particularly when

working with people in the middle to later stages. In addition to the CDM, in Taliesin, theories relating to errorless learning were also mentioned and the work of Teepa Snow, for example Positive Approach to Care (PAC) [237]. Reference was made across Health Boards to procedural or 'working' memory, which they advocated could preserve occupational therapy interventions introduced during the early stages, through to the middle and possibly later stages:

> *"Well as I said it's just supplementing the memory deficit at the beginning, isn't it? …because generally they still have learning potential then, if we can put in the routines to start with, it will help them through, well almost to the severe stage really."*
>
> Gemma, Occupational therapist

9.2.1.2. Research

In contrast to theory, the majority of participants across Health Boards were unable to identify research that currently, or could inform, an occupational therapy intervention for early-stage dementia. Instead, some participants made broad references to Welsh Government policy, NICE guidelines, and practice examples, including Home Based Memory Rehabilitation [42]. Carol emphasised that there is a dearth of research on this area of practice, and like other participants, she uses her own practice or experience-based evidence to inform her work:

> *"…I do try and read, I think the evidence, our evidence in this space is quite limited in that there's not been huge amount of research being done over what we can do and how we do it, so I read, I try and read lots of the articles of people's experience and trying to learn from other people that way. …a lot of the time it is my own knowledge, own experience that's done it really…there's not a lot there…what we need to get better at is being able to try something out, generating the outcomes and then getting our research, because I think we're probably all doing similar things without knowing what we're doing and putting it all together."*
>
> Carol, Occupational therapist

Two participants stated that their practice as occupational therapists was similar to research on cognitive rehabilitation, however, did not specify a specific cognitive rehabilitation intervention

programme. Hannah reflected on the implications this similarity has for occupational therapy as a profession:

> *"…this kind of intervention…probably relates closest to cognitive rehabilitation. Though it makes me uncomfortable because its, psychology have penned it, but actually it describes an OT process… but I would say there's probably more to our process… because of the occupational focus and the environment. So, although cognitive rehabilitation is about setting goals for the person about what matters in their day-to-day life, occupational therapists look at much more, they look at habituation, they look at environment, they look at volition. …and I don't believe other professions, I know other professions don't do that, even psychologists, so I, …feel frustrated that that maybe the nearest to this, but I would say that has proceeded the occupational therapy intervention rather than be our evidence base for what we do now, it's just reflective of it. Yeah so, we've got a poor evidence base and that's our fault…"*
>
> Hannah, Occupational therapist

9.2.1.3. Aims and Goals

Across Health Boards, maintaining or enabling "*independence*", "*functioning*" or *"skills*" was repeatedly identified as a primary intervention aim. Given the importance placed by participants on taking a person-centred approach, Delyth spoke about the need to ensure that independence is viewed in the context of what is important or meaningful to the person:

> *"I think the aim should be to keep a person as independent as possible in their own home because that's what most people would want, to stay where they are, what they're familiar with, what they know, who they love, the pets or whatever. Yeah, and to be, still be able to carry out those activities that are really important to them, …and again you need to look at, OK if it's too hard and takes too much effort to get washed and dressed and the person has said, well actually I'd rather have somebody helping me with that because then I've got energy left to actually take the dog out for a walk or, then I think that needs to be taken into consideration,*

you can't just say, well everybody needs to be independent with washing and dressing, because they might not feel that that's their value..."

Delyth, Occupational therapist

As articulated by Delyth, independence, in the context of an occupational therapy intervention for early-stage dementia, may not necessarily mean enabling people to do everything for themselves. Rather, it may mean supporting someone to "*live life to the full*" by enabling them to function as best as they can in their chosen activities, with or without support. Reflecting Delyth's account, participants from Taliesin consistently emphasised that a new intervention must enable "*independence*", "*functioning*" or *"skills*" in all activities and occupations, including leisure and work, rather than limiting intervention to self-care activities:

"…the only thing that concerns me in the jobs that I've worked has been the focus on personal care is massive and as occupational therapists we're meant to be holistic and look at their entire life and nothing seems to take into consideration the relationships, the role that person has within their life, a spirituality which may be very dear to them. And it does concern me there seems to be a very heavy weighting on personal care when perhaps their personal care's all right but the rest of it might be falling apart."

Carys, Occupational therapist

Akin to Carys' concerns, participants currently working in MAS and other settings across Health Boards highlighted that occupational therapy intervention is typically restricted to occupations associated with risk and certain occupations categorised as instrumental and basic activities of daily living (e.g., cooking, accessing the community, medication, washing and dressing). The emphasis on managing risk in some Health Boards appeared greater than others, and as Hannah's extract illustrates, referrals from other professionals typically centred around risk:

"The kind of referrals we get from, direct from Memory Clinic or the medics in Memory Clinic would be, it tends to be around things like they're not managing, are they neglecting their eating, are they leaving the gas on, are they disoriented in time and place? So they've gone out with their carer and they've got lost in a local town, or they've always got the bus to and from but they've, they started

walking and they got lost on route. So it's mostly to do with risks in, from a, to do with the change in their cognition in day to day life."

Hannah, Occupational therapist

Although not as prominent, some participants additionally spoke about aiming to improve quality of life and wellbeing, whilst others emphasised aims to intervene early to prevent loss of skills and service use.

9.2.2. Content and Components

9.2.2.1. Personalising and Tailoring

Reflecting occupational therapy's theoretical and philosophical background, practitioners across Health Boards advocated that an occupational therapy intervention for people living with early-stage dementia must be person centred and individually tailored. To facilitate this, Anita emphasised that whilst an intervention must be structured, it must also be flexible and adaptable:

"It has to be structured, but it has to be flexible and adaptable, has to be individual, has to fulfil the individual's needs, their views have to count big time, what matters to them is the most important thing."

Anita, Occupational therapist

Given the individualised nature of interventions, a number of participants, like Maria, expressed that it was difficult to describe in general terms what an intervention would comprise and many participants required prompting during interviews to articulate what their interventions constitute:

"It depends what the issue is. I think it's really difficult to say what interventions you'd use because I think whatever they highlight as a problem or I would identify as a problem then that is what I would tackle as an intervention while I was there"

Maria, Occupational therapist

9.2.2.2. Establishing a Therapeutic Relationship

Spending time establishing a therapeutic relationship and getting to know the person living with dementia and their support network was described as an essential initial intervention activity, as articulated by Alys:

> *"…the first week would be getting in there, getting to know the person, introducing yourself…what your role is. How do they feel about us being there…working with them?"*
>
> Alys, Occupational therapy practitioner

Alys and Sara went on to highlight that the "*groundwork*" involved in developing a therapeutic relationship may not be understood by other professionals and included getting to know a person's preferences for communicating and interacting:

> *Alys:* *"I think people don't understand that there is groundwork when you're working with someone. That you… need to get to know that person. You need to get to know how they are, what they like what they don't like, how to approach someone. Some people love being approached with a hug and kiss on the cheek and like hiya, and then other people are a handshake or, other people you just have to sit down and say hello from afar, everyone is completely different."*
>
> *Sara:* *"It's getting to know isn't it? So that our intervention then can be"*
>
> *Alys:* *"Is more successful."*
>
> *Sara:* *"Yeah and can be worked around that person. You need to know all that in order to provide an intervention that's going to work. Because there's no point in knowing nothing, going in doing an intervention and then you're like, oh it doesn't work. Well, no because then you haven't got to know the person, you need to get all that information and then do the intervention because the intervention goes round what you find out isn't it?"*
>
> Alys and Sara, Occupational therapy practitioners

Owing to the breadth of data generated during semi-structured interviews, the process of developing a therapeutic relationship was not described in detail by many participants, however, Hannah's extended extract reinforces the importance of "*groundwork*" and time needed to establish rapport and trust when working in MAS:

> *"…A really, really important aspect of people knowing what OTs do in Memory Service is that it is not about numbers and how quick you see someone, there are times when you need to build rapport. It's times you need to ask them what matters to them… you might have a more pressing issue, but you need to build their trust and work on the thing that matters most to them. …I'll give you a classic example: you, family are really worried about personal care neglect… but when you meet with that person there's nothing wrong, I've always been washed every day, and you can see the bath and the shower's not been used for months on end. But the slightest mention of it you can feel the boots will be behind you, pushing you out the door, but you might in your discussion find out that they'd really like to do something socially, they've been isolated, yeah, really up for that. And then… you can slowly start to address the things that you might want to address, so yeah, that's something I think is the subtleties of understanding what might be very different about OT that works in Memory Clinic compared to a pure reablement, that you know that you might have to invest in a relationship. I know all healthcare is an investment in relationships but there's a very particular style and art to that, it's very, very, from an ethical point of view, very based in relational care and... the staff that get the furthest in terms of outcomes that, know that it's about the relationships that they form in the time and the approach, so that can't be underestimated as far as I'm concerned."*
>
> Hannah, Occupational therapist

9.2.2.3. Identifying Occupational (Functional) Needs and Goals

Identifying "*needs*", "*difficulties*", "*problems*" and "*concerns*", in addition to "*goals*" and "*priorities*" from the perspective of the person living with dementia, their support network, and occupational therapist was described in Hergest, Rhydderch, Dyfed and Arberth. A range of activities were associated with this, including an initial interview, assessment, and goal or priority setting. Noticeable overlaps were evident between accounts described in the theme *'Establishing a Therapeutic*

Relationship' and descriptions of initial interviews and goal / priority setting, suggesting that these activities may coincide.

Initial Interview

In Hergest, Rhydderch, Dyfed and Arberth, participants described conducting initial interviews or discussions to ensure that people living with dementia and their supporters have an opportunity to discuss what they feel their needs, difficulties or concerns are, and an opportunity to identify their own intervention priorities or goals. Emphasis was placed by some on the need to include family and supporters in these initial discussions, particularly if people lack insight or may be reluctant to discuss the difficulties that they are experiencing, as Harri highlighted:

> *"…I guess the picture you get from the patient typically is, yeah, I'm fine, I'm managing everything etc, etc and the family member's just like shaking their head, no, it's not the case. So as part of an intervention then it's to get a bigger picture, isn't it, and speaking to family..."*
>
> Harri, Occupational therapist

Assessment

Across Health Boards observational, functional assessments were described as an important activity to ensure intervention contents meet individual needs and are personalised and tailored. Participants advocated that these assessments should occur in the home environment, or where activities are routinely carried out, for example in a work environment or in the community. These functional assessments were typically non-standardised and often locally developed, however, the need to use standardised assessments was raised in Taliesin, particularly assessments that were sensitive to change after an occupational therapy intervention to evaluate impact. Standardised assessments were being used across Health Boards by some participants and included the Pool Activity Level (PAL), as well as MOHO and CDM based assessments. However, it is unclear if these assessments were being used as outcome measures as their use during the assessment process only was described. Participants in Arberth were critical about the utility of MOHO based assessments as service wide assessments, stating that they are not suitable for people who may not have insight into their difficulties or may not wish to discuss these:

"…we were finding that… we weren't able to use the assessments for the MOHO, because they involved quite a lot of personal reflection from those individuals and goal setting, which they weren't always able to engage in, but …the people with early-stage it probably [would] have been more appropriate with them. So yeah, there is a lot of transition at the moment in terms of models and assessments."

Seren, Occupational therapist

Criticisms were also noted about the language used by MOHO based assessments and the time required to complete these. Given their experiences, a move to CDM based assessments was being considered in Arberth. In contrast, participants in Rhydderch were currently unable to use MOHO based assessments as a service budget to purchase licences and assessments was not available, however they expressed a desire to use these assessments in the future:

"I don't use any standardised assessment tools because nothing, we don't have access to much. So whereas we would like to as an OT service move towards using, being affiliated with MOHO and be able to access a lot of that, I think because of, again, we haven't had an OT budget and the financial implications of that..."

Carol, Occupational therapist

In Taliesin, Anita emphasised the need for an assessment that was able to be personalised, for example using an individual's goals, although did not feel that the Morriston Occupational Therapy Outcome Measure (MOTOM), which she was currently using, was sensitive to change in this population. Anita also raised concerns about the need to avoid over-assessing people living with early-onset dementia using standardised assessments:

"…people, [with] early onset…can be barraged with lots and lots of assessments, as OTs we're particularly good at looking at function and using observation…I think we also need to be careful not to over assess people using standardised tools because they feel things are a test and I think it's very important that we work alongside people and they, yes we're assessing every minute we're with somebody, but that they don't see us as assessors."

Anita, Occupational therapist

Co-producing Goals / Priorities

Whilst not prominent within the data, a minority or participants provided insight into the process of working in partnership to establish and refine intervention priorities or goals. Listening to the persons views whilst also sharing expert knowledge and information were described as activities by Lydia:

> *"I think making sure that we work in partnership with the people that are our patients and they, the unit, the family unit, whoever. So making sure we're aware of what their needs are and what they feel are their needs. Bringing also our own clinical expertise and skill in the area, so, and working jointly in partnership, so that sense of co-production. So, someone might have some specific concerns but then maybe when we bring some of our knowledge it might help them shape some of the priorities. So it's about education as well…If they do have a diagnosis and you know things are going to get worse, maybe talking about do they, at that stage, want to simplify down things with using the cooker while they're still able to learn and do that or do they want to carry on doing."*
>
> Lydia, Occupational therapist

Some participants highlighted that the goal / priority setting process on occasions required managing conflicting priorities, including those of the therapist and those of the person's support network. This was often described as a difficult and challenging activity, particularly when conflicting priorities existed between a person living with dementia who has capacity and their support network. Carol described how she tries to overcome this by ensuring that she sees both the person living with dementia and their supporter together and facilitates open and honest discussions:

> *"…it is always a massive challenge with the family because…if somebody's got capacity to choose they don't want family involved… they're absolutely entitled to that, and then I have to tell them [family] that actually I can't, I can't do too much but perhaps signpost them to other support groups, that kind of thing but if the person is happy which nine times out of ten they are, I always try and say to the carer, we need to have an open and honest dialogue with the person because sometimes they don't always. So for example, when they come into follow up clinic they get separated, the person goes in to do a memory test and the other person sees the nurse so often they will bring up issues around that but the person's*

oblivious. So I always say to them, look, I know these are difficult conversations to have but unless we have this open and honest dialogue about it, we're really limited in what we can do so I try… not to have too many conversations in the early stages without the person there because I just think they need to feel in control, a lot of the time… their control is taken away both physically and perhaps just from their own fear of where this condition's going to go..."

Carol, Occupational therapist

9.2.2.4. "*It's all about those strategies*"

Across Health Boards, interventions to enable people living with early-stage dementia to overcome or compensate for functional / occupational difficulties were typically described collectively as *"strategies*" or "*memory strategies*". Prompting was frequently required to ascertain what participants meant by the word strategy, with a range of strategies evident in the data, which will be described in the remainder of this section. Significantly, participants emphasised that strategies must be determined on an individual basis and required extensive personalising and tailoring. Anita illustrated the multiple strategies that can be used for managing medication, arguing that the person living with dementia should be offered a choice of available strategies:

"I think it's a good idea to point out or suggest different ways of actually managing medication and for the person to choose the one that they think most suits them…For instance, for some people it's blister packs, laminated, for some people it might be ticking medication off in a book…for some people it might be actually having a calendar, using a calendar or a diary."

Anita, Occupational therapist

"Routines"

In Taliesin, establishing, re-establishing or maintaining "*routines*" was discussed repeatedly as an initial core intervention strategy, which participants advocated provided structure and familiarity, however, was not mentioned by participants from other Health Boards. In Taliesin the word "*routines*" was used to refer to multiple different types of routines, including temporal routines, routines in the way the home environment is used, and routines in the way activities are carried out.

Gemma provided an example of routines pertaining to the way space and objects are used in the home environment:

> *"…the needs of anyone who has got early-stage dementia is that they need structure and routine so that if they've always got a place where they put the keys, they'll always find the keys, they'll always find their glasses. You always put the remote control on the coffee table because otherwise you'll spend three hours tomorrow looking for that. So it's about trying to put routines and structure and therefore they're spending less time actually looking or trying to find something."*
>
> Gemma, Occupational therapist

An example of a temporal routine was provided by Anita:

> *"…some of my patients have always gone to get their pensions on a Monday, now if that's the case you… keep that going. I've recently had a client whose daughter started collecting her pension and that confused the lady so much and it just caused so much distress the daughter's now backed off and allows the client to go and collect her pension, go to the corner shop which was always her routine and then come back home with her purchases."*
>
> Anita, Occupational therapist

Prompts, Reminders, and Cues

Prompts, reminders, and cues were the most commonly described strategies across Health Boards. This included diaries, calendars, white boards, checklists, step by step instructions (pictures and words), labels, stickers, and written prompts to facilitate orientation to time and date, and to prompt action. The need to make adaptations to the colour and size of visual prompts and to carefully consider their location in accordance with individual needs was emphasised by Anita to ensure they were effective. Aids and equipment, for example timers, smart technology, and alarms were also described as prompts. Leah spoke about a piece of equipment which prompts people to take their medication and highlighted that strategies must be personalised:

> *"…a carousel is a piece of equipment that's like… a round plastic thing, that basically, you put the medication in and at the time at which the medication is due*

it goes around, the flap opens, and it just does this incredibly loud buzz…And it won't stop buzzing until that person takes their medication…. Because a lot of the problems… is, even if someone has a Dossett box, getting confused with the days, and even, perhaps with a lot more early dementia, the dementia clocks are very good, because it can orientate people a bit more to the day but even then it's not a full safe strategy, so yeah, the carousels can be amazing but they can also just not work. So, it's about trying what works for that person."

Leah, Occupational therapist

Environmental Adaptation

Strategies that involved adapting a person's physical, occupational and social environments were also discussed. The former included removing and minimising distractions and complexities to aid concentration, for example removing or turning off a TV or telephone, or by decluttering:

"…in the early stages you might be able to give more visual clues, so maybe if you declutter the kitchen they would still be able to actually make that cup of tea because they can see where everything is and they have learned that behaviour, that making the cup of tea because they've done it so many times before, …with the less clutter around they're able to concentrate on the task."

Delyth, Occupational therapist

Another example included structuring or adapting the physical environment to provide prompts and reminders, for example placing clothes somewhere visible rather than in a cupboard and changing cupboard doors from solid to glass. Adaptations to the physical environment to meet physical needs were also mentioned in passing by some participants. Modifications to occupations or activities included reducing the complexity of an activity by removing the number of actions required to achieve the desired outcome, for example by using a microwave instead of an oven. Adaptations to the social environment were typically spoken about in the context of delivering family or caregiver "*education*", "*advice*" and "*information*", for example providing information about prompting or an instruction at certain stages during an activity. Some participants described using the CDM or the PAL to develop advice and information for a person's support network. Catrin provided an account of using the CDM

caregiver manual and its associated assessment, LACLS, to grade interventions and provide advice and information:

> *"…I do find the Lacing assessment [LACLS]… can give you some useful information and some guidance around, look this person will be able to do these sorts of procedural tasks that are familiar, but if the X, Y and Z changes they can't, or if this is going on in the environment when that is occurring, then this won't be able to happen. …So, it's often a conversation between the person and the person they're living with trying to establish where they're at, and trying to give some basic guidance then, perhaps if you did this, that might help a little. Or if you gave one instruction here that might help this bit move on, or if you thought about presenting, clearing this work surface and presenting it in this way, perhaps someone might be able to do that."*
>
> Catrin, Occupational therapist

Participants also highlighted that providing general advice to family and supporters about the importance of enabling people living with dementia to continue doing, rather than doing for, was often necessary. In Taliesin, caregiver interventions were typically spoken about in the context of what participants called "*deskilling*", as described by Gemma:

> *"…it's about educating the family members to try to stop them from deskilling people by stopping them doing things because they're making a mistake. I remember going to a young onset lady… whose husband wouldn't let her wash the dishes anymore because she didn't wash them clean. So I said, well let her wipe the dishes. So she was wiping the dishes but she was putting them back in the wrong cupboard, so again he stopped her doing those tasks, so he stopped her doing so much that generally she sat in front of the television all day and did nothing. And then because… she had chronic word finding… she got really frustrated because she couldn't say to him what she actually wanted, which led to hostility towards him, but she was just so frustrated at not being able to do anything at all."*
>
> Gemma, Occupational therapist

Anita highlighted that it is also possible to support people themselves to provide "*education*" and "*advice*" to people within their social networks about the support they may need to continue participating in activities:

> *"…My…[patient]…, everybody knows that she's got dementia, we talked it through when she was in a terrible state to start off with and it took me a number of sessions, but she was able to tell people sometimes I'm a bit forgetful because I have dementia and people were, because she was open about it and didn't try and hide it I think…people seemed to accept it, they didn't blink an eyelid. Most families have somebody with dementia in their family…"*
>
> Anita, Occupational therapist

Meeting Mental Health and Emotional Needs

Whilst not prevalent within the data, strategies to overcome occupational difficulties due to depression, anxiety, and the emotional impact of living with dementia were described. Carol spoke about using graded exposure, goal setting and breathing exercises to facilitate community re-integration:

> *"…I'll start off by going to see somebody within their own home because…I'm trying… to build up their confidence, put some strategies in place in order to manage some of that, often they've got a lot of anxiety problems as well, in the earlier stages that manifest, and mood disorders as well even though it's not necessarily a mood disorder. So then I'll try and do things around anxiety management with them, basic stuff around breathing techniques… so that they can use them out and about and then… I'll do a graded exposure programme where I will be just trying to get people… I've got one lady that's taken to her bed so I'm trying to, right now, get her out of bed first and… So I'm doing first of all going there regularly at the same time saying, setting our goal with her, this is what we're going to do…"*
>
> Carol, Occupational therapist

In Taliesin, some participants spoke about providing interventions to help people come to terms with the impact of receiving a diagnosis. Drawing on their current experience of working with people living with early-stage dementia, Anita reported that she provided coping strategies based on Cognitive Behavioural Therapy (CBT) and what she called an "*eclectic*" approach. Their long extract provides an important insight into the activities and strategies inherent in meeting these needs:

> *"The first thing that you do as an OT, I think, is to listen and you will pick up various cues and triggers and people's fears, and their concerns and then you need to address those. I like to try and use a CBT approach but that is also very much mixed with, I use quite an eclectic approach, …to try and help people move forward with it. …when somebody first has a diagnosis it is devastating, absolutely devastating, and one of the people… I had to work just two weeks on just talking about fears, emotions and things like that. …it doesn't stop, it's not a specific time because they will crop up right throughout the intervention, but…you need to give people information and you need to give them strategies to cope with those thoughts and those feelings, and what strategies and what coping mechanisms you suggest will completely depend on the individual and what works for them, because what works for you possibly wouldn't work for me.*
>
> *I think also with the emotional stuff, people don't listen, people think they have to talk, they don't, silence is golden and it enables the person who is feeling, to actually get their emotions out. …you don't have to constantly, well yes of course you have to reassure, but you don't have to constantly say, well this is what you should do, blah, blah, blah, it's very important that you listen and you might be the only person who's actually listening because a lot of people say, well you don't want to worry about that, now, you've just had a devastating diagnosis and people are telling you not to worry about it, you have to give permission, people permission to worry about it, but be there as a vessel so that they can talk this through. And it may be you're just about at the end of your intervention and you think everything's simply tickety boo and then the emotions will resurface… and you need to give them the time again to work through that."*
>
> Anita, Occupational therapist

As articulated by Anita, meeting mental health and emotional needs involves a number of activities, including listening, giving people time to talk, work through difficult thoughts and feelings and validating them by giving people permission to feel frightened and concerned. Providing reassurance to people, by giving information and advice about the possibility of living well with dementia was also highlighted by other participants:

> *"I think they'd need to have a conversation with people about, it's not that bad, it doesn't mean it's the end, and I think positively to say, well you can live well with dementia, I think they really need to have a positive spin on it because you can."*
>
> Carys, Occupational therapist

Strategy Implementation

Activities associated with strategy implementation were not described in detail by participants, however, those identified in the data included:

- Pragmatic problem-solving
- Providing advice, information, and education about strategies
- Providing aids and equipment
- Creating, amending, or developing strategies (personalised cue cards, step by step guides)
- Training to support strategy and skill acquisition
- Supporting strategy practice to ensure transfer to day-to-day routines
- Evaluating strategy implementation, taking a trial-and-error approach

Leah described a process of problem solving and trial and error in order to find a strategy or strategies that work for the person:

> *"So, it's about trying what works for that person… very much trial and error. A lot of my job, I think, is having an idea, seeing if it works and then evaluating it and being like, they don't get on with that, it's not working, we need to try something else, yeah…and it might just be that it's completely not the right thing for that person, especially older people."*
>
> Leah, Occupational therapist

Reflecting themes identified in Chapter 8, some participants highlighted barriers related to the implementation of interventions, including the lack of telecare in some Health Boards, which people living with dementia were required to buy. Others mentioned that having an occupational therapy technician and support worker was important in being able to ensure that intervention strategies were practiced regularly and facilitated a graded approach when re-learning or learning new skills, for example accessing the community using a bus.

9.2.2.5. Advice, Information and Education

Providing "*advice*", "*information*" and "*education*" were widely reported intervention activities, sometimes described in the context of strategies, as outlined in the preceding sections, and sometimes described independently. Advice and information was reportedly delivered on a broad range of topics, including dementia, to facilitate understanding about the condition and its impact particularly on day-to-day activities, as Catrin articulated:

> *"…what I find…is that families find it really difficult to understand that the person [living with dementia] seems to do one thing but not another, one day they did this, then they couldn't do that, or they'd get frustrated when they've asked them something and they haven't done that. So sometimes what we try to do is… illustrate to families how the dementia may be affecting their functioning, and what you can expect of someone, and what way a carer can help that person to function. …we can work out that they score 64 on an ACE but what does that mean? It's the every-day practicalities of this illness that we try to deal with..."*
>
> Catrin, Occupational therapist

As Catrin stated, providing information on real world functional impact, as opposed to a score on a cognitive measure, was highlighted as an important occupational therapy intervention. This was reiterated by Harri:

> *"…I've sat in reviews where family members have always said, so where are they in terms of the dementia continuum. And it's very hard for doctors to say they're at this level because people react differently to the dementia, whereas these kind of measures [PAL] put it in terms of function and what people can expect to be*

doing which from an everyday life point of view is more, it's worthwhile knowing, isn't it?"

Harri, Occupational therapist

Signposting was also described in the context of providing information and advice about local services that could meet needs, which were not able to be met by occupational therapy. This frequently included community transport and community groups, as Ffion reflected:

"Yeah, referring for telecare aids, reducing risks in terms of environment, maybe with smoke alarm detectors or community alarm buttons. We've also looked at social situation to avoid social isolation and referred people onto third sector agencies to keep them more out and about and reducing the risk of isolation."

Ffion, Occupational therapist

Power of Attorney and care planning, particularly around dying, which rely on the person living with dementia to have capacity, were also described as important information to provide during the early stages. Others highlighted the importance of giving information about eligibility for financial assistance, driving, and how to contact services should circumstances deteriorate.

9.2.3. Mode of Delivery

9.2.3.1. Face to Face

All participants from Taliesin advocated that an intervention for early-stage dementia should be delivered on a face-to-face basis, reflecting current practice in Hergest, Rhydderch, Dyfed and Arberth. The benefits and disadvantages of both face-to-face group and individual or dyad formats were discussed in detail by participants from Taliesin. These discussions were often intertwined, for example, the benefits of an individual or dyad format would correspond with the disadvantages of a group format and vice versa. As Gwen stated, there are "*pros and cons [of] both*". The need to take an individualised approach towards intervention format was emphasised, respecting individual preferences. Given this, some participants advocated for the availability of both group and individual or dyad formats.

9.2.3.2. Individual or Dyad Formats

In Taliesin, individual or dyad formats were deemed to provide the greatest opportunity for personalisation and tailoring and therefore more individualised interventions. A home visit and assessment, which for logistical reasons occurs on an individual or dyad basis, was cited frequently as essential in ensuring interventions were personalised, given that all home environments are different:

> *"…you can do that individualised personal assessment, you can see the home environment and the home environment can often give you masses of clues or prompts as to what actually is happening. You can go in and not be judgmental, but you can see sometimes if someone is really struggling with certain tasks or things. …You can do much more practical based assessments, you could ask them to operate the washing machine, you can't do all those things in a group. So, you can personalise it a lot more than in a group setting…"*
>
> Angharad, Occupational therapist

In addition to the benefits of home assessments, some participants felt that individual or dyad formats provided time to build therapeutic rapport and carry out more in-depth work, whilst others mentioned that it may help a person to concentrate and attend to intervention content without distractions. In Hergest, Rhydderch, Dyfed and Arberth Health Boards, interventions were delivered overwhelmingly on an individual or dyad basis. Participants in these Health Boards highlighted the importance of working with the person living with dementia's supporter or family, as well as the person themselves, to enable strategy practice and to ensure transfer into day to day life. However, in Taliesin, individual or dyad interventions were viewed as more expensive, given the demands upon therapist time, including travel time. Alys and Sara also emphasised that therapeutic rapport is contingent upon both the person and therapist being able to relate to each other, and some people may not like the intensity or formality of individual or dyad interventions.

9.2.3.3. Group

In contrast to individual or dyad formats, group interventions were deemed to be more cost effective by participants in Taliesin, particularly in the context of an increasing population living with dementia. Further perceived benefits of a group format in Taliesin included developing a sense of connection and relationship with others in similar circumstances and learning from, and supporting, peers. Others

spoke about the possibility that people may be more inclined to accept the support and advice of peers rather than a professional. Juliette spoke about the benefits of peer support:

> *"…I think… it's the same in any mental health setting and physical setting where if a person who's sat next to you is having a similar problem, it then becomes a shared problem rather than an individual problem. And strategies that a person has lived through and used rather than a piece of paper or a professional saying what the strategies are, become more realistic and more acceptable and achievable."*
>
> Juliette, Occupational therapist

Despite the benefits arising from relationships with peers, the potential for group dynamics to impact upon the delivery of a group intervention was noted. Delyth highlighted concerns about privacy, for example sharing personal information or diagnosis with others and Alys and Sara reflected on the impact a group format could have on people's ability to be honest about their situation:

> *Alys:* *"…I think there definitely would be barriers. You wouldn't get maybe as honest answers. I think maybe someone might feel like, OK you're doing really, really well and Barbara next to you is doing amazing and I'm really struggling and I'm at my wit's end…I'm struggling, I need more help. I'd be like, yeah great everyone else is doing brilliant I'm doing brilliant –"*
>
> *Sara:* *"…when you get the vibe of, oh everyone's doing good, you don't want to put a negative spin on stuff if I'm not.."*
>
> Alys and Sara, occupational therapy practitioners

Personal preferences were also noted, with Angharad stating that "*some people don't want to go to groups*". Perceptions of groups as "*day-centrey*" and "*old fashioned*" were highlighted as further barriers to group attendance, particularly for people who are younger. The "*fear of what's to come*" was also mentioned as something that could prevent people with early-stage dementia from attending. The need for confidence and motivation to attend a group was also reflected upon, and Carys recalled a previous group that she had facilitated, highlighting that an individual's motivation may wane over time, leading to group attrition. The need to generalise intervention content for delivery in a group was also raised, which participants felt would minimise the extent to which

interventions could be person-centred. Concerns were also expressed about being unable to monitor or assess whether information delivered in a group setting is being transferred and used in the home environment.

Despite the challenges that group formats may present, some solutions were provided by participants in Taliesin. For example, screening people on a 'case by case' basis to determine suitability of format and to match group members with each other, who have similar needs and interests. Combining individual or dyad formats with a group format was suggested by Juliette:

> *"…it can be delivered as part of a group as long as on screening people are matched very well…I think that's important to sound out what service users actually feel…it is on a case-by-case basis I think. And actually, on screening, finding out does that person actually need intervention programme or, on their own within the house in order to show how to modify, or can they conceptualise what actually is being delivered and then transfer that over into the home….So, I think it's something to be explored really as to one to one interventions and then group at the end or group first and then home visits to see, did that work for you. Constant evaluation as well, but home visits for me is definitely something that allows you to see past what you, what the person thinks they're experiencing and actually what is actually going on… for me it would probably be an initial home visit to screen the person at home to find out, does everything match and what difficulties are there and trying to match them up with a group."*
>
> Juliette, Occupational therapist

A minority (n=2) of participants from Hergest, Rhydderch, Dyfed and Arberth Health Boards were delivering occupational therapy interventions in a group format, which they called '*memory strategy groups'.* However, these interventions were not delivered Health Board wide and were confined to the individual therapists' locality. In Hergest Catrin spoke about some of the benefits and challenges delivering interventions in a group format brought:

> *"We encourage the group because actually I think people benefit a lot from seeing other people with a similar condition. But there are some people that just can't tolerate that or perhaps they do have significant transport issues that we can't address, then we might offer that one to one. But ultimately, I like to do as much*

of it [as] I can in the group. I went to see a lady yesterday and I was going to do it one to one, …she is absolutely petrified that the world and their wife are going to know that she's got dementia and she doesn't want anyone to know. …and she's hiding away. But I think, I can see that causing issues for this lady. So, I think we need to address that. So, I was going to do it at home but actually, I think yesterday I did manage to persuade her to come along to the group because I think for her, in itself, she needs to see that other people are very normal with this, and that could really help her."

Catrin, Occupational therapist

9.2.4. Location of Delivery

9.2.4.1. Home

Home was the preferred setting for individual or dyad based interventions in Taliesin, reflecting practice across other Health Boards. Participants offered multiple reasons to support this location, including the familiarity of the home environment, which may enable people to feel less under pressure and more inclined to open up about personal matters. The opportunity to speak and work with family members, and the ability to conduct an assessment of the person and their occupational / functional needs in their day-to-day environment was also deemed important as expressed by Delyth:

"I think home visits are often really useful because you can see what the home is set up, …and who lives there and who has got input with that person and things. You can obviously look at all the physical adaptations like whether they need a handrail and things like that. But also… looking at how that person functions in their day to day living, so actually observing people when they're doing their personal care or their cooking or their cleaning or whatever, so that you can give advice on how things can be improved, so that that person can be able to do it themselves or that the carer doesn't always have to stand there."

Delyth, Occupational therapist

9.2.4.2. Community Settings

In Taliesin, non-clinical community venues, including libraries, community centres, cafes and church halls were perceived as appropriate locations for group interventions, with some participants suggesting GP surgeries. Arberth's memory strategy group was being delivered in a clinical setting and in Hergest both clinical and non-clinical community venues were being used to deliver memory strategy groups. Non-clinical community settings were portrayed by participants in Taliesin as informal locations that help reduce stigma and negative perceptions associated with clinical settings or dementia. Furthermore, they provided the opportunity to link to community groups and locations, for example a library or a café, where people could meet once the group ended. Significantly, the need for community venues to be accessible was emphasised in Hergest and Taliesin, particularly since the latter covers a vast geographical area with poor transport links, and many individuals are without cars or are unable to drive. Like Delyth, many participants felt that groups would need to be facilitated in a number of Taliesin's localities, rather than one group held centrally:

> *"…if you're doing a group, it needs to be somewhere that's accessible, say if you haven't got a car, for example… if you're from Locality X and it's up in Locality Y people aren't going to attend, you've got to have it localised to the person and be at the local library or somewhere that's like a centralised area. So I think that's going to be better having smaller groups in a variety of places for some generalised coping strategies rather than one centralised one because it's such a vast area… it's got to be accessible to them."*
>
> Delyth, Occupational therapist

In addition, for individual and dyad interventions, accessing community venues and locations that are personally meaningful for people and where occupational needs had been identified, for example third sector groups or groups that reflect interests and work environments was also highlighted as important.

9.2.5. Duration and Intensity

A flexible and individualised approach was advocated when discussing duration of individual and dyad interventions in Taliesin, and this was reiterated across Health Boards as Carol stated:

"…our interventions are very varied, …I could go and see somebody to do a one off road safety assessment, it's done, I've managed to get it all done in one session... And yet another person that's far more complex, loads of stuff going on I might see them over months. So I think the longest person I've had on my caseload has been a year and that's because the lady herself, her needs kept changing so I started off with one objective but then other things happened so… it changed… I would say probably if I was going to average it out, I'd probably keep somebody on my caseload doing intervention for around about a month, I would say."

Carol, Occupational therapist

Whilst maintaining that duration and intensity must be personalised, when asked to be specific about duration, participants in Taliesin stated that they anticipated interventions for early-stage dementia would typically take between 6 – 8 weeks, with an evaluation to ascertain if further input was necessary. This duration was deemed to provide time to build rapport, assess, implement, and practice strategies, and time to provide support for emotional needs. Frequency of contact was typically advocated on a diminishing intensity basis, with potentially multiple visits in the initial weeks, reducing over time. Participants often made reference to the way reablement services in Taliesin currently operate on a 6 week diminishing intensity basis when discussing intervention timescales and intensity. However, some highlighted that the intensity of reablement may be too much for some people and advocated that contact should be once a week. Gwen also argued for greater flexibility and individualisation pertaining to the time of day that interventions are delivered:

"I think it should be client led again, we should be flexible and fluid as well because if they want us to be there at 6pm because that's where they're struggling the most, we should be there. We cannot just say, oh I'm sorry, I work 8am to 4pm, and how long again should be… client led and …perhaps depends on their skills, current skills, depends what we're delivering. Yeah, I would say again six to eight weeks as minimal but if they want more they should… have that opportunity to have more sessions."

Gwen, Occupational therapist

Data relating to the duration and frequency of group interventions was provided by three participants in Taliesin. However, all three recommended a duration of between 5 – 8 weeks, although they emphasised that this would be dependent on group members' needs. This duration was deemed to

provide enough time for people to develop relationships with other group members and time to implement strategies and report on their success. Gwen cautioned that 8 weeks may be too long, leading to attrition and Juliette suggested that the group could be delivered over a shorter period of time with more frequent contact. Again, being mindful of conducting groups at a convenient time for participants was emphasised. Group interventions in Hergest and Arberth were being delivered for 5 and 6-weeks' duration respectively, with contact once a week.

9.2.6. Interventionist

Across Health Boards, a consensus was evident regarding the input of occupational therapists and occupational therapy support workers. For intervention delivered on an individual or dyad basis, participants explained that occupational therapists would typically conduct assessments, goal setting, initiate intervention programmes and deliver more complex interventions or those that aimed to reduce risk. Where available, occupational therapy support workers typically delivered interventions that were longer term, that required practice or a graded approach, for example community re-integration, as Hannah stated:

> *"So maybe some of the more assessment work might be done [by me], so quite commonly same with the risk for getting lost… a gas cooker risk, it may only need two or three visits so I might not involve somebody else in that. But if it's something which… you want to go in quite often or you want to practice a skill, so there's a lady that we had to, her family had to isolate her cooker quite quickly because of the risk, lived in flats …and we were looking at getting a heat sensor connected to Careline put in but that wasn't going to happen overnight… But in the meantime I did a piece of work with her to look at her using the microwave, so I did an assessment with her and she could do it, it was something she was happy to do and then the Support Worker did that practice with her over a number of sessions. …Sometimes it's really worth having the Support Worker there because you know it's going to be really difficult to have conversations with carers and the person, that is invaluable because you can get the Support Worker to go and get the person to show them round the house… And then the qualified OT can have a bit more of a chat with the carer about things that are uncomfortable to talk about with a person with dementia for fear of really upsetting them..."*
>
> Hannah, Occupational therapist

For group interventions, some participants in Taliesin spoke about the need to have people living with dementia deliver or co-deliver group sessions alongside occupational therapy practitioners. However, in Hergest and Arberth, group interventions were delivered by occupational therapists and support workers.

