An Exploration of the Factors that Influence the Use of Child-Centred Outcome Measures in Occupational Therapy: An Action-Based Research Study in Malta

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Abstract

Background/Introduction: A child-centred approach is key to upholding children's rights. The concept of child-centredness is embedded in client-centred practice - an essential component of the professional identity of occupational therapy (OT). In paediatric OT services, children’s voices tend to be smothered by adult-driven priorities as children’s intervention goals most commonly focus on issues identified by the parents, rather than the child. However, research has shown that parents and children often have different goals, necessitating a shift to a more authentic child-centred approach. Occupational therapists can consciously strive to listen to children’s voices and enable their active engagement through the use of child-centred outcome measures. This research sought to identify and explore factors that facilitate and/or inhibit a measurable, child-centred OT practice in Malta.

Methodology: This study used a participatory action research design. All the paediatric occupational therapists (n=20), working in the Maltese public health service at the time of the study, were selected through purposive sampling and participated in this research. Data were collected through eight action research meetings, characterised by ongoing cycles of discussions and reflections, and underwent reflexive thematic analysis.

Findings/Discussion: This study has revealed that determining who the client is poses the most significant challenge faced by paediatric occupational therapists. Besides the child, parents and significant others need to be involved, making the practice of child-centredness or client-centredness a complex one. A fundamental gap between rhetoric and reality was exposed. This study highlighted various factors leading to a measurable child-centred service. Moreover, some child-centred outcome measures, applicable for Maltese paediatric OT service, were identified.

Conclusion/Implications: These findings will facilitate the active involvement of children in all aspects of the therapeutic process, including outcome measurement. Such tools will target the child’s perspective to measure outcomes of OT intervention, thus potentially shifting the current service to a more child-centred and client-centred one.

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Dedication

This PhD is about children's right to participation. Therefore, I dedicate this work to children, whose rights are not being met and those who struggle to be heard.

I would also like to dedicate this thesis to my children, who have helped me recognise that dealing with reality is invariably far more complicated than dealing with theory. As I have learnt throughout this research, the same can be said of any attempts made to ensure children's participation.

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This PhD study has been a rewarding learning experience. I faced more challenges than I could have anticipated in my journey to this point; however, an incredible network of family, friends and colleagues constantly supported me along the way, and helped me be “strong in will/ To strive, to seek, to find, and not to yield” (taken from Ulysses by Alfred Tennyson).

I thank God, who made all this possible.

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List of Abbreviations

AAM	All About Me
ADHD	Attention Deficit / Hyperactivity Disorder
ADLs	Activities of Daily Living
AG	Action Research Group
AG-PEGS	Austrian-German Version of the Perceived Efficacy and Goal Setting System
AOTA	American Association of Occupational Therapists
ASI	Ayres Sensory Integration
CAOT	Canadian Association of Occupational Therapists
CAPE	Children's Assessment of Participation and Enjoyment
CMOP	Canadian Model of Occupational Therapy
CMOP-E	Canadian Model of Occupational Performance and Engagement
COPM	Canadian Occupational Performance Measure
COSA	Child Occupational Self Assessment
COSMIN	COnsensus-based Standards for the selection of health status Measurement INstruments
DCD	Developmental Coordination Disorder
GAS	Goal Attainment Scaling
ICC	Intraclass Correlation Coefficient
ICF	The International Classification of Functioning, Disability and Health
ICF-CY	The International Classification of Functioning, Disability and Health – Children and Youth Version
INCFCC	International Network of Child and Family Centred Care
KiPP	Kid Play Profile
MOHO	Model of Human Occupation
NHS	National Health Service
OT	Occupational Therapy

PAC	Preferences for Activities of Children
PACS	Paediatric Activity Card Sort
PCSA	Pictorial Scale of Perceived Competence and Social Acceptance
PEGS	Perceived Efficacy and Goal Setting System
SDM	Shared Decision-Making
TA	Thematic Analysis
UCRPD	United Nations Convention on the Rights of Persons with Disabilities
UN	United Nations
UNCRC	United Nations Convention on the Rights of Children
UNICEF	United Nations Children’s Fund
VMI	Developmental Test of Visual-Motor Integration
WISC-R	Wechsler Intelligence Scale for Children-Revised
WFOT	World Federation of Occupational Therapists
WHO	World Health Organization

Chapter 1: Introduction

1.1 Problem and Significance of the Study

The right of children to take part in decisions that affect them has garnered international attention since the publication of the United Nations Convention on the Rights of the Child (UNCRC; United Nations [UN] 1989). Article 12 of the UNCRC (UN 1989) supports the children's right to be heard in issues that affect them, including children's active involvement in their own health care. Consequently, occupational therapists need to ensure that children are engaged in any activity that may directly or indirectly influence them.

The application of UNCRC's (1989) implication in paediatric occupational therapy (OT) is rather complex and is compounded by a paucity of research on this matter, especially in addressing the very young and challenging children that are typically encountered in OT clinics. Research about children's right to participate in OT intervention and their experiences in shared decision-making is also scarce (O'Connor et al. 2021), despite the OT profession's claim to be an exponent and advocate of client[1]-centred practice.

In my clinical practice, I identified a gap between the recommendations set out by the UNCRC (UN 1989) regarding children's rights to participation and what is actually occurring, especially the lack of shared decision-making. In a recent scoping review, Antoniadou (2022) asserts that whilst there is a recognition of children's right to be engaged in activities related to their health care, "there is often a breadth between rhetoric and clinical implementation" (p. ii). My definition of children's engagement in this study conforms with the UNCRC (UN 2009), which defines it as an:

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[1] Whether the recipient of health care services is referred to by means of the term "client", "patient" or "person" depends on the context in which care is provided (Hughes et al. 2008). For the purpose of this study, the terms "client", "client-centred" and "client-centredness" will be used, with the understanding that knowledge will be drawn from literature that makes use of other synonymous terminology.

> Ongoing process, which includes information-sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes. (p. 3)

This definition acknowledges that children's rights "do not operate in a vacuum" (Brady 2020, p. 13) apart from the interdependence of these children's rights on adults' actions (Matthiesen 2022). Indeed, when working with children, occupational therapists need to make a conscious effort to listen to children's voices and to enable their active engagement (Lundy 2007). One way to do this is through the use of child-centred[2] outcome measures, which enable the child to participate during assessment and setting of goals as well as during evaluation of outcomes.

It is critical to provide children with the means to express themselves and have their voices heard. Occupational therapists need to be aware of both offering child-centred interventions and fostering an environment of respect that encourages children to express themselves in meaningful ways (Gagné-Trudel et al. 2024).

Previous occupational therapy research has relied heavily on the accounts of adults (namely parents[3]) when setting treatment goals. This has also been the case in clinical practice. In paediatric OT practice, information about the child is typically gathered from the parents and from the observation of the child, but not directly from the child (Brewer et al. 2014). Indeed, parent interviews tend to be used to initiate goal setting. O'Connor et al.'s (2021) study indicate that clinical decision-making in paediatric OT services "is mostly adult-directed, and children's voice are subsumed by adult-led services, priorities and

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[2] Various terms such as "child-centred care" (Coyne et al. 2016; Ford et al. 2018; Foster and Shields 2020) or "child-driven approach" (Pritchard et al. 2022) have been used when discussing health care services for children. As Hughes et al. (2008) note, what is significant when similar terminology is used is the notion of centredness. For the purpose of this study, the term "child-centred" or "child-centredness" is used to refer to intervention that is focused primarily on the child, and literature that uses synonymous terminology will be referred to.

[3] In this paper, the term "parents" is used to refer to either or both parents or guardians, or to the primary caregivers.

agendas.” (p. 1). However, research has shown that parents and children often have different goals (Costa et al. 2017). Such different opinions further confirms the need to identify both the parents’ and the child’s concerns.

This accentuates the importance of a child-centred approach. In order to uphold children's rights, a child-centred approach is recommended (Coyne et al. 2016), in addition to a commitment to incorporating children’s rights in service delivery and ensuring that there is a good understanding of such rights. Children's participation needs to be perceived as an evolving process whereby children are involved in sharing or negotiating responsibilities. Therefore, a child-centred approach is clearly based on the fundamental values of autonomy, respect, trust, and self-determination. The application of a child-centred approach entails appreciating children’s voices, experience and engagement as well as acknowledging and focusing on children’s rights (Coyne et al. 2016). The focus on child-centred care is consistent with international reports in Europe (Council of Europe 2022).

Occupational therapists can assist children and their parents in achieving their occupational performance goals because they possess the necessary knowledge and expertise. Nonetheless, outcomes of intervention could be significantly influenced if the child cannot be fully involved in the OT process. Research has shown that client engagement is essential to achieving positive outcomes (Brewer et al. 2014). Without such involvement the occupational therapist's efforts in intervention planning and therapeutic intervention may be ineffective (D’Arrigo 2018). Research on child-centred OT practice, especially the child’s participation in the OT process, including outcome measurement is limited, despite the recognised importance of child engagement. This is particularly so for children with disabilities. Indeed, Callus (2024) questions whether the rights of children as stated in the UNCRC (UN 1989) are also being applied to children with disabilities. She argued that although in theory disabled children have the same rights as typically developing children, this is not always the case in practice.