9.3. Discussion

Themes identified during Study 2 to meet Thesis Objective 3, to identify practice and research-based occupational therapy interventions have been presented in this Chapter. Themes informed by the TIDieR Checklist [121] were utilised as an a priori thematic framework to ensure detailed information about interventions was captured, with sub-themes developed inductively. As outlined in Section 9.1, these themes were generated in response to the research questions:

2.3.1. *What interventions are occupational therapy practitioners currently delivering to meet the needs of people affected by early-stage dementia living in the community?*
2.3.2. *What interventions could occupational therapy practitioners deliver to meet the needs of people affected by early-stage dementia living in the community?*
2.3.3. *What barriers and facilitators do they / could they face?*

This discussion will commence by discussing themes relating to interventions identified (Research Questions 2.3.1 and 2.3.2.) and will then discuss barriers and facilitators (Research Question 2.3.3.).

9.3.1. Interventions

Intervention Rationale, Theory or Goal

There was a distinct difference between the theoretical model of occupational therapy used currently in services for people living with early-stage dementia, the MOHO [79], and the model proposed by the majority of participants in Taliesin, the CMOP-E [37]. Both are internationally recognised models of practice and currently there are no recommendations in the UK for the use of one model over another. Reflecting this, the MOHO, CMOP-E and Reed and Sanderson's Human Occupational Model were the most frequently reported models utilised by occupational therapists working with people living with dementia of all stages in NHS Wales [39]. A common critique across sites about these models included the lack of focus on memory and cognition, with the need for additional theories to

address this gap, for example the Cognitive Disability Model (CDM) [238], which was used across three Health Boards. Aims and goals discussed across sites typically mirrored those utilised by intervention programmes described in Study 1, namely to maintain or increase "*independence*", "*functioning*" or "*skills*", and reflects the definition provided by RCOT [36] of occupational therapy presented in Chapter 1.

There was a notable lack of awareness about occupational therapy specific research that underpins current, and could underpin future, practice across Health Boards. However, as Study 1 highlighted, at the time of interviews there was a lack of UK based evidence investigating occupational therapy specific intervention programmes for early-stage dementia. Nevertheless, two participants spoke about the similarities between cognitive rehabilitation research and the occupational therapy interventions that they provide. This was noted in Study 1, in particular, Clare et al's [89] cognitive rehabilitation programme, which was delivered by occupational therapists, used the COPM as an assessment and outcome measure and included problem solving, strategy-based interventions which aimed to improve occupational functioning. The similarity between cognitive rehabilitation and occupational therapy intervention is perhaps acknowledged by NICE [2] when they state "*Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia"* (no page number). This raises important questions about what the differences are, if at all, between both interventions, and whether research investigating cognitive rehabilitation can be used by occupational therapists to underpin their day-to-day work. In this study, participants' reluctance to use this evidence was based on concerns that cognitive rehabilitation was associated with psychology as a profession. The preceding Chapter (Section 8.2.2.2.) identified the lack of influence participants perceived they had compared to psychology and the medical profession in influencing what interventions or services were available locally and prioritised in policy.

Content and Components

The subtheme "*It's all about those strategies*" attests that like intervention programmes in Study 1, strategies constituted the primary intervention component described across Health Boards. Strategies primarily consisted of adaptations to the occupational, social and physical environments, which included equipment, aids, prompts, reminders and cues, akin to intervention programmes described in Study 1. Whilst not mentioned by participants from other Health Boards or by intervention programmes in Study 1, establishing, re-establishing or maintaining "*routines*" was described as a strategy in Taliesin Health Board. This was however, identified as a self-initiated

strategy (habituation) in Study 1's population synthesis, with participants from Nygård and Öhman [136] and Brorsson et al's [130] studies utilising time and place routine-based strategies. Whilst only discussed by a minority of participants and again only noted in two programmes in Study 1, CBT based strategies to meet mental health and emotional needs, including the impact diagnosis can have on the person, was discussed.

In addition to strategies, and akin to programmes from the modality of occupational therapy in Study 1, across sites participants spoke about a pre-intervention assessment process consisting of interviews and observational assessments. Furthermore, like programmes from the modalities of occupational therapy and cognitive rehabilitation in Study 1, pre-intervention goal or priority setting with the person and their family was also described as an activity. In this study, the importance of developing and maintaining a therapeutic relationship was also identified as an important activity, however, this was only identified by one study in Study 1 [159].

Mode and Location of Delivery

Reflecting the practice context prior to the COVID-19 pandemic, all participants at Taliesin advocated for the face-to-face delivery of a future intervention, in accordance with current practice in other Health Boards and intervention programmes identified in Study 1. The majority of participants in Rhydderch, Hergest and Dyfed were delivering interventions on an individual or dyad basis in the home environment, akin to programmes from the modalities of occupational therapy and cognitive rehabilitation in Study 1. When considering a new intervention, participants in Taliesin were eager to discuss the "*pro's and con's*" of both group and individual or dyad formats. Personal preferences, demand and cost effectiveness as well as individual needs were all considered important in relation to mode, leading a number to suggest that mode should be determined on a case-by-case basis or by combining both formats, akin to Sprange et al's [159] intervention, identified in Study 1.

Duration and Intensity

Intensity and duration across Health Boards was described as flexible, tailored in accordance with a person's needs. However, participants In Taliesin identified 6 – 8 weeks' duration for both a group and individual or dyad interventions, which mirrors the length of the majority of interventions identified in Study 1.

Interventionist

In contrast to intervention programmes identified in Study 1, occupational therapy support workers were identified alongside occupational therapists as interventionists, where available. Whilst not standard practice in the localities where groups were being offered, in Taliesin participants advocated that people living with dementia should be co-facilitators akin to Fmeiola and Tilki [239].

9.3.2. Barriers and Facilitators

Barriers and facilitators (Research Question 2.3.3.) were primarily reported in Chapter 8 in relation to the intervention context. However, in the context of this Chapter, some barriers already identified in Chapter 8 were also noted, including a lack of resources leading to an emphasis on interventions to support personal care and activities associated with risk, as well as a lack of support workers. The impact a lack of evidence to support the delivery of occupational therapy interventions in primary care, including MAS as well as the strength of other professions in generating evidence, was described as contributing to having low levels of control and influence on the provision of occupational therapy intervention. Additional barriers were noted, including individual factors relating to the person living with dementia, for example a lack of insight or awareness into their difficulties, which was utilised to highlight the importance of involving family members or caregivers in the assessment process. A lack of agreement between a person living with dementia and the priorities of family was also described, which required negotiation and specific strategies to enable an open and honest conversation. Whilst not identified as a barrier, the need to meet emotional and mental health needs was described as something that could impact on the length or progress of an intervention. Accessibility of venue was also identified as a significant barrier to the delivery of group interventions.

9.4. Chapter Conclusion

Findings associated with Thesis Objective 3, to identify and explore practice or research based occupational therapy interventions, have been presented and discussed in this Chapter. Parallels with intervention programmes from the modality of occupational therapy in Study 1 were identified in practice across sites. Individually tailored strategies that problem solve and prevent occupational performance problems and difficulties were the most prevalent component reported, along with a pre-intervention assessment process. Uncertainties about the optimum mode of delivery (group or individual or dyad) was identified, with a hybrid model additionally proposed. Due to the personalised

nature of occupational therapy intervention, duration and intensity were reported to be variable. A lack of occupational therapy specific research to support clinical practice was highlighted, with a reluctance to use evidence in relation to cognitive rehabilitation reported, given its association with psychology as a profession.

Study 3: Intervention Programme Theory and Design

Chapter 10: Methodology

10.1. Introduction

This Thesis' overall aim is to describe and develop an occupational therapy intervention for people living in the community with early-stage dementia. To do this, Study 3 (Chapters 10 – 11) synthesises data generated during Study 1 and 2 with data generated from stakeholder engagement and existing theory, to develop an intervention programme theory and specify a programme design. As described in Chapter 2, an Intervention Mapping approach [65] has been utilised to guide this process. This Chapter will describe methods used and tasks undertaken during Study 3, with Chapter 11 reporting on the proposed programme theory and design.

10.2. Objectives

Intervention Mapping involves 6 key steps (Figure 3, Chapter 2), with Steps 1 - 3 and their associated tasks reported on in Study 3. Thesis Objectives 4 – 7 were developed based on these tasks and are action orientated[10]: -

- **Thesis Objective 4**: Develop a logic model of the problem and population.
- **Thesis Objective 5:** Specify intervention context, components, and characteristics (programme design).
- **Thesis Objective 6**: Specify mechanisms, methods, and applications of change.
- **Thesis Objective 7:** Develop a logic model of the intervention.

Thesis Objectives 4, 6, and 7 collectively aim to articulate a proposed programme theory and Thesis Objective 5 constitutes articulating a proposed programme design. Intervention development is often iterative and does not necessarily occur linearly, and Intervention Mapping permits a flexible approach towards its use [65, 68]. Since this programme of work involved identifying existing interventions deriving from research (Study 1) and practice (Study 2), a proposed programme design (Thesis Objective 5) was specified before identifying mechanisms, methods, and applications of change

[10] Appendix M provides a more detailed account of how Intervention Mapping Steps 1 - 3 were utilised to inform Study 3.

(Thesis Objective 6). A solely bottom up theoretically driven approach was not appropriate given existing research and practice-based evidence, and therefore the order in which Intervention Mapping's tasks have been reported in Study 3 differ to the sequence in which they are described by Intervention Mapping.

10.3. Methods

Study 3 synthesises data generated during Study 1 and 2 with data generated from stakeholder engagement as well as existing theories of change. Figure 8 depicts the overall programme of research's design, akin to Figure 4 (Chapter 2), however, provides greater detail about tasks undertaken during Study 3. This section will provide an account of the methods used to inform these tasks, and the tasks themselves will be described in Section 10.4.

10.3.1. Needs Assessment: Study 1 and 2

Study 1 and 2 generated data to meet Thesis Objectives 1 – 3, which in the context of this programme work constituted an Intervention Mapping needs assessment. Knowledge gleaned from both studies about the intervention population (Thesis Objective 1) and intervention context (Thesis Objective 2), was used to populate a Logic Model of the Problem and Population at Risk (Thesis Objective 4, Section 10.4.1.). Data generated about existing research and practice-based interventions (Thesis Objective 3) and the intervention context (Thesis Objective 2) was used to inform the proposed programme design (Thesis Objective 5, Section 10.4.2.).

10.3.2. Stakeholder Engagement

The revised MRC Framework emphasises the importance of involving stakeholders in complex intervention research [65], and during Study 3, workshops with occupational therapy practitioners and Patient and Public Involvement (PPI) were utilised to triangulate and build upon data generated through formal research methods during Study 1 and Study 2.

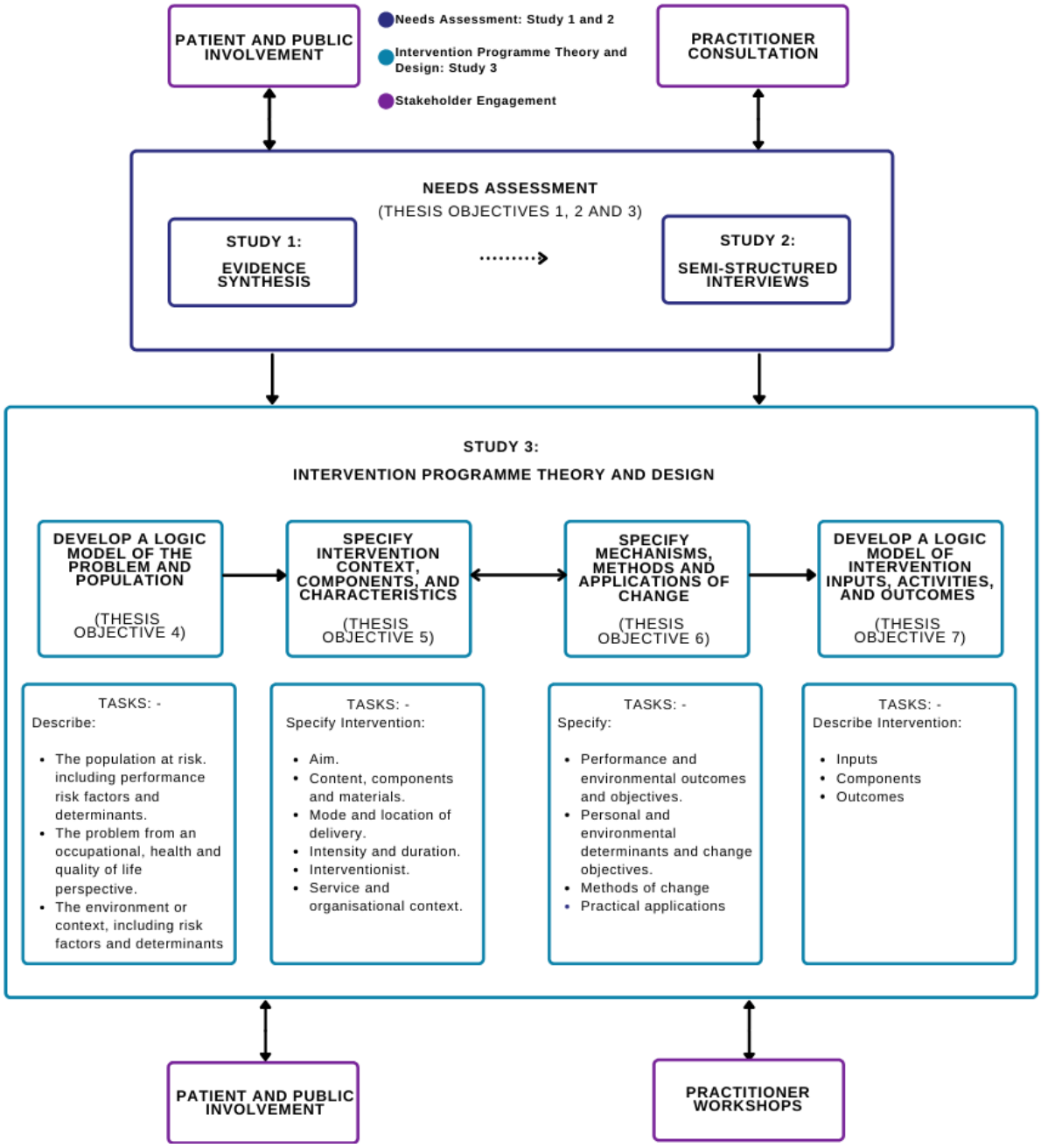

Figure 8: Research Programme Design (Extended Study 3)

10.3.2.1. Occupational Therapy Practitioners

Three workshops with occupational therapy practitioners were facilitated in Taliesin Health Board, with the intention of generating feedback on the development process as required. All members of the Older Persons Mental Health Occupational Therapy Mental Health Team were invited to attend on a voluntary basis and at least 10 practitioners, including occupational therapists and occupational therapy support workers, participated on all occasions.

Workshop 1: Intervention Logic Model

Before a decision to use an Intervention Mapping approach was taken, a simple logic model, as defined by the revised MRC Framework [65], combining both the problem and intervention, was developed. The model consisted of a brief description of the problem, intervention inputs, activities, and outcomes (immediate, short-term, and long-term), and was developed by drawing on preliminary findings from Study 1 and 2. During a workshop on the 20.9.2018, lasting 2 hours, practitioners were split into sub-groups of three to five and encouraged to critique the logic model, with written prompts provided to aid discussion (Table 32). In their sub-groups, participants were encouraged to write feedback on a large, printed copy of the logic model or on a separate piece of paper. Before concluding, all sub-groups gathered for an overall feedback session, where written notes were also made of the discussion. Feedback was collated (Appendix N) and was utilised to inform Thesis Objectives 4, 5 and 7 and their associated tasks.

Table 32: Practitioner Workshop Prompts: Simple Logic Model

- *What are your overall impressions of the Logic Model? What do you like and what do you not like?*
- *What would you change? Would you add or take away anything? Think about the different components: Situation / Problem, Inputs, Activities and Outcomes.*
- *Does it reflect what you do / think you would do as an occupational therapy practitioner working in MAS? If yes / no – why?*

Workshop 2: Occupational Performance Outcome Measures

Maximising or optimising occupational performance or functioning was identified as an outcome in the simple intervention logic model utilised in Workshop 1. Nevertheless, a lack of consistency was identified in measures utilised to capture occupational performance outcomes in Study 1's Intervention Synthesis, which was also identified by Harrison et al [240] in their systematic review of outcome measures utilised in intervention studies for dementia and Mild Cognitive Impairment (MCI). Study 2 also identified that only one participant was using an outcome measure in practice, which they did not perceive to be sensitive to change. In this context, a second workshop was facilitated on the 15.10.2018 over the duration of 2 hours to discuss the suitability of five outcome measures that could be used during a pre-intervention assessment process and as an outcome measure in a future evaluation. These outcome measures consisted of the Model of Human Occupation Screening Tool

(MOHOST) [241], Occupational Circumstances Assessment and Interview Rating Scale (OCAIRS) [242], Canadian Occupational Performance Measure (COPM) [174], Bristol Activities of Daily Living Scale (BADLS) [243] and the Interview for Deterioration in Daily Living Activities in Dementia (R-IDDD2) [244]. Participants again were split into groups of three to six participants, with copies of outcome measures provided and written prompts to aid discussion (Table 33). The outcomes of this workshop were used to inform Thesis Objective 5.

Table 33: Practitioner Workshop Prompts: Occupational Performance Outcome Measures

- *What outcomes do you think we should be measuring as occupational therapists? Would you add any to the logic model?*
- *Have a look at the outcome measures and think: -*
  Is it sensitive enough to measure an improvement after occupational therapy?
  Will is measure the impact we have as occupational therapists on people's lives?
  Is it suitable for people living with early-stage / mild dementia?
- *Please rank outcome measures from 1 – 5 in accordance with your preference. 1= most preferred, 5 = least preferred. Please give reasons for your choices.*

Workshop 3: Drafting Programme Structure and Contents

A third workshop was convened in order to develop an overview of what would occur during the developing intervention programme design on a session-by-session basis. During Workshop 3 practitioners met to brainstorm what they perceived would need to happen pre-intervention and during the first two intervention sessions. This was utilised to inform Thesis Objectives 5, 6 and 7.

10.3.2.2. Patient and Public Involvement

Two Lived Experience Advisory Group (LEAG) meetings were utilised to gather feedback on a proposed intervention design, components, and structure. On the 02.05.2018 four members of the LEAG provided feedback on a preliminary intervention programme design, including components, mode, service context, duration, and population, which can be found in Appendix O and used to inform Thesis Objective 5.

One LEAG meeting on the 25.04.2019 was utilised to describe and discuss draft proposed intervention contents and to further inform Thesis Objective 5, particularly in relation to intervention mode. Four

members of the LEAG were present, with feedback collated in Appendix P. Two participants who participated in semi-structured interviews also reviewed and provided comments on proposed intervention contents after their interviews.

10.3.3. Using Existing Theory During the Development Process

To aid the development of an intervention's theory of change, a pragmatic and pluralistic use of existing theories is encouraged by Intervention Mapping and other intervention development approaches, for example the Behaviour Change Wheel [245]. In this study, Social Cognitive Theory (SCT) [75] was the primary theory of choice. SCT identifies multiple determinants (e.g., self-efficacy, skills, knowledge) relating to the person, as well as methods of change relating to these determinants (e.g. information, guided practice, active learning), that have been utilised extensively to inform interventions across diverse populations and settings [75], including one intervention programme identified in Study 1's Population Synthesis [159].

As outlined in Chapter 2, theories pertaining to intervention development and theories of change were used during this research akin to the way "*frames of reference*" are used in occupational therapy clinical practice [81] p40. In Study 3, the Model of Human Occupation (MOHO) [79] has been utilised as a conceptual model of practice to broadly inform the intervention's design and theory of change. Like SCT, it describes factors or determinants relating to the person that influence occupational performance, which like SCT, includes self-efficacy and skills. Additionally, the MOHO describes determinants relating to the social, occupational, and physical environments, which it purports offer demands, constraints, resources, and opportunities for performance. Whilst the MOHO conceptualises personal and environmental factors or determinants, it currently does not provide a detailed or evidence-based account of methods of change that directly address these determinants, akin to SCT.

The MOHO and SCT, informed the identification of personal and environmental factors or determinants in the Logic Model of the Problem and Population (Thesis Objective 4, Section 10.4.1.) and personal and environmental factors or determinants identified as targets of change (Thesis Objective 6, Section 10.4.3.). SCT was the primary theory utilised to identify methods of change (Thesis Objective 6, Section 10.4.3.).

10.4. Tasks

10.4.1. Developing a Logic Model of the Problem and Population

Logic models are frequently utilised to depict and communicate an intervention's programme theory, and are also, albeit less frequently, utilised to depict the problem or situation that an intervention seeks to address [69]. The latter enables a more detailed, structured, and theoretically informed approach towards understanding the problem and population in the first instance, upon which an intervention programme theory can be based. To meet Thesis Objective 4, a logic model of the problem and population was developed to identify individual and environmental factors or determinants, the impact these may have on occupational performance, as well as potential longer term negative health and quality of life sequalae. Intervention Mapping offers a logic model of the problem template (Figure 9), and this was amended to ensure an occupational therapy perspective or 'filter' (Figure 10) [79]. This template was used as a "*framework for organizing*" (p226) data generated during Study 1 and 2, from stakeholder engagement, as well as existing theory.

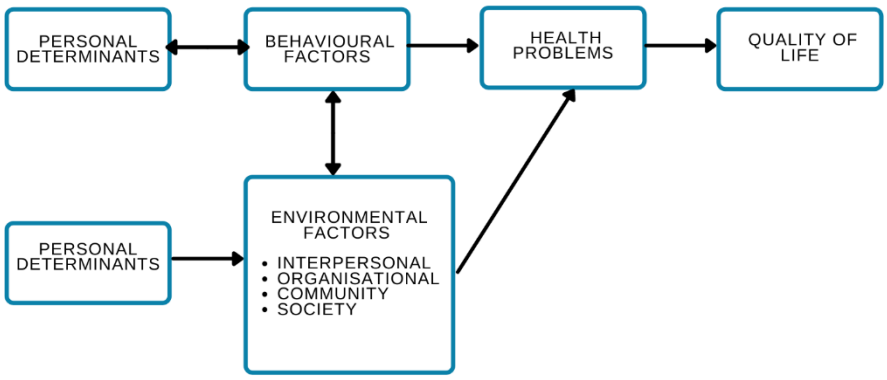

Figure 9: Bartholomew Eldridge et al's [68] Logic Model of the Problem and Population at Risk.

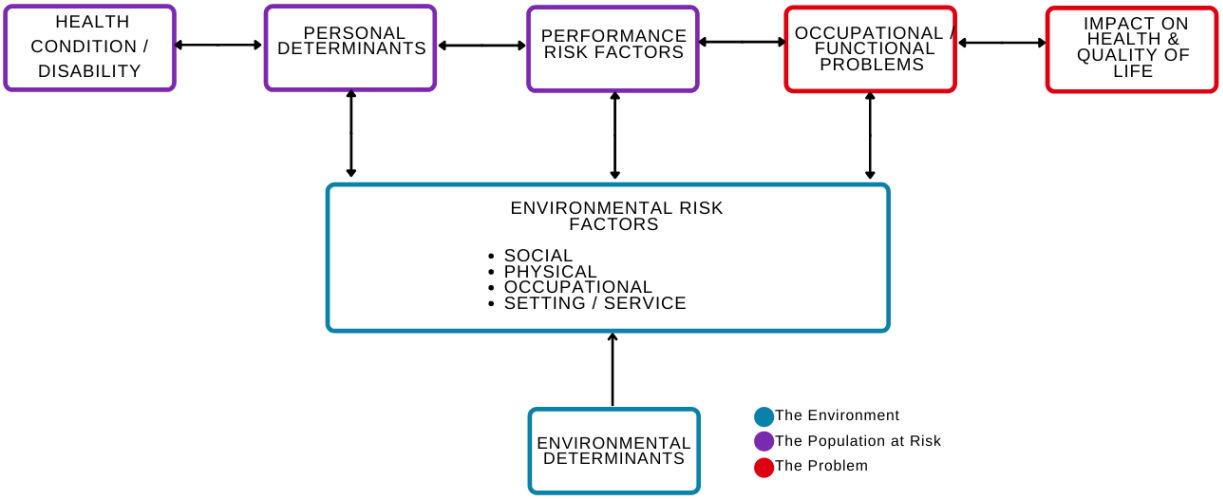

Figure 10: Logic Model of the Problem and Population at Risk used in this Study

10.4.2. Specifying Intervention Context, Components and Characteristics (Programme Design)

Thesis Objective 5 involved developing an initial description of the interventions' context, components, and key characteristics. As per Intervention Mapping and the revised MRC Framework this included identifying intervention components, dosage, scope, and sequence [65, 69]. Given its use in Study 1 and 2, the TIDieR Checklist [121] was utilised to inform the specification of the intervention's components and characteristics. Whilst Intervention Mapping Step 5 is concerned with intervention implementation, the importance of considering context and the feasibility of implementing an intervention early on the in the development process is emphasised by the revised MRC Framework [65]. Accordingly, the setting or service context was also specified.

10.4.3. Specifying Mechanisms, Methods, and Applications of Change

As well as generating a programme theory in relation to the problem, the revised MRC Framework [65] and O'Caithan et al [69], among others, emphasise the need to identify and / or develop a theoretical understanding of an intervention's process or mechanisms of change. Thesis Objective 6 therefore, sought to identify and describe these mechanisms, firstly by developing matrices of change, and secondly by identifying methods and applications of change.

10.4.3.1. Matrices of Change

Matrices are endorsed by the revised MRC Framework [65] as a method that can be used to develop and articulate programme theory, in addition to logic models. Whilst logic models depicting intervention inputs, activities and outcomes have frequently been utilised to depict programme theory, the revised MRC Framework [65], highlights that alone they are insufficient to articulate an intervention's full programme theory. In Study 3, an Intervention Mapping approach towards the development of matrices, known as matrices of change was taken, which are tables that provide a detailed breakdown of who and what is hypothesised to change. The process of developing matrices of change is complex and detailed, and Figure 11 provides an overview of the components or steps involved as well as questions utilised to guide this process, based on those recommended by Intervention Mapping which are summarised below [68].

Performance and Environmental Outcomes

Firstly, performance outcomes for intervention recipients, and environmental outcomes for people in their environment, were developed in relation to the intervention programme aim. This involved utilising the performance and environmental risk factors identified in the logic model of the problem and population to answer the questions posed in Figure 11.

Performance and Environmental Objectives

Secondly, performance and environmental objectives specifying and breaking down the discrete actions or steps required to achieve outcomes were developed by drawing on proposed key intervention components and characteristics (Thesis Objective 5 Section 10.4.2.).

Personal and Environmental Determinants

Thirdly, determinants or individual factors relating to the person and people in their environment specified in the logic model of the problem and population at risk were refined in light of the renewed focus upon change. At this stage, Intervention Mapping recommends prioritising determinants for inclusion within the matrices of change in preparation for the development of change objectives, therefore they do not include all possible determinants, only those that are deemed modifiable.

Change Objectives

Fourthly and finally, change objectives for determinants were specified, which involved breaking down the changes or conditions necessary at the determinant level to enable the achievement of performance and environmental objectives and outcomes.

10.4.3.2. Identifying Methods and Applications of Change

As depicted in Figure 11, the identification of methods and applications of change, which seek to propose how change will occur in practice, followed the development of matrices of change. Intervention Mapping highlights that methods of change should be theory and evidence-based, however, intervention studies identified in Study 1's Intervention Synthesis did not describe or report upon a programme theory, including theoretical methods of change. Furthermore, to my knowledge, occupational therapy as a profession, does not currently have a shared understanding, akin to the behavioural sciences of what constitutes a method of change in the context of an occupational therapy intervention, although recent attempts have been made to address this [66]. Sikkes et al [50] indicate that the absence of programme theories is likely to extend to other non-pharmacological interventions for people living with dementia, and in light of this, methods of change identified in Study 3 primarily derive from SCT. Nevertheless, towards Thesis completion, Orgeta et al [186] published what they describe as the first intervention for people living with early-stage dementia developed using an Intervention Mapping Approach. Given that Study 3 had been completed at this stage, it was not possible to utilise Orgeta et al's [186] programme theory to inform this programme of work.

10.4.4. Developing an Intervention Logic Model

As described in Section 10.4.1., logic models are frequently utilised to depict and communicate aspects of an intervention's programme theory and a simple logic model of the intervention was developed in order to meet Thesis Objective 7 [69]. The revised MRC Framework describes a simple logic model as a model that is linear and represents inputs, intervention outputs or activities and outcomes [65] and this is the approach utilised in this Study.

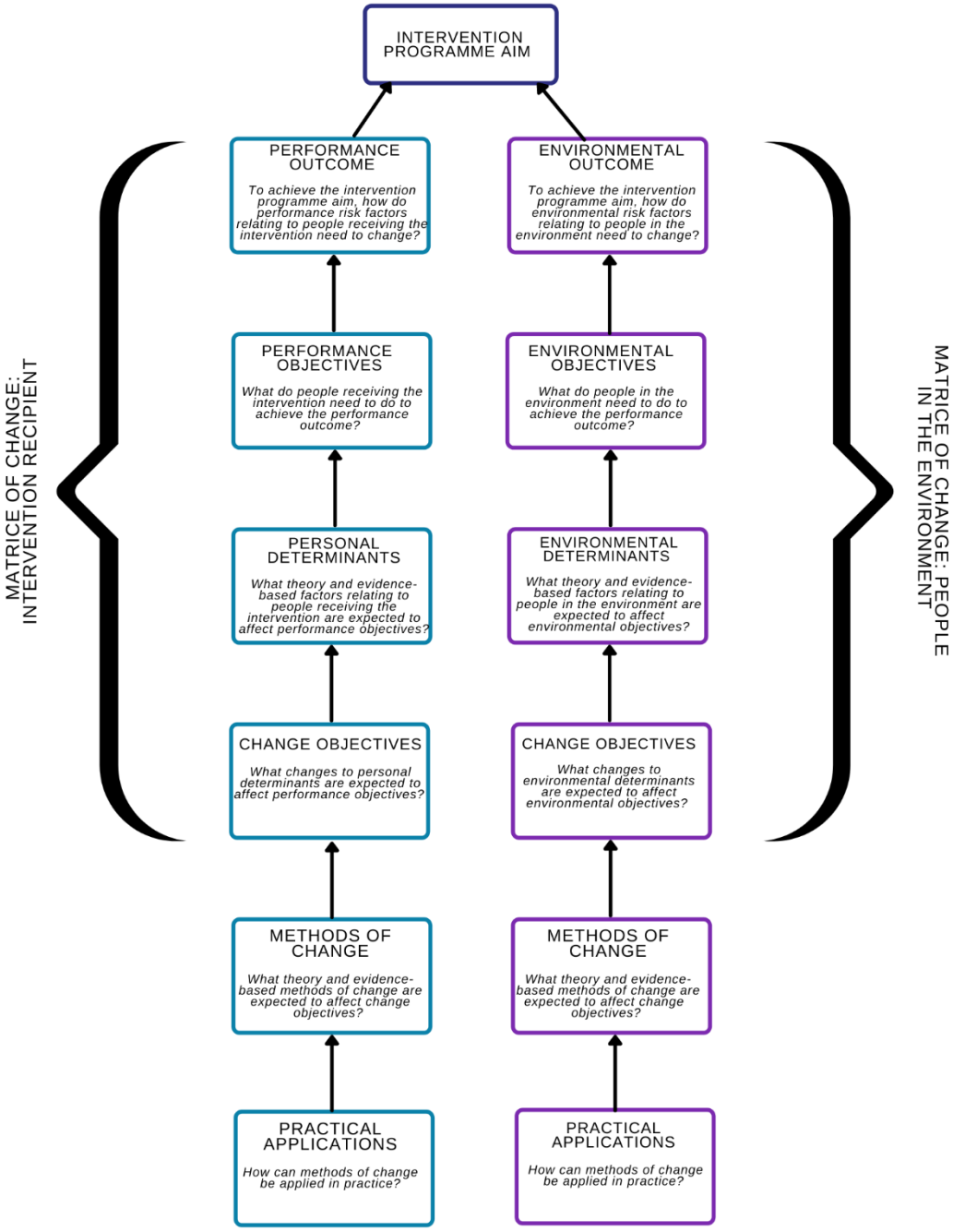

Figure 11: The Process of Specifying Mechanisms, Methods, and Applications of Change

10.5. Strengths and Limitations

Limitations during the development process must be acknowledged, primarily the absence of a central planning group consisting of intervention recipients and potential interventionists to make decisions. All decisions were therefore made by myself in consultation with, and following advice, from my supervisory team. Additional practitioner workshops and greater engagement with occupational therapy practitioners from all sites that participated in semi-structured interviews was planned, as

well as greater involvement of the LEAG and people affected by early-stage dementia. However, a change in employment as well as COVID-19 meant that this was not possible within the PhD candidature time frame. Further engagement with practitioners and people affected by dementia will be necessary prior to a future evaluation in order to refine the intervention programme theory and design. Aside from the limitations acknowledged, a published, structured approach was utilised to inform the development process, as recommended by the revised MRC Framework [65], enabling the description and development of a detailed programme theory that is evidence and theory-based.

10.6. Chapter Conclusion

This Chapter has provided an account of the tasks undertaken during Study 3, as well as methods used to inform these tasks, to meet Thesis Objectives 4 – 7. It has described methods utilised to engage with stakeholders, as well as the use of theory, namely SCT. The influence Study 1 and Study 2 had upon these tasks has also been described. Study 3's findings will now be reported in Chapter 11.

Chapter 11: Findings

11.1. Introduction

Chapter 10 gave an account of the methods utilised and tasks undertaken during Study 3 to develop an intervention programme theory and to design the intervention. It also identified Social Cognitive Theory (SCT) as the primary underpinning theory of change. In this Chapter, Study 3's findings are presented sequentially in accordance with Thesis Objectives 4 – 7: -

- **Thesis Objective 4**: Develop a logic model of the problem and population.
- **Thesis Objective 5:** Specify intervention context, content, and characteristics (programme design).
- **Thesis Objective 6**: Specify mechanisms, methods, and applications of change.
- **Thesis Objective 7:** Develop a logic model of the intervention.

As recommended by the revised MRC Framework [65], key uncertainties at this stage of development will also be described where relevant. In this Chapter these uncertainties concern further work required at Intervention Mapping Steps 4 – 6 before a future evaluation at the MRC's feasibility phase.

11.2. Logic Model of the Problem and Population

Figure 12 presents the evidence, practice and theory informed logic model of the problem and population developed to meet Thesis Objective 4. The model's focus, as per an Intervention Mapping approach, is upon the population at risk of negative health and quality of life sequalae who may benefit from the intervention under development, and therefore it is framed negatively as opposed to taking an asset or strengths-based approach [68]. It is also important to acknowledge that the model is not all-encompassing, rather it is a springboard upon which a programme theory can be developed. The remainder of this section elaborates on the contents of Figure 12 in accordance with its components.

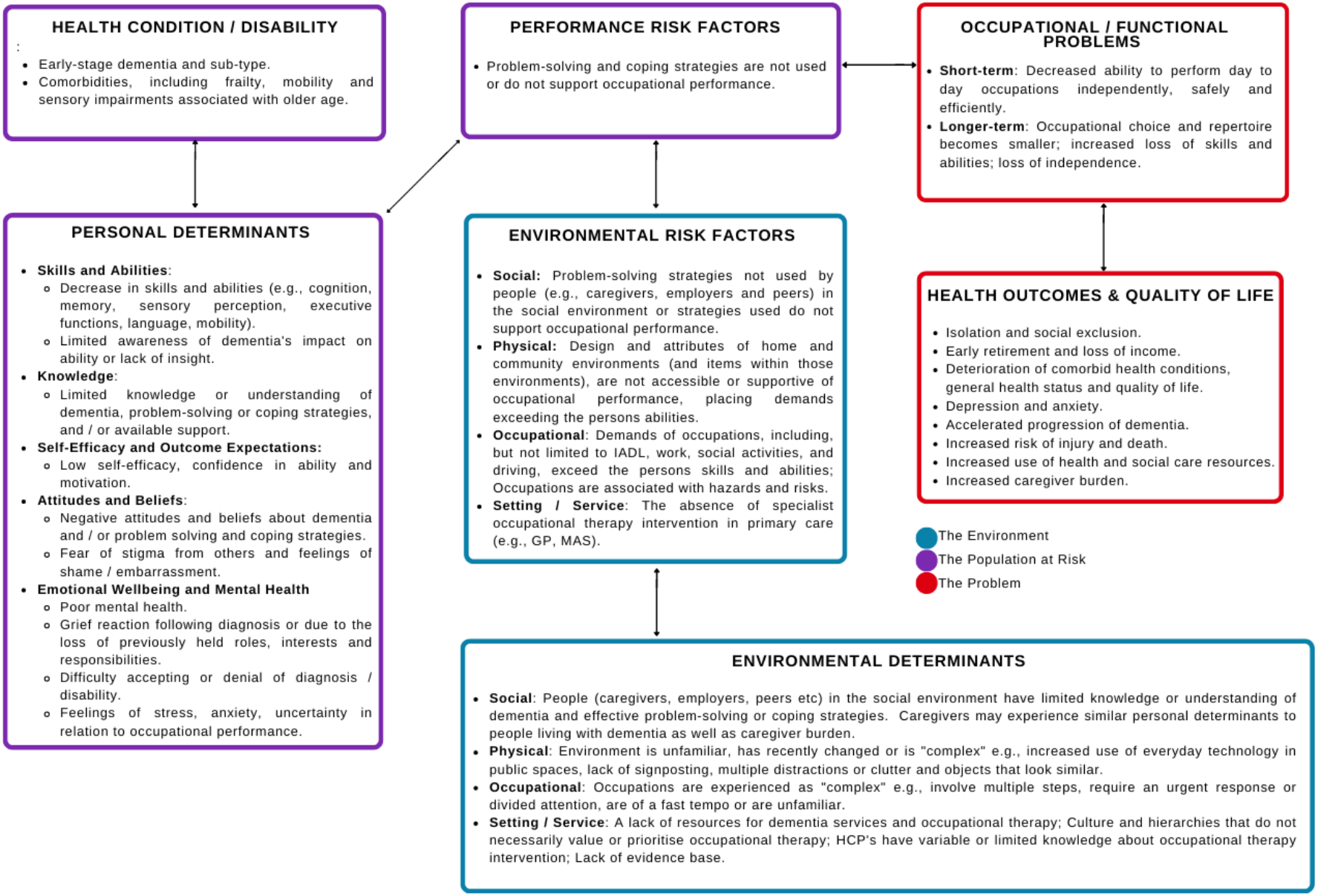

Figure 12: Logic Model of the Problem and Population at Risk

11.2.1. The Population at Risk

Three components pertaining to the population at risk feature within Figure 12. As outlined in Section 10.4.1., these relate to the health condition of interest (in this study, early-stage dementia), personal determinants (e.g., skills and abilities, knowledge) and risk factors associated with occupational performance (what the person does or does not do during performance that could lead to problems).

11.2.1.1. Health Condition

Early-stage Dementia

The population at risk comprises people living in the community with early-stage dementia, and therefore, early-stage dementia is the primary health condition depicted in the logic model. Early-stage dementia has also been identified by Van't Leven et al [246], Tsertsidis [247] and Burgess et al [187] as the optimum time for occupational therapy intervention. Nevertheless, Study 1 and Study 2 have highlighted that there is an absence of a cross-disciplinary standardised definition or shared understanding about what constitutes early-stage dementia. Study 2 has indicated that occupational therapists' perception of early-stage dementia is likely to be in accordance with the ICD's [22] definition in relation to impact on activity performance and independence, in addition to the emphasis upon capacity for new learning, echoed in the wider literature [246]. However, Study 2, in concurrence with existing research [40] identified that people typically receive occupational therapy following a referral from another healthcare professional. Therefore, a number of key uncertainties remain in relation to defining the intervention population in a manner that enables a shared understanding across professionals to aid implementation and further work will be required at Intervention Mapping Step 5 to address these uncertainties. This could include developing referral criteria or checklists to enable screening by other healthcare professionals alongside an agreed score range on assessment tools utilised by referrers, for example scores ranging from 15 – 25 on the MoCA [214], 18 – 26 on the MMSE [25] or 60 – 90 on the ACE [217] as proposed by Harwood et al [197].

Comorbidities

In addition to early-stage dementia, comorbidities, namely sensory impairments, and frailty associated with older age have also been described in Figure 12. The risk of developing dementia increases with age [55] and increased age is also associated with frailty [248] and sensory loss [249].

Adverse impacts upon occupational performance due to difficulties mobilising and sensory impairments were identified in Study 1's Population Synthesis [131, 137] and participants living with late-onset dementia in Study 2 also described experiencing sensory impairments (sight and hearing) as well as difficulties mobilising, which appeared to be unrelated to their dementia diagnosis.

11.2.1.2. Personal Determinants

Skills and Abilities

Theoretically, skills and abilities are identified by both the MOHO[11] and SCT as determinants or factors relating to the person that impact upon occupational performance and behaviour, respectively [75, 79]. Early-stage dementia's impact on a person's skills and abilities featured prominently in the findings of both Study 1's Population Synthesis and Study 2. During the latter, these were described by occupational therapy practitioners using clinical terminology namely cognition, memory, sensory perception, executive functions, and orientation, and the influence dementia sub-type can have on the specific skills and abilities that are impacted was highlighted [4].

Awareness of occupational performance difficulties was also identified as a skill or ability that may be impacted in both Study 1 and 2, with data deriving from Workshop 1 indicating that occupational therapy practitioners use the word insight as opposed to awareness. Both Study 1 and 2 identified that awareness varies, and that some people living with early-stage dementia may not be aware that their ability has changed or may alternatively attribute changes to external or other internal factors. Without a subjective awareness that dementia has impacted upon ability, a person living with dementia may continue to do things that put them at risk and omay not consider adapting the way they perform occupations to compensate or overcome difficulties.

Knowledge

Knowledge of a health problem, as well as what can be done about it is described as a "*precondition for change*" [250] p144 by SCT. Data generated in Study 2 about context, namely the lack of occupational therapy provision in primary care in Wales, indicates that information and therefore knowledge about how to adapt to occupational performance problems may be difficult for people

[11] Skills and abilities in this thesis correspond with MOHO's conceptualisation of 'skills' and 'objective performance capacity', respectively.

living with dementia to access. Furthermore, international studies indicate that knowledge about occupational therapy amongst the general population may be limited [235, 251], and the theme 'Awareness and Understanding of Occupational Therapy' in Study 2, identified perceptions among practitioners that people living with dementia may not be aware of the interventions that they can provide.

Self-efficacy and Outcome Expectations

Self-efficacy and outcome expectations are concepts purported by both the MOHO and SCT [76, 78, 252]. The former comprises a person's perception about their effectiveness in performing an occupation or behaviour and the latter constitutes perceptions about the outcome of performance. Study 1 and Study 2 have described how dementia impacts negatively on a person's ability to achieve what they want or need to do, and therefore if a person living with dementia is aware of the difficulties that they experience, their sense of self-efficacy and outcome expectations may be low. Bandura notes that repeated experiences of failure can lower self-efficacy, particularly if failure occurs early on, which can lead to the avoidance of performance [76]. Study 1's Population Synthesis identified that people living with early-stage dementia perceive certain activities as more difficult to accomplish, including using everyday technology, complex economic activities, and driving [146-148]. Whilst these studies did not measure self-efficacy, they suggest that prior experience engaging in such activities as someone living with early-stage dementia may have influenced perceptions of confidence or efficacy and expectations of success.

Negative impacts on motivation to perform occupations were identified in Study 2's theme 'Mental Health and Motivation'. However, motivation has not been identified itself as a determinant in the logic model of the problem and population since multiple theories pertaining to motivation exist, and rather than being a singular concept, it is considered multi-faceted and interacts, and is influenced, by other personal and environmental determinants [250, 253]. Bandura [78] purported that "*motivation is a general descriptor that does not say much about the problem or the remedy for it*" (p 348) and SCT conceptualises motivation as primarily a cognitive process, during which, self-efficacy and outcome expectations play a central role.

Attitudes and Beliefs

Values, defined as beliefs about what is good, right, and important are an integral aspect of the MOHO [252] and theoretical models of behaviour change, including SCT [75]. Values and beliefs shape what occupations people perceive are worth doing, as well as perceptions about how occupations should be performed [252]. Attitudes are based on beliefs and constitute a positive or negative reaction or evaluation about something [68]. Dementia, like any progressive and life changing health condition may mean that someone's changed occupational performance conflicts with their life long held values and identity [252]. Furthermore, values are often shaped by cultural norms [75], and negative attitudes and beliefs about dementia, particularly in relation to the middle to late stages, may be held by people living with dementia [11, 254, 255]. Being unable to actualise life long held values or holding negative attitudes about dementia could impact on the likelihood a person will perform occupations as well as engage with services for people living with dementia.

Emotional and Psychological Wellbeing

The complex relationship between mental health and dementia is increasingly recognised, and research indicates that depression may be a prodromal symptom of dementia, a risk factor in the development of dementia, or a symptom of dementia itself [256, 257]. Reflecting this, the impact mental health difficulties, for example depression, can have on a person's ability, interest in, and motivation to perform occupations was described in the theme 'Mental Health and Motivation' in Study 2. Study 1's Population Synthesis and Study 2 additionally highlighted the impact experiencing problems during occupational performance can have on a person's emotional and psychological wellbeing, including feeling vulnerable, fearful, anxious, and stressed. Study 2 also provided insight into the negative impact receiving a diagnosis can have on mental health, particularly for people who were younger, and a grief or loss reaction is attested in the wider literature [220, 258]. Denial has additionally been identified as an immediate response to a diagnosis and diminishing ability [11, 220], and Study 1's Population Synthesis identified that accepting the impact early-stage dementia can have on occupations was not always an easy process. Theoretically, SCT purports that emotional arousal (stress, anxiety or fear) can impede performance, and self-efficacy and outcome expectations associated with occupational performance that has previously been experienced as stressful, is likely to be low [76]. Bandura [78] also highlights that negative affect (depression, anxiety) can have a broad generalised negative impact on beliefs about self-efficacy across many areas of performance.

11.2.1.3. Performance Risk Factors

The final component relating to the person in Figure 12 summarises in a short statement the cumulative impact early-stage dementia, comorbidities, personal determinants as well as environmental risk factors and determinants have on occupational performance. Study 1's Population Synthesis identified that some people living with early-stage dementia develop their own adaptations or strategies to manage or overcome difficulties during occupational performance, however these were not always successful and could lead to additional problems or difficulties, and sometimes strategies were not used at all. Strategies additionally constituted the primary occupational therapy intervention component described in Study 1's Intervention Synthesis, and in Study 2 by occupational therapy practitioners. Therefore, the primary performance risk factor depicted in the logic model is the use of adaptations or strategies that do not support occupational performance, or alternatively, that no adaptations or strategies are used.

11.2.2. The Environment

11.2.2.1. Social Environment: Risk Factors and Determinants

Study 1's Population Synthesis demonstrated that family caregivers can provide both negative and positive support, as identified in the theme 'Strategies Initiated by Others'. The logic model's focus, given its emphasis on the population at risk, is the former. Study 2 additionally identified that the absence of adaptations supportive of occupational performance extends to employers, colleagues, and peers and the former was also described by Chaplin and Davidson [132], identified during Study 1's Population Synthesis. The primary risk factor described in the social environment therefore are people that do not use, or support the use of, adaptations and strategies that facilitate the person living with early-stage dementia's own performance.

Data generated during this research has focussed primarily on people living with early-stage dementia themselves, however, hypothesised determinants based on data generated during Study 1 and 2, as well as from the wider literature have been described in Figure 12. People in the social environment are likely to have determinants reflecting those specified for the person living with dementia (11.2.1.2.), for example, participants in Study 2 highlighted that there is a lack of information for family members about dementia, available services, as well as what they can do to support the person, which is supported in the wider literature [259]. They may therefore also have limited knowledge or

understanding of dementia as well as adaptations and strategies that support occupational performance. Values and beliefs incongruent with the changed occupational performance of the person living with dementia may also be held, as identified in Study 1's Population Synthesis in the subtheme 'Dilemmas faced by caregivers', as well as negative attitudes towards dementia [11, 260]. Caregiver burden is well documented [261], and isolation, feelings of exhaustion and frustration were identified in Study 1's Population Synthesis. Family caregivers may also experience poor emotional wellbeing and mental health following a diagnosis due to changes in their own occupational performance, including the loss of previously held roles and interests. A grief reaction has also been observed amongst family caregivers, as well as denial [11].

11.2.2.2. Physical Environment: Risk Factors and Determinants

The MOHO emphasises that the physical environment provides resources and opportunities for occupational performance, as well as demands and constraints [262]. Likewise, SCT highlights that the physical environment can provide both barriers and opportunities, making behaviours easier or harder to perform [75]. Study 1's Population Synthesis and Study 2 identified aspects of the physical environment at home and in the community which people living with early-stage dementia experienced as inaccessible or challenging, leading to problems or difficulties performing occupations. Physical environments and items within these environments that place demands on the person exceeding their abilities and skills, have therefore been identified as the primary risk factor in the physical environment in Figure 12.

Determinants in the physical environment were identified in both Study 1's Population Synthesis and Study 2. Environments that have recently changed as well as those that were non routine and unfamiliar were described as particularly challenging in Study 2 in the theme 'Occupations and Environments'. Study 1's Population Synthesis also identified determinants associated with the complexity of the physical environment, for example the increasing presence, as well as the design, of everyday technology.

11.2.2.3. Occupational Environment: Risk Factors and Determinants

Like the physical environment, the occupational environment offers resources and opportunities as demands and constraints in relation to occupational performance and may also place demands upon people living with early-stage dementia which exceeds their skills and abilities [262]. This has

therefore been identified as a risk factor in Figure 12. Instrumental Activities of Daily Living (IADL), particularly those involving everyday technology were identified in Study 1's Population Synthesis and in Study 2 as activities associated with difficulties. Whilst not featuring as prominently in Study 1, driving, social activities and work were identified by participants affected by dementia in Study 2 and during Workshop 1, practitioners were eager to highlight that difficulties may be experienced during any and all occupations when demands exceed skills and abilities.

Determinants in the occupational environment include the qualities or nature of the activities listed above, which occupational therapy practitioners in Study 2 frequently described as "*complex*" as well as unfamiliar and non-routine. What constituted "*complex*" was not always clearly defined, however appeared to refer to activities that rely heavily on executive functioning and may involve multiple steps, require an urgent response, or divided attention.

11.2.2.4. Setting / Service Environment: Risk Factors and Determinants

Study 2 has highlighted that there is variable, and in some instances, an absence of specialist occupational therapy intervention for people living with early-stage dementia in primary care in Wales. This is therefore identified as the primary risk factor in the setting or service environment. Determinants in this environment identified in Study 2 primarily included barriers which limited or prevented the availability of, and access to, occupational therapy intervention. This consisted of a lack of resources, consistent with the survey of practice conducted as a precursor to this work [39] and with contextual barriers identified in Study 1's Intervention Synthesis by Cummins and Warren [168]. The influence and control other professional disciplines have in determining policy and service provision, as well as a lack of knowledge and understanding about occupational therapy and its value amongst other professional disciplines, were also identified as determinants contributing to limited access. The perceived absence of evidence to support occupational therapy for people living with early-stage dementia was also identified as a barrier in Study 2.

11.2.3. The Problem

The problem portrayed in Figure 12 has been conceptualised occupationally and in relation to adverse health outcomes and quality of life, reflecting the cumulative impact of personal and environmental determinants and risk factors.

11.2.3.1. Occupational / Functional Problems

The "*problems*". "*difficulties*" and "*critical incidents*" that people living with early-stage dementia experience, or were observed to experience, whilst performing occupations at home and in the community, were identified as a primary theme in Study 1's Population Synthesis. This was reiterated in Study 2 by participants affected by dementia and occupational therapy practitioners. As noted in Study 1's Population Synthesis and Study 2, problems and difficulties were typically reported at the skills or determinant level, as opposed to the overall impact on performance. However, some insights were provided by data generated during Study 1 and 2, including problems associated with: -

- Mistakes and errors.
- The intended outcome of an activity is not achieved or is partially achieved.
- Interruptions to the flow and continuity of an activity as difficulties are encountered and attempts are made to overcome difficulties using self-initiated strategies that may not work.
- Increased time and effort.
- Not completing an activity due to withdrawal, avoidance of activities, early termination of performance or the activity is completed by someone else.
- An increased risk of harm.
- Feelings of stress and anxiety.

Figure 12 has therefore defined the problem occupationally as a decreased ability to perform day to day occupations independently, safely, and efficiently.

11.2.3.2. Health and Quality of Life Outcomes

There is a lack of research attesting to the long-term impacts on health and quality of life associated with difficulties performing occupations for people living with early-stage dementia; no studies reporting on this were identified during Study 1. However, hypothesised impacts are described in Figure 12 based on data generated during Study 1 and 2, as well as existing research relating to health and quality of life outcomes, external to the profession of occupational therapy. For example, Douglas et al [263] and An et al [264] report that people living with dementia are at increased risk of injury or accidental death due to difficulties orientating outside, maintaining nutrition and hydration, managing medication, and fire hazards. These health sequalae can result in an increased use of health and social care services. Study 1 and 2 also identified that people living with early-stage dementia may have

difficulties attending social events and activities, which can lead to isolation and social exclusion, which are associated with depression [265]. The lack of stimulation from engaging in activities has also been associated with a deterioration in cognition and other symptoms of dementia [266]. Furthermore, people living with early-onset early-stage dementia who participated in Study 2 described having to take early-retirement, which was also reported by Chaplin and Davidson [132] in Study 1's Population Synthesis. Early-retirement can lead to a loss of income if welfare support is not equivalent to a person's prior wage.

11.3. Programme Design: Context, Content, and Characteristics

Thesis Objective 5 constituted specifying the proposed intervention's context, content, and characteristics, also known as a programme design [65, 69]. An overview of the proposed intervention's context, content and characteristics is provided in Table 34, and its contents are elaborated upon in the remainder of this section. Key uncertainties are also described, including areas of further work necessary at Intervention Mapping Steps 4 – 6, which will be elaborated on in Chapter 12.

11.3.1. Aim

Study 1's Intervention Synthesis identified that improving, maintaining, or maximising occupational performance, functioning or independence was the most frequently described intervention programme goal, which was also reiterated in Study 2 by occupational therapy practitioners. Study 1's Population Synthesis also highlighted that people living with dementia value their independence, autonomy, and freedom and wish to maintain a sense of normality (Section 4.4.5.), which has also been described by Van't Leven et al [246]. Drawing on this data as well as the short-term occupational / functional problem described in the Logic Model of the Problem and Population at Risk (Figure 12), an intervention programme aim was developed and is as follows: -

- To optimise people living with early-stage dementia's confidence and ability to perform personally meaningful occupations (activities) independently.

Workshop 1 and Study 2 highlighted that occupational therapy practitioners in Taliesin wanted a new intervention that addressed all occupational needs and not be confined to Basic Activities of Daily

Living (BADL) or activities associated with risk. Therefore, activities in this aim includes any and all activities, including, but not limited to, BADL, IADL, work and social activities.

11.3.2. Content and Materials

11.3.2.1. Assessment

Akin to programmes from the modality of occupational therapy in Study 1's Intervention Synthesis, occupational therapy practitioners across sites in Study 2 spoke about a pre-intervention assessment process consisting of interviews and observational assessments to identify what they called occupational or functional "*needs*", "*problems*" or "*concerns*". Assessment was also identified during Workshop 1 and 3 as an activity that should be specified in an intervention logic model and it is considered a core occupational therapy skill [267] and a key element of what is widely known as the occupational therapy process [268]. An initial interview and an observational functional assessment of areas of occupational need, have therefore been included in Table 34.

Whilst non-standardised assessments were most frequently used by practitioners currently working with people living with early-stage dementia, participants from Taliesin in Study 2 emphasised the importance of using standardised assessments capturing data on occupational performance which were also sensitive to change following occupational therapy intervention. However, only one participant spoke about using an outcome measure in clinical practice, with participants using a range of standardised assessments to inform the tailoring or grading of interventions only. The most frequently used, included those associated with the MOHO, the Pool Activity Level (PAL) [269] and the Cognitive Disabilities Model (CDM) [238] (including the Allen Cognitive Level Screen [ACLS] and the Routine Task Inventory [RTI]). Whilst the PAL's content, criterion, concurrent validity, internal consistency, and inter-rater and test-retest reliability has been evaluated by Wenborn et al [270], it is not validated as an outcome measure. The ACLS or LACLS, is a commonly used CDM assessment, which was utilised by Wesson et al [156] identified in Study 1's Population Synthesis. However, it is also not validated as an outcome measure and neither is the RTI; rather, like the PAL, they are validated assessments or screening tools to inform the assessment process and the tailoring of interventions [271]. Assessments associated with the MOHO, for example the Model of Human Occupation Screening Tool (MOHOST) and Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS), do not appear to have been validated as outcome measures for people living with early-stage dementia, although may frequently be used in clinical practice [272].

Whilst potential outcome measure candidates capturing occupational performance outcomes were identified in Workshop 2 (the MOHOST, OCAIRS, Canadian Occupational Performance Measure [COPM] [174] and Revised Interview for Deteriorations in Daily living activities in Dementia [R-IDD2] [244]), overall, practitioners felt that none of the outcome measures reviewed were sufficiently comprehensive on their own to inform the assessment process and / or would sufficiently capture changes relating to occupational performance in a population that has a progressively deteriorating condition. Nevertheless, practitioners were clear in their views about the Bristol Activities of Daily Living Scale (BADLS) [243], which was not deemed detailed or sensitive to change. This was also identified by Wenborn et al [49] who utilised the BADLS in their multi-site RCT of COTiD-UK as their primary outcome measure. Key uncertainties therefore remain about the most appropriate outcome measure to capture outcomes inr elation to occupational performance.

11.3.2.2. Goal or Priority Setting

Like assessment, goal-setting is also identified as a core occupational therapy skill [267], a key element of the occupational therapy process [268], and featured within the intervention logic model reviewed in Workshop 1, with no objections raised. Study 1's Intervention Synthesis identified seven intervention programmes, primarily from the modalities of Occupational Therapy and Cognitive Rehabilitation that reported goal-setting as a pre-intervention activity, and a recent scoping review identified that goal-setting is commonplace in rehabilitation research with people living with a cognitive impairment or early-stage dementia [273]. Nevertheless, goal setting did not feature as prominently in Study 2, although was mentioned by a minority of participants. This may in part be due to participants' association of goal setting with assessment, since goal or priority setting was typically described in the context of, or as the outcome of, assessment. Furthermore, the COPM, as a well-recognised occupational therapy-based goal-setting tool and validated outcome measure for people living with dementia [89], is also an assessment, which was utilised by four intervention programmes in Study 1's Intervention Synthesis. Based on their scoping review, a structured approach towards goal-setting is recommended by Jogie et al [273] and to facilitate this the COPM has been specified in Table 34, given that is a well-known tool amongst occupational therapists, in addition to its validation in this population. Nevertheless, it is important to acknowledge that the GAS was identified as a potential goal-setting tool in Workshop 2 and has recently received attention in the literature in relation to people living with early-stage dementia [274]. Furthermore, the Bangor Goal Setting Interview (BGSI) [275] has also recently been utilised in clinical trials with this population, most notably Clare et al's [193] cognitive rehabilitation programme. To address these potential

uncertainties, an evaluation of GAS and the BGSI's appropriateness and feasibility in context compared to the COPM could be conducted prior to, a future evaluation.

11.3.2.3. Intervention

Three primary intervention components are proposed in Table 34: Problem-solving strategies, coping strategies and information, signposting and referral.

Problem-Solving Strategies

Strategies that problem-solve difficulties experienced during occupational performance were the most frequently reported intervention contents in Study 1's Intervention Synthesis, and this was reiterated in Study 2, in the theme '"*It's all about those strategies*"'. Strategies primarily included adaptations to the physical, social, and occupational environments, including assistive technology, prompts and reminders, support from others and reducing the complexity of an activity.

Despite the prominence of strategies in Study 1 and Study 2, a lack of detail was generated about the specific nature of strategies delivered by practitioners. The personalised nature of occupational therapy intervention was frequently cited by practitioners in Study 2 as a barrier to being able to describe specifics. However, no national, local, or professional standards or consensus appears to exist that outline what an occupational therapy strategy entails, which strategies are evidence-based, for whom and in what circumstances. There also appears to be an absence of a shared terminology to describe strategies in research and in clinical practice. For example, Study 1 and Study 2 identified that the word strategy or variations of the phrases 'cognitive / memory strategies' and 'problem-solving / coping strategies' were used to refer to a broad range of possible interventions. The proposed intervention distinguishes between problem-solving strategies that aim to address or minimise occupational performance or functional difficulties and coping strategies that specifically target emotional wellbeing (the latter is described below).

Whilst problem-solving strategies appear to be second nature to occupational therapy practitioners working in clinical practice, featuring prominently in their day-to-day work, further work at Intervention Mapping Step's 4 – 6 (described in Chapter 12) will be necessary to articulate in greater detail what constitutes a strategy, what occupational problem or need a strategy can support, for whom, and in what circumstances. For the purposes of Intervention Mapping Step 3, four broad areas

of occupational needs deriving from Study 1 and 2 have been proposed to thematically structure strategies: -

- Strategies to support your independence at **home**.
- Strategies to support your independence **socialising** and **connecting with others**.
- Strategies to support your independence in the **community**.
- Strategies to support your independence at **work, including voluntary work** (optional).

These were refined after feedback from occupational therapy practitioners and members of the Lived Experience Advisory Group (LEAG), who provided input into the contents as well as the language used to describe areas of need (Appendix O and P).

Coping Strategies

Coping strategies that address and meet emotional needs constitute the second proposed intervention component. Strategies to meet emotional and mental health needs were rarely described in Study 1's Intervention Synthesis, although were acknowledged by Cummins and Warren's [168] qualitative study in their theme "*Looking Beyond the Diagnosis*", and in Study 2 these were described by a minority of participants. However, Study 1's Population Synthesis and data generated during Study 2 indicates that people living with early-stage dementia have emotional and psychological needs that can impact on motivation (including self-efficacy and outcome expectations), confidence, and interest in occupational performance. Key uncertainties therefore remain about the specifics of what constitutes a coping strategy in the context of an occupational therapy intervention for people living with early-stage dementia, however, from data generated, it is likely that these are based on the principles of Cognitive Behavioural Therapy (CBT), person-centred therapy and motivational interviewing. Akin to problem-solving strategies members of the LEAG and practitioners helped develop a title for this area of need (Appendix O and P): -

- You are still you: Making sense of changes and coping with challenges.

Information, Signposting and Referral

The third component consists of information provision about local services, financial support and more as described in Table 34. Providing information of relevance to the person living with dementia

and their caregiver was described as an intervention activity by participants from Taliesin in Study 2 and by six intervention programmes in Study 1's Intervention Synthesis.

11.3.2.4. Materials

A lack of information was reported about materials used during intervention programmes in Study 1's Intervention Synthesis. Furthermore, beyond discussing specific aids and equipment, little information was provided in Study 2 about materials associated with interventions in current practice, for example written materials. In addition to aids and equipment, Table 34 outlines the materials that will need to be developed before an evaluation, including written materials about the intervention programme during Intervention Mapping Step 4.

11.3.3. Interventionist

All intervention programmes identified in Study 1 from the modality of occupational therapy utilised occupational therapists as interventionists, and occupational therapists were the primary interventionists identified in Study 2. In contrast to Study 1, occupational therapy practitioners in Study 2 emphasised the role occupational therapy support workers have in supporting the practice and grading of problem-solving and coping strategies and this is the approach proposed in Table 34. Voigt-Radloff et al [48] reported that a number of COTiD subprocesses were implemented poorly and the lack of experience of therapists was noted as a potential contributory factor. This was again reported by Morgan-Trimmer et al [188] in relation to COTiD UK, and therefore a minimum of 1 years' duration working with people affected by dementia at a Band 6 has been specified for occupational therapist interventionists.

11.3.3.1. Therapeutic Alliance / Relationship

In addition to whom, occupational therapy participants in Study 2 spoke about the importance of establishing and developing a therapeutic relationship with intervention recipients, highlighting that this can impact on engagement with, and the outcomes of, occupational therapy. This was also noted by Sprange et al [159], whose qualitative data indicated that the therapist had a significant influence on attendance and engagement with their group intervention. A qualitative study associated with COTiD UK's multi-site RCT [187] also highlighted the value therapists and participants placed on the development of a relationship, as did a process evaluation of Goal-Oriented Cognitive Rehabilitation's multi-site RCT [188]. Furthermore, building a relationship as well as continuity of therapist was

deemed particularly important by the LEAG (Appendix O). Despite this, there is a lack of research operationalising how a therapeutic relationship is established and maintained during occupational therapy interventions, as well as its impact on the process and outcomes of occupational therapy. However, interest theoretically has grown [66, 276, 277] and identifying an existing model or approach to inform the development of an intervention manual during Intervention Mapping Step 5 should be a priority.

11.3.3.2. Training and Supervision

Further consideration will need to be paid during Intervention Mapping Step 5, given its focus on intervention implementation, to the training and supervision of interventionists, which both Sprange et al [159] and Voigt-Radloff et al [170] identified as facilitators to the delivery of their interventions and outcomes reported.

11.3.4. Mode of Delivery

Diversity in relation to mode of delivery was evident in Study 1's Intervention Synthesis and in Study 2. During the former both group and individual or dyad based interventions were identified, however, all interventions from the modality of Occupational Therapy identified in 2017 were delivered on an individual or dyad basis. This was also identified as the most prevalent mode of delivery in Study 2 in clinical practice. However, group-based interventions were being delivered in specific localities in two Health Boards and on updating the evidence in 2022, one group-based occupational therapy intervention was identified [191].

When considering a new intervention programme, occupational therapy practitioners in Taliesin concluded that decisions should ultimately be made on a case-by-case basis in accordance with personal preferences. A hybrid model was also proposed by some participants, consisting of assessment on an individual or dyad basis, with the delivery of some components, for example problem-solving strategies in a group setting. This is not without precedent, since a hybrid model in relation to mode was utilised by two intervention programmes identified in Study 1's Population Synthesis [153, 159]. In contrast to the views of practitioners, members of the LEAG expressed clear preferences to be seen on an individual or dyad basis, emphasising that everyone living with dementia will have individual needs, which may not be able to be met in a group (Appendix P).

Data generated during Study 2 and from stakeholder engagement identified that there is a lack of consensus about mode of delivery. In line with the most prevalent mode of delivery in practice and in research, and the preferences of the LEAG, an individual or dyad basis was determined as the mode of delivery for an initial evaluation. However, there remains uncertainties about the optimal mode of delivery, and hybrid options should be considered once the local intervention population, their preferences, as well as the feasibility of appropriate and accessible locations in a local context is determined.

11.3.5. Delivery Context

The primary intervention delivery contexts identified in Study 1's Intervention Synthesis and in Study 2 were the persons home and clinical and non-clinical community settings. In both Study 1 and 2, location of intervention delivery was associated with mode of delivery (group or individual and dyad formats). Since the proposed intervention will initially be delivered on an individual or dyad basis, the home environment will be the primary delivery context, in addition to the community or work-based environments, determined by a person's needs following assessment. As identified in Study 2, whilst being resource intensive, the home environment provides a number of advantages, including the opportunity to assess and deliver the intervention in a person's natural environment, aiding the transfer of problem-solving strategies to a person's everyday routine and context.

11.3.6. Setting / Service Context

From the outset of this programme of work, Memory Assessment Services (MAS) were considered to be the most appropriate service context, given their association in policy and practice with early assessment and intervention for dementia [26, 51]. Whilst occupational therapy practitioners from only two of five participating sites in Study 2 were providing intervention to people living with early-stage dementia in MAS at the time of interview, two sites were awaiting funding from the Welsh Government to commence working in MAS as identified in the theme 'Change', suggesting that MAS is a feasible service context.

To ensure all other potential options were explored, occupational therapy practitioners from Taliesin in Study 2 were asked about their perceptions of the appropriate service context. In contrast to the precedent in policy and practice, GP surgeries were identified as the preferred setting, which participants advocated would enable intervention to commence at the earliest opportunity, in light of

the delays they perceived from GP referral to receiving assessment and intervention from MAS. This perspective was also reiterated by the LEAG who expressed that occupational therapy should be available earlier than MAS (Appendix O). Since this Thesis commenced, there has been an increased emphasis in Welsh policy on the role of Allied Health Professionals (AHP's) in other services in primary care, for example GP surgeries [278].

Key uncertainties therefore remain about where occupational therapists may be working with people living with early-stage dementia in the future, as well as the impact late presentation or barriers to access could have on the appropriate service context, as described in Study 2. Considering this, the intervention has not been specified in Table 34 as service specific and could be delivered in MAS, GP surgeries or other primary care services where those services exist. This seeks to ensure that future development work is nonservice specific, which will aid implementation in a real-world context that is changing and evolving, as identified in Study 2.

11.3.7. Intensity and Duration

Study 1's Intervention Synthesis identified the heterogeneity in duration and frequency of intervention programmes, and this was again identified on updating the synthesis in 2022. Intervention programmes from the modality of Occupational Therapy identified in 2017 and 2022, ranged from two sessions' [95] duration to 20 sessions [192], and due to the differences in study designs, quality, and outcome measures utilised, it is not possible to conclude with any certainty from the current evidence, the optimum number of sessions. For example, whilst Voigt-Radhloff et al [48] concluded that there were no differences on any outcomes between a one hour occupational therapy consultation and COTiD delivered over 10 sessions, implementation fidelity was poor on a number of COTiD subprocesses and other factors including interventionist experience and commitment as well as participants' need for support, may have contributed to these results.

In contrast to the prescriptive approach towards number of sessions identified in Study 1's Intervention Synthesis, participants in Study 2 placed a significant emphasis on personalising duration and intensity. Some participants currently working with people living with early-stage dementia reported that assessment and intervention could last for only two to three sessions if there were few needs that could be addressed quickly, however, emphasised that duration could be extended over weeks and months if there were greater or multiple needs. Participants in Taliesin, identified as the proposed initial evaluation context, expressef preferences for a duration of 6 – 8 weeks, with 8

sessions of diminishing intensity, based on how the local Reablement service was currently operating. Given the uncertainty based on the evidence identified during this research on the optimum duration and intensity, which has also been identified by Sikkes et al [50], and the emphasis on personalisation in practice, Table 34 proposes 3 – 8 sessions delivered flexibly over the duration of up to 8 weeks, which can be tested and refined during a future evaluation.

Table 34: Proposed Intervention Characteristics and Key Uncertainties

	Proposed Intervention Content and Characteristics	Key Uncertainties
Intervention Aim	• To optimise people living with early-stage dementia's confidence and ability to perform personally meaningful occupations (activities) independently. (Activities include, but are not limited to, BADL, IADL, work and social activities).	• A lack of resources across Health Boards (Study 2) indicates that without additional resources it may not be feasible to implement the intervention if it has a broad focus beyond BADL and activities associated with risk.
Content: Pre-intervention	• Assessment to identify occupational needs or difficulties, consisting of an initial interview, an observational functional assessment, and a validated standardised assessment.	• Locally developed non-standardised initial interview and observational assessments were being used in clinical practice (Study 2). An initial interview and observational functional assessment pro-forma will need to be developed or adapted at Intervention Mapping Step 4. • In clinical practice standardised assessments were being used to inform the tailoring or grading of interventions, rather than as outcome measures (Study 2). When moving to the MRC's feasibility phase, outcome measures utilised for research purposes may be different to assessments utilised in clinical practice to ensure they are validated and sensitive to change.
	• Goal setting to identify priorities or goals utilising the COPM.	• The Goal Attainment Scale (GAS) and the Bangor Goal Setting Interview (BGSI) have also been identified as potential goal-setting tools (Section 11.3.2.2.). An assessment of GAS and the BGSI's acceptability and feasibility compared to the COPM could be conducted when planning a feasibility evaluation (Intervention Mapping Step 6).
Content: Intervention	• Personalised intervention programme consisting of three primary components: - **1.** Problem-solving strategies to prevent and respond to occupational (functional) needs or difficulties. Four modules or areas of focus are proposed, entitled: -	• Whilst problem-solving and coping strategies appear second nature to occupational therapists working in clinical practice, a lack of data was generated during this research about what a strategy entails in detail. Intervention Mapping Step 4 and 5 (described in Chapter 12) will provide an opportunity to specify strategies when developing an intervention manual and materials for people affected by dementia.

	Proposed Intervention Content and Characteristics	Key Uncertainties
	• Strategies to support your independence at **home**. • Strategies to support your independence **socialising** and **connecting with others**. • Strategies to support your independence in the **community**. • Strategies to support your independence at **work / voluntary work** (optional). **2.** Coping strategies to enhance emotional wellbeing. This module / area proposed is entitled: - • You are still you: Making sense of changes and coping with challenges. **3.** Information, signposting and referral about: - ○ Dementia and the impact it can have on day-to-day activities. ○ Local services and support (e.g., community transport and peer support groups). ○ Financial support (e.g., council tax, PIP). ○ Power of attorney and care planning for the future. ○ Driving and community transport options, including bus passes.	
Content: **Materials**	• Materials associated with strategies, including aids and equipment. • Written materials about intervention programme, which could be bound into a book or be provided in a ring binder and information added to the ring binder as the person progresses through intervention programme. An online version could also be produced if resources permitted. • Intervention manual	

	Proposed Intervention Content and Characteristics	Key Uncertainties
Interventionist	• Occupational therapist (Band 6 with at least 1 years' experience working with people affected by dementia) and occupational therapy support worker (where available), with a significant emphasis placed on: - ○ Developing and maintaining a therapeutic relationship. ○ Continuity of therapist • Supervision • Training	• Occupational therapy support workers may not be available in every service (Study 2). The intervention can be delivered by an occupational therapist; however, this is likely to increase the overall cost of the intervention. An economic analysis during a future evaluation would be able to demonstrate cost-savings associated with occupational therapy support workers delivering certain elements under supervision. • A lack of data was generated in this Thesis on the therapeutic relationship and intervention content associated with this. A model, for example the Intentional Relationship Model [276] could be utilised to inform Intervention Mapping Step 5. • The level of training and supervision required will also need to be specified during Intervention Mapping Step 5.
Mode	• Delivery face to face on an individual or dyad basis. Future developments / iterations of the intervention could include the delivery of some components in a group format (problem-solving and coping strategies) depending on local context and individual preferences.	• There is a lack of consensus relating to mode of delivery. Further consultation with intervention recipients about their preferences as well as occupational therapists is necessary prior to utilising a hybrid or group format.
Delivery Context	• As indicated following assessment e.g., home, community, or workplace.	
Setting / Service Context	• Any service where occupational therapists work with people living with early-stage dementia, this can include, but is not limited to: MAS, GP Surgeries, other primary care services.	
Duration and Intensity	• 3 - 8 intervention sessions lasting approximately 1 hour delivered flexibly over the duration of up to 8 weeks	• Given the heterogeneity of intervention duration and intensity in Study 1 and the emphasis placed on tailoring duration and intensity in Study 2, duration and intensity should be reviewed when refining the programme design during Intervention Mapping Step 4 and evaluated during a feasibility evaluation (Step 6) and amended as necessary.

	Proposed Intervention Content and Characteristics	Key Uncertainties
Tailoring	• The interventions three components (problem-solving strategies, coping strategies and information) will be individually tailored.	
Abbreviations: Basic Activities of Daily Living (BADL), Instrumental Activities of Daily Living (IADL), Canadian Occupational Performance Measure (COPM), Goal Attainment Scale (GAS), Bangor Goal Setting Interview (BGSI).		

11.4. Mechanisms and Methods of Change

The preceding section and Thesis Objective 5 has provided a high-level overview of the intervention's preliminary and proposed context, content, and characteristics. Thesis Objective 6 moves from high level descriptors to the intervention's underpinning programme theory, including mechanisms and methods of change [65, 69]. As described in Section 10.4.3. and depicted in Figure 11, this involved the incremental development of matrices of change, followed by the identification of methods and applications of change.

11.4.1. Matrices of Change

11.4.1.1. Performance and Environmental Outcomes

To initiate the development of matrices of change, performance and environmental outcomes were developed to target performance and / or environmental risk factors identified in the Logic Model of the Problem and Population. Three outcomes were prioritised and are depicted in Figure 13 alongside the intervention programme aim, described in Section 11.3.1. For each outcome specified in Figure 13, a matrix of change, which seeks to articulate the conditions upon which change is hypothesised to occur to enable the outcome, was developed (Tables 35, 36 and 37). The process of developing matrices was described in Section 10.4.3., and involved the identification of performance or environmental objectives, determinants, and change objectives for each outcome. Figures 14 – 16 depict the overall components of the three matrices, and owing to the detail involved in specifying change objectives, these must be viewed in Tables 35, 36 and 37.