The concept of child-centredness is embedded in client-centred practice. Therefore both approaches are discussed in this study. Client-centredness forms an essential component of the professional identity of occupational therapy. Although the importance of client-centred practice has featured prominently in OT literature, research indicates that practice falls short of ideal client-centred practice (Duggan 2005; Gupta and Taff 2015). It is therefore essential for occupational therapists to reflect on whether they are genuinely putting the client at the core of their practice. Therapists need to discuss what these client-centred and child-centred strategies really entail and whether they are being incorporated into their practice.

It could be argued that paediatric OT services should be child-centred, follow a rights-based approach, and conform with the principles underpinning UNCRC (UN 1989), the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; UN 2006), the World Federation of Occupational Therapists (WFOT)'s position statement on client-centredness (WFOT 2010), and the WFOT's position statement on human rights (WFOT 2019).

1.2 Context of the Study

The OT profession in Malta has long recognised that its services should be supported by a model of practice. This need emerged following a national exercise to establish a vision for OT services in 2011, where all occupational therapists working in the public sector were asked to reflect on their practice. A series of meetings and discussion led to an agreement whereby one model of practice was to be chosen in order to synchronise the services. This aim is embedded in one of the OT profession's national strategies (WFOT 2016).

To that end, a steering group comprising the Professional Lead of OT services and four occupational therapists was formed. Following research and feedback from the vision meeting, the group concurred that the best model to meet the demands of all service users would be the Canadian Model of Occupational Performance and Engagement (CMOP-E; Polatajko et al. 2013). There was a general consensus that all OT services would hinge on a client-centred centred and an occupation-based approach (WFOT 2016).

This study stemmed from this drive to apply the CMOP-E to Maltese OT services. Being a member of the steering group, I facilitated a number of focus groups, which the steering group was conducting with the therapists, with a view to adopting and applying this model of practice. During these CMOP-E focus groups, the paediatric occupational therapists had identified concerns over the application of a client-centred approach with children. While the Canadian Occupational Performance Measure (COPM; Law et al. 2014) was recommended as an outcome measure and goal setting tool for Maltese OT services (WFOT 2016), the paediatric occupational therapists expressed concerns over the application of this tool with children.

The use of the COPM with children younger than 8 years of age has proved unsuccessful, mainly because of the level of understanding and abstract thought needed to use this measure (Missiuna and Pollock 2000). The COPM can be administered to parents not to the child. However, this poses serious challenges for the therapist to judge the importance of an activity on behalf of the child (Pollock 1993). The need for a client-centred outcome measure that can be used with children was therefore identified. The COPM was developed on the basis of research with adults. It is to be noted that adapted instructions on how to administer this tool to children with a mental age of 8 years that were developed by Verkerk et al. (2023) were not available at the initial stages of this PhD. A child-centred outcome measure that is culturally relevant and suited to the OT services in Malta, and is based on the CMOP-E was not available. This need prompted me to conduct this study. Moreover, the chosen topic of my research was relevant to my organisation and it met the needs and interests of my OT colleagues.

1.2.1 Conceptual Framework

Two theoretical frameworks were used to guide this study: the CMOP-E and the International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY; World Health Organisation [WHO] 2007).

1.2.1.1 Canadian Model of Occupational Performance and Engagement (CMOP-E)

The CMOP-E is an OT model that developed from the Canadian Model of Occupational Performance (CMOP; Law et al. 2002). This model, grounded in occupational performance and client-centred practice, illustrates the dynamic interplay between persons, the environment, and their occupation. Spirituality, which lies at the very core of the person, provides meanings to their occupations. Importance is given to occupations that are meaningful for the client (Canadian Association of Occupational Therapy [CAOT] 1997). Occupational performance, or a person's capacity to perform daily tasks and occupations, is the outcome of interactions among an individual, their environment, and their occupation. In contrast to the CMOP, the CMOP-E encompasses the idea of occupational engagement and occupational performance. This extension pertains to the empowerment of clients to select and perform their meaningful activities in their environment (Polatajko et al. 2013). The CMOP-E seeks to advance client-centred practice and the OT profession's belief that occupation is the primary area of focus (Polatajko et al. 2013).

1.2.1.2 The International Classification of Functioning, Disability and Health – Child and Youth Version (ICF-CY)

The ICF-CY (WHO 2007) is increasingly being used in international paediatric research (Harding et al. 2009; Kjellberg et al. 2012; Costa et al. 2017; Mathews et al. 2020). Being an international and interdisciplinary model, the ICF-CY recognises that a child's health condition is determined by a variety of elements, including participation, activities, personal and environmental contexts, and body structures and functions (Costa et al. 2017). The accent is on function instead of impairment. OT is ideally suited to this perspective on health (Baum and Christiansen 2005; Wilcock 2006). The International Classification of Functioning, Disability and Health (ICF; WHO 2001) and its paediatric version, the ICF-CY, view health vis-à-vis function, namely a person’s capabilities and the difficulties they encounter in performing daily life activities. Schiariti et al. (2014) highlight the ICF-CY’s acknowledgement of both the UNCRC (UN 1989) and the UNCRPD (UN 2006).

1.2.2 The Structure of the Local Paediatric Occupational Therapy Service in the Research Study

During the time of the study, I worked as an occupational therapist in the public health sector in Malta. At that time, most paediatric OT services in Malta were provided through the paediatric OT department, which fell under the remit of the Department of Health. This paediatric OT department was the main setting that covered paediatric OT services. The former comprised a large OT Department in Malta that catered for the island of Malta, and a relatively smaller one in Gozo, Malta's sister island. I worked at this smaller department.

The paediatric OT department caters for children from 0 to 16 years of age. Therefore, for the purpose of this research, the term "paediatric/child/children" is used for simplicity's sake to refer to children and adolescents up to the age of 16 years. The paediatric OT department mainly provides out-patient occupational therapy clinic-based services (Buhagiar 2021), providing both assessment and intervention to these children. Client groups that are seen at this department include children with a variety of conditions, mainly neurodevelopmental disorders such as autism, learning disabilities, attention-deficit/hyperactivity disorder (ADHD), communication difficulties, developmental delays and cerebral palsy; other medical conditions and children without any specific diagnosis. Children would be referred to OT if they were encountering participation challenges in a variety of settings, including at home, at school and in the community. "Paediatric occupational therapy seeks to improve children's engagement and participation in life roles" (Novak and Honan 2019, p. 258).

During the time of the study, the OT service was short of qualified OT staff. There was a relatively long waiting list for new referrals to receive services, and the occupational therapists could not meet the heavy demand for services. Moreover, when the study was initiated, the service was undergoing changes regarding management. Such background information should be acknowledged when considering this study's findings.

1.3 The Purpose and Objectives of the Study

The purpose of this participatory action research was to identify and explore factors that facilitate and/or inhibit a measurable, child-centred OT practice in Malta. The objectives were:

- To investigate the way in which paediatric OT practice is currently being conducted in Malta, and determine whether the therapists are evaluating children's participation in occupational performance;

- To identify ideal properties of a suitable child-centred outcome measure, which would meet the needs of the OT service in Malta;
- To identify child-centred outcome measures that could be used to evaluate children's participation in occupational performance for OT practice in Malta in the future.

1.4 The Methodology Used in this Research Study

Action research enables participants to engage in determining the future of their organisation by potentially affecting change in their organisation (Coghlan and Shani 2015); it was therefore considered a suitable methodology for this study. Action research is frequently referred to as a tool for managing change in health care environments (Koshy et al. 2011; Williamson 2012a), and generating new knowledge about an issue (Williamson 2012). These two aims are interdependent: “it is difficult to change a situation without working to understand it more fully, and in trying better to understand things, the possibilities for change often emerge.” (Williamson 2012c, p. 7)

Action research can challenge preconceived notions. Indeed, by encouraging deep reflection on practice and interventions, it has the potential to alter our understanding of the topics under investigation. I was aware that I was running the risk that such an action research project may “raise more questions than it answers” (Mac Naughton and Hughes 2008, p. 12) but I knew that the latter outcome would facilitate the development of new ways of thinking (Gaventa and Cornwall 2015).

Through a reflection on whether current OT practice was client-centred and child-centred and the identification of factors that impact the use of outcome measures, new knowledge about client-centredness and child-centredness and related outcome measures would be created. Consequently, such fresh knowledge would hopefully generate direly-needed change that would facilitate the delivery of a measurable child-centred service.

In a research study, researchers may solicit various engagement levels from their participants, ranging from solely providing data to actively participating throughout the project. The latter are referred to as a co-researchers (Pope 2020). I wanted to work alongside my OT colleagues to improve our service. Since in action research, participants are viewed as co-researchers (Coghlan and Brannick 2014), rather than subjects of research, an action research methodology was deemed suitable. More specifically, a participatory action research approach was selected due to its collective and participatory nature. Participatory action research "empowers people to bring change by generating knowledge through reflection on their personal experiences and situations." (Glasson et al. 2008, p. 34), thus generating new knowledge and empowering participants to make the best use of that knowledge (Reason 1994; Loewenson et al. 2014).

The term "co-researchers" is occasionally used in this study's write up as an alternative to the term "participants" in order to highlight the sharp distinction between the occupational therapists' role in this research and that of traditional research paradigms. In this participatory action research study, participants collaborated to generate knowledge and professional change (Starodub 2018) and they participated in various levels of the research (Macaulay et al. 1999). Indeed, the therapists' involvement was more than "simply participants for data collection" (Benjamin-Thomas et al. 2018, p. 1).