11.4.1.2. Performance and Environmental Objectives

As depicted in Figures 14 – 16, multiple performance and / or environmental objectives have been specified in each matrix of change, and as per an Intervention Mapping approach, these are action oriented, reflecting the actions associated with intervention content described in Section 11.3.2. relating to assessment, goal setting and intervention. During future refinements of the interventions programme theory, performance objectives could be broken down further, to specify in greater detail the actions necessary to meet outcomes.

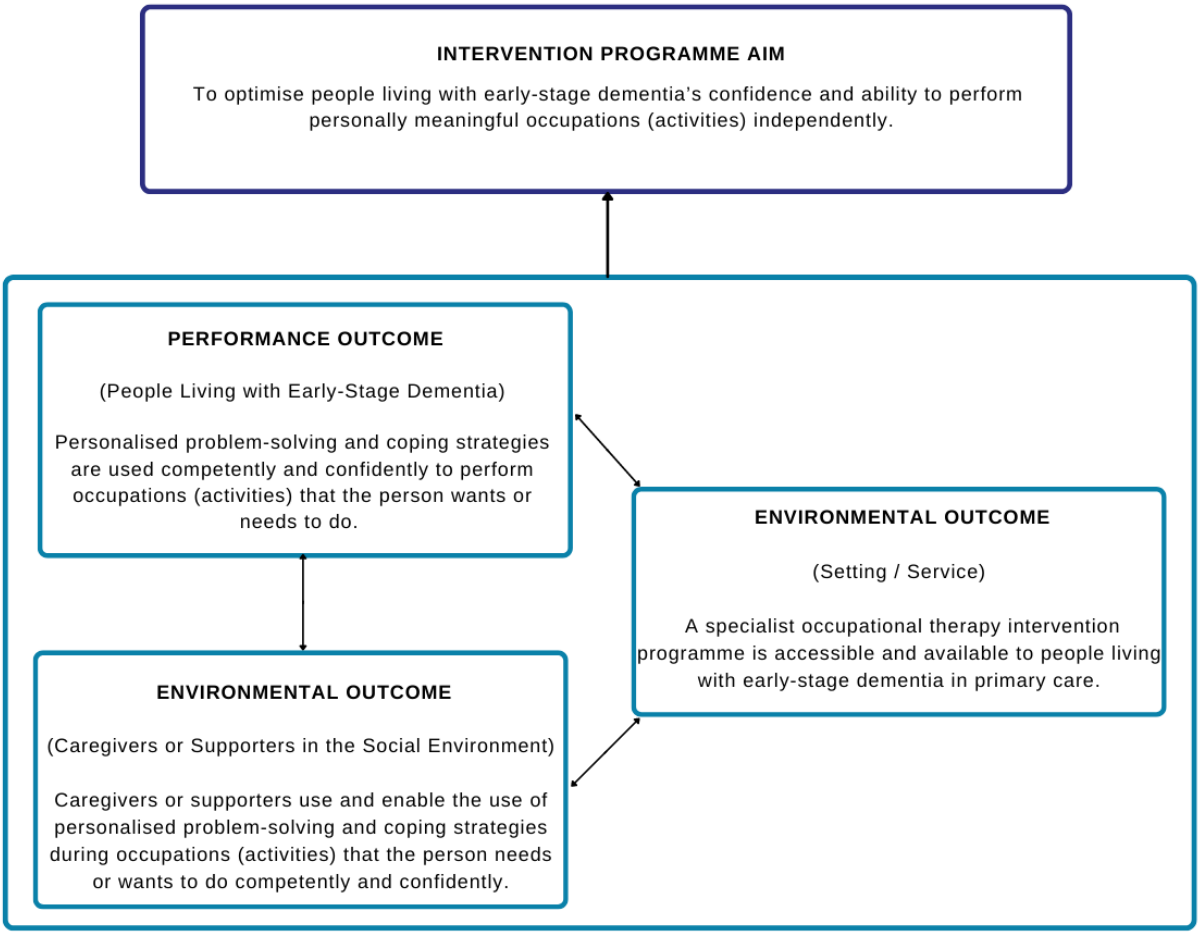

Figure 13: Intervention Programme Aim and Performance and Environmental Outcomes

11.4.1.3. Personal and Environmental Determinants

Personal determinants for the person living with early-stage dementia (Figure 14) and their caregiver (Figure 15) were specified based on those identified in the Logic Model for the Problem and Population at Risk, Figure 12. Two minor amendments have been made, reflecting the shift in focus to conditions of change, rather than defining the problem. Knowledge and awareness have been brought together into one category since similar methods of change (described later in Section 11.4.2.) target awareness and knowledge. Efficacy as opposed to self-efficacy has been specified, since SCT highlights that efficacy can pertain to perceptions of both self-efficacy and collective efficacy [76], the latter is likely to relate to the perceived efficacy of caregivers (or the person living with dementia for caregivers) and the therapist. Determinants for the setting or service environment (Figure 16) are for healthcare practitioners within that environment.

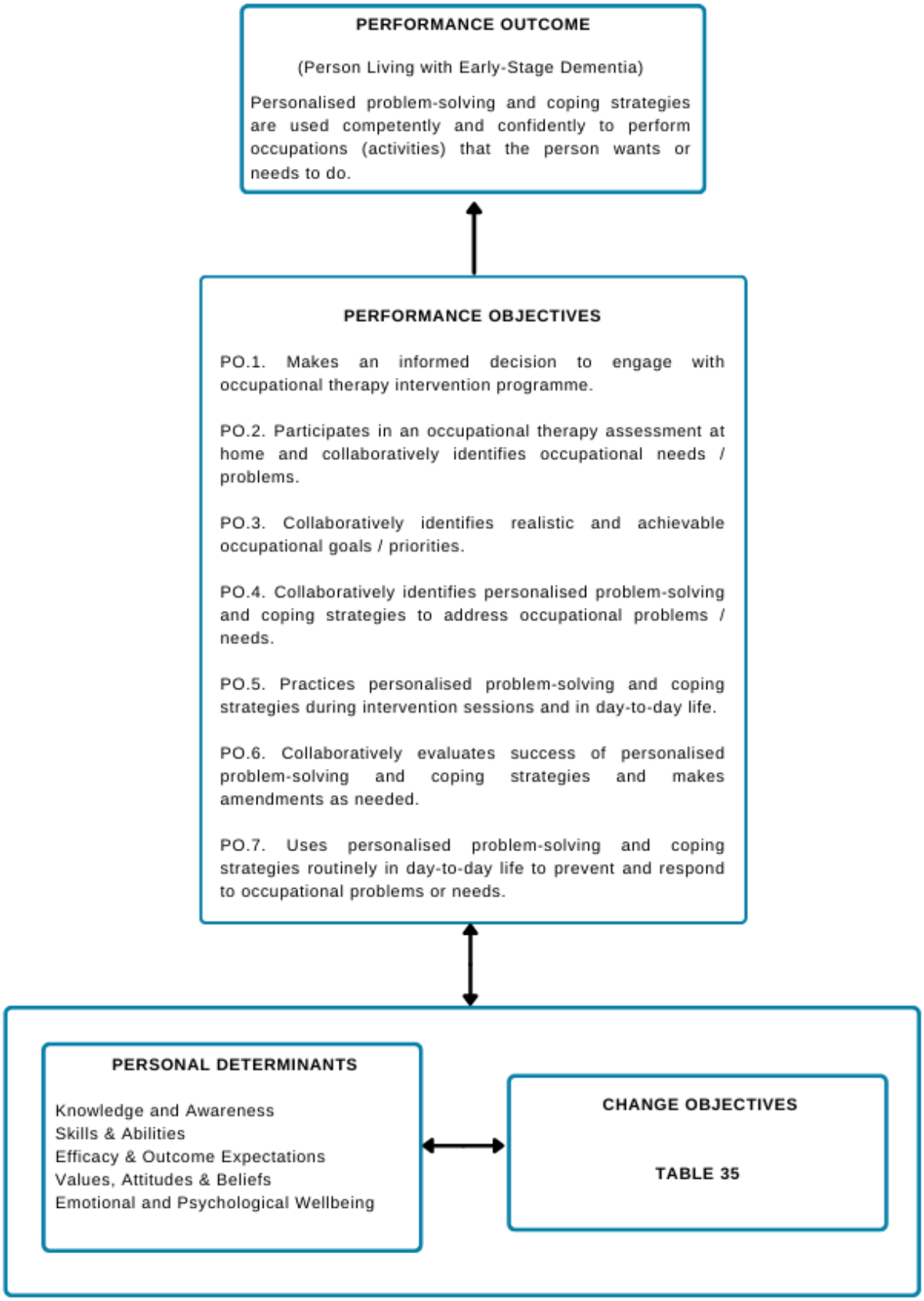

Figure 14: Components of the Matrix of Change (Table 35) for the Performance Outcome: Personalised Problem-Solving and Coping Strategies are used Competently and Confidently to Perform Occupations (Activities) that the Person wants or needs to do.

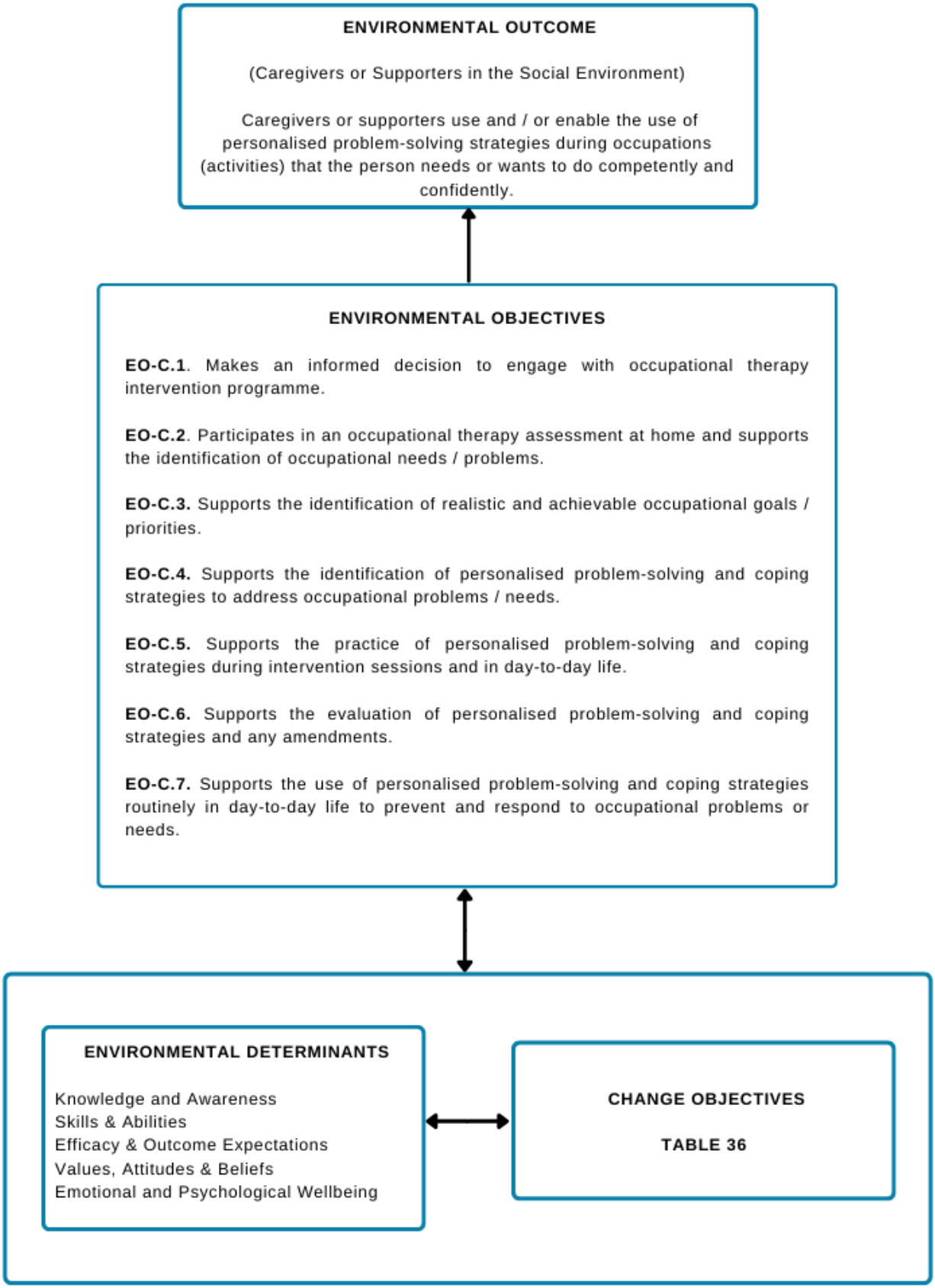

Figure 15: Components of the Matrix of Change (Table 36) for the Environmental Outcome: Caregivers or Supporter use and / or Enable the use of Personalised Problem-Solving and Coping Strategies during Occupations (Activities) that the Person needs or wants to do, Competently and Confidently.

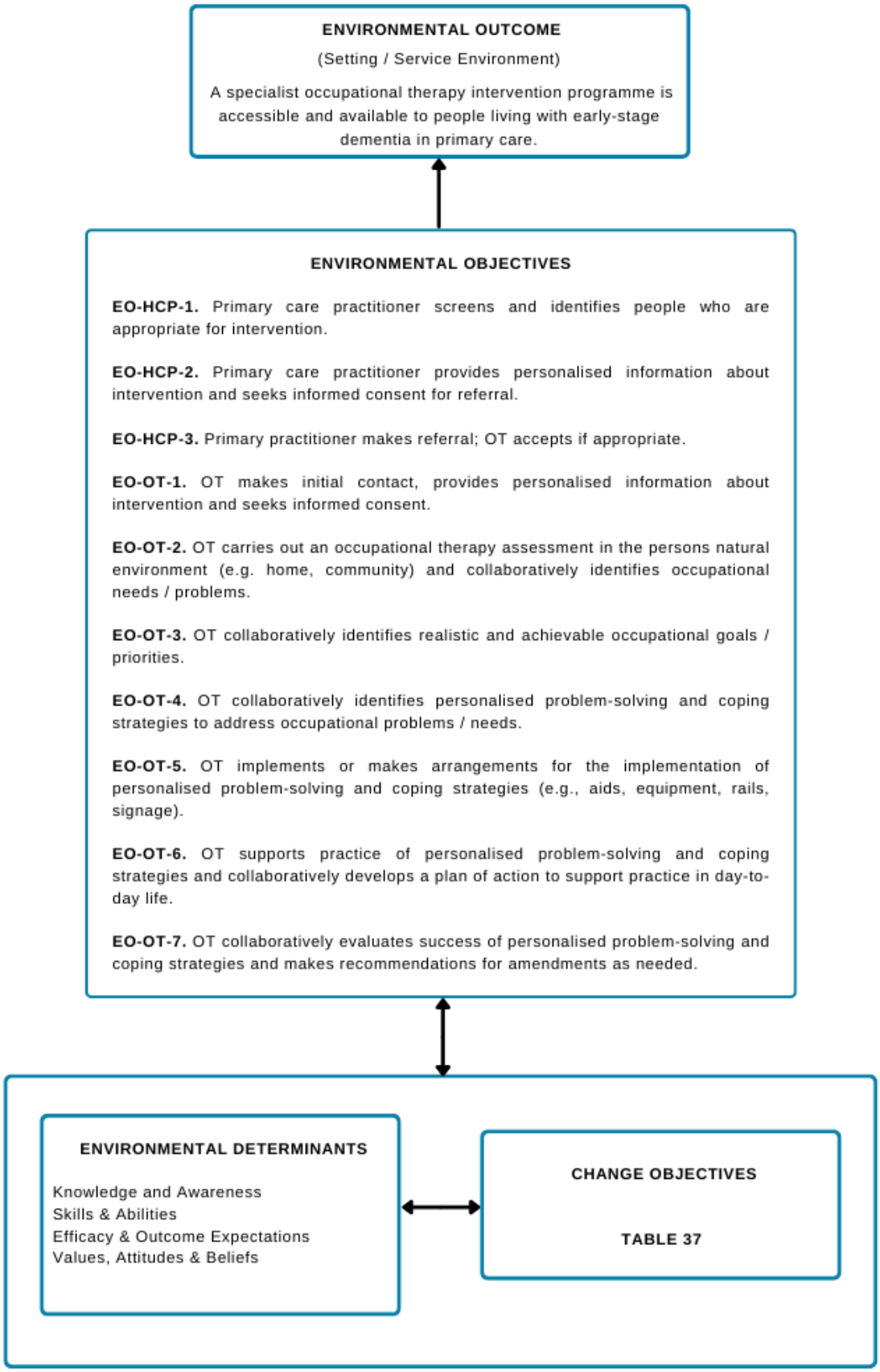

Figure 16: Components of the Matrix of Change (Table 37) for the Environmental Outcome: A Specialist Occupational Therapy Intervention Programme is Accessible and Available to People Living with Early-Stage Dementia in Primary Care.

Table 35: Matrix of Change for Performance Outcome: Personalised Problem-Solving and Coping Strategies are used Competently and Confidently to support the Performance of Occupations (Activities) that the Person wants or needs to do.

Performance Objectives (PO): Person Living with Early-stage Dementia	Personal Determinants and Change Objectives				
	Knowledge and Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
PO.1. Makes an informed decision to engage with occupational therapy intervention programme.	K.1.1. Acknowledges the impact early-stage dementia has on occupational performance. K.1.2. Understands programme rationale and content. K.1.3. Identifies the benefits and disadvantages of programme. K.1.4. Communicates that sufficient information about programme has been received.	S.1.1. Able to appraise own ability with support. S.1.2. Able to weigh up options and alternatives and make a decision. S.1.3. Able to communicate decision.	E.1.1. Feels able to engage with programme and therapist. E.1.2. Feels that significant others (e.g., caregiver) are able to engage with intervention and therapist. E.1.3. Feels that the intervention programme and therapist have the potential to help.	A.1.1. Feels that the programme is in line with personal values, beliefs, and interests. A.1.2. Perceives that engaging with occupational therapy is standard practice for people living with early-stage dementia.	W.1.1. Feels that their thoughts, feelings and experiences have been taken seriously. W.1.2. Feels that their therapist understands and is empathetic.
PO.2. Participates in an occupational therapy assessment at home and collaboratively identifies occupational needs / problems.	K.2.1. Understands the rationale for, and importance of an occupational therapy assessment at home. K.2.2. Appropriately identifies occupational problems / needs with support.	S.2.1. Able to appraise own ability with support. S.2.2. Able to communicate and / or demonstrate areas of occupational need / difficulty.	E.2.1. Feels able to participate in home assessment. E.2.2. Feels that significant others (e.g. caregiver) are able to participate in home assessment. E.2.3. Feels that home assessment and the therapist has the potential to help.	A.2.1. Feels that home assessment is in line with personal values, beliefs, and interests. A.2.2. Perceives that participating in a home assessment is standard practice for people living with early-stage dementia.	W.2.1. Feels that their thoughts, feelings and experiences about a home assessment have been taken seriously. W.2.2. Feels that the therapist understands and is empathetic.

Performance Objectives (PO): Person Living with Early-stage Dementia	Personal Determinants and Change Objectives				
	Knowledge and Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
PO.3. Collaboratively identifies realistic and achievable occupational goals / priorities.	K.3.1. Understands the rationale for, and importance of goal / priority setting. K.3.2. Appropriately identifies realistic and achievable goals / priorities.	S.3.1. Able to weigh up options and alternatives and prioritise goals.	E.3.1. Feels able to identify goals or priorities. E.3.2. Feels that goals or priorities are achievable for themselves and their caregiver with intervention programme. E.3.3. Feels that goal setting, goals themselves, and the therapist, has the potential to help.	A.3.1. Feels that goals or priorities are in line with values, beliefs, and interests. A.3.2. Perceives that goal setting is standard practice for people living with early-stage dementia.	W.3.1. Feels that their thoughts, feelings and experiences about goals and priorities have been taken seriously. W.3.2. Feels that therapist understands and is empathetic.
PO.4. Collaboratively identifies personalised problem-solving strategies to address occupational problems / needs as well as coping strategies to support emotional wellbeing.	K.4.1. Understands available intervention strategies. K.4.2. Selects intervention strategies in line with ability with support.	S.4.1. Able to weigh up options and alternatives and make a decision about strategies.	E.4.1. Feels able to use strategies. E.4.2. Feels that significant others (e.g. caregiver) are able to use or support strategies. E.4.3. Feels that strategies and therapist have the potential to help overcome occupational performance problems and enhance emotional wellbeing.	A.4.1. Feels that strategies are in line with values, beliefs, and interests. A.4.2. Perceives that identifying personalised strategies collaboratively is standard practice for people living with early-stage dementia.	W.4.1. Feels that their thoughts, feelings and experiences about strategies have been taken seriously. W.4.2. Feels that therapist understands and is empathetic.
PO.5. Practices personalised problem-solving and coping strategies during intervention sessions and in day-to-day life.	K.5.1. Understands importance of practicing strategies.	S.5.1. Able to learn and retain information about how and when to practice strategies.	E.5.1. Feels able to practice strategies. E.5.2. Feels that significant others (e.g. caregiver) are able	A.5.1. Feels that practicing problem-solving strategies is in line with values, beliefs, and interests.	W.5.1. Feels that their thoughts, feelings and experiences in relation to practicing strategies have been taken seriously.

Performance Objectives (PO): Person Living with Early-stage Dementia	Personal Determinants and Change Objectives				
	Knowledge and Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
	K.5.2. Understands how, when and where to practice strategies.	S.5.2. Able to utilise strategies.	to practice and / or support their practice of strategies. E.5.3. Feels that practicing strategies will help overcome occupational performance problems and enhance emotional wellbeing.	A.5.2. Perceives that practicing personalised problem-solving strategies is standard practice for people living with early-stage dementia.	W.5.2. Feels that therapist understands and is empathetic.
PO.6. Collaboratively evaluates success of personalised problem-solving and coping strategies and makes amendments as needed.	K.6.1. Understands the rationale for, and benefits of, evaluating progress. K.6.2. Appropriately identifies any difficulties or barriers using strategies. K.6.3. Understands how to use amended strategies.	S.6.1. Communicates any difficulties or barriers experienced when using strategies. S.6.2. Able to adapt strategies in response to difficulties or barriers with support.	E.6.1. Feels able to use strategies after amendments. E.6.2. Feels that significant others (e.g. caregiver) are able to use strategies after amendments. E.6.3. Feels that evaluating progress and making amendments will help overcome occupational performance problems and enhance emotional wellbeing.	A.6.1. Feels that evaluating strategies and making amendments as needed is in line with values, beliefs, and interests. A.6.2. Perceives that evaluating and amending personalised strategies is standard practice for people living with early-stage dementia.	W.6.1. Feels that their thoughts, feelings and experiences about evaluation and strategy amendments have been taken seriously. W.6.2. Feels that their therapist understands and is empathetic.
PO.7. Uses personalised problem-solving and coping strategies routinely in day-to-day life to prevent and respond to occupational problems or needs and	K.7.1. Understands importance of utilising strategies day to day.	S.7.1. Able to utilise strategies day to day as needed.	E.7.1. Feels able to use strategies competently and confidently in day to day life. E.7.2. Feels that significant others (e.g., caregiver) are able to use strategies competently	A.7.1. Feels that routine use of strategies is in line with values, interests, and beliefs. A.7.2. Perceives that using personalised strategies is the norm for people living with early-stage dementia.	W.7.1. Feels that their thoughts, feelings and experiences about using strategies in day to day life have been taken seriously.

Performance Objectives (PO): Person Living with Early-stage Dementia	Personal Determinants and Change Objectives				
	Knowledge and Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
maintain emotional wellbeing.			and confidently in day to day life. E.7.3. Feels that using strategies in day-to-day life will help overcome occupational performance problems and enhance emotional wellbeing.		W.7.2. Feels that therapist understands and is empathetic.

Table 36: Matrix of Change for Environmental Outcome: Caregivers or Supporter use and / or Enable the use of Personalised Problem-Solving and Coping Strategies Competently and Confidently to support the Performance of Occupations (activities) that the Person wants or needs to do.

Environmental Objectives (EO): Caregiver	Environmental Determinants and Change Objectives: Caregiver				
	Knowledge & Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
EO-C-1. Makes an informed decision to engage with occupational therapy intervention programme.	K-C-1.1. Acknowledges the impact early-stage dementia has on occupational performance. K-C-1.2. Understands programme rationale and content. K-C-1.3. Identifies the benefits and disadvantages of programme. K-C-1.4. Communicates that sufficient information about programme has been received.	S-C-1.1. Able to weigh up options and alternatives and make a decision. S-C-1.2. Able to communicate decision.	E-C-1.1. Feels able to engage with intervention and therapist. E-C-1.2. Feels that the person living with dementia is able to engage with intervention and therapist. E-C-1.3. Feels that the intervention programme and therapist have the potential to help.	A-C-1.1. Feels that the intervention programme is in line with personal values, beliefs, and interests and those of the person living with dementia. A-C-1.2. Perceives that engaging with occupational therapy is standard practice for people living with early-stage dementia and their caregivers.	W-C-1.1. Feels that their thoughts, feelings, and experiences have been taken seriously. W-C-1.2. Feels that their therapist understands and is empathetic.
EO-C-2. Participates in an occupational therapy assessment at home and supports the identification of occupational needs / problems.	K-C-2.1. Understands the rationale for, and importance of, an occupational therapy assessment at home.	S-C-2.1. Able to communicate and / or demonstrate areas of occupational need / difficulty.	E-C-2.1. Feels able to participate in home assessment. E-C-2.2. Feels that their significant other with dementia is able to participate in home assessment. E-C-2.3. Feels that a home assessment has the potential to help.	A-C-2.1. Feels that occupational therapy assessment is in line with personal values, beliefs, and interests and those of the person living with dementia. A-C-2.2. Perceives that participating in a home assessment is standard practice for people living with early-stage dementia.	W-C-2.1. Feels that their thoughts, feelings and experiences about a home assessment have been taken seriously. W-C-2.2. Feels that the therapist understands and is empathetic.

Environmental Objectives (EO): Caregiver	Environmental Determinants and Change Objectives: Caregiver				
	Knowledge & Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
EO-C.3. Supports the identification of realistic and achievable occupational goals / priorities.	K-C-3.1. Understands the rationale for, and importance of goal priority setting. K-C-3.2. Support the person living with dementia to appropriately identify realistic and achievable goals / priorities.	S-C-3.1. Able to support the person living with dementia to weigh up options and alternatives and prioritise goals.	E-C-3.1. Feels that goals or priorities are achievable for themselves and their significant other living with dementia, with the intervention programme. E-C-3.2. Feels that goal setting, goals themselves, and the therapist, has the potential to help.	A-C-.3.1. Feels that goals or priorities are in line with personal values, beliefs, and interests and those of the person living with dementia. A-C-3.2. Perceives that goal setting is standard practice for people living with early-stage dementia.	W-C-3.1. Feels that their thoughts, feelings and experiences about goals and priorities have been taken seriously. W-C-3.2. Feels that therapist understands and is empathetic.
EO-C.4. Supports the identification of personalised problem-solving and coping strategies to address occupational problems / needs and enhance wellbeing.	K-C-4.1. Understands available intervention strategies.	S-C-4.1. Able to support the person living with dementia to weigh up options and alternatives and make a decision about strategies.	E-C-4.1. Feels able to support the person living with dementia to use selected strategies. E-C-4.2. Feels that the person living with dementia is able to use strategies. E-C-4.3. Feels that strategies and therapist have the potential to help overcome occupational performance problems and enhance emotional wellbeing.	A-C-4.1. Feels that strategies are in line with values, beliefs, and interests, and those of the person living with dementia. A-C-4.2. Perceives that identifying personalised strategies collaboratively is standard practice for people living with early-stage dementia.	W-C-4.1. Feels that their thoughts, feelings and experiences about strategies have been taken seriously. W-C-4.2. Feels that therapist understands and is empathetic.

Environmental Objectives (EO): Caregiver	Environmental Determinants and Change Objectives: Caregiver				
	Knowledge & Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
EO-C.5. Supports the practice of personalised problem-solving and coping strategies during intervention sessions and in day-to-day life.	K-C-5.1. Understands importance of practicing strategies. K-C-5.2. Understands how, when and where to support practice.	S-C-5.1. Able to support the use and practice of strategies.	E-C-5.1. Feels able to support the person living with dementia to practice strategies. E-C-5.1. Feels that practicing strategies will help overcome occupational performance problems and enhance emotional wellbeing.	A-C-5.1. Feels that practicing strategies is in line with values, beliefs, and interests and those of the person living with dementia. A-C-5.2. Perceives that practicing personalised strategies is standard practice.	W-C-5.1. Feels that their thoughts, feelings and experiences in relation to practicing strategies have been taken seriously. W-C-5.2. Feels that therapist understands and is empathetic.
EO-C.6. Supports the evaluation of personalised problem-solving and coping strategies and any amendments.	K-C-6.1. Understands the rationale for, and benefits of, evaluating progress. K-C-6.2. Appropriately identifies any difficulties or barriers using strategies. K-C-6.3. Understands how to support the use of amended strategies.	S-C-6.1. Communicates any difficulties or barriers experienced when supporting the use of strategies. S-C-6.2. Able to adapt support in response to difficulties or barriers.	E-C-6.1. Feels that evaluating progress and making amendments will help overcome occupational performance problems and enhance emotional wellbeing. E-C-4.2. Feels able to support the use of strategies after amendments.	A-C-6.1. Feels that evaluating strategies and making amendments as needed is in line with values, beliefs, and interests and those of the person living with dementia. A-C-6.2. Perceives that evaluating and amending personalised strategies is standard practice.	W-C-6.1. Feels that their thoughts, feelings and experiences about evaluation and strategy amendments have been taken seriously. W-C-6.2. Feels that their therapist understands and is empathetic.

Environmental Objectives (EO): Caregiver	Environmental Determinants and Change Objectives: Caregiver				
	Knowledge & Awareness (K)	**Skills & Abilities (S)**	**Efficacy & Outcome Expectations (E)**	**Attitudes & Beliefs (A)**	**Emotional Wellbeing (W)**
EO-C.7. Supports the use of personalised problem-solving and coping strategies routinely in day-to-day life to prevent and respond to occupational problems or needs.	K-C-7.1. Understands importance of supporting the use of problem-solving strategies day to day.	S-C-7.1. Able to utilise and support the use of strategies day to day as needed.	E-C-7.1. Feels able to support the use strategies competently and confidently in day to day life. E-C-7.2. Feels that their significant other living with early-stage dementia is able to use strategies competently and confidently. E-C-7.3. Feels that using strategies day to day will help overcome occupational performance problems and enhance emotional wellbeing.	A-C-7.1. Feels that routine use of strategies is in line with values, interests and beliefs and those of the person living with early-stage dementia. A-C-7.2. Perceives that using personalised strategies is the norm for people living with early-stage dementia.	W-C-7.1. Feels that their thoughts, feelings and experiences about using strategies in day to day life have been taken seriously. W-C-7.2. Feels that therapist understands and is empathetic.

Table 37: Matrix of Change for the Environmental Outcome: A Specialist Occupational Therapy Intervention Programme is Accessible and Available to People Living with Early-Stage Dementia in Primary Care.

Environmental Objectives (EO): Occupational Therapists (OT) and Healthcare Practitioners (HCP)	Environmental Determinants and Change Objectives			
	Knowledge (K)	**Skills (S)**	**Attitudes & Beliefs (A)**	**Efficacy & Outcome Expectations (E)**
EO-HCP-1. HCP screens and identifies people who are appropriate for intervention programme.	K-HCP-1.1. Understands intervention programme eligibility criteria.	S-HCP-1.1. Able to screen and identify people living with early-stage dementia who have occupational needs / problems.	A-HCP-1.1. Perceives that screening / identifying people living with early-stage dementia for OT is standard practice. A-HCP-1.2. Recognises the value and role of OT for people living with early-stage dementia.	E-HCP.1.1. Expresses confidence in ability to identify people appropriate for OT. E-HCP.1.2. Recognises the benefits and outcomes OT can have for people living with early-stage dementia.
EO-HCP-2. HCP practitioner provides personalised and accessible information about intervention programme and seeks informed consent for referral.	K-HCP-2.1. Understands intervention programme rationale and an overview of its content. K-HCP-2.2. Understands the process of informed consent and capacity, as per the Mental Capacity Act (2010) (MCA).	S- HCP-2.1. Adapts communication mode, style and content to the needs and preferences of the person.	A-HCP-2.1. Perceives that providing information about the OT intervention programme is standard practice for people living with early-stage dementia.	E-HCP-2.1. Expresses confidence in ability to communicate information about the OT intervention programme.
EO-HCP-3. HCP practitioner makes referral to intervention programme and OT accepts referral if appropriate.	K-HCP-3.1. Understands local referral processes and procedures.	S-HCP-3.1. Able to use local referral processes and procedures.	A-HCP-3.1. Perceives that making a referral to the OT intervention programme is standard practice for early-stage dementia.	E-HCP-3.1. Expresses confidence in ability to make referral.

Environmental Objectives (EO): Occupational Therapists (OT) and Healthcare Practitioners (HCP)	Environmental Determinants and Change Objectives			
	Knowledge (K)	**Skills (S)**	**Attitudes & Beliefs (A)**	**Efficacy & Outcome Expectations (E)**
EO-OT-1. OT makes initial contact, provides personalised information about intervention programme and seeks informed consent.	K-OT-1.1. Understands OT intervention programme rationale and content. K-OT-1.2. Understands the process of informed consent and capacity, as per the MCA. K-OT-1.3. Understands the principles and values of person-centred practice, including informed decision making. K-OT-1.4. Understands how to make information accessible to people living with dementia.	S-OT-1.1. Adapts communication mode, style and content to the needs and preferences of the person. S-OT-1.2. Listens to persons views and concerns empathetically and answers questions transparently.	A-OT-1.1. Respects the persons autonomy to make an informed decision and their right to accessible information about benefits and disadvantages of intervention programme. A-OT-1.2. Perceives that providing accessible information about the OT intervention programme and obtaining informed consent is standard practice for people living with early-stage dementia.	E-OT-1.1. Expresses confidence in ability to adapt information about programme to the preferences and needs of the person and in obtaining informed consent. E-OT-1.2. Expresses confidence in ability to obtain informed consent.
EO-OT-2. OT carries out an assessment in the persons natural environment (e.g., home, community) and collaboratively identifies occupational needs / problems.	K-OT-2.1. Understands the rationale for, and importance of an OT assessment at home. K-OT-2.2. Understands theory underpinning assessment and how to use assessment battery and associated paperwork. K-OT-2.3. Understands how to work collaboratively to identify occupational needs / problems.	S-OT-2.1. Able to utilise assessment and analytical skills to identify occupational needs. S-OT-2.2. Adapts assessment and / or communication style and content to the needs and preferences of the person. S-OT-2.3. Listens empathetically to the persons perspective about their occupational needs.	A-OT-2.1. Respects the persons knowledge, experience, and views about occupational needs / priorities. A-OT-2.2. Recognises the value and importance of working collaboratively. A-OT-2.3. Perceives that working collaboratively to identify occupational needs / problems is standard practice for people living with early-stage dementia.	E-OT-2.1. Expresses confidence in ability to carry out an assessment in the home environment and identify needs collaboratively.

Environmental Objectives (EO): Occupational Therapists (OT) and Healthcare Practitioners (HCP)	Environmental Determinants and Change Objectives			
	Knowledge (K)	**Skills (S)**	**Attitudes & Beliefs (A)**	**Efficacy & Outcome Expectations (E)**
		S-OT-2.4. Able to discuss identified occupational needs sensitively. S-OT-2.5. Able to negotiate and agree on areas of occupational need.		
EO-OT-3. OT collaboratively identifies realistic and achievable occupational goals / priorities.	K-OT-3.1. Understands the rationale for, and importance of goal setting. K-OT-3.2. Understands theory underpinning goal or priority setting and how to use any goal setting tools and associated paperwork. K-OT-3.3. Understands how to work collaboratively to identify realistic and achievable goals.	S-OT-3.1. Able to translate occupational needs into goals. S-OT-3.2. Adapts goal setting and / or communication style and content to the needs and preferences of the person. S-OT-3.3. Listens to persons views about goals and priorities empathetically. S-OT-3.4. Able to negotiate and agree on occupational goals / priorities.	A-OT-3.1. Respects the persons knowledge, experience, and views about goals and priorities. A-OT-3.2. Respects the persons views about occupational needs / priorities. A-OT-3.3. Perceives that working collaboratively to identify occupational goals / priorities is standard practice for people living with early-stage dementia.	E-OT-3.1. Expresses confidence in ability to collaboratively identify realistic and achievable goals / priorities.

Environmental Objectives (EO): Occupational Therapists (OT) and Healthcare Practitioners (HCP)	Environmental Determinants and Change Objectives			
	Knowledge (K)	**Skills (S)**	**Attitudes & Beliefs (A)**	**Efficacy & Outcome Expectations (E)**
EO-OT-4. OT collaboratively identifies personalised problem-solving strategies to address occupational problems / needs and coping strategies to enhance emotional wellbeing.	K-OT-4.1. Has knowledge of available and appropriate problem-solving and coping strategies. K-OT-4.2. Understands how to work collaboratively to identify strategies.	S-OT-4.1. Adapts communication style and content in relation to strategies to the needs and preferences of the person. S-OT-4.2. Listens empathetically to persons views and concerns about potential strategies and answers questions transparently. S-OT-4.3. Able to negotiate and agree on strategies.	A-OT-4.1. Respects the persons views and preferences about strategies. A-OT-4.2. Perceives that working collaboratively to identify personalised strategies is standard practice for people living with early-stage dementia.	E-OT-4.1. Expresses confidence in ability to collaboratively identify personalised strategies.
EO-OT-5. OT provides or makes arrangements for the provision of personalised problem-solving strategies that involve equipment and adaptations to the physical environment (e.g., aids, rails, signage).	K-OT-5.1. Has knowledge of local processes and procedures for the provision of equipment, aids and adaptations.	S-OT-5.1. Able to use local systems to order or acquire equipment, aids and adaptations.	A-OT-5.1. Respects the persons views and preferences about equipment, aids and adaptations.	E-OT-5.1. Expresses confidence in ability to provide equipment, aids and adaptations.