This approach was deemed appropriate for this project since it would allow occupational therapists to "collectively know, problematise, understand, act on and transform" issues that affect them (Loewenson et al. 2014, p. 14). This is the first participatory action study in which the researcher worked in partnership with occupational therapists as co-researchers to improve Maltese paediatric OT practice.

1.5 Organisation and Structure of this Thesis

The following section provides an overview of the thesis layout, which is presented in four parts.

Part One presents the foundation and context for this research study, by providing an overview of the key literature that informs this study. It includes the search strategy employed in this research. **Chapter 2** provides an overall literature review to explore the current knowledge about client-centred and child-centred practice in OT. **Chapter 3** addresses literature that is related to outcome measurement, and particularly child-centred outcome measures.

Part Two deals with the research design of the study. **Chapter 4** explains in detail the methodology used in this study, namely action research and more specifically participatory action research. **Chapter 5** then outlines the methods that were used to conduct the study and analyse the data.

Part Three describes the findings. **Chapter 6** gives an overview of the evolution of themes. **Chapter 7** presents the findings related to client-centred and child-centred practice. The findings related to outcome measures are presented in **Chapter 8**.

Part Four deals with the application of a measurable child-centred and client-centred OT service. **Chapter 9** presents the discussion of the findings, situating the findings in the literature. It includes the limitations and strengths of the research. **Chapter 10** presents the conclusion of this study, tying together the themes presented in this body of work with recommendations and key implications for OT practice and research. These implications serve facilitate the delivery of a measurable child-centred OT service. This final chapter also highlights the contribution that this thesis has made to the field of OT and ends with consideration of the way forward.

Part One: Literature Review: Laying the Foundation

This participatory action research sought to identify and explore factors that facilitate and/or inhibit a measurable, child-centred OT practice in Malta. This part of the thesis lays the foundation for the study by contextualising the research in the relevant literature, in order to address this study's research question. **Chapter 2** reviews literature on client-centred and child-centred practice in OT. **Chapter 3** discusses pertinent literature about outcome measures, focusing mostly on child-centred outcome measures. The search strategy that was employed in this study is described below.

Search Strategy

I conducted a narrative review using a systematic approach. "In a narrative review, researchers can pursue an extensive description and interpretation of previously published writing on a chosen topic. Narrative reviews provide a flexible and rigorous approach to analysing and interpreting the literature" (Sukhera 2022, p. 418). This review sought to explore and cover a wide range of issues related to child-centredness and the application of child-centred outcome measures, rather than to assess the quality of the individual studies identified. Moreover, since I wanted to track the development of the child-centredness concept, a narrative review was deemed appropriate. "The efficacy of narrative reviews is irreplaceable in tracking the development of a … clinical concept." (DistillerSR 2024, p. 6). Another aim of this review, which could be achieved through a narrative review, was to establish the context for understanding current knowledge about child-centred practice and child-centred outcome measures, and to highlight any gaps or inconsistencies in the body of knowledge, which would support the design and justify the purpose of my research study.

The literature search started with a keyword search to identify the range of available literature identified via the following databases: Medline, PubMed, CINAHL, EBSCO (health), Web of Science, ProQuest and Google Scholar. The search was performed using Boolean operators "AND" and "OR" to combine the search strings. In addition, truncation was used in order to include several grammatical declensions. The following key words were used alone and in combination: child-centred, child-friendly, client-centred[4], family-centred, child's rights, paediatric, OT, outcome measures, goal setting, shared decision-making, and self-reports. Due to the paucity of papers that were found in the paediatric OT sector, the search was initially extended to the general OT field and later to the overall health care field. This was especially the case for literature on child-centred practice and shared decision-making.

A hybrid search, as recommended by Wohlin et al. (2022), was conducted, with an electronic search conducted in combination with snowballing for a more effective literature search. Both backward snowballing (hand-searching the reference lists of articles to identify additional papers) and forward snowballing (finding citations to the identified articles) were used (Jalali and Wohlin 2012; Wohlin et al. 2022). Additionally, my personal article collections were screened for relevant literature.

The time period selected for this literature review was any literature post 1990, since the first articles on client-centred practice and the importance of outcome measures in OT started to emerge at around that time. Secondly, this time frame was chosen because children's participation in consultations and decision-making started to be researched from the 1990s onwards (following the UNCRC report).

Most articles were published in a peer-reviewed journal between 1990 and 2023. Books and book chapters were also included. Moreover, some older historic references were included. Grey literature was subject to less rigid criteria and was included if it was deemed to be relevant and informative. Since local (Maltese) literature was very limited, international publications were considered.

Articles were included if they met the following criteria:

- Published in English.

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[4] "Client-centred" is the term that is most commonly used in the OT profession. Therefore, the keywords were restricted to this framework. Other concepts, such "patient-centred" or "patient-focused care," were excluded because, despite their similarities, they define organisational procedures as opposed to theoretical strategies for ensuring client participation and engagement (Larson et al. 2018).

- Records were not limited to any particular research methodology; all relevant literature (i.e., research, reviews and discussion articles) were included.
- Only electronically available articles were included.
- Books and manuals were included as e-copies or if hard copies could be accessed.
- Literature post 1990.

Once the papers were identified, they were read and critically evaluated for the contribution they made to the research question. The process of searching was initiated at the proposal stage of the dissertation (in 2015) and continued throughout the study. A final thorough literature review was conducted at the end stage of the writing process (in 2023) to ensure the inclusion of newer and more recent literature. Whilst outlined as distinct stages here, the search process was iterative and non-linear with steps being revisited with constant comparison of new and emerging concepts. This literature search and write-up of the literature review was an ongoing process with ideas developing throughout. Even though the literature search was conducted over multiple times, I was aware that the results could have been influenced by my experience and background as a researcher. Furthermore, relevant data sources could have been missed in my search.

Several themes were identified from the literature and these themes were used to structure the literature review. This literature review is presented in two chapters, based on the two overarching themes that emerged from the literature review: one on client-centred and child-centred practice (**Chapter 2**), and the other on child-centred outcome measures (**Chapter 3**).

Chapter 2: Client-Centred and Child-Centred Occupational Therapy Practice

This chapter discusses the first few themes that were identified during the literature search, namely those related to client-centred and child-centred practice.

Despite being at the heart of OT, the client-centred philosophy has never been easy to understand or implement. This chapter provides an overview of client-centred practice within the context of working with children and their families. It begins with a historical perspective on client-centred practice, addressing the development and application of client-centred practice in OT. This literature review seeks to explain and discuss the main concepts of client-centredness and its application to a paediatric area of practice.

Family-centred practice, a well-known paediatric service approach, is also discussed. The chapter then proceeds to address child-centredness. It considers the involvement of the child in the therapeutic process, including shared decision-making and goal setting. Important concepts of child-centred practice are then addressed, and the positive impact of this service delivery method on client satisfaction and functional outcome is illustrated. This chapter also demonstrates how paediatric therapists tend to define a child's goals based on issues observed by carers or educators, instead of involving the child in the goal setting process. Finally, the effects of ignoring the child's involvement and goals and focusing on parents' and teachers[5]' perspectives are discussed.

2.1 A Historical Overview of a Client-Centred Approach in Health Care

The literature demonstrates a number of global factors and social influences over the past 40 years, which have led to notable changes in the definition and delivery of health care (Pollock 1993; Law and Mills 1998; Rebeiro 2000; Gupta and Taff 2015). Rising costs, the need to shift services from institutions to communities and the discontentment with health

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[5] The term 'teachers' is used to refer to both teachers and Learning Support Educators. This is the term that is used in paediatric OT literature.

outcomes have transformed the management and provision of health care (Law and Mills 1998; Gupta and Taff 2015). There has been a change in the definition of health (Law and Mills 1998), with a shift from having illness as the central point of health care, to one which focuses on health and well-being (Rebeiro 2000).

Moreover, the incidence of chronic disease has resulted in an accelerated need and interest in clients to direct their own health (Pollock 1993; Law and Mills 1998). There has been a considerable shift in health care towards concerns over quality of life (Pollock 1993). Clients have also become more critical consumers (Pollock 1993). A need was felt to respond to the client within health practice and research. All of these influencing factors led to the development and application of a consumer-led and client-centred approach to health care, resulting in improved client care and an improved therapeutic outcome.

Similar changes were reported in the OT profession. Law et al. (1998) describe how the afore-mentioned issues have impacted OT practice and led to an increased value of client involvement in services provided, thus triggering the development of a client-centred OT practice (Law and Mills 1998). This change in the client's role has influenced not only the client-therapist relation, but also the research methods used and the evaluation of OT intervention (Wressle 2002).

2.2 Historical Development of Client-Centred Practice in Occupational Therapy

Client-centred practice is a popular approach in contemporary rehabilitation (Antoniadou 2022), including OT. Indeed, encouraging closer collaboration with and involvement of service users is now common in professions, such as medicine and nursing (Sumsion 2006b; Parker 2012). However, this review will focus on client-centredness in OT.

Occupational therapists were among the first health professionals to adopt a client-centred approach as an integral part of their work (Restall and Egan 2021). "Client-centred practice has been a cornerstone of occupational therapists' identity for several decades" (Restall and

Egan 2021, p. 225) and is still considered to be as such by the American Occupational Therapy Association (AOTA; 2020). The concept and fundamental value of client-centredness resonates well with the theoretical framework of occupational performance (CAOT 1991). This intimate relationship between client-centredness and OT is aptly described by Law (1998), when she states that "Occupational therapy at its best, is client-centred" (Law 1998, p. xv).

Professional standards, such as those set up by AOTA (1998) also reflect the importance of client-centred practice. OT literature tends to highlight the perspectives of clients (Corring and Cook 1999; Rebeiro 2000). Occupational therapists encourage patients to actively participate in the daily activities that are important to them. Therefore, it would be expected to have clients in charge of OT services (Law and Mills 1998). Client-centred practice provides the means and the structure for OT to be holistic and distinctive for each client (Sumsion 2006b).

Through the emergence of client-centred practice, one could observe a "paradigm shift in … occupational therapy from a medical-based practice to a practice based on the needs of the client" (Wressle 2002, p. 8). This paradigm shift was prompted by the need for OT to regain its identity and refocus on its values, including client-centred, occupationally-focused interventions. These values underpinned the update to the 4th edition of the *Occupational Therapy Practice Framework* (OTPF; AOTA 2020).

In order to discuss its application to practice, there is a need to identify the concepts and issues that are fundamental to client-centred OT practice. Canadian OT literature has discussed client-centred practice since the 1980s (Corring and Cook 1999). There was a lot of debate about client-centred practice in the 1990s and 2000s in the OT field. Key authors were Law et al. (1995) and Law (1998). Other international OT literature, including British and American literature, has followed and continued to develop this debate. This drive towards client-centred practice was influenced by the work of Carl Rogers. Rogers (1939) was the first to use the term "client-centred practice" to describe a practice that adopts a non-directive approach to enable individuals to discover strategies to address their issues. Rogers (1939) describes a practice that involves the individual receiving the service. The notion of client-centredness has yielded multiple interpretations (Corring and Cook 1999). Law et al. (1995) coined the first definition of client-centred practice in the Canadian OT context, describing client-centred practice as an “approach to occupational therapy, which embraces a philosophy of respect for, and partnership with, people receiving services” (Law et al. 1995, p. 253). Law et al.’s (1995) definition included the concepts of respect, partnership, client autonomy, and client participation in decision-making.

The definition by Sumsion (2000), which was written against a background of UK OT practice (Parker 2012), echoed the main principles of client-centred OT, namely respect, partnership, client involvement in decision-making and the environment. Empowerment of the client was also emphasised (Sumsion 2000). The definition that the CAOT provided in their guidelines, *Enabling Occupation: An Occupational Therapy Perspective* (CAOT 2002), includes all of the aforementioned concepts, with the addition of enablement, which refers to:

> … processes of facilitating, guiding, coaching, educating, prompting, listening, reflecting, encouraging, or otherwise collaborating with people so that individuals, groups, agencies, or organisations have the means and opportunity to participate in shaping their own lives. (CAOT 2002, p. 50)

The constructs underpinning the application of client-centred practice in OT have been explored by a number of scholars (Law et al. 1995; Hong et al. 2000; Wressle 2002; Duggan 2005; Maitra and Erway 2006).

2.3 Key Features of Client-Centred Practice

The application of client-centred practice depends on the value of respect (Gupta and Taff 2015). When a client-centred approach is applied, decision-making regarding the treatment is taken by the client (Sumsion 1993). This involvement in decision-making is not only viewed as the client’s right (Law et al. 1995) but it is also expected of the clients when this approach is implemented (Wressle 2002). Indeed, Maitra and Erway (2006) suggest that a successful implementation of client-centred practice relies on two main elements: the client’s willingness and ability to participate in the decision-making process, and the occupational therapists' willingness and ability to include the clients in this process. Some other key assumptions of client-centred practice include the uniqueness of each client and the clients' right to receive information to enable them to engage in the decision-making process (Law et al. 1995; Sumsion 2006a).

Power plays a part in all professional relationships, and anyone considering to adopt a client-centred approach needs to reflect on the balance of its power (Sumsion 2006a). In client-centred practice, the power of the therapeutic relationship is shifted from the expert therapist on to the client (Rodger and Keen 2017), who is considered to be a partner (CAOT 2002). When choosing the focus and type of therapeutic intervention, the individual receiving OT services takes the lead (Law 1998; Sumsion 2006a), and collaborates in goal setting (Rodger and Keen 2017). Restall and Egan (2021) stress the importance of such collaboration in client-centred practice.

In client-centred practice, the individual's participation is crucial throughout the assessment and therapeutic process (Hong et al. 2000). Sumsion (1993) highlighted that when occupational therapists apply a client-centred approach, assessments revolve around the problem areas identified by the client, as opposed to being determined solely by the therapist. Treatment planning is consequently based on these client-identified occupational performance issues (Wressle 2002). OT assessment and intervention are based on the client's values and vision, taking into consideration the environment in which they live and the roles that they have (Law et al. 1995).

Through enabling, clients are valued as expert knowers about their life situation (Duggan 2005) and about their own occupational function (Law et al. 1995). Client-centred practice recognises that the clients are the ones who can voice their needs and choose options about their occupations. As a partner and through such knowledge, the client thus contributes to the therapeutic relationship (Duggan 2005), bringing strengths to the therapy experience (Law et al. 1995).

Law et al. (1995) further argue that the client-therapist partnership proves to be beneficial and inter-dependent. It is instrumental in resolving occupational performance issues and achieving the client's goals (Law et al. 1995). Moreover, client engagement is believed to positively influence therapy outcomes (King et al. 2018). OT services that adopt a client-centred approach yield higher levels of satisfaction and better functional outcomes. Since the intervention concentrates on the topics that are most essential to the client and his or her family, time and resources are maximised (Law 1998).

In spite of all the aforementioned benefits, client-centred practice lacks consistency. One possible reason is that being client-centred is challenging (Sumsion 1993; Law 1998; Sumsion and Smyth 2000; Wilkins et al 2001; Duggan 2005; Sumsion 2006a). Occupational therapists claim to support the concepts of client-centred practice, but these time-honoured principles do not easily translate into practice (Wilkins et al. 2001).

The challenges posed by the implementation of this service delivery approach can be attributed to time and resources constraints, the health care system structure, and the uniqueness of each client and their family, among other reasons (Law et al. 1995; Sumsion 2006a). Moreover, practising from a client-centred perspective can be even more challenging with some populations or clients than others, such as with paediatrics (Stewart and Cameron 2006).

A number of researchers have tried to explore the factors that affect the implementation of a client-centred practice in OT. Wilkins et al. (2001) examined the findings from three qualitative studies to demonstrate the challenges posed by implementing client-centred practice. These studies were from three different populations, including family-centred care for children and their families. Based on these findings, the challenges were categorised into three groups, namely challenges at the level of the system in which the service was delivered, at the level of the therapist and at the level of the client receiving the service. Similar barriers were identified by Law et al. (1995) and Sumsion (2006a).

Sumsion and Smyth (2000) sought to identify the barriers perceived by therapists as preventing the implementation of client-centred practice and the method that the therapists deemed the most effective to resolve the identified barriers. Sixty occupational therapists from various OT areas across the UK completed a questionnaire that featured barriers and resolutions drawn from the literature. Their findings showed that the highest ranked barrier that the therapists perceived was the fact that the client and therapists had different goals. The next two ranked barriers were therapists' lack of acceptance of clients' goals and their unease at allowing clients to select their own goals. Sumsion and Smyth (2000) recommended that therapists review the congruency of the goals with their clients and aim to implement enabling, client-centred mind-sets. Having case examples about how to implement client-centred practice was perceived as being the most effective method to resolve such barriers. Further research was recommended to investigate the effectiveness of this strategy.

Besides the identification of possible barriers, researchers have also sought to identify how frequently a client-centred approach was being applied. Some of these studies were conducted with occupational therapists, others with clients, whereas some others included both. Understanding how occupational therapists are implementing client-centred practice within the constraints in the settings that they practise is vital. One way of exploring this is through an action research study, similar to that implemented by Duggan (2005). Duggan (2005) conducted an action research study with four occupational therapists working with an adult population, in which they reflected on the extent of client-centredness in their practice. While the therapists in this study showed a commitment to client-centred practice, the findings showed that they did not manage to constantly achieve this in their practice.

Maitra and Erway (2006) conducted a comparative study which investigated how clients and occupational therapists perceive their involvement in the client-centred process, specifically vis-à-vis goal setting. The study was carried out in adult/geriatric health, with 11 occupational therapists and 30 clients, who participated in a semi-structured interview. The findings indicate a perceptual gap between occupational therapists' and clients' reported use of and participation in client-centred practice. The researchers attributed this perceptual gap to the therapists' and clients' lack of understanding of their roles within client-centred practice. They recommended that a systematic strategy be developed by therapists, to enable clients to perform their roles in a client-centred approach.

Occupational therapists who participated in Maitra and Erway's (2006) study expressed their readiness to practise in a client-centred way; however, they also identified a number of challenges posed by the adoption of this approach. These challenges include: 1) clients with low cognitive abilities; 2) clients who are reluctant to participate in setting their goals and who expect their therapist to do this; 3) low productivity at the facility; 4) clients who are non-verbal; 5) working in an environment in which the team might not prioritise the client's own goals; and 6) clients who do not wish to be independent (Maitra and Erway 2006). Similar challenges could be encountered when working with a paediatric population; however, no such study was found in this area.