Environmental Objectives (EO): Occupational Therapists (OT) and Healthcare Practitioners (HCP)	Environmental Determinants and Change Objectives			
	Knowledge (K)	**Skills (S)**	**Attitudes & Beliefs (A)**	**Efficacy & Outcome Expectations (E)**
EO-OT-6. OT supports the use and practice of personalised problem-solving and coping strategies, and collaboratively develops a plan of action to support practice in day-to-day life.	K-OT-6.1. Has knowledge of methods to support learning which is tailored to the needs of people living with early-stage dementia.	S-OT-6.1. Adapts communication style and content and learning approach to the needs and preferences of the person. S-OT-6.2. Listens empathetically to persons views and concerns about learning new skills. S-OT-6.3. Able to negotiate and agree on a plan of action to support day to day learning.	A-OT-6.1. Respects the persons views, preferences and learning style. A-OT-6.2. Perceives that supporting the use and practice of strategies collaboratively is standard practice for people living with early-stage dementia.	E-OT-6.1. Expresses confidence in ability to support learning, tailored to the needs of people living with early-stage dementia.
EO-OT-7. OT collaboratively evaluates success of personalised problem-solving and coping strategies and makes recommendations for amendments as needed.	K-OT-7.1. Understands the rationale for, and importance of evaluation. K-OT-7.2. Understands how to use any evaluation tools and associated paperwork.	S-OT-7.1. Adapts communication style and content to the needs and preferences of the person. S-OT-7.2. Listens empathetically to the persons views and concerns about strategies as well as potential amendments. S-OT-7.3. Able to negotiate and agree on amendments to strategies.	A-OT-7.1. Respects the persons views and preferences about strategies. A-OT-7.2. Perceives that evaluation of strategies is standard practice for people living with early-stage dementia.	E-OT-7.1. Expresses confidence in ability to collaboratively evaluate personalised strategies and recommend amendments.

11.4.2. Methods and Applications of Change

Theoretically informed methods of change, deriving primarily from Social Cognitive Theory (SCT) [75-78, 250] and suggestions for their real-world practical application were developed. Table 38 provides an overview of methods of change proposed for people living with early-stage dementia along with examples of practical applications. It is important to note that methods of change and their practical applications can impact upon multiple personal or environmental determinants, however, for brevity, methods and applications have been described in accordance with the primary determinant that they target in the remainder of this section.

11.4.2.1. Methods relating to Knowledge and Awareness

The provision of information is a commonly cited method of change deriving from SCT [75], as well as multiple other theories of change [68, 279]. SCT highlights that knowledge about a particular skill or behaviour is necessary to perform that skill or behaviour, as well as raising awareness about a particular problem or risk [75]. Personal relevance is considered to enhance motivation to attend, process, memorise, and recall new information, as well as the intention to act on information, and therefore the practical application of information provision is described as personalised in Table 38 [68, 279]. Information Processing Theories propose that elaboration and discussion enables greater personal meaning and relevance to be associated with information and therefore have been included as an additional method of change in Table 38 [68, 279].

On its own, increased knowledge and awareness is not considered to lead directly to change, however, it is considered a pre-requisite for change in relation to other determinants (e.g. skills, attitudes and beliefs and efficacy) [68]. Furthermore, methods targeting other determinants (e.g. guided practice, enactive mastery experiences) will also lead to a change in knowledge and awareness [68].

11.4.2.2. Methods relating to Skills and Abilities

Methods relating to skills and abilities proposed for people living with early-stage dementia and their supporters or caregivers (Table 38), are twofold and constitute methods associated with the acquisition or re-acquisition of skills (guided practice and goal setting), as well as methods that compensate for lost skills or abilities (minimising barriers and maximising opportunities).

To develop or re-acquire skills, guided practice of performance has been proposed as a method (Table 38), which SCT maintains develops skills and sub-skills through demonstration, repeated practice, discussion of the experience, and the provision of feedback [76]. The MOHO utilises the word coaching to describe this method of change, and additionally specifies that cueing can also be provided during performance [280]. Study 1's Intervention Synthesis identified that 11 intervention programmes also described intervention contents that involved 'practicing' or 'training'. In addition to guided practice, goal setting can bridge what Bartholomew Eldredge et al [68] describe as the "*intention-behaviour gap*" (p 85) which, along with methods of change that target efficacy and outcome expectations, increases the likelihood that new behaviours are performed. Many theories of change advocate goal-setting as a method, including SCT [75, 77], and performance is considered more likely when goals are specific, achievable (with a moderate level of difficulty) and are proximal [281, 282].

To compensate for lost skills or abilities, methods associated with what SCT calls minimising or removing environmental barriers that prevent performance or make it harder have been proposed, in order to increase opportunities for successful performance [75]. In practice, adapting the social, physical or occupational environments to overcome or minimise occupational performance problems is considered a key occupational therapy intervention [267], and will likely constitute a significant proportion of what has been described broadly in this Chapter as problem-solving strategies

11.4.2.3. Methods relating to Efficacy and Outcome Expectations

As purported by SCT and the MOHO, actively performing an activity not only develops skills through guided practice, but it can also improve efficacy, outcome expectations and confidence through direct experiences of mastery or success [76, 252]. To facilitate the experience of success or mastery, the practice and performance of strategies can be graded in terms of complexity incrementally over time and this is the approach proposed in Table 38 [76].

Encouragement to instil confidence and expectations of success, as well as positive reinforcement to enhance efficacy and outcome expectations when performance is successful are also proposed as methods deriving from SCT [75, 76]. However, Bandura [76] notes that verbal encouragement alone it is not as effective as enactive experiences of mastery since it does not provide concrete evidence of efficacy through direct experience. Modelling is also proposed as a method that can increase efficacy and positive outcome expectations through observational learning [75, 76]. Theory and research

indicates that people are more likely to pay attention to models who have similar experiences, and in Table 38, this includes other people living with early-stage dementia [75, 76].

11.4.2.4. Methods relating to Attitudes and Beliefs

Proposed methods of change targeting attitudes and beliefs are twofold in focus. Firstly, the methods information (11.4.2.1.) and modelling (11.4.2.3.) are proposed to target negative normative beliefs (e.g., in relation to dementia). Secondly, the methods participation and personalising seek to facilitate engagement with the intervention programme by tailoring content in accordance with a person's own values, attitudes, and beliefs to ensure personal relevance. As outlined in Section 11.4.2.1. personalising increases engagement with the process of change and the likelihood that change will occur [279]. Furthermore, active participation in the intervention process and collaboration with intervention recipients is identified as a method of change by the MOHO [280] and is a key occupational therapy intervention principle, deriving from the profession's emphasis on person-centred practice [283]. In line with this emphasis, occupational therapy interventions are routinely personalised and tailored to a person's needs, values and beliefs [283]. Whilst personalising and tailoring has been identified as a method relating to attitudes and beliefs, it is a method that underpins the entire intervention process.

11.4.2.5. Methods relating to Emotional and Psychological Wellbeing

Modelling and enactive mastery experiences, described in Sections 11.4.2.1. and 11.4.2.3. are also anticipated to target the determinant emotional and psychological wellbeing. SCT highlights that modelling can diminish perceptions of anxiety and fear associated with occupational performance, although Bandura [78] reports that enactive mastery experiences, through the acquisition of skills and more positive perceptions of efficacy and outcome expectations, is more effective in reducing negative emotions and feelings of stress [76]. In the context of emotional and psychological wellbeing, coping strategies that facilitate what Bandura calls "*enabling styles of thinking*" [78] (p348), for example those associated with Cognitive Behavioural Therapy (CBT), can be acquired through guided practice (11.4.2.2.) and information provision (11.4.2.1.). By targeting negative cognitions associated with anxiety, depression and stress, perceptions of efficacy and outcome expectations that support occupational performance can be increased and attitudes and beliefs that pose barriers to performance, modified [78].

Emotional and esteem support is also proposed as a method of change, which Kelder et al [75] associates with SCT's emphasis on social support. Social support can be broken into four domains and includes emotional support, described by Kelder et al [75] as "*expressing positive affect, caring… and companionship*" and esteem support, described as "*validating beliefs, emotions and actions*" (p168) [75]. Whilst Kelder et al [75] do not describe how emotional and esteem support facilitate change, demonstrating empathy, positive unconditional regard, and validating thoughts and feelings, are commonly cited methods of change deriving from person-centred therapy [284]. Rogers describes these as facets of the therapeutic relationship which help establish the relational conditions upon which change or learning can occur [285].

Table 38: Proposed Theoretical Methods of Change and Application Examples that Target Personal Determinants (Person Living with Early-stage Dementia)

	Personal Determinants: Person Living with Early-stage Dementia				
	Knowledge and Awareness	**Skills and Abilities**	**Efficacy and Outcome Expectations**	**Attitudes and Beliefs**	**Emotional Wellbeing**
Theoretical Methods of Change and Application Examples (Based on SCT, unless otherwise stated)	**Information** *Application: OT provides personalised information verbally and in writing about:-* *• The importance of practicing problem-solving strategies.* *• When, where, and how to use and practice strategies.* **Elaboration and Discussion** (Information Processing Theories) *Application: OT facilitates personalised discussion about when, where, and how to use and practice problem-solving strategies.*	**Minimising Barriers and Maximising Opportunities** *Application: OT implements personalised problem-solving strategies that involve changing or adapting the characteristics of the social, physical, and occupational environment to match the persons skills and abilities.* **Guided Practice** *Application: OT demonstrates how to use personalised problem-solving strategies and provides guidance and practical support to enable the person to practice themselves. Feedback and cueing are provided when necessary.*	**Enactive Mastery Experiences** *Application: OT grades guided practice, to enable the person to experience success and mastery.* **Modelling** *Application: OT provides personalised information about others' ability to use problem-solving strategies successfully.* **Encouragement** *Application: OT provides personal verbal encouragement and reassurance to instil confidence in ability to utilise and practice problem-solving strategies.*	**Personalising** *Application: OT tailors problem-solving strategies to ensure personal relevance and meaning.* **Participation** (MOHO) *Application: OT facilitates the persons active participation in the identification of how, when, and where to practice problem-solving strategies.* **Modelling** *Application: OT provides information about other people living with early-stage dementia who have received occupational therapy.*	**Emotional and Esteem Support** *Application: OT listens empathetically, acknowledges, and validates the persons experiences, thoughts, and feelings about using and practicing problem-solving and coping strategies.* **Guided Practice** *Application: OT provides information and guidance about personalised coping-strategies (e.g., based on the principles of CBT) and provides opportunities and practical support to enable the person to practice strategies.*

	Personal Determinants: Person Living with Early-stage Dementia				
	Knowledge and Awareness	**Skills and Abilities**	**Efficacy and Outcome Expectations**	**Attitudes and Beliefs**	**Emotional Wellbeing**
		Goal Setting *Application: OT works collaboratively with the person to make short-term goals to support the practice of strategies day to day prior to next appointment.*	**Positive Reinforcement** *Application: OT provides positive reinforcement during guided practice of problem-solving strategies.*		

11.5. Intervention Logic Model

Thesis Objective 7 and its associated tasks involved developing a proposed simple intervention logic model that could inform a future evaluation, including a feasibility study [65]. The model is depicted in Figure 17 and brings together intervention inputs consisting of materials (Section 11.3.2.4.) and interventionists (Section 11.3.3), intervention components (Section 11.3.2.3.) as well as theoretical methods of change (Section 11.4.). Proposed immediate outcomes based on theory relating to methods of change have been specified along with medium to longer term outcomes.

11.6. Chapter Conclusion

This Chapter has presented Study 3's findings, which constituted developing a proposed intervention programme theory (Thesis Objectives 4, 6 and 7) and a programme design (Thesis Objective 5). In order to do develop the latter, the TIDieR Checklist was used to inform the specification of the intervention's aim (maximising confidence and ability to perform meaningful occupations [activities]); intervention mode (individual or dyad format); location (home environment); duration (8 sessions) and components (problem-solving strategies, coping strategies and information, signposting and referral). In order to develop the former, a logic model of the problem and population at risk was compiled which identified personal and environmental risk factors and determinants that can lead to occupational performance problems and negative health and quality of life outcomes (Section 11.2.). These were utilised to identify risk factors and determinants that the intervention could target, with matrices of change developed to articulate the interventions proposed mechanisms as well as practical methods and applications of change (Section 11.4.). A simple intervention logic model was presented comprising of intervention inputs, components, and outcomes (Section 11.5). The programme theory and design were developed based on theory (the MOHO and SCT) as well as evidence deriving from practice (Study 2 and stakeholder engagement) and research (Study 1).

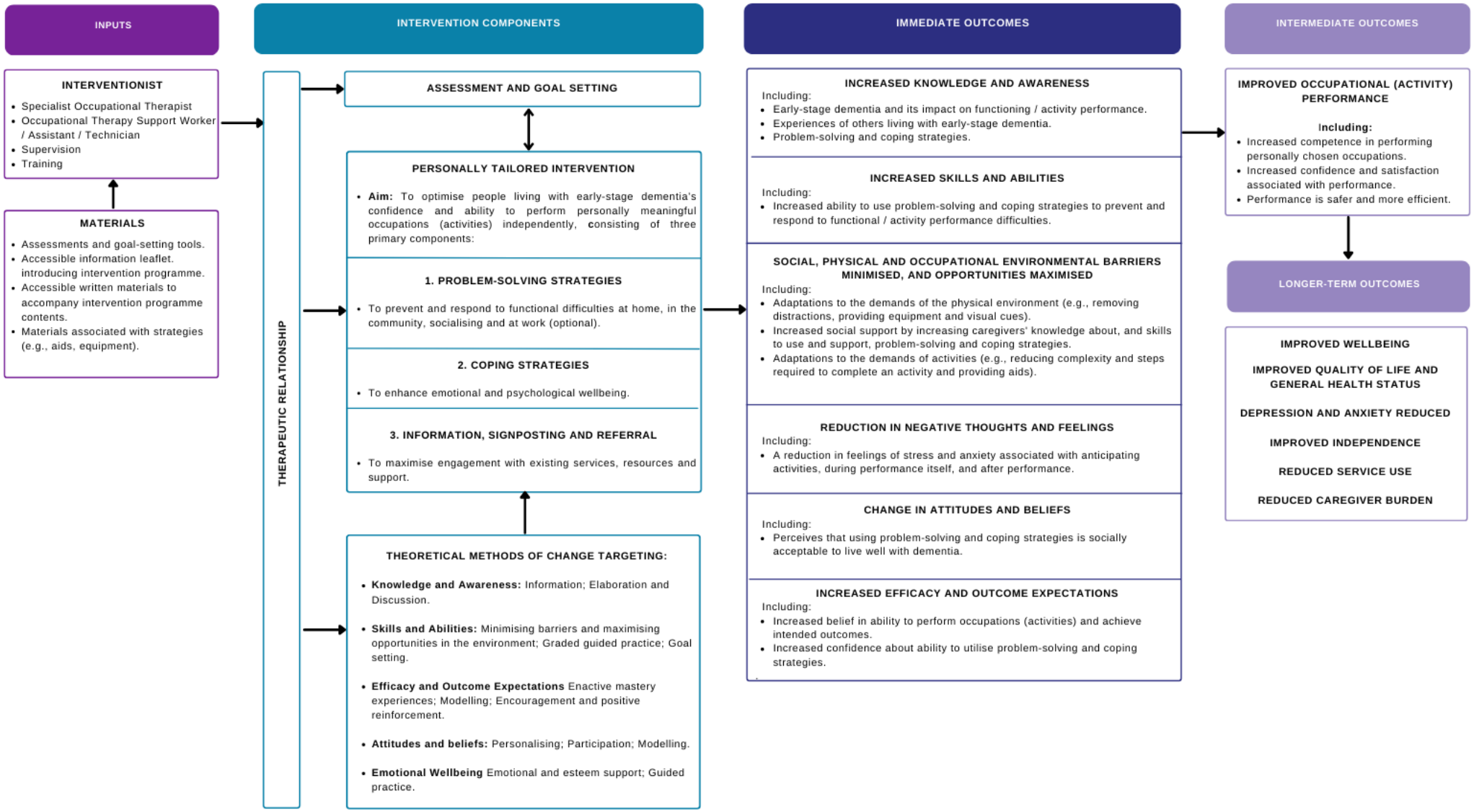

Figure 17: Simple Intervention Logic Model

Chapter 12: Conclusion and Implications

12.1. Introduction

This is the final Chapter in this Thesis and as such it will provide an overview of the programme of research presented in preceding Chapters followed by a summary of the Thesis' main findings. Strengths and limitations of the Thesis itself will be described along with implications for research and practice.

12.2. Overview of Programme of Research

12.2.1 Rationale and Aim

Chapter 1 provided an introduction and context to the programme of research contained in this Thesis, including the emphasis in policy and practice guidelines across the UK's four nations on early assessment, diagnosis and intervention for people living with dementia, including occupational therapy [2, 26, 51]. The absence of published research in 2017, when this work commenced, pertaining to occupational therapy interventions for early-stage dementia in the UK was also outlined. An account of my prior research in this area was also described which identified a potential practice gap in Wales in primary care, including Memory Assessment Services (MAS), as well as an absence of standardised or manualised programmes of intervention [39]. In this context, and to prepare for a future evaluation, this Thesis' aim was to: -

- **Systematically describe and develop an evidence, theory, and practice informed occupational therapy intervention for people living with early-stage dementia.**

12.2.2. Approach

To meet this aim, Chapter 2 outlined that the Medical Research Council's (MRC) Complex Intervention Research Frameworks [64, 65] were used as an overarching framework for this programme of research, with Intervention Mapping the chosen intervention development approach [68]. Thesis Objectives were developed based on Intervention Mapping Steps 1 – 3, and to meet these objectives, this Thesis consisted of three studies.

12.2.3. Study 1: Evidence Synthesis

Study 1 (Chapters 3 – 5) comprised a two-stage mixed methods evidence synthesis informed by the EPPI-Centre's guidelines for multi-stage mixed methods reviews [86]. It aimed to identify, describe, appraise, and synthesise peer-reviewed research relating to occupational therapy and people affected by early-stage dementia living in the community. Following screening for eligibility, studies were synthesised methodologically and thematically, resulting in two syntheses. The Population Synthesis (Chapter 4) thematically synthesised studies using a qualitative approach and those using an observational, cross-sectional design, reporting on the impact early-stage dementia can have on occupational performance (Thesis Objective 1). Chapter 5 constituted the Intervention Synthesis, which thematically summarised studies investigating occupational therapy interventions for early-stage dementia (Thesis Objective 2) using any methodology, including experimental and quasi-experimental studies, as well as process analyses and qualitative studies.

12.2.4. Study 2: Semi-Structured Interviews

Chapters 6 – 9 constituted Study 2, which consisted of semi-structured interviews with people affected by early-stage dementia and occupational therapy practitioners. Twenty-two interviews were conducted with 31 participants, five were people affected by dementia, five were caregivers or supporters and 21 were occupational therapy practitioners. Data generated was categorised in accordance with Thesis Objectives 1 – 3 and thematically analysed, drawing on Miles et al's [120] pragmatic approach.

12.2.5. Study 3: Programme Theory and Design

Study 3 was reported in Chapters 10 and 11 and constituted the development of an intervention programme theory and programme design utilising an Intervention Mapping approach [68], with Thesis Objectives 4 – 7 and their associated tasks based on Intervention Mapping Steps 1 – 3. Data deriving from Study 1 and 2 that sought to understand the intervention population, context and existing practice and research-based interventions, constituted an Intervention Mapping needs assessment which was used to inform development tasks alongside stakeholder engagement. Social Cognitive Theory (SCT) was the primary theory of change utilised to identify personal and environmental determinants and theoretical methods of change [75-78, 250].

12.3. Summary of Main Findings

12.3.1. Thesis Objective 1: Understanding the Intervention Population

In order to inform the proposed intervention programme theory and design, including the logic model of the problem and population at risk (Chapter 11, Figure 12), Study 1's Population Synthesis, (Chapter 4), and Study 2 (Chapter 7) generated data to understand the intervention population and their occupational or functional needs.

12.3.1.1. Early-Stage Dementia: Impact on Occupational Performance

Both Study 1 (Chapter 4) and Study 2 (Chapter 7) identified that people living with early-stage dementia experienced occupational performance 'problems', 'difficulties' or 'changes' due to dementia itself, as well as comorbid conditions, for example, physical and sensory impairments. Whilst difficulties were highly individual, the consequences of difficulties in the short-term were associated with making mistakes, increased risk, increased duration of time and effort, non-completion or cessation or an activity, and a negative impact on emotional wellbeing (e.g., stress, anxiety, fear).

Impacts on occupational performance were typically described in the context of dementia's effect on personal factors or determinants, namely skills and abilities (e.g., memory, executive functioning), with dementia sub-type highlighted as significant in determining the specific skills and abilities impacted. Motivation, emotional wellbeing, and mental health emerged as a prominent theme, initially described in Study 1, where feelings of stress, anxiety and fright were identified in anticipation of performance, during performance, and after, which were considered by authors to compound the impact dementia and co-morbid conditions had on performance. Study 2 built on this theme in relation to the negative impact on mental health and wellbeing associated with receiving a diagnosis, which can decrease motivation and interest in occupational performance. Participants living with early-onset dementia in Study 2 were more likely to experience these negative effects, including difficulties accepting or coming to terms with a diagnosis.

In addition to personal factors, determinants and risk factors in the social, physical, and occupational environments were described in both Study 1 and 2. This included environments that were experienced as unfamiliar, non-routine and complex or demanding (e.g., busy, noisy, multiple

distractions, multiple steps in an activity). Specific emphasis was placed on difficulties performing Instrumental Activities of Daily Living (IADL), using everyday technology and work in Study 1, whilst Study 2 additionally noted problems socialising and driving. Risk factors in the social environment were also highlighted in Study 1 in particular the support caregivers provide which can be both supportive and unsupportive of a person's own doing.

12.3.1.2. Defining Early-Stage Dementia

A lack of consistency in the way early-stage dementia was defined using the Mini Mental State Examination (MMSE) by studies eligible for inclusion in Study 1 was identified early during this programme of research. Furthermore, Chapter 1 described the multiple ways in which early-stage dementia is described in the literature (symptom based, impact on independence and cognitive assessments). In this context, and in order to inform future implementation, Study 2 additionally sought to explore the perspectives of occupational therapy practitioners and people affected by early-stage dementia about what early-stage dementia meant to them. Again, multiple perspectives were identified, with emphasis on the lived experience of change as well as clinical perspectives based on cognitive assessments and impact on occupational performance or functioning. Significantly, and in contrast to its prominent use in research, the MMSE was not being used in clinical practice at participating sites, with the Addenbrooke's Cognitive Examination (ACE) and Montreal Cognitive Assessment (MOCA) utilised. These findings highlight that there may not be a shared understanding amongst professional disciplines about what constitutes early-stage dementia, which will need to be considered when developing implementation strategies for a future evaluation.

12.3.2. Thesis Objective 2: Understanding the Intervention Context

Considering the intervention context is a core element of the revised MRC Framework across its four phases [65]. Accordingly, Study 2 generated data in relation to the setting or service context (Chapter 8) and about the intervention delivery context (Chapter 9), which were utilised to inform the proposed intervention's programme design (Section 11.3), as well as implications relating to intervention implementation during a future evaluation (Section 12.5.).

12.3.2.1. Setting / Service Context

A survey of practice conducted as a precursor to this programme of work (Section 1.5.1.) identified that there were uncertainties about the availability of occupational therapy intervention for people living with early-stage dementia, particularly in primary care including Memory Assessment Services (MAS) in Wales [39]. To address these uncertainties, Study 2 (Chapter 8) sought to generate data on the current service and practice context. A complex and variable picture of practice was identified, with an absence of standardisation between and within Health Boards, indicating that people living with early-stage dementia across the five participating sites are not receiving an equitable service. At the time of data generation, only two Health Boards were routinely providing occupational therapy assessment and intervention in MAS. Participants were not working in other practice settings in primary care (e.g., primary care mental health services or GP surgeries). Of those Health Boards providing occupational therapy intervention, variability was identified in terms of intervention mode (groups or individual / dyad), duration and intensity. These findings underscore the importance of understanding an intervention's service and practice context prior to an evaluation, to ensure that the intervention can be implemented as intended [65].

Chapter 8 concluded by presenting findings relating to contextual barriers, which centred around a common barrier, the confined availability of occupational therapy intervention for people living with early-stage dementia. As identified by Edwards' [39] survey of practice in Wales and Cummins and Warren's [168] study in Ireland, a lack of human resources was identified as the primary contextual barrier. This resulted in the absence of services at two participating sites and confined to whom and how interventions were provided at other sites (e.g., in a group setting, of limited duration, to people considered at risk). A lack of resources more broadly was also described, in particular the impact this was perceived to have on the length of time people typically wait following referral from a GP to MAS. Participants noted that this often resulted in late presentation to services, which was considered a barrier particularly in Taliesin to MAS as a service context. This specific finding, in addition to the emphasis in policy on developing the Allied Health Professional (AHP) workforce in primary care, informed the intervention programme design and its specification, that the intervention should not be service specific, to enable implementation in a real-world context that is changing.

Two further contextual barriers were noted impacting upon the availability of occupational therapy intervention, namely a lack of professional influence in the development and organisation of services, as well as a limited understanding and awareness amongst other professionals about the interventions

occupational therapists can deliver. Multiple participants spoke about the impact an absence of evidence to support their practice with this population had in contributing to the perceived lack of control and influence they reportedly experienced.

12.3.2.2. Intervention Delivery Context

The home environment was the most preferred and prevalent delivery context in Study 2 (Chapter 9). Occupational therapy practitioners associated home with the ability to provide a more personalised and individualised intervention programme as well as the opportunity it provided to conduct an assessment of the persons functioning in their natural environment. However, delivery context was ultimately associated with mode of delivery in both Study 2 and Study 1's Intervention Synthesis. Home was typically the context of individual and dyad interventions and community and clinical settings, the context of group interventions. In relation to the latter, community venues as opposed to clinical settings were deemed most appropriate by participants from Taliesin, who perceived that they would reduce stigma associated with clinical settings and enable people to create links to community venues and locations. However, barriers and challenges were discussed, including the need for community and clinical venues to be accessible, which was deemed particularly challenging in Taliesin owing to poor public transport links and its large geographical coverage. In addition to the home environment, community locations associated with specific occupations (e.g., work, shopping, public transport) were also advocated as intervention delivery contexts as indicated during individual or dyad interventions. Building on these findings and given the proposed initial mode during a feasibility evaluation of an individual or dyad format, the intervention delivery context in Study 3 was specified as the home environment and other community locations as indicated.

12.3.3. Thesis Objective 3: Identifying Existing Practice and Research-Based Occupational Therapy Interventions.

Reflecting the renewed emphasis in the revised MRC Framework on identifying existing interventions, Study 1's Intervention Synthesis (Chapter 5) and Study 2 (Chapter 9) generated data to meet Thesis Objective 3. Data generated about existing practice and research-based interventions informed the proposed intervention's programme design (Section 11.3), as well as implications relating to intervention implementation during a future evaluation (Section 12.5.).

12.3.3.1. Interventions

Study 1's Intervention Synthesis (Chapter 5) identified five distinct occupational therapy intervention programmes: Community Occupational Therapy in Dementia (COTiD) [43, 48, 49, 190]; Brief Occupational Therapy Intervention [95]; Supporting Everyday Activities in Dementia [96, 97]; Occupational Therapy Memory Strategy Education Group [188]; and Home-Based Occupational Therapy Intervention [189]. These programmes were heterogenous in terms of intensity and duration and delivery context, and whilst four programmes were delivered on an individual or dyad basis, in 2022 a group-based intervention was also identified. Significantly, these programmes were not specifically for people living with early-stage dementia, and no publicly available manuals in English or intervention programme theories were reported that would enable the replication of these programmes in another context. Of the five occupational therapy intervention programmes identified, only COTiD was evaluated using an RCT design [43, 48, 49], however, there were inconsistencies in outcomes reported by these RCTs, with COTiD UK no more effective than usual care. COTiD was the only occupational therapy intervention programme evaluated in a UK context and therefore there is an absence of evidence deemed 'high quality' to support the specific practice and core skills of occupational therapists in the UK. In relation to interventions identified in clinical practice, Study 2 (Chapter 9) did not identify any standardised, manualised occupational therapy intervention programmes or programme theories. Of those Health Boards providing occupational therapy intervention, variability was also identified in terms of intervention mode (groups or individual / dyad), duration and intensity.

Despite the heterogeneity identified, 'strategies' to prevent or overcome occupational performance or functional problems were the most frequently reported intervention component or content in practice (Chapter 9) and from the research evidence (Chapter 5). However, a lack of detail about what constituted a strategy was identified in both studies, as well as the diverging terminology utilised to describe similar strategies. In addition to strategies, additional components described in Study 1 and Study 2 included a pre-intervention assessment process to ensure that the intervention delivered was personally tailored; goal setting (which was not reported frequently during Study 2); and establishing and developing a therapeutic relationship (which was not reported frequently in Study 1). Intervention components, contents, mode, frequency and duration identified in Study 1 and 2 were utilised to inform the proposed intervention design (Section 11.3.).

12.3.3.2. Barriers and Facilitators

In addition to contextual barriers (Section 12.3.2.), individual factors were identified as potential barriers to the delivery or implementation of interventions in both Study 1's Intervention Synthesis and in Study 2 (Chapter 9). Study 1 specifically highlighted that intervention recipients' attitudes towards, and perceptions of, the intervention programme, interventionist, and specific strategies (aids and equipment in particular), could be a significant barrier as well as dementia severity, and caregiver burden. Furthermore, Study 1's Intervention Synthesis identified that greater therapist experience in delivering an intervention programme, high commitment, and supervision are associated with higher implementation fidelity [159, 170, 189].

12.3.4. Thesis Objectives 4 – 7: Programme Theory and Design

Thesis Objectives 1 – 3 were exploratory and descriptive in nature in order to generate evidence to inform the description and development of an occupational therapy intervention for people living with early-stage dementia. To achieve this aim, Thesis Objectives 4 – 7 were action orientated and developed based on Intervention Mapping Steps 1 – 3, which included describing an intervention programme theory and design.

12.3.4.1. Intervention Programme Theory

Thesis Objectives 4, 6 and 7 collectively sought to develop a proposed programme theory for an occupational therapy intervention for people living with early-stage dementia using an Intervention Mapping approach. A logic model of the problem and population at risk (Figure 12, Section 11.2.) was developed in order to succinctly describe and define the problem that the intervention would seek to address. The problem was defined occupationally in the short-term as a decreased ability to perform activities independently, safely and efficiently. Potential targets of change consisting of personal and environmental determinants and risk factors were also mapped. Matrices of change were developed (Section 11.4.) by selecting and refining personal and environmental determinants identified and specifying change objectives for people living with dementia, caregivers, and Healthcare Practitioners (HCPs). Informed by Social Cognitive Theory (SCT), theoretical methods of change were selected and suggestions for practical applications were described. A simple intervention logic model (Figure 17, Section 11.5.) was proposed depicting intervention inputs, components, and outcomes.

12.3.4.2. Intervention Programme Design

Thesis Objective 5 constituted specifying a programme design, including intervention aim, context, components, and characteristics (Section 11.3.). Since research and practice-based interventions were identified in Study 1 and 2, these were utilised to inform the proposed intervention aim (optimising confidence and ability to perform meaningful activities); intervention mode (individual or dyad format); location (home environment and others as indicated e.g., work, community); duration (3 - 8 sessions) and components (problem-solving strategies, coping strategies and information, referral, and signposting).

12.4. Thesis Strengths and Limitations

Strengths and limitations in relation to Study 1, 2 and 3 have been discussed previously and therefore this section will discuss strengths and limitations pertaining to rigour and those that relate to the Thesis as a whole.

12.4.1. Limitations

Limitations in relation to the rigour of the programme of research contained in this Thesis must be acknowledged. Items five and six on the AMSTAR 2 (A MeaSurement Tool to Assess systematic Reviews) [126] identify that high quality systematic reviews should conduct study selection and data extraction in duplicates. This is also highlighted in the Cochrane Handbook for Systematic Reviews of Interventions [286, 287], which highlights that study selection and data extraction should be conducted by at least two individuals working independently to minimise the risk of bias and the risk of mistakes being made during the selection process and data extraction. Unfortunately, study selection and data extraction did not occur in duplicates during Study 1, and therefore limitations in relation to potential bias during selection and data extraction must be highlighted.

Methods to enhance the rigour or trustworthiness of qualitative research include the triangulation of methods, sources, researchers and theory [288]. Whilst Study 3 triangulated data generated using multiple methods (evidence synthesis, semi-structured interviews, and stakeholder engagement) to develop a programme design, and whilst multiple sources (people affected by dementia, occupational therapists) were interviewed in Study 2 from differing contexts, the use of multiple researchers to

code and analyse data deriving from semi-structured interviews in Study 2 did not occur. This may have resulted in researcher bias during the analysis process.

It must also be noted that despite the involvement of stakeholders in the development of Study 3's programme design during occupational therapy practitioner workshops and the study's Lived Experience Advisory Group (LEAG), the proposed programme theory and matrices of change were not developed with the involvement of stakeholders. The development of programme theory with a diverse range of stakeholders and consensus methods is recommended by the revised MRC Framework [65] and Intervention Mapping [68]. Whilst it was developed with input from my supervisory team, which included an expert in the development and evaluation of complex interventions and Intervention Mapping, the absence of wider stakeholder involvement must be acknowledged. As described in Section 12.5.1., Intervention Mapping Step 4 provides an opportunity to refine the proposed intervention programme design and theory and this must be a priority when progressing this research, to ensure the programme design and theory is acceptable to stakeholders and has ecological validity [289].

Contextual circumstances limiting this programme of work's rigour described above include a change in employment in October 2019. Whilst stakeholder engagement with occupational therapy practitioners occurred prior to this change and informed this research's design, data generation tools and programme design, it was not possible to continue this engagement post October 2019. Furthermore, the COVID-19 pandemic and infection control procedures, prevented the LEAG from meeting post March 2020. This impacted their involvement in developing the proposed programme theory and owing to the limitations inherent in relation to a PhD, namely resources and time scales, greater involvement for example by using a genuine co-produced or participatory approach and methods, was not possible.

More broadly, it is important to acknowledge that the focus throughout this Thesis on problems and difficulties and understanding these in greater detail to inform an intervention programme theory. Unfortunately, this meant that data generated on remaining skills and achievements were not centred, perhaps providing an overall pessimistic portrayal of living with early-stage dementia. Additionally, it is important to highlight that the focus of this research has centred the person living with early-stage dementia, rather than caregivers and their occupational or performance needs.

12.4.2. Strengths

Existing research relating to occupational therapy interventions, including effect evaluations and evidence syntheses have typically utilised combined populations of people living with early, middle, and late-stage dementia, despite their differing needs and the contexts in which services to meet these needs are delivered. Consistent with Sikkes et al's [50] recommendations for future occupational therapy research on identifying subgroups "*most likely to benefit from treatment*" (p264), this Thesis has focused on the specific needs of people living with early-stage dementia.

In this context, Study 1's evidence synthesis is the first, to my knowledge, that has identified and synthesised evidence about occupational therapy interventions for this specific sub-population. This more focused approach has gleaned new insights into the current evidence base for this population which can be utilised by practitioners to inform their practice, as well as researchers seeking to address uncertainties that remain about this area of practice. Study 2 also generated new knowledge using semi-structured interviews about the specific impact early-stage dementia has on occupational performance from the perspective of people affected by dementia and practitioners in a UK context. Prior research in this area, conducted primarily at the Karolinska Institute, Sweden, has focused on specific activities or occupations; however, Study 2 took a broader approach to identify a range of difficulties experienced during occupational performance as well as personal and environmental determinants associated with these difficulties. Two surveys of practice have been conducted in a UK context generating data about the practice of occupational therapists with people living with dementia of all stages [39, 40], one was a precursor to the programme of research [39]. Evidence generated in Study 2 builds upon these prior surveys, firstly by generating data with a specific focus on people living with early-stage dementia, and secondly by utilising semi-structured interviews in order to generate detailed information, which compliments and builds upon the findings of both surveys.

Finally, a systematic approach informed by the MRC Frameworks and Intervention Mapping was utilised to develop an intervention programme theory and design. In contrast to the MRC Frameworks' emphasis on developing a programme theory, no studies identified in Study 1's Intervention Synthesis made reference to, or published, a programme theory. Study 3 therefore has provided new insights into a proposed programme theory for occupational therapy interventions with this population. To my knowledge, Study 3 is also the first study to utilise an Intervention Mapping approach to develop an occupational therapy intervention for people affected by dementia,[186] and

thereby contributes methodologically to complex intervention research for this population and intervention.

12.5. Implications: This Programme of Research

Chapter 2 explained that Intervention Mapping consists of six key Steps (Figure 3), and Steps 1 – 3 have been reported and described in this Thesis, namely Study 3 (Chapters 10 – 11). Implications for this research beyond this Thesis will therefore be discussed broadly in accordance with Intervention Mapping Steps 4 – 6. This will include:

- Refining the proposed intervention design and programme theory (Step 4).
- Intervention implementation (Step 5).
- Developing and producing intervention and implementation materials (Step 4 and 5).
- Designing a feasibility evaluation (Step 6).

As well as Intervention Mapping, this research has been informed broadly by the MRC Frameworks (Chapter 2, Figures 1 and 2) [64, 65]. In the context of this programme of research, Step 4 and Step 5 relate to the development phase, and Step 6 to the MRC's feasibility phase[12].

12.5.1. Refining Intervention Design and Programme Theory

A proposed intervention programme theory and design was outlined during Study 3 and Intervention Mapping Step 4 provides an opportunity to refine these in collaboration with key stakeholders before developing and producing intervention materials. Crucially, feedback about whether the proposed programme design is feasible, contextually relevant, and acceptable to people affected by dementia and occupational therapy practitioners should be sought at this stage. Methods to achieve this could include focus groups, interviews, and input from a central planning group, which will need to be established when progressing this research. Key uncertainties described in relation to the programme design (Table 34, Section 11.3.), about intervention mode, duration, and intensity, as well as limitations in relation to the interventions focus on the person living with dementia (Section 12.4.1.) can be further explored at this stage.

[12] The word 'implementation' is utilised differently by the MRC and Intervention Mapping. The former utilises the term to denote the final phase of research concerned with increasing uptake of interventions that have been evaluated. The latter utilises the term to describe activities associated with delivering the intervention, which will occur during the MRC's feasibility, evaluation, and implementation phases.

12.5.2. Intervention Implementation

Study 2 highlighted that the implementation context across participating sites is complex, variable, and susceptible to change, with multiple barriers identified, including a lack of resources, awareness and understanding about occupational therapy, and a lack of strategic influence. Ensuring that the proposed intervention can be delivered as planned and with fidelity during the MRC's feasibility phase will need to be robustly considered, particularly in the context of COTiD's multi-site RCTs in Germany [48] and the UK [49]. Both reported that the intervention, or elements of the intervention were not delivered with high fidelity, which may have influenced results reported [170, 189]. To anticipate and address potential barriers to implementation, Intervention Mapping offers a detailed, theoretically informed approach towards the development of implementation strategies which will be discussed below.

Identifying Programme Context, Adopters, Implementers and Maintainers

Study 2 and 3 described that Taliesin Health Board was the anticipated setting for a future evaluation at the MRC's feasibility phase, and detailed data about this context was generated in Study 2. However, in light of the theme 'Change' (Section 8.2.1.3.), it is important that the feasibility of Taliesin as an implementation site be reviewed when progressing this research, and alternative NHS sites in the UK may need to be considered. Adopters (those who make a decision to adopt the intervention), implementers (those who deliver the intervention), and maintainers (those who maintain implementation) will need to be identified once the feasibility context has been determined, and suggestions about who may fulfil these roles have been outlined in Table 39.

Specifying Implementation Mechanisms, Methods, and Applications of Change

To establish who will need to do what to ensure that the intervention is adopted, implemented, and maintained as intended with fidelity, Intervention Mapping replicates Thesis Objective 6 (Section 10.4.3.) in relation to implementation. Implementation matrices of change will therefore need to be developed, which will involve the identification of implementation outcomes, performance objectives, determinants, and change objectives. Implementation theories, for example the Consolidated Framework for Implementation Research [290] or the Context and Implementation of Complex Interventions (CICI) framework [228] could be used to inform this, particularly when identifying determinants as targets of change.

In addition to implementation theories, Study 1 and 2 identified determinants that will need to be considered as outlined in Table 39. A significant determinant influencing adopters, implementers and maintainers will be resources, namely human, which has been a recurrent theme in this Thesis as well as the survey of practice conducted prior to this research [39]. This is particularly significant since the time and the opportunity to deliver the intervention as well as undertake tasks associated with an evaluation was identified as a potential factor impacting COTiD UK's implementation [189]. Funding will need to be obtained to progress this research, and any future grant application must adequately secure resources for intervention implementers and maintainers, as well as resources associated with the evaluation itself.

In relation to implementers, COTiD in Germany [170] and the UK [189] hypothesised that less experience in delivering the experimental intervention as well as lower levels of commitment and motivation, compared to interventionists in the Netherlands [43], may account for the moderate to low levels of fidelity they reported. When progressing this research, applications to address a lack of experience are likely to include an intervention manual to support implementation with fidelity, training, and supervision. However, these implementation strategies were also used by COTiD in the UK and Germany, and therefore careful consideration about the parameters of these interventions will need to be considered, to ensure that learning from COTiD can be applied to this research.

12.5.3. Producing Intervention and Implementation Materials

Study 3 identified materials (Section 11.3. and 11.5.) that will need to be developed before any evaluation, including information about the intervention for people affected by dementia as well as an intervention manual. During Study 2, no intervention programme materials were described by practitioners, and publicly available materials in English were not identified in relation to occupational therapy intervention programmes identified in Study 1's Intervention Synthesis. In this context, Intervention Mapping provides a structure to plan, design and pre-test intervention and implementation materials that are grounded in Study 3's proposed intervention programme theory (Section 11.4) and the implementation theory that will need to be developed (Section 12.5.2.).

At the designing and prototype stage of development, significant stakeholder engagement will be required to evaluate and ensure that materials are acceptable, feasible and contextually and culturally relevant. Consideration will need to be given to making materials accessible to people living with

early-stage dementia and guidance produced by people living with dementia about typography, layout, graphics, and language will be utilised [291].

Table 39: Implementation Adopters, Implementers and Maintainers and Determinants Identified in this Research

Role (Adopter, Implementer, Maintainer)	Implementation Determinants Identified in this Research
Adopters Directorate and Service managers (Primary care mental health / dementia services and Occupational therapy). Occupational therapists.	• Resources (human, materials) • Lack of awareness and understanding about occupational therapy • Low strategic professional influence and control • Organisational change
Implementers Occupational therapists, assistants, technicians or support workers (where available). Health care professionals who refer to occupational therapy. People who supervise and line manage implementers.	• Resources (human, materials). • Experience working with people living with early-stage dementia. • Experience of the experimental intervention and associated processes and procedures. • Motivation (self-efficacy and outcome expectations) and commitment. • Organisational change
Maintainers All individuals listed above.	• All of the above.

12.5.4. Feasibility Evaluation

An evaluation at the MRC's feasibility phase, involves "a*ssessing the feasibility and acceptability of the intervention and evaluation design to make decisions about progression to the next stage of evaluation*" [65] (p26). It also provides an opportunity to address key uncertainties that remain after the additional development work described above, before progressing to a summative evaluation. In order to evaluate the feasibility and acceptability of both the intervention, implementation strategies and evaluation design, a process evaluation will be necessary in addition to an effect (outcome or impact) evaluation.

Effect Evaluation

Findings from this research, particularly about the complexity and variability of current occupational therapy interventions in clinical practice and the setting / service context (Section 8.2.1.2.) will have significant implications for the feasibility of a future evaluation. The traditional 'gold standard' design,

the RCT, requires the identification of a control or comparison group. However, it is unclear whether an appropriate control group will be able to be identified that would enable a robust multi-site evaluation given the variability of occupational therapy interventions in routine practice. This is particularly pertinent in the context of COTiD UK's multi-site RCT, with Wenborn et al [49] noting that their treatment as usual (TAU) group consisted of occupational therapy at some sites which was variable, and may have impacted on results reported. Whilst Taliesin had been anticipated as the initial implementation context, a feasibility study using a multi-site RCT design would provide an opportunity to address uncertainties relating to an appropriate control group and identify potential contextual barriers across multiple sites, before determining if a summative evaluation using this design is possible.

Whilst considered of lower quality, given the absence of a control or comparison group and randomisation, a multi-site one group pre-post design may need to be considered at the MRC's evaluation phase, if a multi-site RCT is deemed unfeasible. It is noteworthy that this design, rather than an RCT, was utilised in the most recent evaluation of COTiD in Italy to inform its national implementation [190]. Alternatively, it is important to consider, given the existence of existing interventions in practice, the potential of a natural experiment design. However, since natural experiments evaluate interventions that are naturally occurring, intervention materials and implementation strategies developed during this research would not be able to be utilised to optimise current practice when using this design [292].

The proposed intervention logic model (Section 11.5, Figure 17) identified intermediate and longer-term outcomes that could be measured during a feasibility evaluation (e.g., improved performance / functioning, quality of life, depression, and anxiety). However, COTiD's RCT's in Germany [48] and the UK [49], identified during Study 1's Population Synthesis, highlight the need to identify outcome measures that are sensitive to change following occupational therapy intervention for people living with early-stage dementia. An effectiveness feasibility evaluation will provide an opportunity to address these uncertainties, particularly given the absence of the use of outcome measures in clinical practice, identified in Study 2. The COPM [174] was proposed as a goal-setting tool that also functions as an outcome measure to capture outcomes relating to occupational performance and independence in Study 3 (Section 11.3.2.2.). However, uncertainties about whether the Bangor Goal Setting Interview (BGSI) [275] or the Goal Attainment Scaling (GAS) are more acceptable and feasible than the COPM were identified, which can be addressed in the context of a feasibility evaluation.

The MRC's Process Evaluation Guidance [173] highlights that the role of a process evaluation during the MRC's feasibility phase is to evaluate the feasibility and acceptability of the effect evaluation design, the intervention, as well as its implementation. In relation to the evaluation design, the updated MRC Framework recommends that the feasibility and acceptability of recruitment and data generation procedures and outcome measures are evaluated, and any unintended outcomes are identified. A process evaluation will also provide an opportunity to test and refine the proposed intervention programme theory which was developed in Study 3. This includes immediate outcomes specified in the intervention logic model (Section 11.5), for example increased knowledge, skills and self-efficacy, as well as the developed matrices of change (Section 11.4.1.), for example performance and environmental outcomes and objectives.

12.6. Implications: Practice and Research

12.6.1. Practice

This research has systematically identified that people living with early-stage dementia experience difficulties and problems during occupational performance, in particular Instrumental Activities of Daily Living (IADL), work and when using everyday technology. These needs may be associated with risk, for example if medication is not taken correctly, if difficulties shopping or cooking lead to insufficient nutrition and hydration, and risk of harm when accessing the community (e.g., crossing the road). People living with early-stage dementia therefore have occupational needs that would benefit from occupational therapy intervention in primary care, including MAS to prevent adverse outcomes, and to optimise independence and wellbeing.

Despite having occupational needs, and the recommendations of NICE [2], the Memory Assessment National Accreditation Programme (MSNAP) [26] and the Dementia Action Plan for Wales [51], intervention availability was variable within and across participating sites. In contrast to the Welsh Government's long-term plan for health and social care [293], which advocates for "*an equitable system which achieves equal health outcomes for all*" (p9), there was an inequity in access to and availability of occupational therapy intervention for people affected by dementia living in the five participating Health Boards.

Multiple reasons were identified that may account for this inequity, particularly in Chapter 8, including a lack of awareness or understanding of the interventions occupational therapists can provide by national and local decision makers. Greater involvement of occupational therapists in strategic, policy and decision-making roles nationally and locally, for example regional national partnership boards [294], may help overcome this. Clinicians can utilise NICE and MSNAP guidelines to highlight any gaps within their existing services and ensure they are kept abreast of funding, for example transformation funds associated with the Dementia Action Plan for Wales, administered through regional partnership boards which can be utilised to develop and increase service provision [294].

Some participants in this study were critical of the lack of evidence to support their practice in primary care and MAS, and sometimes attributed confined availability of occupational therapy intervention to this. Whilst Section 12.5. has described implications in relation to the current programme of research, it is important to highlight that only one practitioner who participated in Study 2 was routinely using an outcome measure in clinical practice. Practitioners themselves could generate practice-based evidence, by introducing validated outcome measures into routine clinical practice, to capture evidence in the context of a robust evaluation plan. If outcome measures were standardised across Health Boards, a national data set could be called upon to provide evidence as needed.

Barriers accessing occupational therapy intervention were also identified in relation to referrers or gatekeepers who are not occupational therapists, who may not understand the interventions dementia specialist occupational therapists can provide for people living with early-stage dementia. Whilst some methods of overcoming these barriers were identified by participants in Study 2, including increasing knowledge and awareness about occupational therapy amongst referrers, alternative methods could be used, for example direct referrals from caregivers or people living with dementia themselves. Whilst this is not a routine form of referral for occupational therapy for people living with dementia, and whilst there is absence of evidence to support this practice, direct referral has proven successful with other populations, for example vocational rehabilitation [295]. Another access barrier identified included a lack of knowledge amongst people affected by dementia about occupational therapy. Accessible public facing resources that provide information about problem-solving and coping strategies could reduce this barrier whilst also enabling self-management before or whilst waiting for a referral to occupational therapy.

The impact a lack of resources had on how and to whom occupational therapy interventions were delivered were described, including pressures to deliver interventions in a group rather than on an

individual or dyad basis, and limiting interventions to people deemed at risk. In this context, practitioners should be mindful of pressures within the service context that can undermine the extent to which their interventions are delivered in accordance with the needs and preferences of people affected by dementia. Greater involvement of people affected by dementia at a strategic level, as well as in the design and delivery of services could help ensure that interventions are shaped by their needs as opposed to the services' needs.

12.6.2. Research

In light of COTiD UK's findings [49], and in the absence of other RCTs or quasi-experimental studies conducted in a UK context, there is a dearth of evidence to support the effectiveness of interventions based on occupational therapists' core skills in the UK. No pilot or feasibility studies in this context were identified in Study 1, and therefore there is an urgent need to generate evidence in this area to support and inform existing practice. Aside from COTiD in the Netherlands' [45] economic analysis, no additional economic analyses were identified globally. There is therefore a gap in the existing knowledge base about the cost-effectiveness of occupational therapy for people living with early-stage dementia, particularly in the UK, which has been recognised by the RCOT as one of their top 10 research priorities for the profession [176]. An absence of studies using a qualitative methodology generating data on views and experiences as well as acceptability was also noted. Despite this gap in evidence, much can be learnt from the multiple studies investigating COTiD identified in Study 1, to inform future research in this area.

The findings of COTiD UK [49], as well as stakeholder engagement during Study 3 (Workshop 2), have highlighted the need to judiciously select outcome measures that are sensitive to change following occupational therapy intervention for people living with a progressive condition, including dementia. The Bristol Activities of Daily Living Scale (BADLS) [243] was utilised by COTiD UK as a primary outcome measure, which is surprising in the context of this research, since practitioners who participated in Workshop 2, who had limited post-graduate research experience, were unanimous in their view that the BADLS would not be sensitive to change after an occupational therapy intervention with this population. This possibly highlights the need to engage with a wide range of stakeholders, including practitioners when selecting outcome measures for clinical trials. More broadly, given the scarcity of outcome measures utilised in clinical practice identified during this research, in addition to concerns about outcome measure sensitivity during clinical trials, the generation of a core outcome set for

occupational therapy interventions for people with a cognitive impairment or dementia would be beneficial [296].

Significantly, Wenborn et al [49] note that future studies should "*consider measuring person-centred outcomes that are more meaningful and closely aligned to participants' priorities, such as goal achievement*" (p 15). Whilst COTiD UK's study protocol [297], which outlined procedures for their RCT and its internal pilot, did not identify the COPM in their schedule of assessments and outcome measures, Wenborn et al [49], reporting on the trial's outcomes state that it was initially utilised during their internal pilot, however, a decision to cease using it was made when proceeding to the full trial. Challenges experienced in administering the COPM and administration time were utilised to justify this decision, however, no information was provided by Wenborn et al [49] about the training received by researchers in its administration. In contrast, UK based studies evaluating cognitive rehabilitation, some predating COTiD UK, have recognised the value of using goal-based outcome measures with this population, including the COPM [89, 172]. It is noteworthy that Clare et al's RCT's of cognitive rehabilitation [89, 193] and COTiD Italy's one group pre-post design [190] reported statistically significant outcomes in favour of their experimental interventions on goal-based outcome measures only, with no differences noted on any other outcomes. These findings, along with the findings of COTiD UK and Germany, who did not use the COPM, suggest that the COPM or alternative goal-based outcome measures, as described in Section 11.3.2.2., are worthy of serious consideration when considering an outcome measure for occupational performance in this population.

Crucially, evaluations of COTiD in Germany and the UK appear to have moved directly to the MRC Framework's evaluation phase rather than undergo a feasibility phase in the first instance. Wenborn et al [297] briefly describe activities associated with adapting COTiD for a UK context in their trial protocol, and Di Bona et al [298] have reported on the results of a focus group during COTiD UK's 'development' phase, however, a feasibility study has not been published to date. It is unclear why neither appear to have conducted a feasibility evaluation before proceeding to a multi-site RCT design at the MRC's evaluation phase, given that they were implementing COTiD in a different context and evaluating it using a different design and outcome measures compared to the original study in the Netherlands. It is specifically unclear in the context of COTiD UK, since COTiD in Germany predates the commencement of COTiD UK, and a feasibility study could have possibly prevented COTiD UK from replicating the results of COTiD in Germany in relation to effect outcomes, and poor to moderate implementation fidelity. The implications for future research in this field are clear: feasibility studies provide an essential opportunity to identify and address barriers in relation to the implementation

and evaluation of an intervention that has reported promising outcomes in another context prior to moving to the MRC's evaluation phase.

Both MRC Frameworks utilised to inform this research highlight the importance of considering and understanding the context in which the intervention will be implemented [64, 65]. The low to moderate fidelity of intervention implementation reported by COTiD UK and Germany's multi-site RCTs reaffirms this need to understand the intervention context in detail across implementation sites before progressing to a multi-site RCT at the MRC's evaluation phase. Themes that were identified during this research in relation to context, for example organisational change and confined resources, were reported as factors that impacted the implementation of COTiD UK [49, 189]. Whilst COTiD UK conducted a survey of UK practice [40] before its multi-site RCT, it did not include questions about the implementation context and the survey itself was not specific to the 14 sites where COTiD was implemented. Focus groups with occupational therapists during COTiD's 'development' identified that a lack of support from management and protected time were barriers to COTiD UK's delivery as well as the completion of research procedures [298]. However, whilst Di Bona et al [298] reported that steps were taken to address these challenges, Wenborn et al [49] reporting on COTiD's multi-site RCT again identified management support as well as time to implement COTiD as organisational or contextual factors that impacted its delivery across multiple sites. These challenges amplify the importance of the MRC's feasibility phase as an opportunity to understand implementation contexts in greater detail, to evaluate the feasibility of implementing an intervention within intended contexts, as well as evaluating if implementation strategies effectively address implementation challenges.

Significantly, COTiD UK's survey of UK practice [40] did indicate that occupational therapy was prevalent for people living with early to middle-stage dementia in England as treatment as usual (TAU). It is therefore unclear why TAU was deemed an appropriate control group for their multi-site RCT, particularly since the presence of occupational therapy as usual care was listed by Wenborn et al [49] as a factor that may have contributed to their outcome results. Future research in this area must therefore be mindful of the potential challenges in identifying an appropriate control or comparison group when evaluating an intervention that may be being delivered as TAU. As described in Section 12.5.4. in relation to this Thesis' programme of research, alternative designs aside from an RCT may need to be considered when conducting research in this field if an appropriate control or comparison group cannot be identified.

On a general note, an absence of publicly available or published intervention manuals and programme theories was identified during this research, despite the number of studies identified in Study 1 reporting on the outcomes of interventions delivered by occupational therapists. Making both public would enable the replication or refinement of existing interventions, which is particularly significant in the context of the revised MRC Framework's emphasis on identifying existing interventions during the development phase [65]. This would also potentially reduce research waste through the development of entirely new interventions. Whilst the TIDieR Checklist was developed to enable a detailed description and replication of interventions [121], it does not provide sufficient detail to enable replication in practice or for research purposes. Manuals and programme theories could be submitted as supplementary information when publishing outcome evaluations.

12.7. Thesis Conclusion

This Thesis aimed to systematically describe and develop an evidence, theory and practice-informed occupational therapy intervention for people living with early-stage dementia. A systematic approach, informed by the MRC Frameworks and Intervention Mapping was utilised to firstly conduct a needs assessment to understand the intervention population, intervention context and identify existing practice and research-based interventions. A detailed evidence synthesis using a systematic approach was conducted (Study 1), as well as semi-structured interviews generating primary data relating to practice and the implementation context (Study 2), to inform this needs assessment. Study 3 comprised developing an intervention programme theory and design, consistent with Intervention Mapping Steps 1 – 3. This has provided a robust foundation for further development work at Intervention Mapping Steps 4 – 5, including developing theoretically informed implementation strategies and producing materials in preparation for a feasibility evaluation.

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Appendices

Appendix A: Dementia Severity: Impact on Activities of Daily Living and Independence

Table 1: Dementia Severity and Impact on Activities of Daily Living (ADL) and Independence (Adapted from WHO [22])

Severity	Impact: Independence	Impact: ADL
Early-stage (Mild)	Sufficient to interfere with everyday activities, though not severe as to be incompatible with independent living. Causes impaired performance in daily living, but not to a degree making the individual dependent on others.	Difficulty registering, storing and recalling elements in daily living, such as where belongings have been put, social arrangements, or information recently imparted by family members. More complicated daily tasks or recreational activities cannot be undertaken.
Middle-stage (Moderate)	A serious barrier to independent living Unable to function without the assistance of another in daily living, including shopping, and handling money. Within the home, only simple chores are preserved.	The individual is unable to recall basic information about where he lives, what he has recently being doing, or the names of familiar persons. Daily living, including shopping, and handling money. Within the home, only simple chores are preserved.
Later-stage (Severe)	*"An absence, or virtual absence of intelligible ideation."*	Fails to recognise even close relatives.

Appendix B: Lived Experience Advisory Group Minutes: 3.10.17

OT Research Advisory Group

Minutes

Date: 3.10.17

Place: [redacted]

Time: [redacted]

1. Who came to the meeting?

[redacted]

2. What did we talk about?

Introductions:

- Everyone spoke a bit about who they are and what experiences they have of dementia.

- Bethan thanked everyone for coming along!

Terminology:

- We discussed how everyone would like to be described e.g., 'person living with dementia', 'someone who has dementia'.

- 'People affected by dementia' was agreed on by the group as it covers all all people 'affected' by dementia, including people living dementia, family, friends and carers.

Experiences of occupational therapy:

- Everyone spoke about their experiences of occupational therapy – everyone had experience of occupational therapy either personally or through a family member.

- The group spoke very highly about their experiences of occupational therapy, some quotes included:

"I owe them my life…I'd be dead now"
"they were the first out of the blocks"
"they open doors"

- The way occupational therapy helps people stay independent and doing the things that are important to them was talked about.

- The group felt it was important to have access to an occupational therapist early on as soon as possible.

What the group is for:

- The group is being funded by a grant from the UK Occupational Therapy Research Foundation (UKOTRF).

- The group has been set up to make sure people affected by dementia have a say in how the research (Bethan's PhD) is carried out.

What the research is about:

- The research will be about occupational therapy for people living with early-stage / mild dementia.
- More details are on slide 5 of the power point presentation.

What will happen during the research:

- People affected by early-stage dementia will be invited to take part in interviews about their experiences.
- The group felt that interviews were a good way of getting people's views but highlighted that there should be different ways of gathering people's experiences. Suggestions included: -
    - Going to local groups, for example run by the Alzheimer's society or DEEP and asking people's views. This may be better for people who feel more comfortable speaking in a group and people can share ideas with each other.
    - Using video interviews or video diaries. The Dementia Diaries Project have used something similar.

Video Conferencing and Location of Next Meeting:

- Difficulties were experienced with the Video Conferencing facilities.

Appendix C: Evidence Synthesis 2017: Eligibility and Publication Criteria

Table 1: Synthesis Eligibility Criteria

Domain	Eligibility Criteria	Justification and / or Amendments
Population Participants Living with Early-Stage Dementia in the Community	**1. Diagnosis** **1.1.** Must have a diagnosis of dementia, any subtype, OR if the study comprised individuals living with and without dementia, a sub-analysis was conducted on data generated from participants living with dementia. AND	
	2. Dementia severity **2.1.** Must have a Mini Mental State Examination (MMSE) of 18 or above / Clinical Dementia Rating (CDR) 1.5 or below. Alternatively, a sub-analysis was conducted on a subgroup meeting this criterion. OR **2.2.** Experimental studies combining people living with 'mild' and 'moderate' dementia with an MMSE of 11 or above or CDR 2 or below: the study reported a mean sample MMSE 18 or above / mean sample CDR 1.5 or below. OR **2.3.** Non-experimental studies: Participant(s) must be described qualitatively as being in the 'early-stages' or as having 'mild' dementia if criteria 2.1 or 2.2. were not met. OR **2.4.** Participant(s) were providing their views on an occupational therapy intervention for 'early' stage dementia or on their experiences of 'early' stage dementia, irrespective of the severity of their dementia whilst participating. Studies were excluded if no indication of dementia severity was provided.	**2.1.** During full text screening, it became clear that there was a lack of consensus among potentially eligible studies about the use of standardised cognitive measures in determining 'early-stage' or 'mild dementia', ranging from a MMSE score of ≥15 to ≥21. Therefore, to facilitate standardisation, an MMSE of 18 or above was utilised, based on criteria used by Clare et al [89] in their study investigating Goal Orientated Cognitive Rehabilitation. **2.2.** During full text screening it was also observed that a number of studies recruited a mixed population, with 'mild' and 'moderate' dementia, and had not conducted a sub-analysis on those with 'mild' dementia. To avoid excluding studies of relevance, a mean sample score of MMSE 18 or above was utilised. Studies were excluded if they included participants with severe dementia, defined as an MMSE of 10 or below, unless a sub analysis was conducted on participants meeting criterion 2.1. **2.3.** During full text screening additional criteria were developed for non-experimental studies, since the MMSE or alternative quantitative measures of dementia severity were not always utilised.

Domain	Eligibility Criteria	Justification and / or Amendments
Population Participants not living with Early-Stage Dementia	**3.** Participants who were carers / family, occupational therapists and other professionals and individuals were included if the study pertained to occupational therapy for individuals with early-stage dementia living in the community, as defined above.	
Intervention (If applicable)	**4.** An intervention delivered, designed, supervised or managed by an occupational therapy practitioner. An occupational therapy practitioner was defined as: an occupational therapist, assistant, technician, support worker or student.	**4**. In clinical practice, occupational therapists use a range of generic and profession specific interventions which are often not explicitly described as 'occupational therapy' e.g., cognitive rehabilitation, cognitive stimulation, falls prevention, as attested by prior systematic reviews [84, 175]. Therefore, criteria centred on whether occupational therapy practitioners were interventionists or had a significant involvement in the design or management of an intervention. One amendment was made, to include interventions delivered, designed, supervised or managed in collaboration with other professionals. This was in response to the available evidence and reflects clinical practice, where occupational therapists routinely work in multi-disciplinary teams.
Comparison (Experimental studies)	No restrictions	Reflecting the exploratory nature of the review and the limited number of potentially eligible studies, no restrictions were placed upon outcomes, comparison interventions or context / setting.
Outcome (Experimental studies)	No restrictions	
Phenomenon of Interest (Non-experimental studies)	Occupational therapy or the study of occupation in relation to people who have early-stage dementia or their families / carers. Occupational therapy was defined as: - The clinical practice (e.g. assessment, intervention, evaluation, management) and education of occupational therapists, occupational therapy assistants, technicians and support workers. Occupation was defined as: - The study of occupation as it relates to occupational therapy and occupational science. This may include occupations described as 'activities or tasks'.	

Domain	Eligibility Criteria	Justification and / or Amendments
Study Design	No restrictions on research design / methodology, were placed however, a robust account of the study's research methodology was required. Literature reviews that did not outline systematic methods to scope, search and synthesise data were excluded. Editorials and any other non-research content in peer-reviewed journals were excluded.	To meet the reviews broad initial question and subsequent focussed questions, research with diverse methodologies was included. Evidence from a previous scoping review identified a limited number of RCTs reporting on the outcomes of occupational therapy intervention with people living with early-stage dementia, thus the inclusion of all experimental and non-experimental research was deemed necessary to reflect the current available evidence.

Table 2: Publication Criteria

Domain	Eligibility Criteria	Justification
Year of Publication	No restrictions	Evidence from a previous scoping review identified a limited number of potentially eligible studies between the years 2004 and 2015. No restrictions were placed on year of publication or location to increase the number of eligible studies.
Location	No restrictions	
Publication and evidence type	Research published in peer-reviewed journals only. Research published in non-peer reviewed journals and non-research publications, including grey literature and policy were excluded.	Given the limitations upon time and resources, publication and evidence type were limited to research published in peer-reviewed journals only.
Language	English only.	Resource limitations prevented the translation of research published in language other than English.

Appendix D: Evidence Synthesis Update 2022

Table 1: Amendments to Evidence Synthesis Eligibility Criteria, Information Sources and Search Strategy.

Eligibility and Publication Criteria	• **Intervention** (If applicable): An intervention delivered by an occupational therapy practitioner. Only one intervention programme was included using the broader criteria in 2017 when interventions designed, managed or supervised by occupational therapy practitioners were additionally eligible for inclusion [160]. • **Publication and Evidence Type:** Study design: Case studies were not included when updating if the case study constituted the sole publication relating to the intervention programme under investigation. • **Year of Publication**: From 1.01.2017 to 9.2.2022.
Information Sources	• OTSeeker was not utilised in 2022, however, all other information sources remained as in 2017.
Search Strategy	• The search strategy remained as used in 2017 for the following databases: MEDLINE, AMED, EMBASE, HMIC, JBI, PSYCHInfo. An amended search strategy (which constituted reducing the number of terms utilised for dementia) was used when searching CINAHL due to technical difficulties and is reported below. • Citation searching was restricted to studies relating to Community Occupational Therapy in Dementia (COTiD) only.

CINAHL Search Strategy 2022

S17	S6 AND S14 AND S15	Limiters - Published Date: 20170101-20221231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S16	S6 AND S14 AND S15	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S15	S7 OR S8 OR S9 OR S10	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S14	S11 OR S12 OR S13	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S13	"neurocognitive disorder*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S12	(MH "Alzheimer's Disease") OR (MH "Lewy Body Disease") OR "Alzheimer* Disease*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S11	(MH "Dementia") OR "dementia" OR (MH "Frontotemporal Dementia") OR (MH "Dementia, Vascular") OR (MH "Delirium, Dementia, Amnestic, Cognitive Disorders") OR (MH "Dementia, Multi-Infarct") OR (MH "AIDS Dementia Complex") OR (MH "Lewy Body Disease") OR (MH "Dementia, Senile") OR (MH "Dementia, Presenile") OR (MH "Dementia Patients") OR (MH "CADASIL")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display

CINAHL Search Strategy 2022 (Continued)

S10	(MH "Occupation (Human)") OR (MH "Occupational Therapist Attitudes") OR "occupation*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S9	"OT"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S8	"Occupational Therap*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S7	(MH "Occupational Therapy") OR "occupational therapy" OR (MH "Occupational Therapy Assistants") OR (MH "Students, Occupational Therapy") OR (MH "Occupational Therapy Practice, Research-Based") OR (MH "Occupational Therapy Practice, Evidence-Based") OR (MH "Occupational Therapy Assessment") OR (MH "American Occupational Therapy Association") OR (MH "Research, Occupational Therapy") OR (MH "Education, Occupational Therapy") OR (MH "Occupational Therapy Australia") OR (MH "Occupational Therapy Practice") OR (MH "Home Occupational Therapy") OR (MH "Occupational Therapy Service") OR (MH "World Federation of Occupational Therapy") OR (MH "Occupational Therapy Systematic Evaluation of Evidence") OR (MH "Canadian Association of Occupational Therapists")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display

CINAHL Search Strategy 2022 (Continued)

S6	S1 OR S2 OR S3 OR S4 OR S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S5	"early intervention"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S4	"mild"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S3	"early-stage"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S2	"early stage"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display
S1	(MH "Early Intervention") OR (MH "Early Diagnosis") OR "Early"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	Display

Appendix E: Population Synthesis: Quality Appraisal

Table 1: Quality Appraisal, Qualitative Studies Using CASP [113]

Abbreviations: N = No; Y = Yes; CT = Can't Tell	Nygård and Borell [134]	Nygård et al [133]	Nygård and Borell [145]	Nygård and Johansson [112]	Nygård and Öhman [136]	Nygård and Starkhammar [137]	Öhman and Nygård [140]	Vikström et al [143]	Nygård and Starkhammar [138]	Nygård [139]	Öhman et al [141]	Vikström et al [144]	Brorsson et al [130]	Brorsson et al [131]	Rosenberg and Nygård [142]	Chaplin and Davidson [132]
1. Was there a clear statement of the aims of the research? Consider:																
What the goal of the research was.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Why it is important.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Its relevance.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate? Consider:																
If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is qualitative research the right methodology for addressing the research goal.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research? Consider:																
If the researcher has justified the research design.	N	N	Y	N	Y	Y	Y	N	Y	Y	Y	?	Y	Y	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research? Consider:																
If the researcher has explained how the participants were selected.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Abbreviations: N = No; Y = Yes; CT = Can't Tell	Nygård and Borell [134]	Nygård et al [133]	Nygård and Borell [145]	Nygård and Johansson [112]	Nygård and Öhman [136]	Nygård and Starkhammar [137]	Öhman and Nygård [140]	Vikström et al [143]	Nygård and Starkhammar [138]	Nygård [139]	Öhman et al [141]	Vikström et al [144]	Brorsson et al [130]	Brorsson et al [131]	Rosenberg and Nygård [142]	Chaplin and Davidson [132]
If they explained why the participants, they selected were the most appropriate to provide access to the type of knowledge sought by the study.	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
If there are any discussions around recruitment (e.g. why some people chose not to take part).	N	N	N	N	N	N	N	Y	Y	N	N	Y	N	N	N	Y
5. Was the data collected in a way that addressed the research issue? Consider:																
If the setting for the data collection was justified.	N	Y	N	N	Y	N	N	N	Y	Y	N	N	N	Y	Y	N
If it is clear how data were collected (e.g. focus groups, semi-structured interview etc).	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If the researcher has justified the methods chosen.	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N
If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted or did they use a topic guide?).	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If methods were modified during the study. If so, has the researcher explained how and why.	Y	Y	Y	CT	CT	Y	CT	CT	Y	Y	Y	CT	CT	CT	CT	CT
If the form of data is clear (e.g. tape recordings, video material, notes etc).	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If the researcher has discussed saturation of data.	N	N	N	N	N	N	N	N	Y	N	N	Y	Y	N	Y	N

Abbreviations: N = No; Y = Yes; CT = Can't Tell	Nygård and Borell [134]	Nygård et al [133]	Nygård and Borell [145]	Nygård and Johansson [112]	Nygård and Öhman [136]	Nygård and Starkhammar [137]	Öhman and Nygård [140]	Vikström et al [143]	Nygård and Starkhammar [138]	Nygård [139]	Öhman et al [141]	Vikström et al [144]	Brorsson et al [130]	Brorsson et al [131]	Rosenberg and Nygård [142]	Chaplin and Davidson [132]
6. Has the relationship between research and participants been adequately considered? Consider:																
If the researcher critically examined their own role, potential bias and influence during a) formulation of the research questions b) data collection, including sample recruitment and choice of location.	CT	CT	CT	Y	CT	CT	CT	CT	CT	CT	CT	Y	CT	CT	CT	CT
How the researcher responded to events during the study and whether they considered the implications of any changes in the research design.	CT	CT	Y	CT	CT	Y	CT	Y	Y	Y	Y	CT	CT	CT	Y	CT
7. Have ethical issues been taken into consideration?																
If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.	N	N	N	N	N	N	N	N	N	N	N	Y	N	Y	N	N
If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study.	N	N	N	N	N	N	Y	Y	N	N	Y	N	Y	Y	Y	N
If approval has been sought from the ethics committee.	Y	Y	Y	Y	CT	CT	Y	CT	CT	CT	Y	CT	Y	Y	Y	Y
8. Was the data analysis sufficiently rigorous? Consider:																
If there is an in-depth description of the analysis process.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Abbreviations: N = No; Y = Yes; CT = Can't Tell	Nygård and Borell [134]	Nygård et al [133]	Nygård and Borell [145]	Nygård and Johansson [112]	Nygård and Öhman [136]	Nygård and Starkhammar [137]	Öhman and Nygård [140]	Vikström et al [143]	Nygård and Starkhammar [138]	Nygård [139]	Öhman et al [141]	Vikström et al [144]	Brorsson et al [130]	Brorsson et al [131]	Rosenberg and Nygård [142]	Chaplin and Davidson [132]
If thematic analysis is used. If so, is it clear how the categories / themes were derived from the data.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process.	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N
If sufficient data are presented to support the findings.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
To what extent contradictory data are taken into account.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.	CT	CT	CT	Y	CT	CT	CT	CT	CT	CT	CT	CT	CT	Y	CT	CT
9. Is there a clear statement of findings? Consider:																
If the findings are explicit.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If there is adequate discussion of the evidence both for and against the researcher's arguments.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst).	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
If the findings are discussed in relation to the original research question.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Abbreviations: N = No; Y = Yes; CT = Can't Tell	Nygård and Borell [134]	Nygård et al [133]	Nygård and Borell [145]	Nygård and Johansson [112]	Nygård and Öhman [136]	Nygård and Starkhammar [137]	Öhman and Nygård [140]	Vikström et al [143]	Nygård and Starkhammar [138]	Nygård [139]	Öhman et al [141]	Vikström et al [144]	Brorsson et al [130]	Brorsson et al [131]	Rosenberg and Nygård [142]	Chaplin and Davidson [132]
10. How valuable is the research? Consider:																
If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If they identify new areas where research is necessary.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y
If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.	N	N	Y	Y	N	N	N	N	Y	Y	Y	N	N	N	Y	Y

Table 2: Quality Appraisal, Cross-Sectional Studies Generating Quantitative Data Using the AXIS [116]

Abbreviations: N = No; Y = Yes; DK = Don't Know; N/A = Not Applicable	**Rosenberg et al [147]**	**Malinowsky et al [149]**	**Öhman et al [150]**	**Nygård et al [151]**	**Ryd et al [148]**	**Vermeersch et al [146]**
Introduction						
1. Were the aims/objectives of the study clear?	Y	Y	Y	Y	Y	Y
Methods						
2. Was the study design appropriate for the stated aim(s)?	Y	Y	Y	Y	Y	Y
3. Was the sample size justified?	N	Y	N	Y	Y	N
4. Was the target/reference population clearly defined? (Is it clear who the research was about?)	Y	Y	Y	Y	Y	Y
5. Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?	Y	Y	Y	Y	Y	Y
6. Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?	Y/N*	Y/N^	Y/N*	Y/N^	Y/N^	Y/N^
7. Were measures undertaken to address and categorise non-responders?	N	Y	N	N	N	N
8. Were the risk factor and outcome variables measured appropriate to the aims of the study?	Y	Y	Y	Y	Y	Y
9. Were the risk factor and outcome variables measured correctly using instruments/ measurements that had been trialed, piloted or published previously?	Y	Y	Y	Y	Y	Y
10. Is it clear what was used to determine statistical significance and/or precision estimates? (eg, p values, CIs)	Y	Y	Y	Y	Y	Y
11. Were the methods (including statistical methods) sufficiently described to enable them to be repeated?	Y	Y	Y	Y	Y	Y
Results						
12. Were the basic data adequately described?	Y	Y	Y	Y	Y	Y
13. Does the response rate raise concerns about non-response bias?	N/A	Y	N/A	N/A	N/A	N/A
14. If appropriate, was information about non-responders described?	N/A	N	N/A	N/A	N/A	N/A

Abbreviations: N = No; Y = Yes; DK = Don't Know; N/A = Not Applicable	Rosenberg et al [147]	Malinowsky et al [149]	Öhman et al [150]	Nygård et al [151]	Ryd et al [148]	Vermeersch et al [146]
15. Were the results internally consistent?	Y	Y	Y	Y	Y	Y
16. Were the results for the analyses described in the methods, presented?	Y	Y	Y	Y	Y	Y
Discussion						
17. Were the authors' discussions and conclusions justified by the results?	Y	Y	Y	Y	Y	Y
18. Were the limitations of the study discussed?	Y	Y	Y	N	Y	Y
Other						
19. Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	N	N	N	N	N	N
20. Was ethical approval or consent of participants attained?	Y	Y	Y	Y	Y	Y
*Convenience sampling utilised ^ Randomisation or alternative methods to minimise sampling bias were not reported.						