Similar to Maitra and Erway (2006), Sumsion (2005) conducted a study to identify the opportunities and barriers regarding client-centred practice, as seen through clients' perspectives. She interviewed nine clients from a community mental health setting. This study found that client-centredness was valued by these clients and that the opportunities outnumbered the challenges in this specific practice setting. Opportunities mentioned by the clients included the staff's strong support of the clients' engagement; the availability of programmes that target the clients' specific goals and needs; and the ability of trusted staff to listen to the clients. Conversely, the identified barriers were related to the requirement for additional structure of a specific programme; and the staff's limited capacity, which lessened the likelihood of the ideal programme being offered to suit a client's needs. Additionally, the clients realised that their fear and the severity of their condition made it difficult for them to strive towards their desired outcome (Sumsion 2005).

Another study was conducted by Rebeiro (2000) to explore clients' experience with a hospital-based OT service. Rebeiro (2000) conducted two in-depth interviews, with mental health services clients. These clients described their experience as less client-centred and more prescriptive. They felt that a number of issues were hindering their ability to participate in the decision-making process and were negatively affecting the collaborative partnership between the therapist and the client. These factors included activities being prescribed for them by the therapists, limited choice and placing the illness instead of the individual as the focus of intervention. Consequently, the therapeutic value of occupation was diminished. These participants recommended that the therapists offer an occupational choice, that importance be given to the individual within the client, and that clients be professionally guided to engage in meaningful occupation (Rebeiro 2000).

All of the above-mentioned studies were conducted in the UK, the US, or in Canada in other populations, mainly in adult geriatric or mental health clients and not in the paediatric area. No similar studies were conducted in Malta. The studies are also somewhat dated reflecting the interest in client-centred practice in the 1990s and early 2000s, and possibly the assumption that, as a cornerstone of OT practice, client-centredness today is a given.

The literature indicates that while occupational therapists claim to support client-centred practice and wish to implement such practice, a number of obstacles impede the application of this approach. While some of these challenges may require innovative problem-solving techniques, none of them are insurmountable. The discussion above showed that implementing a client-centred approach is neither straightforward nor easy. However, it is crucial for OT clients to continue to be at the core of OT practice (Sumsion 2006a; Restall and Egan 2021).

2.4 The Family as a Client

In paediatrics, the concept of the client “needs to be broadened to include the family” (Stewart and Cameron 2006, p. 148). The term “family-centred service” refers to an approach to the provision of services for children with special needs (Stewart and Cameron 2006). It is “a philosophy and method of service delivery” (King et al. 2002, p. 1). The literature includes various definitions of a family-centred service (Terwiel et al. 2017). “Family-centred principles emphasise a dynamic model of care that ebbs and flows with the hanging context, needs and priorities of children and families.” (Wiart et al. 2010, p. 248).

Family-centred care is at the very heart of client-centredness, which is the core of OT (Phoenix and Vanderkaay 2015). Its evolution is parallel to that of client-centred service and like the latter, it is based on Carl Rogers's work (Stewart and Cameron 2006). The family is acknowledged as the focal point of services in this definition (Stewart and Cameron 2006).

Family-centred care encourages the collaboration between occupational therapists and families to make knowledgeable decisions regarding supports and services (Stewart and Cameron 2006) and to identify meaningful therapy goals for the family (Palisano 2006). It is considered to be the predominant philosophy of practice in paediatric rehabilitation (Rosenbaum et al. 1998; King and Chiarello 2014).

In paediatric practice, a number of researchers have argued that a family-centred approach should be used when working with children and their families (Law et al. 1998; Brewer et al. 2014). An and Palisano (2014) assert that for children with disabilities to get the best possible outcomes out of intervention, collaboration between the family and professionals is vital, referring to this as “family-professional collaboration”. Their study emphasises the importance of including the family but it does not address the need for inclusion and collaboration with the child receiving the service. The involvement of parents and family members in the planning and evaluation of the treatment is a foundational part of a family-centred approach (Hanna and Rodger 2002). This approach is based on the principles of respecting differences, sharing, partnering, negotiating and caring in the context of family and community (Coyne et al. 2016).

Family-centred care has been related to enhanced health and well-being; better family functioning; more involvement of parents in their children's treatment programme; increased satisfaction; increased efficiency; improved communication between the family and the team; and an improvement in health services for paediatrics with disabilities (Rosenbaum et al. 1998, Brewer et al. 2014, King and Chiarello 2014). There is an extensive body of literature, which advocates for family-centred care, but which also identifies the challenges posed by implementation of this approach (Edwards et al. 2003; Coyne 2013; Coyne et al. 2016; Ford et al. 2018).

In family-centred practice, the family is a whole system and thus viewed as ‘the client’ (Darrah et al. 2010). Although family-centred care is strongly acknowledged in paediatric rehabilitation, there is a concern that the child’s views may be overridden by the parents’ views, priorities and expectations (Coyne et al. 2016). While focusing on addressing the families’ need for information, skills and coping strategies, the therapists may get distracted from considering the child’s needs (Coyne et al. 2016). Ford et al. (2018) claim that family-centred care can result in the child taking more of a relatively passive and secondary role vis-à-vis that of their parents, even when the child could have been more actively engaged. By placing a heavy emphasis on the family, the therapist may overlook the larger environment and connections that children interact with, outside of the family.

Phoenix and Vanderkaay (2015) conducted a reflective study about the application of client-centredness in OT with children. Whilst supporting a client-centred approach to OT with children, the researchers point out that occupational therapists may encounter difficulties when applying these concepts to children. In light of this study, therapists are urged to find relevant occasions where they can promote client-centred services. However, the client-centred approach that is emphasised in this study refers mostly to the involvement of parents and family, as is seen in family-centred care, rather than to the specific involvement of the child as a client. Similarly, Edwards et al. (2003) conducted a study to identify factors that enhance or limit the application of family-centred practice. However, this research also emphasised the importance of family-centred practice but not child-centred practice.

Prioritising the child’s needs has gained traction. Shields (2010, 2015) suggests that another framework should replace family-centred care, to model the children’s care in all areas of health care, whereas others argue that family-centred care should be valued (King et al. 2002; Palisano 2006; Fingerhut et al. 2013). Coyne et al. (2016) are amongst the researchers who support a shift from family-centred care to child-centred care. They argue that an asymmetric relationship is created through the parents’ and the professionals’ assumed superiority over the child. Secondly, they highlight the need to promote the cardinal concepts of protection, promotion and participation rights for children, which are recommended in the UNCRC declaration (UN 1989). This UN document emphasises the right of children to have their opinions acknowledged, heard, and taken into consideration when making decisions that impact their daily lives (Savage and Callery 2007). Thirdly, Coyne et al. (2016) note that the child’s view needs to be given more importance and that the child should be regarded as an individual with experiences and desires that merit respect.

Consequently, a number of researchers advocate for a child-centred practice as an alternative way of practice with children (Coyne et al. 2016; Ford et al. 2018; O'Connor et al 2021). In a child-centred approach, the child is at the centre of the care that is provided. The child's rights to actively participate in health-related issues, are respected when a child-centred approach is employed. Intervention is then designed to reflect the child's needs and wishes (Coyne et al. 2016; Ford et al. 2018). Söderbäck et al. (2011) urge health care professionals to value the child's perspective to promote the child's active participation.

2.5 Child-Centred Practice in Occupational Therapy

This literature review found a relatively small number of book chapters or articles specifically pertaining to the application of client-centred practice in paediatric OT. It could be that family-centred practice has been the focus of most research. Another reason could be that the fundamental ideas of client-centred practice are assumed to apply equally to children (Stewart and Cameron 2006).

Child-centred practice is rarely defined separately to client-centred practice. In child-centred practice, the therapist's approach aligns with all of the previously described components of client-centred practice, by acknowledging the child as the focal point. The child's developmental stage, likes and dislikes, strengths and problems, family background, responsibilities, jobs, and performance demands are all considered by the therapist (Rodger and Keen 2017). Child-centred practice entails the acknowledgement of children as unique individuals as well as part of a group (such as a family or class), listening to and respecting what children have to say, focusing on their needs, and viewing things from their perspectives (Rodger and Keen 2017).

Discussions about the necessity to create child health services that are inclusive of children's viewpoints have been influenced by the contemporary understanding that children can actively shape their everyday experiences (Alderson and Montgomery 1996; Gabe et al. 2004). Furthermore, such discussions regarding children's potential to actively participate in their health care have been affected by the children's rights movement, which were encouraged by the UNCRC (UN 1989).

In child-centred practice, children are recognised as individuals, who can take part in a situation within their own competence (Söderbäck et al. 2011; Ford et al. 2018). The children are part of a family but they are the main stakeholders in the partnership (Quaye et al. 2019). The UNCRC has influenced debates about children's role as active participants in their health care (UN 1989). O'Connor et al. (2021) stress that the rights of children should be integrated into child-centred OT practices and education, if best practice is to be sought.

Child-centred practice recognises and respects the right of the child as outlined in UNCRC, Article 12:

> States shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child will be given due weight in accordance with the age and maturity of the child (UN 1989, p. 4).

The UNCRC presents children's rights as being founded on the same principles as child-centred practice, namely protection, promotion and the rights of participation (Coyne et al. 2016).