Appendix F: Intervention Synthesis: Quality Appraisal

Table 1: Quality Appraisal: RCTs, Using the Critical Appraisal Tool for Randomised Controlled Trials [117]

Key: N = No; Y = Yes; DK = Don't Know; N/A = Not Applicable	**Graff et al [43]**	**Voigt-Radloff et al [48]**	**Clare et al [89]**	**Kim [153]**	**Kim et al [154]**	**Santos et al [155]**	**Wesson et al [156]**	**Kumar et al [157]**
1. Was true randomisation used for assignment of participants to treatment?	Y	Y	Y	U	U	U	Y	Y
2. Was allocation to treatment groups concealed?	Y	Y	Y	U	U	U	Y	U
3. Were treatment groups similar at the baseline?	Y	Y/U[1]	Y	Y	U[2]	Y	Y	U[4]
4. Were participants blind to treatment assignment?	N	N	N	N	N	N	N	N
5. Were those delivering treatment blind to treatment assignment?	N	N	N	N	N	N	N	N
6. Were outcomes assessors blind to treatment assignment?	Y	Y	Y	Y	U	Y	U	U
7. Were treatment groups treated identically other than the intervention of interest?	U	U	U	U	U	U	U	U
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Y	Y	Y	Y	Y	U	Y	U
9. Were participants analysed in the groups to which they were randomised?	Y	Y	N	N	N	N	Y	U
10. Were outcomes measured in the same way for treatment groups?	Y	Y	Y	Y	Y	Y	Y	Y
11. Were outcomes measured in a reliable way?	U	Y	U	U	U	U	U	U
12. Was appropriate statistical analysis used?	Y	Y	Y	Y	Y/U[3]	U	Y	Y
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?	Y	Y	Y	Y	Y	Y	Y	Y

[1] Significant difference in financial difficulties reported between groups at baseline was not controlled for during analysis – authors state that this is not a known predictive factor for functional decline.

[2] Significant differences in the degree of disorientation and memory between groups as measured on the Clinical Dementia Rating (CDR). It does not appear that this was controlled for during analysis.

[3] No power calculation was reported.

[4] Significant differences in QoL were reported between groups at baseline – it is unclear if this was controlled for during analysis.

Table 2: Quality Appraisal: Quasi-experimental Studies, Using the Critical Appraisal Tool for Quasi-Experimental Studies [117]

Key: N = No; Y = Yes; U = Unclear; N/A = Not Applicable	**Controlled Trials**			**Quasi-Experimental Studies**			
	Viola et al [158]	**Dooley and Hinojosa** [95]	**Neely et al** [98]	**Chung** [160] Prospective	**Sprange et al** [159] Prospective	**Ibarria et al** [162] Retrospective	**Matuzono et al** [161] Retrospective
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first?)	Y	Y	Y	Y	Y	Y	Y
2. Were participants included in any comparisons similar?	Y	Y	Y	Y	Y	Y	N[1]
3. Were participants included in any comparisons receiving similar treatment / care other than the exposure or intervention of interest?	U	U	U	U	U	U	U
4. Was there a control group?	Y	Y	Y	N/A	N/A	N/A	Y
5. Were there multiple measurements of the outcome both pre and post the intervention / exposure?	Y	Y	Y	Y	Y	Y	Y
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	U	U	U	Y	Y	N/A[2]	N/A[3]
7. Were the outcomes of participants included in any comparisons measured in the same way?	Y	Y	Y	Y	Y	Y	Y
8. Were outcomes measured in a reliable way?	U	Y	U	U	U	Y	U
9. Was appropriate statistical analysis used?	Y/U[4]	Y/U[4]	Y/U[4]	Y/U[4]	Y	Y/U[4]	Y/U[4]

[1] Significant differences in MMSE scores between intervention group and non-intervention group at baseline. Unclear if this was controlled for during analysis.

[2] This was a retrospective study. However, 201 potential participants were excluded from the data set for a variety of reasons, including not completing 3 months of the intervention. No data provided on why those potential participants did not complete 3 months of the intervention.

[3] Again, this was a retrospective study, it is not clear how many people were ineligible for inclusion in the analysis because they did not complete the intervention under investigation.

[4] No power calculation reported.

Table 3: Quality Appraisal: Case Reports Using the Critical Appraisal Tool for Case Reports [118]

Key: N = No; Y = Yes; U = Unclear; N/A = Not Applicable	**Navarro et al [163]**	**Adam et al [94]**	**de Oliveira Assis et al [164]**	**Josephsson et al [96]**	**Josephsson et al [97]**	**Graff et al [165]**	**Nygård et al [112]**	**Lindqvist and Borell [166]**
1. Were patient's demographic characteristic clearly described?	Y	Y	Y	Y	Y	Y	Y	Y
2. Was the patient's history clearly described and presented as a timeline?	N	Y	Y	N	N	Y	N	N
3. Was the current clinical condition of the patient on presentation clearly described?	Y	Y	Y	Y	Y	Y	Y	Y
4. Were diagnostic tests or assessment methods and the results clearly described?	Y	Y	Y	Y	Y	Y	N/A	N/A
5. Was the intervention(s) or treatment procedure(s) clearly described?	Y	Y	Y	Y	Y	Y	Y	Y
6. Was the post-intervention clinical condition clearly described?	Y	Y	Y	Y	Y	Y	Y	Y
7. Were adverse events (harms) or unanticipated events identified and described?	N	N	N	N	N	N	N	N
8. Does the case report provide takeaway lessons?	Y	Y	Y	Y	Y	Y	Y	Y

Table 4: Quality Appraisal: Qualitative Studies, Using CASP [113]

Key: N = No; Y = Yes; U = Unclear; N/A = Not Applicable	**Chung [167]**	**Vx8Cummins and Warren [168]**
1. Was there a clear statement of the aims of the research?		
What the goal of the research was	U	Y
Why it is important	Y	Y
Its relevance	Y	Y
2. Is a qualitative methodology appropriate? Consider:		
If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants	Y	Y
Is qualitative research the right methodology for addressing the research goal.	U	Y
3. Was the research design appropriate to address the aims of the research? Consider:		
If the researcher has justified the research design.	N	Y
4. Was the recruitment strategy appropriate to the aims of the research? Consider:		
If the researcher has explained how the participants were selected.	N	Y
If they explained why the participants, they selected were the most appropriate to provide access to the type of knowledge sought by the study.	N	Y
If there are any discussions around recruitment (e.g. why some people chose not to take part)	N	Y
5. Was the data collected in a way that addressed the research issue? Consider:		
If the setting for the data collection was justified	N	Y
If it is clear how data were collected (e.g. focus groups, semi-structured interview etc.)	Y	Y
If the researcher has justified the methods chosen	N	Y
If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted or did they use a topic guide?)	N	Y
If methods were modified during the study. If so, has the researcher explained how and why.	N/A	N/A
If the form of data is clear (e.g. tape recordings, video material, notes etc)	N	Y
If the researcher has discussed saturation of data	N	N

Key: N = No; Y = Yes; U = Unclear; N/A = Not Applicable	Chung [167]	Vx8Cummins and Warren [168]
6. Has the relationship between research and participants been adequately considered? Consider:		
If the researcher critically examined their own role, potential bias and influence during a) formulation of the research questions b) data collection, including sample recruitment and choice of location.	N	U
How the researcher responded to events during the study and whether they considered the implications of any changes in the research design.	U	U
7. Have ethical issues been taken into consideration?		
If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.	N	N
If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study.	N	Y
If approval has been sought from the ethics committee.	U	Y
8. Was the data analysis sufficiently rigorous? Consider:		
If there is an in-depth description of the analysis process	N	N
If thematic analysis is used. If so, is it clear how the categories / themes were derived from the data.	N	N
Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process.	N	N
If sufficient data are presented to support the findings.	N	Y
To what extent contradictory data are taken into account	Y	Y
Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.	U	U
9. Is there a clear statement of findings? Consider:		
If the findings are explicit	Y	Y
If there is adequate discussion of the evidence both for and against the researcher's arguments	N	Y
If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)	N	Y
If the findings are discussed in relation to the original research question.	U	Y
10. How valuable is the research? Consider:		
If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature.	Y	Y
If they identify new areas where research is necessary.	N	Y
If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.	N	N

Appendix G: Intervention Synthesis: Intervention Programmes

Table 1: Intervention Programmes, Substantive Characteristics

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
Occupational Therapy			
Community Occupational Therapy in Dementia (COTiD) [43, 48, 165]	**Aim:** 1. To Improve the performance or functioning of people living with mild – moderate dementia and their caregivers in meaningful daily activities. 2. To enhance successful interaction between the caregiver and person living with dementia. **Theory**: MOHO, Task Analysis **Development:** Developed through a consensus process and pilot testing [128, 129].	**Assessment:** 4 x 1-hour sessions to conduct an 'OT diagnosis' and establish personalised goals consisting of: • Narrative interview with person living with dementia using the OPHI and with caregiver using the ethnographic interview. • Observation of the person's ability to perform relevant activities and use compensatory and environmental strategies as well as observation of primary caregivers' supervision skills. • An evaluation of whether it is possible to modify the persons home and environment. • Identifying compensatory and environmental strategies to adapt activities and the environment to the persons habits and cognitive abilities. **Goal Setting:** Goal setting with caregiver and person living with dementia using the COPM. **Intervention:** 6 x 1-hour sessions delivering 'OT Treatment' consisting of: • Teaching to optimise compensatory and environmental strategies to improve performance of activities. • Caregiver training using cognitive and behavioural interventions to use effective supervision, problem solving and coping strategies to support the person living with dementia in their own autonomy and.	**Interventionist:** OT Graff et al [43]: 'Experienced' OT's – trained in intervention for approx. 80 hours and had 240 hours experience delivering COTiD in accordance with COTiD guideline. Voigt-Radloff et al [48]: OT's received 16 hours of seminars and one pilot dyad for 10 sessions. **When & how much?** 10 x 1 hour over 5 weeks **How?** Face to face, Dyad **Where?** Home
Supporting everyday activities in Dementia [96, 97]	**Aim:** Supporting occupation rather than improving cognitive abilities in dementia. **Theory:** MOHO **Development**: NR	**Assessment**: Informal observation of engagement in activities at day unit and interviews with participants, staff and relative. **Goal Setting:** Based on interviews and observation, one ADL was chosen for participants using the criteria: they were motivated to perform the activity, it was part of their habits, and they had started to demonstrate a decline in ability to perform the activity. **Intervention: I**ndividualised intervention programme to enable performance that is less dependent on episodic and semantic memory skills and higher order cognitive functions and more dependent on procedural memory skills. Components: external guidance (signs on drawers, closets, organisation of objects) and verbal (prompts, cues, and answers) and physical support (demonstrating). Emphasis also placed on motivational factors and habits.	**Interventionist:** OT **When & how much?** Variable: 5 to 30 minutes, 3 – 5 times per week, over between 5 and 7 weeks. **How?** Individual **Where?** Day care unit

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
Brief Occupational Therapy Intervention [95]	**Aim**: NR **Theory:** Person-environment fit framework [299] to guide strategy recommendations. **Development**: NR	**Assessment:** Assessment of Instrumental Functioning (AIF) **Goal Setting**: NR **Intervention**: Based on the AIF, production of a report summarising findings and providing occupational therapy recommendations (strategies) to the caregiver to help maximise the person living with dementia's quality of life and ability to function. During a 30-minute home visit, recommendations reviewed with person and caregiver. Discussion of potential problems associated with implementing recommendations as well as additional suggestions deriving from this discussion. No opportunities for practicing strategies provided. Strategies fell into three categories – environmental modifications (e.g. labelling drawers, posting emergency telephone numbers, pill reminders), caregiver approaches (advice on ways to interact with person living with dementia to enable more opportunities for success in activities), and community-based assistance (e.g. referrals to locally available services, including carer support groups, information about financial assistance, day services and driving assessments).	**Interventionist:** OT **When & how much?** 2 home visits over an unspecified period of time. **How?** Face to face, dyad. **Where?** Home
Cognitive Rehabilitation			
Goal-oriented Cognitive Rehabilitation [89]	**Aim**: Reducing functional disability and maximising engagement in activity and social participation. **Theory:** Cognitive Rehabilitation **Development**: NR	**Assessment**: NR **Goal setting:** COPM to identify personalised rehabilitation goals, with two goals forming the focus of therapy. **Intervention:** Individualised intervention, addressing personally meaningful goals including the following components: • Compensatory strategies and practical aids; Strategies to facilitate new learning, using face name learning; Practicing maintaining concentration and attention and stress management. • Encouragement to work on goals and practice strategies between sessions. • Involvement of caregiver during last 15 minutes of sessions to support implementation between session.	**Interventionist:** OT **When & how much?** 1 hour per week over 8 weeks. **How? Face to face** Individual and dyad (final 15 mins of each session) **Where?** Home
Cognitive Rehabilitation and Cognitive Training [153]	**Aim**: Decreasing functional disability and maximising social participation and engagements in activities of daily living. **Theory:** Cognitive Rehabilitation **Development**: NR	**Assessment**: NR **Goal setting:** Goal setting using the COPM, with intervention focussing on one personally meaningful goal. **Intervention:** • Individualised element: Practical strategies and aids, compensatory strategies (e.g., using a notebook), and stress management techniques to improve performance and functioning.	**Interventionist:** NR Author OT **When & how much?** 1 hour each week over 8 weeks. **How? Face to face** 30 mins Individual, 30 mins group **Where?** NR, recruited from memory clinic.

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
		• Group cognitive training: Practicing time and place orientation through paper and pencil tasks, using a calendar and personal memory book or phone; Matching faces and names and learning memory; Sustaining attention through paper and pencil exercises.	
Cognitive management of daily life activities [94]	**Aim**: To optimise daily living activities to increase autonomy. **Theory:** NR **Development:** NR	**Assessment:** Battery of assessments for both patient and caregiver, including neuropsychological assessments; Interview about current interests and expertise, needs and environmental barriers; Observational assessment of activities identified as priority. **Goal setting:** Defining 2 primary objectives and signing a 3-month rehabilitation programme – intervention tailored to these objectives / goals. **Intervention**: • Tailored compensatory / problem solving strategies and caregiver training. • Social work input.	**Interventionist:** Neuropsychologist, Occupational Therapist and Social Worker. **When & how much?** 2 x per week for 3 months **How?** Face to face, individual / dyad. **Where?** Day Centre
Cognitive Training			
Collaborative Cognitive Training [98]	**Aim**: Caregiver and person living with dementia together acquire and practice strategies to support everyday mnemonic and occupational performance. **Theory:** Theory of learning methods: hierarchical cueing and spaced retrieval. **Development**: NR	**Assessment:** NR; **Goal setting:** NR **Intervention**: • Psycho-education about dementia and rationale about how to support memory and occupational performance. • Collaborative Training: Caregiver and person living with dementia learning and practicing strategies together to support two standardised activities 1. a face-name task using spaced retrieval and letter cues strategies and 2. table setting activity using hierarchical verbal cueing. • Teaching caregivers to use hierarchical cueing strategies through role modelling.	**Interventionist:** OT and neuropsychologist **When & how much?** 1 hour a week x 8 weeks & 1 psycho-education session 30mins / 40mins in length. **How?** Face to face, dyad. **Where?** Home
Reminiscence			
Intergenerational Reminiscence [160]	**Aim**: To promote interaction, teach and inform, and reinforce self-image. **Theory:** Literature related to autobiographical memories with emotional contents and 'memory bumps' associated with adolescence and young adulthood. **Development**: NR	**Assessment:** NR; **Goal setting:** NR **Intervention**: • Encouraging and facilitating the sharing, teaching and discussion of pleasurable and positive life experiences of adolescence and adulthood in accordance with 15 reminiscence topics. Structured to focus on three reminiscence functions: promoting interaction, teach and inform and reinforcing self-image. • Using interactive old-time activities and reminiscence props to aid memory recall and to provide structured opportunities to talk and share past experiences and wisdom. • Supporting the creation of a personalised story book on the reminiscence topics.	**Interventionist:** Youth volunteers – trained during a workshop and supervised by an OT. **When & how much?** 12 weekly sessions Individual? for 1.5 hours. **How?** Face to face, individual. **Where?** Community venues

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
Self-Management and Peer Support			
Journeying through Dementia [159]	**Aim**: To encourage continued participation by people following a dementia diagnosis and increase self-efficacy. **Theory:** Social Cognitive Theory **Development:** Intervention developed based on the Lifestyle Matters programme, which was developed from a US intervention, Lifestyle Redesign.	**Assessment:** NR; **Goal setting:** NR **Intervention**: Group sessions consist of a 'manualised participant-directed self-management programme' and includes the following themes to facilitate learning, the development of coping strategies and mutual support on the following topics: - • Beginnings: Introductions, principles of self-management, exploring differences • Ways of thinking about dementia: What is dementia, effects on everyday life, challenging stereotypes, sharing coping strategies • Keeping physically well: Relationship between physical and mental well-being, embedding healthy activity in everyday life and diet • Memory: Strategies to aid memory, impact on everyday life, learn and practise new techniques • Keeping mentally well: Relationship between anxiety and memory and dementia and stress • Endings: celebration of achievements and how to move forward. Occupational therapists facilitate participants to select topics of relevance to them and explore them using didactic teaching, peer sharing and active experimentation with support from peers and facilitators. Caregivers joined group sessions on three occasions – first, middle and last. Four Individual sessions are delivered by an occupational therapist, once prior to the commencement of group sessions to introduce the programme and build a relationship. Three sessions throughout programme delivery are provided to provide "*enhanced techniques… for communication and to scaffold memory to promote engagement"* including cue cards, written materials providing summaries of meetings and diaries for appointments or meeting dates (p5).	**Interventionist:** OT **When & how much?** 2 hours per week x 12 (group) 4 x individual sessions at home **How?** Face to face, Group & Individual **Where?** Community Venue & Home
Memory training and psychosocial support [167]	**Aim:** To empower people living with dementia and caregivers and to promote a positive caregiving culture. **Theory: NR**	**Assessment:** NR **Goal Setting:** NR **Intervention:** Group sessions were delivered in 'integrated' and 'parallel' groups. During integrated groups with caregivers / families and people living with dementia the following content was described: - • Education about memory. • Practicing memory strategies and encourage caregivers to practice these in a natural environment.	**Interventionist:** OT **When & how much?** 6 weeks **How?** Face to face, group **Where?** NR

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
	Development: Telephone survey conducted with 4 family caregivers and 2 people living with dementia. Emphasis was placed on the cultural context in Hong Kong, whereby extended families play an active role in caring for relatives, therefore, multiple caregivers / family members attended alongside the individual with dementia.	• Participation in a task-oriented activity – this involved making a photograph frame (to promote communication and co-operation and reinforce sense of achievement). Parallel groups were described as groups that included people living with dementia only and groups for caregivers / family only. Contents of groups for people living with dementia included: - • Discussion of worries and concerns in a supportive environment. • Therapeutic activities designed with 'just-right' challenges, e.g. craft and singing to encourage participation. Groups for caregivers were facilitated by a social worker, which included introducing caring strategies and community resources. Sharing of caring experiences and mutual support was encouraged.	
Assistive Technology (AT)			
Personalised Ambient-Assisted Occupational Therapy [163]	**Aim**: To address psychological and behavioural symptoms of dementia. **Theory:** NR **Development:** Builds on previous work by the authors about the development of the assistive technology (not OT specific).	**Assessment:** NR; **Goal setting:** NR **Intervention**: Occupational therapist guided the performance of 3 selected activities during home visits and facilitated communication between the person living with dementia and their caregiver. Two user interfaces were used: a touch screen computer located in the home environment (AnswerBoard) and a mobile phone (AnswerPad), with the latter additionally gathering data on activity and location. Intervention delivered through the devices was personally tailored by an occupational therapist and comprised: - • Prompting to facilitate awareness of time and place, information on activities and reminders. • Games to facilitate cognitive stimulation and cognitive training. • Intervening in the event of behaviour that challenges by communicating with caregivers or the individual with dementia and recommending an appropriate response / action. • Providing feedback to caregivers about the location and activity of the individual with dementia.	**Interventionist:** OT **When & how much?** 3 home visits a week for 12 weeks (OT) – length of visits NR. **How?** Face to face, dyad **Where?** Home

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
Cognitive Technologies in Geriatric Rehabilitation [164]	**Aim**: To improve performance in activities of daily living and stimulate memory, language, calculation, and spatial-temporal organisation. **Theory:** Cognitive rehabilitation including reality orientation, errorless learning. **Development**: AT developed by the Mechanical Projects Laboratory of the Universidade Federal de Minas Gerais, Brazil.	**Assessment:** NR; **Goal setting:** NR **Intervention**: A home: • Adaptations to the environment, including orientation plaques, calendar and routine organiser to support spatial and temporal orientation. • Training caregivers in using equipment and intervention goals – for example, the calendar – showing date, to participant in the morning and at night; organising participants routine and writing down on the organiser; providing encouragement to consult with organiser if they had a question about when an activity was occurring or when the alarm sounded. • Enhancing sense of competence and integration with family in meaningful activities based on occupational history. At outpatient clinic: • Activities to stimulate cognitive functions, including reality orientation and games with words, geometric figures, numbers and images using the computer program and activity board.	**Interventionist:** NR but intervention described as an 'occupational therapy intervention'. **When & how much?** 2 x 50 minutes per week over 4 months. **How?** Individual / dyad **Where?** Home & outpatient clinic.
Management of temporality using time aids [112]	**Aim:** To find possible solutions to temporal difficulties using time aids. **Theory:** NR **Development:** Time aids were mapped based on criteria for usefulness and clinical experience.	**Assessment:** Discussion about experiences and perception of time, problems connected to time in everyday life and how these problems are solved. **Goal Setting:** NR **Intervention:** Demonstration of potential aids – 7 adaptive clocks, one medicine dosette and 2 calendars. Informal oral contract developed which detailed: 1. How the participant would use the time aid, 2. The period of trying the aid, 3. How aid should be evaluated 4. Caregivers' role in supporting the use of the time aid.	**Interventionist:** OT **When & how much?** 2 sessions to discuss difficulties and develop an intervention contract. 6 weeks without contact to provide an opportunity to learn and use time aids. **How?** Face to face, dyad and individual **Where?** Home
Individually Chosen Assistive Technology [166]	**Aim:** To provide AT based on an individual identified and expressed problems, needs, desires, related to activities that are meaningful to them. **Theory:** Process and procedures based on the 9 steps model proposed by Björneby et al (1999) at the Norwegian Centre for Dementia Research. **Development:** NR	**Assessment:** Semi-structured interview based on the Multidimensional Functional Assessment Questionnaire (OMFAQ) and the Comprehensive Assessment of Prospective Memory (CAPM) to identify persons abilities, habits, context, use of everyday technology and difficulties related to cognition. **Goal Setting:** COPM to identify problems that need to be solved. **Planning**: With team: Discussion based on assessment and goal setting to identify appropriate technology and alternatives. With person living with dementia and caregivers: Making recommendations about AT and facilitate / enable informed choice about technology.	**Interventionist:** OT **When & how much?** 5-7 home visits. **How?** Face to face and phone call, dyad and individual **Where?** Home

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
		Intervention: Implement chosen solutions by providing AT, instruction of how to use AT and training during 1-5 sessions as needed. Phone call follow up. Evaluate if AT has worked as planned three times – home visits if AT has failed.	
Multimodal Intervention			
Multi-domain Cognitive Programming Group [154]	**Aim**: NR **Theory:** NR **Development:** NR	**Assessment:** NR, **Goal setting:** NR **Intervention**: Multi-modal intervention: • Exercise therapy (10mins per day). • Cognitive occupational therapy (1 hour 10 mins per week): Remembering names of different items and craft activities. • Recollection therapy (1 hour 10 mins per week): Recollection therapy using familiar images of Korean nature, Korean culture and familiar environments. • Art therapy (1 hour 10 mins per week). • Horticultural therapy (1 hour 10 mins per week). • Music therapy (1 hour 10 mins per week).	**Interventionist:** 2 x OT's **When & how much?** 2.5hours x 5 per week over 24 weeks. **How?** Face to face, Group **Where?** Clinic
Novel Occupational Therapy Intervention [157]	**Aim**: NR **Theory:** States programme based on Graff et al [43] and MOHO, CMOP, biomechanical and cognitive disability frame of reference. **Development:** NR	**Assessment:** NR; **Goal setting:** NR **Intervention**: Multi-modal intervention: • Relaxation (10 minutes) • Physical exercises (10 minutes) • Personal activities (15 minutes): a) personal care of body, dressing and undressing of upper and lower garments; b) household tasks such as arranging bed sheets, gardening and counting currency. • Cognitive exercise (20 minutes): loud reading, dual task activities, puzzles. • Recreational activity (15 minutes): playing indoor games, table games, quizzes, organized social events.	**Interventionist:** NR **When & how much?** 70 minutes x 2 per week over 5 weeks. **How?** Face to face, group. **Where?** NR: recruited from memory clinic.
Multidisciplinary Rehabilitation Programme [155, 158]	**Aim**: NR **Theory:** NR **Development:** NR	**Assessment:** NR; **Goal setting:** NR **Intervention:** Multi-modal intervention: • Cognitive rehabilitation (1.5hrs per week): Exercises to improve attention, memory, spatial and temporal orientation, and adaptations. • Computer-assisted cognitive training (1.5hrs per week): Engagement in memory and attention games. • Art therapy (1.5hrs per week): Aimed at stimulating cognitive, emotional, and interpersonal skills through expressive and artistic techniques.	**Interventionist:** NR **When & how much?** 2 x per week for 5 hours for 12 weeks. Total of 12hrs of intervention. Caregiver Psychoeducational support group 2 x per week for 1.5 hours. **How?** Face to face, group **Where?** Day hospital

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
		• Occupational therapy (1hrs per week): To develop resources and strategies to improve the completion of functional goals, including training in basic (hygiene, feeding, getting dressed) and instrumental activities of daily living (paying bills, shopping, leisure, and social activities). Patients and caregivers were instructed about household adaptations to enhance orientation and autonomy. In addition, caregivers were also coached to reinforce exercises and habits at home. • Physiotherapy (1hrs per week): was aimed at improving balance and preventing falls through exercises. • Speech therapy (1hrs per week): To enhance general communication and communication strategies. • Cognitive stimulation (1hrs per week): Logic games. • Physical training (1hrs per week): Strength and balance exercises and group walks and stretching sessions. • Caregivers received psycho-educational workshops and psychological support group sessions twice a week for 1.5 hours each. Included explaining clinical aspects of disease, sharing personal experiences.	
Integrated Psychostimulation Programme (IPP) [162]	**Aim**: To enhance, preserve, and promote independence of patients in BADL and reduce caregiver burden. **Theory:** Based on principles of cognitive neuroplasticity, neuropsychology, and behaviour modification techniques. **Development**: NR	**Assessment:** NR; **Goal setting:** NR **Intervention**: Multi-modal intervention: • Cognitive Stimulation Workshop (1.5 hrs per day). • Maintenance of Activities of Daily Living (30 mins per day). • Psycho-expression (1 hr per day). • Maintenance of Activities of Daily Living (45 mins per day). • Occupational Therapy Workshop (1.25 hrs per day): Participation in board games, occupational choice tasks and creative activities.	**Interventionist:** NR **When & how much?** 8 hours x 5 per week – however, varied between participants. Duration – variable, between 3 months and 1 year **How?** Face to face, Group & Individual (maintenance of ADL provided on individualised basis) **Where?** Day Centre
Ambulatory Cognitive Rehabilitation [161]	**Aim**: NR **Theory:** NR **Development:** NR	**Assessment:** NR; **Goal setting:** NR **Intervention**: Multi-modal intervention: • Occupational Therapy (3 hours per week): Group tasks (e.g., leatherwork, knitting and flower arrangement). • Physical Therapy (2 hours per week): Massed calisthenics. • Speech Therapy (2 hours per week): Chorus music and watching theatrical performances.	**Interventionist:** NR **When & how much?** Variable: up to 7 hours per week for 1 year. **How?** Face to face, group. **Where?** Day Centre

Experimental Intervention and Studies	Why? Aim, Theory and Development	What? Contents and Components	Who? When and How Much? How? Where?
Cognitive management of daily life activities [94]	**Aim**: To optimise daily living activities to increase autonomy. **Theory:** NR **Development:** NR	**Assessment:** Battery of assessments for both patient and caregiver, including neuropsychological assessments; Interview about current interests and expertise, needs and environmental barriers. • Observational assessment of activities identified as priorities in objectives. **Goal setting:** • Defining 2 primary objectives and signing a 3-month rehabilitation programme – intervention tailored to these objectives / goals. **Intervention**: Multi-modal Interdisciplinary intervention: • Tailored Therapeutic strategies. For participant described in the study this involved encouraging and training them to use a notebook to record appointments and things they needed to do through role playing. Training caregiver to encourage use of notebook at home. • Simplifying knitting instructions, enlarging pattern, multiple patterns alongside each other's, Practicing knitting – using errorless learning – support to correct error removed gradually, crossing out stitches already completed, writing number of stitches needed. Encouragement to knit at home. Monitoring progress at home – monitoring for new difficulties, encouragement to maintain motivation. • Social work input	**Interventionist:** Neuropsychologist, Occupational Therapist and Social Worker. **When & how much?** 2 x per week for 3 months **How?** Face to face, individual, group or dyad. Must have caregiver to aid transfer of strategies to home environment. **Where?** Day Centre
Falls Prevention			
Tailored Falls Prevention Programme [156]	**Aim**: NR **Theory:** Tailoring according to the Allen's Cognitive Disabilities Model. **Development:** NR	**Assessment:** Using the Westmead Home Safety Assessment for environmental and behavioural fall hazards. And the LACLS-5. **Goal setting:** NR **Intervention**: • Physiotherapy: Strength and balance training exercises and home hazard reduction. • Occupational Therapy: Booklet of home safety recommendations amended using LACLS-5, including descriptions of hazards, why situations are hazardous and habits to change, items to buy and home modification service referrals. Provision of smaller items by OT to trial before participants purchased.	**Interventionist:** OT and PT **When & how much?** 6 x OT home visits & 3 phone calls; 5 x PT home visits over 12 weeks. Session duration NR. **How?** Face to face, dyad **Where?** Home

Abbreviations: Not Reported (NR), Community Occupational Therapy in Dementia (COTiD) Assistive Technology (AT), Activities of Daily Living (ADL), Basic Activities of Everyday Living (BADL), Occupational Therapy (OT), Model of Human Occupation (MOHO), Canadian Model of Occupational Performance (CMOP), Canadian Occupational Performance Measure (COPM), Occupational Performance History Interview (OPHI).

Appendix H: Intervention Synthesis: Views and Experiences, Qualitative Data

Table 1: Themes Identified by Cummins and Warren [168]: Intervention Content.

Themes Identified by Cummins and Warren [168]	Intervention Content Identified from Data Extracts and Author Summary
Reaffirming peoples' right to be independent'	• Education. • Advocacy. • Empowerment.
Looking beyond the diagnosis	• Assisting people living with dementia to "*re-focus their attention not necessarily on a label but on life in general*" (p7) • Supporting family, by "*dispelling the myths that everything is going to go horribly wrong in a couple of months*" (p7)
Facilitating occupational performance	• Interventions based on MOHO and the Canadian Occupational Performance Measure (COPM). • Addressing psychological impact of dementia through: Anxiety management, coping skills, relaxation, maintaining mental health and self-esteem. • Grading and adapting occupations. • Encouraging engagement in meaningful occupation and exploring interests. • Adapting the home environment, including using memory aids and strategies e.g., visual aids, memory checklists, calendars, charts, pocket diaries, lists, calendar clocks and memory boards. • Adapting the social environment by: Collaborating with family, providing education about dementia and its impact on occupations. • Providing information about community resources and liaising with services.
Enabling occupational identity	• Re-introducing previous meaningful occupations. • Exploring new occupations.

Table 2: Themes Identified by Sprange et al [159]: Intervention Content and Format.

Themes identified by Sprange et al [159]	Views on Intervention Identified from Data Extracts and Author Summary (Key: Positive: + Negative: -)
Intervention Content	Views on intervention content: + Flexibility of intervention group programme to explore different and unplanned topics (participants) + Caregiver sessions to maintain contact (participants) + Learning something new every week, including strategies e.g., daily diaries, memory cards (participants) - More information about implementation of activities in information sent home with PLWD for caregivers wanted (participants)
Optimum Programme Format and Delivery	Views on format and delivery: + Length of intervention adequate to learn skills and avoid 'dependency' (facilitators) - Disappointment that the programme was not permanent or couldn't continue for longer in a different format – less frequent (participants) + Size of group enabled inclusivity by sharing and listening (participants) + Venue – accessible, centrally located, with parking and good transport links, big table, coffee (participants) + Outings (art gallery and library) and visits outside were valued, providing opportunities to practice skills (participants) + Involvement of caregivers to alleviate anxiety, provide caregivers with information to take forwards learning from programme (facilitators)
Facilitator Training and Programme Facilitation	Views on training: + Weekly supervision for facilitators supporting programme tailoring and session planning. Support required was dependent on experience of facilitator (facilitators) + Supervision most effective directly after group delivery (facilitators) + Higher level of supervision at the start of delivery (facilitators) Views on facilitation: + Engaging facilitators "*They were fun and.. you felt confident in them. They were imaginative*" (p7) (participants) + Good facilitation encouraged attendance "*I thought it was run exceedingly well, in fact if it hadn't done I might have made an excuse and not go. But no I always felt ready to go*" (p7) (participants)

Appendix I: Intervention Synthesis: Quantitative Outcomes

Table 1: Clinical Outcomes: Participants Living with Dementia

Effect sizes, *p* values and CI's are presented if reported by studies. Shaded boxes indicate that an outcome measure was not used.

Modality	Study		Clinical Outcomes: Participants with dementia				
			Occupational Performance	**Affect**	**Quality of Life & General Health Status**	**Cognition & Dementia Severity**	**Other clinical outcomes**
Analysis: Intervention vs Control							
Occupational Therapy	COTiD	Graff et al [43, 44]	AMPS: 2.5 (p = <0.0001) IDDD: 2.3 (p = <0.0001) Follow up: AMPS: 2.7 (p = <0.0001) IDDD: 2.4 (p = <0.0001)	CSD: 0.7 (p = <0.0001) Follow up: CSD: 0.7 (p = <0.001)	DEMQOL: 1.3 (p = <0.0001) GHQ-12: 0.8 (p = <0.0001) Follow up: DEMQOL: 1.1 (p = <0.0001) GHQ-12: 0.7 (p = 0.001)		
		Voigt-Radloff et al [48]	IDDD: NS Follow up: IDDD: NS	CSD: NS Follow up: CSD: NS	DEMQOL: NS GHQ-12: NS Follow up: DEMQOL: NS GHQ-12: NS		
	Dooley and Hinojosa [95]		PSMS: p = <0.001		AAL-AD: p = <0.001		
Cognitive Rehabilitation	Clare et al [89]		COPM: Performance: 0.908 (CI 0.248-1.568), Satisfaction: 0.865 (CI 0.208 – 1.521); ILS: Health and Safety Subscale: NS Follow up: ILS: Health and Safety Subscale: NS	HADS: NS Follow up: HADS: NS	QoL-AD, Self-Rating: NS QoL-AD, Proxy: NS Follow up: QoL-AD, Self-Rating: NS QoL-AD, Proxy: NS	MARS (Total Score): NS; TEA: NS; Verbal Fluency: NS Follow up: MARS (Total Score): NS; TEA: NS; Verbal Fluency: NS	RMBT-II: NS Follow up: RMBT-II: NS
	Kim [153]		Post Intervention COPM: Performance: p = <0.01 COPM Satisfaction: p = <0.01 MBI: NS		QoL-AD, Self-Rating: p = <0.01	LOCTA-G: NS; MMSE: NS (Orientation Sub-scale p = < 0.01)	

Modality	Study	Clinical Outcomes: Participants with dementia				
		Occupational Performance	**Affect**	**Quality of Life & General Health Status**	**Cognition & Dementia Severity**	**Other clinical outcomes**
Cognitive Training	Neely et al[1] [98]				Researcher developed assessments: Object Recall – Random: p = <.01; Object recall clustered: NS; Word recall: non-categorisable: NS; Word recall: categorisable p = <.02	
Multi-modal Intervention	Kumar et al [157]	BADLS: p = <0.000	GDS: p = <0.009	WHOQOL-BREF: p = <0.003	MMSE: NS	BEHAV-AD: NS
	Kim et al [154]				K-MMSE: NS; CERAD-K: NS; K-BNT: NS.	
	Matsuzono et al [161]				MMSE: p = 0.028	
Falls Prevention	Wesson et al [156]	IDDD: NS	CSD: NS			ABDS: NS; FES-I: NS; ICON-FES: NS; PPA Falls risk score: NS; Hill Step Test: NS; Near tandem test: NS; IPEQ-W: NS
Analysis: Intervention Group Pre-Post						
Multi-modal Intervention	Multidisciplinary Santos et al [155]		GDS: p = <0.001	QoL-AD, Self-Rating: p = <0.003	MMSE: p = <0.021	
	Multidisciplinary Viola et al [158]		GDS: p = <0.001	QoL-AD, Self-Rating: p = <0.004	MMSE: NS	NPI-Q: NS (Significant on distress sub-scale p = 0.02)
	Ibarria et al[2] [162]	RDRS-2: 6 & 12 months: p = <0.05 – Indicates a deterioration not an improvement.	NPI-Q: 3, 6, 9 & 12 months: NS		MMSE: 3 & 6 months = NS; 9 & 12 months = p <0.05 – Indicated a deterioration, not an improvement. ADAS-Cog: 3 & 6 months: NS; 9 & 12 months: p <0.05 – Indicates a deterioration not an improvement.	

Modality	Study		Clinical Outcomes: Participants with dementia				
			Occupational Performance	Affect	Quality of Life & General Health Status	Cognition & Dementia Severity	Other clinical outcomes
Reminiscence	Chung [160]		MBI: NR IADL-CV: NR	GDS: Mean change -1.14 (95% CI = -2.11, -0.17)	QoL-AD: Mean Change -1.91 (95% CI = -3.18, -0.64)	MMSE: NS	
Self-Management	Sprange et al [159]		PSMS: Inconclusive IADL: Inconclusive	GAD-7: Inconclusive	DEMQOL: Trend towards improvement; PHQ-9: Inconclusive; EQ-5D-5L: Inconclusive		GSE: Inconclusive
Analysis: Individual Participants Pre-Post							
Occupational Therapy	COTiD	Graff et al [165]	AMPS Process: Improvement; AMPS Motor: Improvement; IDDD: Improvement; COPM Performance: Improvement; COPM Satisfaction: Improvement	CSD: Improvement	DEMQOL: Improvement	BCRS: Deterioration	
	Supporting Everyday Activities in Dementia	Josephsson et al [96]	AMPS Process Scales: Statistically significant improvement (p = <0.5) on 13 items. Follow up: AMPS Process Scales: Statistically significant improvement (p = <0.5) on 9 items.				
		Josephsson et al [97]	AMPS Process Scales: Statistically significant (p = <0.5) improvement on 6 items. Follow up: AMPS Process Scales: statistically significant (p = <0.5) improvement on 1 item.				

Modality	Study	Clinical Outcomes: Participants with dementia				
		Occupational Performance	**Affect**	**Quality of Life & General Health Status**	**Cognition & Dementia Severity**	**Other clinical outcomes**
Assistive Cognitive Technology	de Oliveira Assis et al [164]	Katz Index: NC			MMSE: Improvement Clock test: NC Verbal Fluency Test: Improvement	
	Navarro [163]		AES: Reduction in apathy, which was supported by qualitative data from caregivers.			NPI-Q: Improvement
Cognitive Rehabilitation	Adam [94]	Teunisse's scale: NC Gelinas's Scale: NC	GDS: Decrease in depressive symptoms.		MMSE: NC Mattis Dementia Rating Scale: Deterioration	RMBC: Improvement. NPI: Improvement.

[1] Analysis conducted between 3 groups x 2 test occasions. Outcome measures were researcher developed.
[2] Data generated at 3, 6, 9, and 12 months during intervention period. Intervention was of variable duration, between 3 – 12 months.

Abbreviations: Not Significant (NS); No Change (NC); Not Reported (NR); Assessment of Motor and Process Skills (AMPS); Interview of deterioration in daily activities in dementia (IDDD); Canadian Occupational Performance Measure (COPM); Independent Living Scale (ILS); Bristol Activities of Daily Living Scale (BADLS); Modified Barthel Index (MBI); Instrumental Activities of Daily Living Scale (IADLS); Instrumental Activities of Daily Living Scale-Chinese Version (IADL-CV); Rapid Disability Assessment Scale (RDRS-2); Cornell Scale for Depression (CSD); Hospital Anxiety and Depression Scale (HADS); Apathy Evaluation Scale (AES); Geriatric Depression Scale (GDS); Neuropsychiatric Inventory (NPI); Neuropsychiatric Inventory Questionnaire (NPI-Q); Generalised Anxiety Disorder 7 Item Scale (GAD-7); Dementia quality of Life Instrument (DEMQOL); General Health Questionnaire (GHQ-12); Quality of Life in Alzheimer's Disease (QoL-AD); World Health Organisation Quality of Life Assessment, short version (WHOQOL-BREF); Memory Awareness Rating Scale (MARS); Mini-Mental State Examination (MMSE); Lowenstein Occupational Therapy Cognitive Assessment-Geriatric (LOTCA-G); Consortium to Establish a Registry for AD Assessment Packet – Korean (CERAD-K); Korean Boston Naming Test (K-BNT); Test of Everyday Attention (TEA); Cognitive Subscale of Alzheimer's Disease Assessment Scale (ADAS-Cog); Rivermead Behavioural Memory Test-II (RBMT-II); Rivermead Memory and Behaviour Checklist (RMBC); Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAV-AD); Agitated Behaviour in Dementia Scale (ABDS); Falls Efficacy Scale – International (FES-I); Iconographical Falls Efficacy Scale – International (ICON-FES); The Physiological Profile Assessment (PPA); Incidental and Planned Exercise Questionnaire – Weekly (IPEQ-W).

Table 2: Clinical Outcomes: Caregivers.

Effect sizes, *p* values and CI are presented if reported by studies. Shaded boxes indicate that an outcome measure was not used.

Intervention Modality	Study		Clinical Outcomes: Caregivers			
			Occupational Performance	Affect, Stress and Caregiver Burden	Quality of Life & General Health Status	Other clinical outcomes
Analysis: Intervention vs Control						
Occupational Therapy	COTiD	Graff et al [43]		CES-D: 1.3 p = <0.0001 SCQ: 1.2 p = <0.0001 Follow up CES-D: 1.3 p = <0.0001 SCQ: 0.8 p = <0.0001	DEMQOL: 1.2 p = <0.0001 GHQ-12: 1.3 p = <0.0001 Follow up DEMQOL: 1.5 p = <0.0001 GHQ-12: 1.1 p = <0.0001	Mastery Scale: 1.6 p = <0.0001 Follow up Mastery Scale: 2.0 p = <0.0001
		Voigt-Radloff et al [48]		CES-D: NS SCQ: NS Follow up CES-D: NS SCQ: NS	DEMQOL: NS GHQ-12: NS Follow up DEMQOL: NS GHQ-12: NS	
	Dooley and Hinojosa [95]			ZBI: p = <0.001		
Cognitive Rehabilitation	Clare et al [89]			HADS: NS RSS:NS Follow up HADS: NS RSS:NS	WHOQOL-BREF: NS (Social Relationships Domain 1.894 (CI: 0.735-3.053). Follow up WHOQOL-BREF: NS	
Cognitive Training	Neely et al [98]			BDI: NS ZBI: NS		
Falls Prevention	Wesson et al [156]		TSMI: NS	ZBI: NS		

Intervention Modality	Study		Clinical Outcomes: Caregivers			
			Occupational Performance	Affect, Stress and Caregiver Burden	Quality of Life & General Health Status	Other clinical outcomes
Analysis: Intervention Group Pre-Post						
Multi-modal Intervention	Multidisciplinary Rehab Programme	Santos et al [155]			QoL-AD: NS	
		Viola et al [158]		GDS: p = 0.02	QoL-AD: p = 0.04	
	Kim et al [154]				QoL-AD: NS	
Self-Management	Sprange et al [159]			ZBI: Inconclusive	EQ-SD-5L: Inconclusive; PHQ-9: Inconclusive; PHQ-9: Inconclusive	Health and social care use: Bespoke. SCQ: Inconclusive
Analysis: Individual Participants Pre-Post						
Occupational Therapy	Graff et al [165]			SCQ: Improvement CES: Improvement	DEMQOL: Improvement	Mastery Scale: Improvement
Cognitive Rehabilitation	Adam et al [94]			GDS: Improvement ZBI: Improvement		
Assistive Technology	Navarro et al [163]			ZBI: Reduction in carer burden.		RSCSE: Increased caregiver self-efficacy.

Abbreviations: Not Significant (NS); No Change (NC); Not Reported (NR); Task Management Strategy Index (TSMI); Relatives Stress Scale (RSS); Beck Depression Inventory (BDI); Geriatric Depression Scale (GDS); Centre for Epidemiologic Depression Scale (CES-D); Hospital Anxiety and Depression Scale (HADS); Zarit Burden Interview (ZBI); Dementia quality of Life Instrument (DEMQOL); Patient Health Questionnaire (PHQ-9); Sense of Competence Questionnaire (SCQ); General Health Questionnaire (GHQ-12); Quality of Life in Alzheimer's Disease (QoL-AD); World Health Organisation Quality of Life Assessment, short version (WHOQOL-BREF); 5-level EQ-5D version (EQ-SD-5L); Physical Health Questionnaire-9 (PHQ-9); Sense of Competence Questionnaire (SCQ); Revised Scale for Caregiving Self-Efficacy (RSCSE).

Appendix J: Intervention Synthesis: Barriers and Facilitators, Qualitative Data

Table 1: COTiD Subprocess Implementation rated 'poor' - Adapted from Voigt-Radloff et al [170]

COTiD Subprocess	% rated as poor	Qualitative Data Extracts provided by Voigt-Radloff et al [170]
Educating patients in new skills and compensatory strategies.	54%	"*Patient needs much guidance. Concentration and endurance very limited. Assistance for simple tasks [is needed].*" *"Lack of training due to negative attitude of carer".*
Adapting the physical environment.	56%	"*The carer is the house owner and refuses any adaptation*" "*An adaptation seems not reasonable to the patient, although necessary*"
Adapting the social environment.	54%	"*The family dynamic is very fixed. Both daughters seem to have difficulty in just letting the mother simply do"* *"The patient is very anxious and avoiding [change]"*
Training caregiver in increasing competence in their instructions and interaction.	41%	*"[The carer] seems to be very overstrained and burdened by the disease. He needs additional professional support, for example, from a psychologist"* *"The carer has need for support but refuses any offer of support for himself".*

Table 2: Extracts from Nygård et al [112] Pertaining to Barriers and Facilitators

Barriers (-) and Facilitators (+) to use of Aids Identified	Extracts from Nygård et al's [112] Commentary	n of Cases
- Physical attributes of aid (e.g size, design)	"*The diary for the year was too big and difficult to handle*" (p91) *"The carousel dosette was too big and awkward to bring along"* (p91) *"He also found it [clock] hard to handle in respect of plugging in and reading the clock-face" (p92)* *"Nils' wife found it [clock] difficult to manoeuvre and read" (p92)*	n = 5
+ Physical attributes of aid (e.g. size, design)	"*Ingrid also liked the design and tried the calendar*" (p91) "*The memory clock could be carried in a pocket, which Dan found appealing".*	n = 3
- Appearance as an assistive device	*"…the speaking clock was rejected because of fear of exposure in public*" (p91)	n = 1
- Perceived 'technicality' / difficulty	*"The other aids she rejected because she felt they were too "technically demanding""* (p91)	n = 1
- Motivation	"*Eva was not motivated because she expressed no experience of problems*" (p92)	n = 2
- Remembering to use aid	"*Sometimes the aid and medicine were left forgotten on a table at home. A change to vibrator signal was made, but Dan still often forgot the aid*." (p92)	n = 2
- Aid not needed	"*He had already accommodated leaving all temporal planning and responsibility to his spouse. Consequently, time aids were unnecessary to him."* (p92)	n = 1

Table 3: Themes Identified by Lindqvist et al [166] Pertaining to Barriers and Facilitators.

Themes identified by Lindqvist et al [166]	Barriers and facilitators to use of AT identified from author summary
The first juncture: Making the decision to use AT as support	Conditions that support the decision to use AT for support: - + Activity during which AT was to be used was highly valued and needed. + This task / Activity was experienced as difficult
	Conditions that reduce the likelihood of making a decision to use AT: - - Activity not valued highly. - Task / activity not perceived as difficult
The second juncture: Making adjustments to everyday routines to include AT	Conditions supporting adjustments to routines: - + Establishing new routines to incorporate AT + Abandoning old routines. + Significant other / caregiver encouraging use of AT and new / adjusted routines. - When daily routines not adjusted, process of using AT stopped or slowed down.
The third juncture: Trusting the AT	Conditions that support trusting the AT:- + Using the AT for a period of time to enable an understanding of the AT and ability to predict its actions (time needed varied between participants). + AT worked as expected.
	Conditions that impede trusting the AT:- - AT did not work as expected (e.g. unpredictability due to technical failures)
The fourth juncture: Perceiving the feeling of having capacity when using the AT	Conditions that support feelings of capacity when using the AT:- + Feeling confident and in control of activity / task + Prior worries and concerns reduced / absent

Appendix K: Interview Schedule: Occupational Therapy Practitioners

Interview Schedule: Occupational Therapy Practitioners - Provisional

Please note: This interview schedule is a guide – dependent upon the interviewees understanding and condition questions may be omitted, modified or re-phrased.

(Start digital recorder)

Thank you for agreeing to take part in this study about occupational therapy intervention for people affected by early stage dementia.

Before we start, I'd just like to confirm that we have discussed the information sheet and that you have signed the consent form.

(Confirm that participant is still happy to take part)

There are no right or wrong answers, if you want to stop the interview, we can stop at any time, or we can have a break – please let me know and we can stop the recording devise.

(Check digital recorder to ensure it is working…)

I'm going to read out a number – this is the number that you will be identified by and not your name, so your information remains confidential.

(Read out code)

A. Defining early-stage dementia

1. We often hear people talking about early-stage dementia, what does this phrase mean to you?

    Follow up questions:

    a. Are there any differences between the work of an occupational therapist with people affected by early-stage dementia and their work with people affected by moderate to later stage dementia?

    Probes: Assessment cut off scores, functional ability, strengths, and needs.

B. Occupational needs

2. What occupational needs do you think people affected by early-stage dementia have?

3. What occupational strengths do you think people affected by early-stage dementia have?

C. Setting / Service Context

4. In what services do occupational therapists currently work with people living with early-stage dementia?

5. What is the role of the occupational therapist in these services?

6. Thinking about the services / settings you have mentioned, what barriers do you or others face when working with people living with early-stage dementia in these services / settings?

Follow up questions:
How can these be overcome or prevented? What facilitators are there in this setting?

D. Prior or current experience or providing occupational therapy intervention for people living with early-stage dementia

7. Can you tell me about the interventions you provide for people affected by early-stage dementia?

Probes: Format, method, mode of delivery, duration, intensity, content, components

8. Thinking about the interventions you have described, what barriers do you face when delivering these interventions?

Follow up questions:
How can these be overcome or prevented?

E. Views on a new occupational therapy intervention for people living with early-stage dementia

You may have heard that we are developing an occupational therapy intervention for people affected by dementia [redacted] The next interview questions aim to capture your views and thoughts on this.

Intervention Aims, Outcomes and Rationale

9. Thinking about the strengths and needs we discussed earlier, what aims do you think an occupational therapy intervention for people affected by early-stage dementia should have?

10. If the intervention is effective, what impact or outcomes would it have?

Probes: clinical outcomes, other outcomes / impact

Intervention content, format and method of delivery

11. What type of interventions do you think occupational therapists should be providing when working with people living with early-stage dementia?

Follow up questions:

Should this intervention be delivered in a group or on an individual basis (or both)?
Who should deliver the intervention?
Where should the intervention be delivered?
How long should the intervention last?

12. Thinking about the interventions you have described, what barriers do you think may arise when delivering these interventions?

Follow up questions:
How can these be overcome or prevented?

Underpinning theory and evidence base

13. Thinking about the interventions you have described, are you aware of any research or practice-based evidence, or theory that underpins / supports the use of these interventions?

Probes: OT Models, theoretical frameworks, research evidence, guidelines, best practice examples.

Service Context and Implementation Strategies

14. In what service / setting do you think the intervention should be delivered?

15. Thinking about the service / setting you have mentioned, what barriers do you think may arise when delivering the intervention in this setting / service?

Follow up questions:
How can these be overcome or prevented? What facilitators are there in this setting?

Referral and Assessment

16. What assessments or outcome measures do you think should be used?

17. What referral criteria do you think should be used? Who should referrals be accepted from?

Contextual Influences, Barriers and Facilitators

18. We've already discussed potential barriers or difficulties that you think we may face, are there any others that you think may arise during any stage of the OT process?

Probes: Social, organizational, political, economic barriers etc.

Follow up questions:
How can these be overcome or prevented? What facilitators or strengths can we use?

Views and experiences:

19. Do you have any other views and experiences about your work with people affected by early-stage dementia or the intervention we are developing that you would like to share?

Appendix L: Interview Schedule: People Affected by Dementia

Interview Schedule: People Affected by Dementia - Provisional

Please note: This interview schedule is a guide – dependent upon the interviewees understanding and condition questions may be omitted, modified or re-phrased.

(Start digital recorder)

Thank you for agreeing to take part in this study about occupational therapy for people affected by early-stage dementia.

Before we start, I'd just like to confirm that we have discussed the information sheet and that you have signed the consent form.

(Confirm that participant is still happy to take part)

There are no right or wrong answers, we'd just like to know about your views and experiences. If you want to stop the interview, we can stop at any time, or we can have a break – please let me know and we can stop the recording device.

(Check digital recorder to ensure it is working…)

I'm going to read out a number – this is the number that you will be identified by and not your name, so your information remains confidential.

(Read out code)

Experiences of Support / Services

1. Can you tell me about the support you've had since your (your relatives) diagnosis?

2. What's been good about this support?

    What's been most helpful?

3. What's been bad / not so good about the support you've received?

    What hasn't been helpful?

4. Is there any support you wish you could have had but didn't?

    How could support for people with early-stage dementia be improved?

5. Have you received any support from an occupational therapist since diagnosis?

    Probes: *What did they do / what support did they provide you? What was good / bad about this? Could they have done anything else / better?*

Occupations and Activities: Goals / Strengths / Needs

6. Can you tell me a bit about your day-to-day life, for example what you do in a typical day?

Is there anything you'd like more support in doing?
Are there things you can do on your own without support?
Are there things that you have stopped doing? Would you like to start doing these things again?
What support do you think would help you to continue to do the things you are doing or to start doing the things you've stopped doing?
What do you enjoy doing the most?

New Intervention

7. What support do you think occupational therapists should give to people affected by early-stage dementia?

Probes: content, mode, context, duration, intensity, aim, outcomes

Views and experiences:

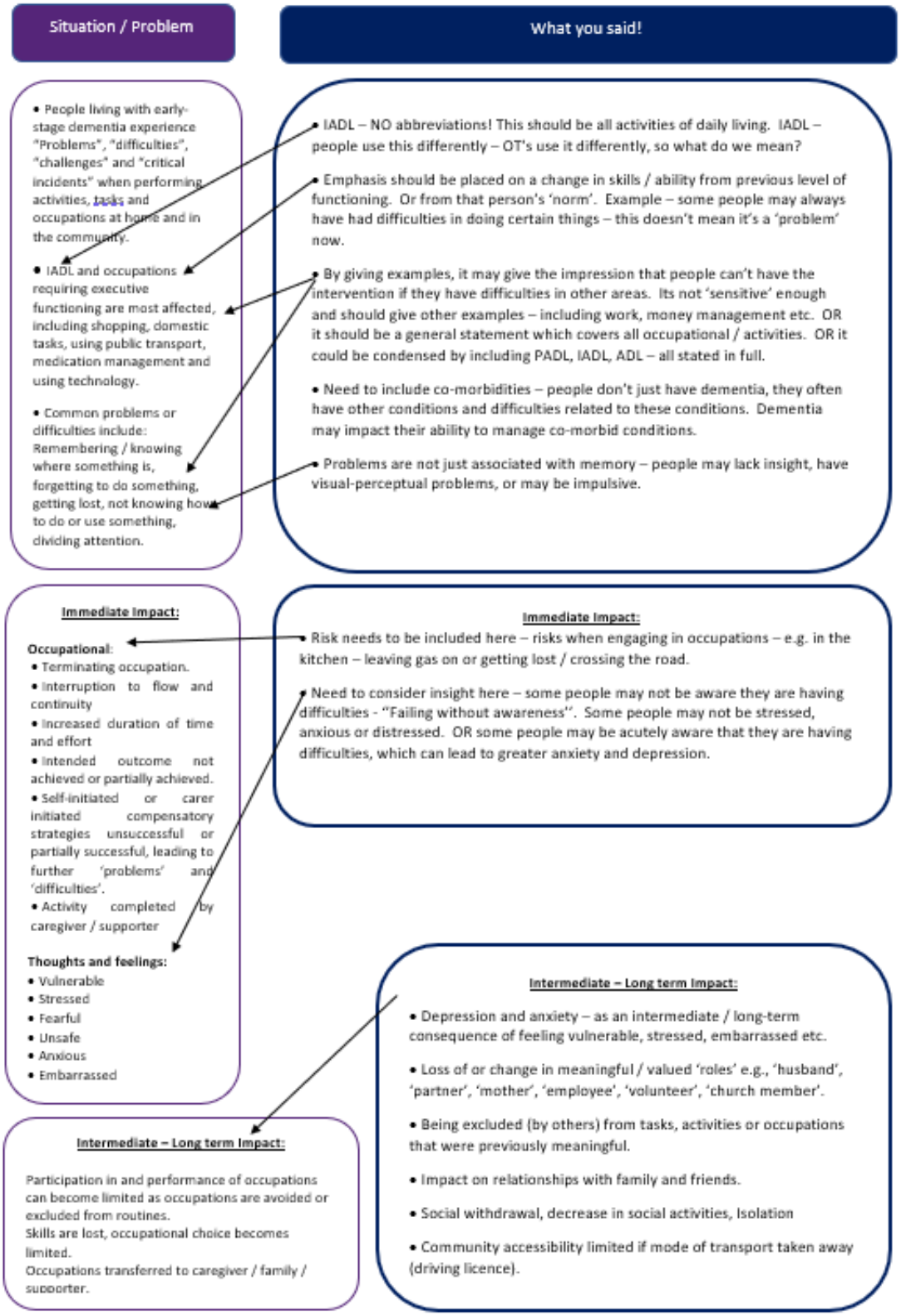
8. Do you have any other views about what an occupational therapy support for people living with early-stage dementia should look like?

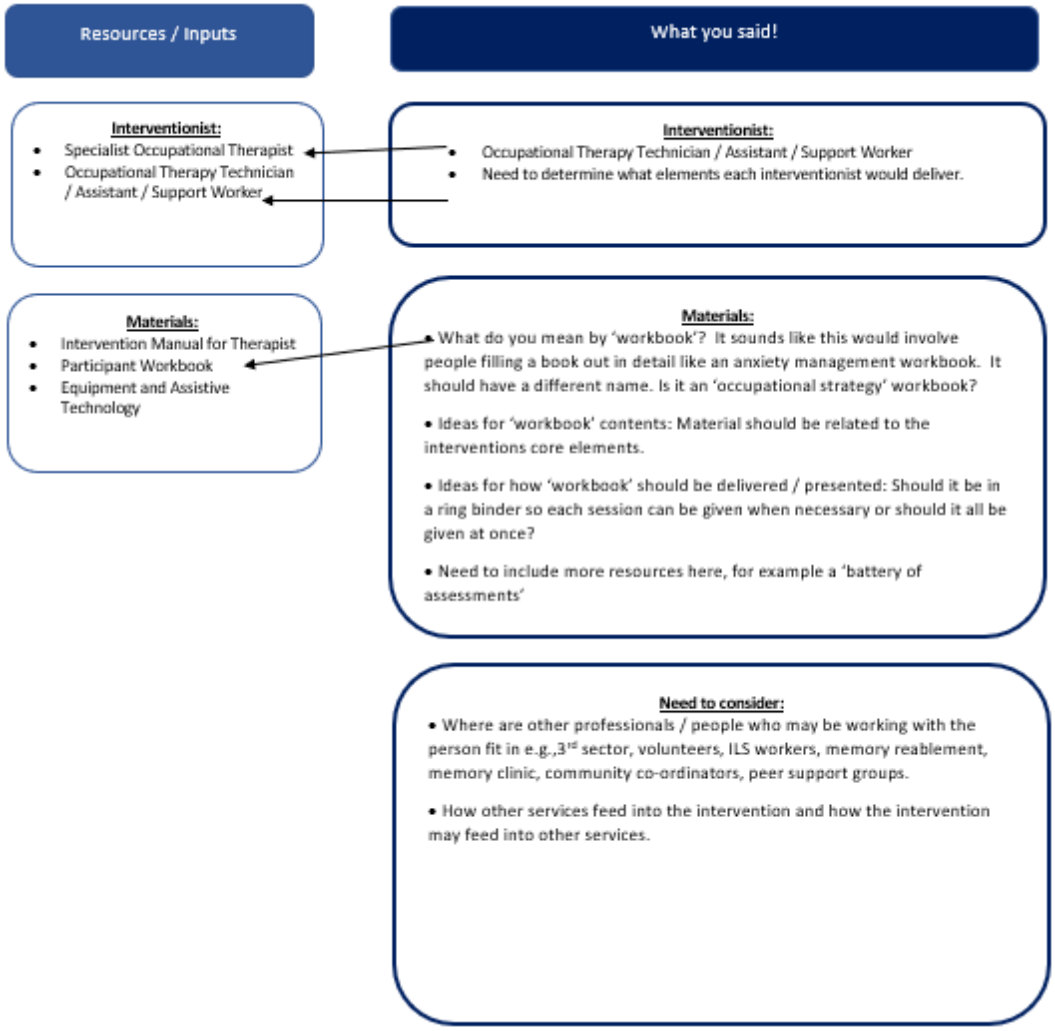
Appendix M: Intervention Mapping Steps and Tasks utilised in Study 3

Table 1: Intervention Mapping Steps and Tasks utilised in Study 3

IM Step	IM Tasks	Study 3
1. Logic Model of the Problem	1.1. Establish and work with a planning group	Whilst Intervention Mapping recommends establishing a Central Planning Group to aid the development process (IM Step 1, Task 1.1.), this was not possible owing to the confines of time and resources during this programme of research. However, practitioner workshops and PPI sought to fulfil some of the functions pertaining to the Central Planning Group as well as PhD Supervision.
	1.2. Conduct a needs assessment to create a logic model of the problem	Thesis Objective 4 (Section 10.4.1)
	1.3. Describe the context for the intervention including the population, setting and community	Thesis Objective 4 & 5 (Sections 10.4.1 and 10.4.2.)
	1.4. State programme goals	Thesis Objective 5 (Section 10.4.2.)
2. Programme Outcomes and Objectives; Logic Model of Change	2.1. State expected outcomes for behaviour and the environment	Thesis Objective 6 (Section 10.4.3.)
	2.2. Specify performance objectives for behavioural and environmental outcomes	
	2.3. Select determinants for behavioural and environmental outcomes	
	2.4. Construct matrices of change objectives	
	2.5. Create a logic model of change	Thesis Objective 7 (Section 10.4.4.). IM's logic model of change is based on the contents of matrices of change developed during Task 2.4. In this study, a simple logic model of the intervention was developed outlining intervention inputs, activities, and outcomes instead.
3. Programme Design	3.1. Generate programme themes, components, scope, and sequence	Thesis Objective 5 (Section 10.4.2.)
	3.2. Choose theory and evidence-based change methods	Thesis Objective 6 (Section 10.4.3.)
	3.3. Select or design practical applications to deliver change methods.	

Appendix N: Simple Logic Model Workshop Feedback




Resources / Inputs
What you said!
Interventionist:
Specialist Occupational Therapist
Occupational Therapy Technician / Assistant / Support Worker
Interventionist:
Occupational Therapy Technician / Assistant / Support Worker
Need to determine what elements each interventionist would deliver.
Materials:
Intervention Manual for Therapist
Participant Workbook
Equipment and Assistive Technology
Materials:
What do you mean by 'workbook'? It sounds like this would involve people filling a book out in detail like an anxiety management workbook. It should have a different name. Is it an 'occupational strategy' workbook?
Ideas for 'workbook' contents: Material should be related to the interventions core elements.
Ideas for how 'workbook' should be delivered / presented: Should it be in a ring binder so each session can be given when necessary or should it all be given at once?
Need to include more resources here, for example a 'battery of assessments'
Need to consider:
Where are other professionals / people who may be working with the person fit in e.g.,3rd sector, volunteers, ILS workers, memory reablement, memory clinic, community co-ordinators, peer support groups.
How other services feed into the intervention and how the intervention may feed into other services.

Activities	What you said!

Overview: A home and community based occupational therapy intervention delivered over 12 appointments over 6 weeks. Participants will be supported to increase their competence and confidence to independently perform personally meaningful occupations and participate in occupational roles.

Intervention Components:

Therapeutic Strategies:

Supporting agency, choice and control:
- Respecting views, values, experiences, thoughts and feelings.
- Establishing goals / priorities collaboratively drawing on values and interests.
- Problem solving and evaluating progress collaboratively.

Promoting empathy and providing emotional support
- Listening to and validating thoughts, feelings and experiences about: Living with dementia, New ways of doing.
- Providing reassurance and positive reinforcement.

Providing Information about:
- Possibilities: How others live a meaningful life with dementia and the strategies they find helpful
- Occupational Therapy and the benefits of 'doing': what's familiar, meaningful and important, staying in touch with family and friends.
- New ways of doing: adaptations to physical and social environments, adaptations to occupations, compensatory strategies.
- Developing and maintaining mastery in new ways of doing: The importance of using and practicing adaptations / compensatory strategies outside therapy appointments.

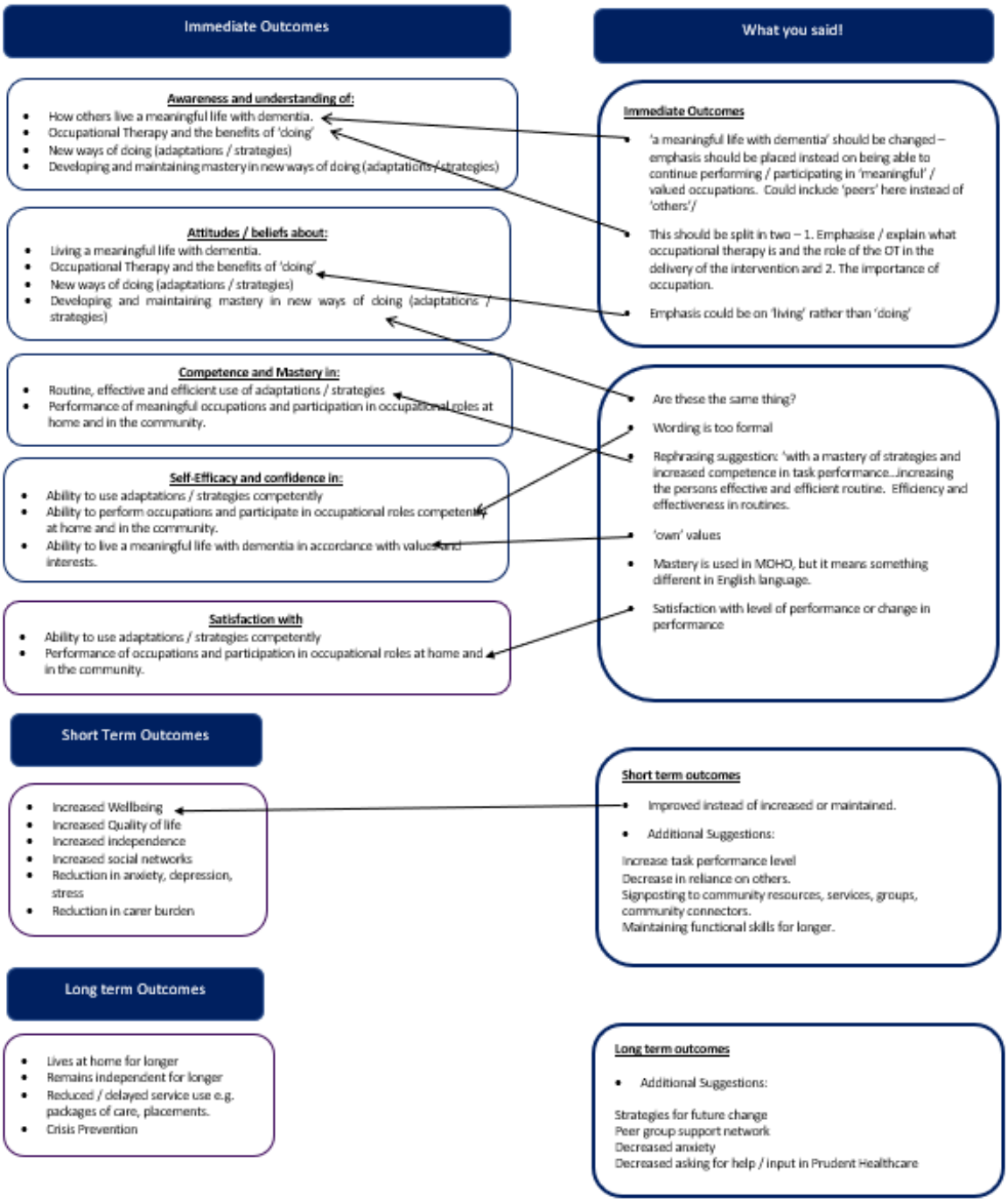
Providing opportunities to explore, and develop mastery in, new ways of doing:
- Prescribing / Providing / Implementing adaptations and compensatory strategies.
- Encouraging use and practice of adaptations / compensatory strategies through positive reinforcement, role modelling, demonstration.
- Supporting effective and efficient use of adaptations / compensatory strategies through prompting, cueing, feedback, role modelling, demonstration, problem solving.

Supporting the integration. and maintenance of, new ways of doing in day-to-day routines, habits, and occupations:
- Encouraging use and practice of adaptations / compensatory strategies outside intervention sessions, by setting between session goals, providing positive reinforcement.

Overview:
- Timescale: – Is 12 visits realistic? What if the person needs more time / interventions than just a few weeks? Is there scope to increase timescales on a case-by-case basis?
- Groupwork for some of the activities would free up more time for the green – time intensive activities.
- People could be referred to memory reablement if they required more intensive support or community OT for longer term work.

Intervention 'Components':
- Group 1: The 'components' make sense – we knew what we're doing before you explained it.
- Group 2: The components need to be explained a bit – what do they mean?
- Component 1: Group 1. The name of this 'component' should be changed. It should be the same as the therapeutic strategy 'Supporting agency, choice and control'. We don't like the word 'hope' here. Group 2. We don't like the word 'agency' – what does it mean – services / resources? Group 3. ~~It~~ is not clear what this means. Group1, we like the word agency.
- Component 2: Group 3. Everyday language name for component 2 – 'What's meaningful to you?
- There needs to be a key here to explain what the different colour circles (blue and green) mean.

Therapeutic Strategies:
- Group 1: This is like the 1st intervention 'component' Hope and Agency – should they be the same? Group 3: It's not clear what this means.
- Wording here could be looked at. Should it be 'establishing the persons thoughts and feelings'?
- Include here – in the home / community / work / leisure environment get rid of 'outside therapy appointments.
- Wording should it be 'Supporting the integration, mastery and maintenance of the interventions therapeutic strategies in day-to-day routines, habits and occupations'? Leave new ways of doing out.
- Things to add: Supplementary memory aids; Errorless learning; failure free; positive risk taking.


Immediate Outcomes
What you said!
Awareness and understanding of:
How others live a meaningful life with dementia.
Occupational Therapy and the benefits of 'doing'
New ways of doing (adaptations / strategies)
Developing and maintaining mastery in new ways of doing (adaptations / strategies)
Attitudes / beliefs about:
Living a meaningful life with dementia.
Occupational Therapy and the benefits of 'doing'
New ways of doing (adaptations / strategies)
Developing and maintaining mastery in new ways of doing (adaptations / strategies)
Competence and Mastery in:
Routine, effective and efficient use of adaptations / strategies
Performance of meaningful occupations and participation in occupational roles at home and in the community.
Self-Efficacy and confidence in:
Ability to use adaptations / strategies competently
Ability to perform occupations and participate in occupational roles competently at home and in the community.
Ability to live a meaningful life with dementia in accordance with values and interests.
Satisfaction with
Ability to use adaptations / strategies competently
Performance of occupations and participation in occupational roles at home and in the community.
Immediate Outcomes
'a meaningful life with dementia' should be changed – emphasis should be placed instead on being able to continue performing / participating in 'meaningful' / valued occupations. Could include 'peers' here instead of 'others'/
This should be split in two – 1. Emphasise / explain what occupational therapy is and the role of the OT in the delivery of the intervention and 2. The importance of occupation.
Emphasis could be on 'living' rather than 'doing'
Are these the same thing?
Wording is too formal
Rephrasing suggestion: 'with a mastery of strategies and increased competence in task performance...increasing the persons effective and efficient routine. Efficiency and effectiveness in routines.
'own' values
Mastery is used in MOHO, but it means something different in English language.
Satisfaction with level of performance or change in performance
Short Term Outcomes
Increased Wellbeing
Increased Quality of life
Increased independence
Increased social networks
Reduction in anxiety, depression, stress
Reduction in carer burden
Short term outcomes
Improved instead of increased or maintained.
Additional Suggestions:
Increase task performance level
Decrease in reliance on others.
Signposting to community resources, services, groups, community connectors.
Maintaining functional skills for longer.
Long term Outcomes
Lives at home for longer
Remains independent for longer
Reduced / delayed service use e.g. packages of care, placements.
Crisis Prevention
Long term outcomes
Additional Suggestions:
Strategies for future change
Peer group support network
Decreased anxiety
Decreased asking for help / input in Prudent Healthcare

Appendix O: Lived Experience Advisory Group Feedback 05.02.2018

Table 1: LEAG Feedback 05.02.2018

General Comments about the Proposed Programme Structure / Design
• People should be able to have the programme flexibly – not necessarily in the order described.
• A coffee morning / informal meet up would be helpful for people before the programme if it's delivered in a group.
• It would be helpful to have a leaflet about the service. • This can be given to people interested in the programme. • It could include the wording:-"We are here to support you on your journey and to help create strategies to make your life easier. If you have a problem with:- X, Y, Z……."
• Seeing the same person is important.
• After the programme, dementia doesn't stop. What happens after?
• Alternatives to the word strategy. We talked about possibly using the phrases – 'Different, new or alternative ways of doing things to make your life easier'.
• Consent to receive information about the service should be obtained. Obtaining consent for contact, information and information sharing is part of routine and ethical practice.
• Appointment letters - These could ask people to think about any questions they have about the service / diagnostic process. • Sometimes people have lots of questions and they don't know who to ask.
• Occupational Therapy should be earlier than Memory Assessment Services
• Not everyone living with dementia has difficulties with their Memory – is it possible to change the name?
• Travel and finances should be in the intervention programme.
Comments about the component: 'Coming to terms with a diagnosis and coping with thoughts and feelings'
• This section is very important.
• It should include things like finance and work as this can be very worrying and stressful.
• It should include information about the future – to give people hope. • There is a lot of uncertainty and people need to know what's possible.
• People need to feel that they have a reason and a purpose. • To continue, to get out of bed… • They need to know that they can still maintain an active life.
• The programme could include a section / question about 'What are your fears'.
• Not everyone will have a 'diagnosis', so another word might be better. • Coming to terms / coping with changes might be better. • Or 'making sense of changes or adapting to changes'. • Or You are still you: Making sense of changes and coping with challenges.
• This part can sound quite frightening.
• Isn't this something that should come in at all stages of the programme?

Appendix P: Lived Experience Advisory Group Feedback 25.04.2019

Table 1: LEAG Feedback 25.04.2019

Comments about Pre-intervention Activities
• Remove 'clinical' before decision (Point 2)
• The information leaflet about the programme should include more information about contact details, names of contacts etc (Point 3)
• People should be invited to wear badges to any group / coffee morning (Point 4)
Comments about Mode
• We had a long discussion about whether a group format is the right way to deliver occupational therapy.
• You mentioned the importance of personalising occupational therapy and that may be hard in a group. For example, [redacted] is good at using technology, but [redacted] prefers using a diary and writing lists. A group format may make it difficult to deliver personalised interventions, without giving confusing or conflicting information to people. Occupational therapy also looks at the persons environment – in a group you cannot make changes or recommendations about the environment.
• However, you felt that a group was appropriate to receive general information, for example information on finances, locally available services, peer support, lasting power of attorney etc.
• Bethan spoke about the expectations of services and the emphasis they are now placing on groups. You felt that this was a service led service rather than a service led by people affected by dementia.
Comments about Session 1
• The order of the programme should be changed. Proposed new order: - 1. Getting to know you and what's important to you. 2. You are still you: Making sense of changes. 3. What is occupational therapy and how can it help me?
• Change title: Getting to know you and what's important to you. To: Getting to know each other. • The focus should be on establishing a relationship – with the OT.
Comments about Draft Strategies: Routines and Familiarity
• Some people don't want a routine and like being able to be spontaneous. • Some members said they would not want these strategies.
Comments areas of need / strategies
• Change and simplify names of areas to: - ○ Strategies to support your independence at home. ○ Strategies to support your independence socialising and connecting with others. ○ Strategies to support your independence in the community ○ Strategies to support your independence at work. ○ You are still you: Making sense of changes and coping with challenges.