The idea of client-centred practice was viewed by occupational therapists as being both ethically sound and effective, thus resulting in its widespread use in OT practice (Sturgess et al. 2002). Subsequently, it was applied to the paediatric area, hoping that it could contribute meaningfully to the child's therapy, mostly in assessment and in goal setting (Sturgess et al. 2002). Occupational therapists became increasingly aware of the need to listen to and respect children's perceptions about themselves, whilst therapists were aiming to deliver specialised services with successful outcomes (Coster 1998; Missiuna and Pollock 2000).

Heah et al. (2007) note that the application of client-centred practice in paediatric OT stipulates that the child's perception is sought and respected. The role of the child in society, including the child's position within health care, is constantly being debated and challenged.

The concept of child-centred care has been proposed as a way of situating children to a more focal position within health care (Ford et al. 2018). According to Savage and Callery (2007), in client-centred care, the therapist should be sensitive to children's ways of communicating their views, and guidance should be provided when required.

2.6 The Child's Participation in Decision-Making

Researchers have sought to explore the extent of children's involvement in health-related matters. Employing a mixed-methods approach featuring in-depth interviews, questionnaires and observations, Coyne (2006) conducted a study to investigate children's, parents' and nurses' views about participation in health care related issues. The majority of children aged 9 to 15 years indicated that they wished to be consulted and involved in decisions about their care. These child participants expressed feelings of anger and depression when health professionals ignored them (Coyne 2006).

Coyne (2008) reviewed the literature on children's, parents' and health professionals' narratives in participating in consultations and decision-making in health care settings. The ages of children in the reviewed studies ranged from 0 to 18 years. The review suggested that the perceptions of children in health care settings are rarely sought or acknowledged. Children were rarely involved in decision-making processes and their position in health care information-exchange situations seemed to be considered insignificant. Participating children were not involved or supported even when they indicated their willingness to participate in decision-making. Coyne's (2008) overall data suggests that children would like to participate and that such participation has a number of advantages.

Coyne's (2008) review indicates that the child's age and maturity are usually viewed as significant barriers to children's active participation due to the assumption that they may lack the cognitive capacity to understand complex treatment-related information and medical terminology. However, Coyne's (2008) review suggests that children encounter significant barriers to actively participate in health care interactions, mostly from medical professionals and to some extent from their parents. Parents and medical professionals were in fact shown to have a crucial role in the consultation process, since they have the authority to encourage or prevent children from participating.

Coyne (2008) reports that some professionals seem to question whether it is permissible to discuss health-related decisions and information with minors. She explains how professionals might address their conversations to parents, and parents, for whatever reason, consent to this and cooperate with the consultation, thus reinforcing this behaviour. Parents may also unconsciously silence their child’s voice during the consultation, when they interrupt or dispute their child's answers. Children become used to taking on a submissive role and learn not to interfere with adults' or their parents' conversations. Consequently, children tend to take on a passive position to avoid facing criticism from professionals or parents if they do not (Coyne 2008). It is worth mentioning that Coyne’s (2006, 2008) studies reviewed health care services in general and were focused mostly on the nursing or medical field. Further research is required to establish whether the same factors affect child decision-making in the OT area.

O’Connor et al. (2021) conducted a qualitative study to describe the decision-making experiences in OT. Seventeen participants (six children, five parents and six occupational therapists) participated in semi-structured interviews. The findings of this study indicate that adults tend to direct decision-making, and that “children’s voices are subsumed by adult-led services, priorities, and agendas” (O’Connor et al. 2021, p. 1). The children aged six to eleven years, who participated in their study felt that it was important for them to be listened to and respected.

Costa et al. (2017) insist that standard child rehabilitation practice for all health disciplines should involve the exploration and integration of children’s perspectives in treatment planning. Wyatt et al. (2015) highlight that children are valuable contributors in health care as they can provide information about how they experience health and their care. The term shared decision-making (SDM) is used to refer to “the ways in which children can contribute to the decision-making process, independent of who makes the final decision.” (Coyne et al. 2014, p. 274). Wyatt et al. (2015) argue that SDM in paediatrics is not well defined, especially when regarding the expected role of the child and parent respectively. SDM is a multi-phase process that includes the development of relationships between professionals and patients in order to share information. It is also what is meaningful for the patient, recommended intervention possibilities, and the advantages and disadvantages of these possibilities (Wijngaarde et al. 2021).

Tam-Seto and Versnel (2015) note that clients have the right to make choices, even if they run risks when they have choices. They should be participants in SDM. Occupational therapists use enablement skills to participate in SDM together with their clients, irrespective of the clients' condition or occupational challenges (Tam-Seto and Versnel 2015). These researchers (Tam-Seto and Versnel 2015) conducted a qualitative study with six occupational therapists working in an adolescent mental health setting. Their research showed that thoughts and actions which shaped the role that the participants took, are traits that influenced SDM in OT. These traits are impacted by client characteristics, the therapeutic relationship, and the nature of the decision being made.

Health and social care services widely express the value of partnership and SDM with patients. However, these recommendations are given less attention in paediatric services (Young et al. 2006). Young et al. (2006) investigated SDM with children with cerebral palsy in physiotherapy. They explored children's, parents' and practitioners' reports of SDM. Their findings suggest that children's involvement is less than that of their parents.

Similar outcomes were found by Quaye et al. (2019). Their research, which focused mainly on medical and nursing care, explored the child's active participation in children's hospitals in Sweden, regarding daily health care practice. Findings showed that children were not always involved, despite participation being considered a basic right for children. The study also found that children's active participation was affected by the actions of children themselves, parents and health care professionals (Quaye et al. 2019).

The involvement of children in SDM has been found to have several upsides. Wijngaarde et al. (2021) conducted a scoping review in the medical literature to explore how children participate in paediatric SDM. Their data shows an increased awareness among both professionals and parents, that children's engagement in SDM can yield improved health outcomes (Wijngaarde et al. 2021). Unfortunately, no OT literature was included in this scoping review. In fact, Rodger and Keen (2017) point out the scant evidence of the application of SDM in the area of decision-making related to therapy interventions.

Lynch and Lynch (2013) argued that even research about children's involvement in decisions on whether or not to participate in OT research has been limited. Therefore, they conducted a study to explore the perceptions of six typically developing children, aged 9 to 12 years, about their decision to take part in an OT study. The participants showed a limited understanding of the study they participated in. The children also expressed their appreciation of their inclusion in the decision to participate in this study. Following this study, recommendations were made for therapists to carefully consider the child's participation in the consent process, as a rights-based approach to research (Lynch and Lynch 2013).

The issue of collaborative intervention planning is a complex one, based on the triadic relationship of the therapists, parents and children (Kramer et al. 2012b; Coyne et al. 2014; O'Connor et al. 2021). Based on the UNCRC (UN 1989), a child has the right to participate in all matters concerning their wellbeing (Wijngaarde et al. 2021). Coyne et al. (2014) insist that these rights of children to participate should be supported and respected by adults, even though children's willingness to participate in SDM tend to vary. Coyne et al. (2014) found that children demanded choices and appreciated their participation in SDM; however, their involvement was found to be rather limited. Therefore, adults were encouraged to provide children with choices and opportunities that allow them to participate.

In OT, child decision-making serves as a foundation of client-centred practice, notably when it comes to goal setting (O'Connor et al. 2021). However, a limited number of studies have investigated the child's role in decision-making in goal setting. This area will be further explored in the following section.

2.7 The Child’s Participation in Goal Setting

An essential part of therapeutic intervention is that of identifying clients’ priorities and understanding which daily life activities are meaningful for them to develop relevant goals. In addition to the family, children are important and valid sources of information for goal setting (Costa et al. 2017). Goal setting is a key element of the rehabilitation process (Pritchard-Wiart and Phelan 2018) and of client-centred practice (Law et al. 1995; Polatajko et al. 2013; Fisher 2009). The quality of care can be improved through the use of a solid goal setting process. Such a process would also improve knowledge about best practice in the application of collaborative goal setting as part of client-centred or family-centred practice (Brewer et al. 2014). Collaborative goal setting is indeed considered to be a core element of paediatric rehabilitation (Brewer et al. 2014; Pritchard et al. 2022).

Some researchers (e.g., Curtis et al. 2022) have looked at goal setting with children focusing on the term ‘family-centred’ services rather than client-centred practice. While Pritchard et al. (2022) recognises that children should be one of the parties involved in collaborative goal setting, together with the parents and the therapists, Brewer et al. (2014) address mainly the collaboration between the clinician and the client/families, referring mostly to the family as ‘the client’ but not specifically to the child. Moreover, a few studies have examined the application of goal setting in paediatric OT by investigating the therapists’ perspectives (D’Arrigo et al. 2020a) and the process of setting goals (Schwartz et al. 2020) without exploring the issue from a child’s perspective.

Both Wiart et al. (2010) and Pritchard et al. (2022) report a general tendency for children not to be optimally involved in setting their own rehabilitation goals. Curtis et al. (2022) conducted a scoping review to investigate published research about the involvement of children in goal setting, decision-making or conduct of occupational or physical therapy. This review sought to explore whether children or adolescents’ voices were being included when therapists set goals and implement treatment. Only nineteen studies out of a total of 2114 articles had documented evidence of addressing and including the children’s voices in therapy. Children with cognitive or communication difficulties, and those under 5 years of age, were especially excluded. The researchers lamented the limited knowledge about the way and the extent to which the voices of children are heard in therapy (Curtis et al. 2022).

Pritchard-Wiart and Phelan (2018) conducted a scoping review and found that the voices of the children were conspicuously lacking from rehabilitation literature, including OT. They did not find any qualitative studies that examine children' experiences with goal setting procedures, and any strategies for involving children in the process were not clearly described. The parents' role in goal setting is far more comprehensively reported than that of the children, with scant attempts to engage children in this process (Pritchard-Wiart and Phelan 2018). These researchers recommended the need to investigate the child's views of the goal setting process. Subsequently, Pritchard et al. (2022) addressed this gap by including the child's experiences in a child-driven approach to goal setting, exploring the experiences of children, parents and therapists. Through children's engagement in goal setting, functional goals that were perceived as motivating by the children, could be identified. The children reported that they felt valued and heard. However, therapists and parents acknowledged that the ability of children to identify their own goals had been underestimated (Pritchard et al. 2022).

Vroland-Nordstrand (2008) argue that paediatric rehabilitation services claim to be family-centred, with the goals focusing on the occupations that they would like their children to engage in, often being set with parents, rather than with the children themselves. As aforementioned, client-centred practice is built on the premise that clients are listened to, that their priorities are understood and that that they are actively involved in achieving meaningful goals (CAOT 1997). However, occupational therapists working with children tend to focus their goals on issues that are identified by the parents (Brewer et al. 2014) and teachers (Missiuna and Pollock 2000). Therapists tend not to even attempt to engage young children in the goal setting process (Missiuna and Pollock 2000). The aforementioned studies suggest that children's voices tend to be over-powered by adult-led needs, goals, plans and services, clearly indicating that services tend to be largely adult-led (O'Connor et al. 2021).

2.7.1 The Relationship between Goal setting and Self-Efficacy

Being able to identify which occupations are challenging for the child to perform, and the areas of improvement the child wishes to work on, forms the basis of establishing goals of intervention (Missiuna and Pollock 2000; Pollock and Missiuna 2015). The construct that is referred to as perceived competence or self-efficacy demonstrates children's ability to evaluate their ability to satisfactorily complete a task (Missiuna and Pollock 2000). The experience acquired when interacting with the environment forms the basis of self-efficacy (Costa and Lindenthal 2015). Self-efficacy is a term used to refer to children's perception of their ability to master life challenges (Missiuna 1998). A child's self-efficacy can potentially change following intervention due to better mastery of the activity or to adjustment in the children's internalised measures against which they judge success or failure (Missiuna 1998).

2.7.2 Advantages of Collaborative Goal Setting with the Child

Research evidence shows that in addition to being possible, listening to the child's voice is also beneficial (Curtis et al. 2022). There is a growing body of literature that focuses on children's participation (Shier 2001). Brewer et al.'s (2014) review demonstrates that when collaborative goal setting is done with the parents, there is more focus on and better understanding of treatment goals, facilitating communication and improving teamwork; an increased feeling of competency in parents; and more collaboration between the parents and the team (Brewer et al. 2014). When clients are involved in collaborative goal setting, the increase in motivation and identification with the set goals improves the outcomes of intervention (Wressle et al. 2002a; Brewer et al. 2014), as clients are more prepared for therapy (Wressle et al. 2002a). The same applies to children. The involvement of children in prioritising the goals of treatment, in addition to the parents, is reported to influence the efficacy and efficiency of the therapeutic service provided (Brewer et al. 2014). Moreover, children's self-control is linked to an increase in their engagement in intervention (D'Arrigo et al. 2020b).

Conversely, when clients do not set the goals themselves, they cannot resolve them either, undermining their engagement and feeling of mastery over their own health (Pollock 1993).

As the child can be considered the main client in paediatric OT, it may well be expected that such positive outcomes would be achieved if the child set the goals of intervention.

Additionally, children's rights need to be respected (UN 1989). Vroland-Nordstrand et al. (2016) argue that a child can be trusted to set the goals so that they can be involved in their own therapy. Involving the child in goal setting would increase their motivation to engage in goal-related intervention, thus improving therapy outcomes (Poulsen et al. 2015); otherwise the child could feed demotivated to achieve goals (Missiuna and Pollock 2000; Pritchard-Wiart and Phelan 2018). Children's ability to be engaged could possibly be "thwarted by adults' actions" (Coyne 2008, p. 1687), leading to an intervention that is less motivating for them. According to Pritchard et al. (2022), one cannot assume that the goals set by others, namely parents and therapists, will be intrinsically motivating for the children too. The most significant finding in the aforementioned study was the strong link made by clinicians, parents and children between enhanced motivation to engage in therapy and child-identified goals (Pritchard et al. 2022). Furthermore, involving children in identifying their own goals would direct therapy to focus on more meaningful goals, given that children tend to have different treatment aims than their parents (Vroland-Nordstrand et al. 2016).

Costa et al. (2017) propose that the process of creating participatory goals with children and their proxies needs to be adopted as a crucial component of therapeutic intervention. It can be difficult to define and clarify therapeutic intervention goals in conjunction with clients, especially young children, but making these goals intelligible to all stakeholders may be vital to a meaningful and successful treatment outcome. As using individualised client-centred measures can enhance children's and families' motivation, and direct their attention to intervention goals, it is important for occupational therapists to use measures that facilitate the engagement of families and children in goal setting and in the evaluation of treatment outcomes (Tam et al. 2008).

Even though there is awareness of the aforementioned benefits, the goal setting process is not consistently foregrounded in clinical practice and research, and children, most particularly, are often excluded from the goal setting process (Wiart et al. 2010; Pritchard-Wiart and Phelan 2018).

2.7.3 Challenges to Collaborative Goal Setting in Paediatric Occupational Therapy

There are a number of challenges which hinder the application of collaborative goal setting in paediatric OT, foremost among which is the abstract nature of the process to identify and prioritise goals (Missiuna and Pollock 2000). The differences in opinions and the concerns that clinicians have when clients propose unrealistic goals can also be a challenge (Pritchard-Wiart and Phelan 2018).

Other factors that may hinder goal setting with children include cognitive difficulties, language issues (Wilkins et al. 2001) and lack of insight about their occupational performance challenges or issues (Stewart and Cameron 2006). Indeed, the ability of clients with cognitive impairment to engage in client-centred care is questioned (Hobson 2006b). Clients with limited problem-solving abilities are especially cited by Law et al. (1995) when they discuss the difficulties in the implementation of client-centred care. They note that the therapist might need to be more directive with a client who lacks strong problem-solving abilities vis-à-vis other clients. Furthermore, the age at which children can make their own decisions is a client challenge that is unique to the paediatric population.

The aforementioned challenges may explain why therapists opt to set their goals with parents (Tam et al. 2008). Other barriers to goal setting, that were cited in Brewer et al.'s (2014) review, include the limited time and families' possible inability to establish realistic goals. Despite these challenges, Hobson (2006b) makes a compelling case for the implementation of a client-centred approach even with clients with cognitive impairments.

2.8 Child-Centred versus Child-Friendly

In OT, participation in decision-making is a pillar of client-centred philosophy (Sumsion 1993; Parker 2012). Rodger and Keen (2017) argue that paediatric practice is often a '*child-friendly'* one, and not a child/client-centred one. Many paediatric therapists consider themselves child-centred therapists but, according to Rodger and Keen (2017) are in fact child-friendly ones. Such clinicians work in attractive environments, with child-appropriate toys and equipment. However, they work on therapists’ goals, which they develop themselves from the use of age-appropriate assessments, possibly liaising with the parents or the teachers, but excluding consultation with the children themselves (Rodger and Keen 2017).

Rodger and Keen (2017) argue that unless goal setting tools are used with children, or the latter are at least consulted about their concerns and preferred areas to address in therapy (given that they are cognitively able to do so), and intervention is then based on these child-identified preferences, then therapists cannot be considered child-centred.

2.9 Why is it Important to Avoid Relying on Adults’ Goals?

A large body of research in paediatric OT suggests that children’s perceptions about their competence in activities of daily living often vary from those of relevant adults (Missiuna and Pollock 2000; Sturgess et al. 2002; Missiuna et al. 2006; Tam et al. 2008; Costa and Lindenthal 2015). Their goals and priorities also differ (McGavin 1998; Missiuna and Pollock 2000; Vroland-Nordstrand and Krumlinde-Sundholm 2012b; Costa et al. 2017).

Using the COPM (Law et al. 2014) to identify goals and priorities, McGavin (1998) conducted a study to determine any differences in the rehabilitation goals between adolescents and their parents. Their findings showed that parents identified more issues than their children, with an 8.77% level of agreement. The study also indicated that their identified priorities were also different, with the percentage of agreement being only 10.94%.

Although Missiuna and Pollock (2000) found a high level of agreement about the activities that were challenging for the child, their results showed that parents tended to rate the children’s competence lower than the children did. In this study, through the Perceived Efficacy and Goal Setting (PEGS; Pollock and Missiuna 2015), children perceived themselves to be more competent, vis-à-vis their peers, than their parents did. Furthermore, children and their parents disagreed over the selected tasks or the priority given to these tasks.

Missiuna et al. (2006) obtained similar results in terms of perceived competence. They compared children's ratings on the PEGS with those of their parents and teachers, who rated their children's abilities by completing a parallel questionnaire. These researchers found that parents and teachers rated children's abilities lower than the children's self-perceptions.

Fayed and Kerr (2009) also examined the similarities and differences in occupational challenges between children and their parents. The COPM was administered to both parents and their children, and their findings indicated low levels of agreement. Moreover, the results indicate overlapping as well as separate priorities between children and their parents. Such diversity of priorities may depend on individual experience, which can impact both their respective lives and their priorities for therapy (Fayed and Kerr 2009).
Similarly, using the Swedish version of the PEGS, Vroland-Nordstrand and Krumlinde-Sundholm (2012b) found poor agreement between parents' goals and their children's goals. Indeed 48% of the children identified goals that were different from their parents'. Echoing the aforementioned studies, children were found to have a higher rating of their competence in everyday tasks than their parents did, apart from different goal priorities (Vroland-Nordstrand and Krumlinde-Sundholm (2012b).

Mixed results were obtained by Costa and Lindenthal (2015). They investigated the perceived competences in daily activities in children, parents and teachers and compared their respective perceived competences. The Austrian-German version of the PEGS (AG-PEGS) was filled in with the children while the adults were asked to fill in the AG-PEGS questionnaire separately from the child. The parents had a lower scoring of the children's competences, than the children themselves. The perception of children, parents and teachers was found to be statistically different in a small number of areas, while there was also agreement in some other areas.

Costa et al. (2017) explored collaborative goal setting with children, parents and teachers, through the use of the AG-PEGS. The goals of the three categories were compared using an ICF-CY perspective. The findings showed that for their primarily participation-oriented goals, children prioritised their independence, competence, and joy in valued everyday activities. They additionally highlighted social motives, such as acquiring a sense of belonging and being accepted by others. While teachers based OT interventions mostly on body functions and school activities, parents were more concerned with their children's academic success.

Schiariti et al. (2014) conducted a study to investigate the strengths and limitations in functional performance. They conducted self-reports or caregiver proxy-reports. Their findings showed that although children and their parents mentioned some similar areas of functioning, each of these provided a unique perspective. Similar outcomes were found regarding motor performance. In their study investigating changes in motor performance, Green and Wilson (2008) found differences between parents' and children's perceptions. A weak relationship was also observed between the parents' and children's perceptions of progress (Green and Wilson 2008). Timler et al. (2018) also investigated the congruence between parents' and adolescents' self-reported motor competence. Fewer motor difficulties were identified by parents when compared to adolescents, especially females. The researchers concluded that since adolescents may be more aware of their own competencies, their self-reports may be more realistic (Timler et al. 2018).

Contrary to the aforementioned studies, Galvin et al. (2010), who researched functional concerns identified by children and their parents, found a high degree of agreement between the goals identified by the parents and their children. Unlike the other studies, it selectively used either the PEGS or the COPM, depending on the child's age, rather than consistently one single tool. Additionally, neither the COPM nor the PEGS were scored. Moreover, the children and parents were in the same room during most of the assessment, so whether the goals were identified independently or not is a moot point (Galvin et al. 2010).

Most of the literature, therefore, supports the view that children tend to perceive themselves as being more competent than other relevant adults (Missiuna and Pollock 2000; Sturgess et al. 2002; Missiuna et al. 2006; Costa and Lindenthal 2015). Given the discordance between the perspectives of children and their caregivers and the emphasis of different areas for targeting interventions, it is important to explore the child's and parents' perspective, rather than relying on one or the other. It is essential for children to be included in the assessment process (Fayed and Kerr 2009), since "…children are also the only agents present for the entirety of their daily experience; therefore, in certain ways, they are the most knowledgeable about their own lives” (Fayed and Kerr 2009, p. 91).

Sturgess et al. (2002) emphasise that children’s total and constant involvement in their experiences validates their views. Parents may be in close proximity to their child for an extensive amount of time, and teachers may observe them for several hours. Moreover, both may try to understand the child. However, it is only the child who is present all the time. “Parent, caregiver, and clinician perspectives are invaluable to describing and understanding these experiences, but these third-person views should not replace – nor should they be confused with – the child’s perspective” (Kirby et al. 2015, p. 317).

Aldiss et al. (2009) note that professionals working with children should be aware of these discrepancies in what children and their parents perceive as important, due to related implications regarding intervention. Green and Wilson (2008) question whether the “lack of relationship between the opinions of parent and child raises some ethical issues regarding how to determine the need to begin, or when to terminate, intervention” (Green and Wilson 2008, p. 217).

The discrepancy between children’s and parents’ goals stresses the importance of using measures that reflect the child’s opinions and enhance collaboration between the child and relevant adults in the OT process. Costa et al. (2017) argue that given the limited time and financial resources in health care, the development of meaningful, client-centred priorities for rehabilitation, which are relevant and sustainable, can be reinforced by the children’s underlying motives for achieving their objectives. “There is a need for child-appropriate assessment and goal setting tools and procedures” (Costa et al. 2017, p. 1589). Pritchard-Wiart and Phelan (2018) warn therapists that if children’s voices are excluded from the goal setting process, the intervention that is offered might not be meaningful for the child, leading to the child’s disengagement from their rehabilitation.

In order to meet international policies, children’s perspectives should be explored and integrated in intervention planning. Such practice should be considered state of the art in paediatric health care services (UN 1989; Costa et al. 2017). Together with parents, health care professionals have a key role to play in empowering and promoting children’s attempts to engage in the treatment setting (Coyne 2008). Children’s and their parents’ opinions and contributions form a vital part of the intervention process and outcome evaluation. Both have an essential role to play in the evaluation of occupational performance issues, in goal setting and in identification of the perceived benefits of OT intervention (Green and Wilson 2008).

2.10 The Being Child

The concept of 'being child' (James and Prout 2015) was proposed to emphasise the idea that childhood is socially constructed, viewing children not as individuals in the process of becoming adults but as social actors in their own right (James et al. 1998; Prout and James 1990; Messiou 2008). This perspective challenges traditional views that portray children as passive objects of socialisation or development (James and Prout 1997; Brady et al. 2015). Instead, it recognises children as active participants in shaping their social environments and societies, underscoring the dynamic nature of childhood (Prout and James 1997, Rengel 2014). The shift from seeing children as 'becoming' to 'being' (Messiou 2008) highlights the importance of acknowledging children as human beings with agency and rights equal to adults (Sundhall 2017).

This concept also emphasises the importance of considering children's voices and perspectives in research and understanding how children define and perceive the concept of 'a child' (Adams 2014). This links to the contemporary perspective of ‘amplification of voice’ to listen to the child's voice, which involves recognising children as active agents able to express their views, experiences and concerns (Carnevale 2020). This approach emphasises the importance of creating safe, inclusive spaces where children's voices are not only heard but also valued and acted upon (Carnevale 2020, Zubizarreta and Salvador 2023).

The latter aligns with the idea that children should be recognised as full human beings with the right to be heard and taken into consideration from an early age, allowing them to influence aspects that affect their lives (Gillett-Swan and Sargeant 2017). Eliciting children’s voices and acknowledging their ethical relevance (Carnevale 2020), is a child’s right that is upheld by the UNCRC (UN 1989).

By giving voice to children and making their perspectives heard, researchers and practitioners aim to promote children as active agents with interests and capacities to participate in discussions and decisions that affect them and others (Delgado et al. 2022). However, challenges exist in ensuring that children's voices are effectively amplified. Despite efforts to create spaces for children's voices, there are instances where the majority of voices are silenced by adult perceptions of children (Gillet-Swan and Sargeant 2017). Koller (2021) highlights the questionable practice of using parents as proxies for children's opinions.

Several challenges related to children’s physical, cognitive and communication abilities can be overcome through the use of various visual techniques, picture communication symbols and creative art-based methods (Stafford 2017). Researchers and practitioners should reflect on the processes that shape children's voices, address power imbalances, and consider the ideological contexts that influence the production and reception of children's voices (Spyrou 2011).

2.11 Children’s Ability to Self-Report

Some scholars challenge the ability of young children to self-evaluate and report their own problems, assuming that such young children cannot carry out a self-assessment (Missiuna and Pollock 2000). It has been assumed that goal setting is too abstract a process for young children (Missiuna et al. 2006). Others argue that a child might be unable to return a valid and reliable report on the participation challenges that will form the foundation for the OT therapeutic relationship (CAOT 2017). However, an emergent body of evidence questions these assumptions (Missiuna and Pollock 2000; Missiuna et al. 2006; Galvin et al. 2010; Vroland-Nordstrand and Krumlinde-Sundholm 2012a; Vroland-Nordstrand and Krumlinde-Sundholm 2012b; Vroland-Nordstrand et al. 2016; Pritchard et al. 2022).

Although young children may be unable to carry out complex abstract thinking, the crux of the matter is how to gather their input, rather than with whether children can self-evaluate (CAOT 2017). The measures used to assist the child in setting the goals for therapy need to be suitable to their developmental level (Missiuna and Pollock 2000). Some important adaptations, such as the type of language used when interviewing children, adding pictures of concrete items or activities that the children are being assessed on, having clear response options and considering the assessment context (Missiuna et al. 2004) enable young children to communicate their desired goals, facilitating their estimation of their level of competence (Tam et al. 2008).

Having children reporting on their own problems forms the fulcrum of the client-centred approach, which assumes that it is the client who identifies the focus of therapy. Therefore, the client's view is essential (CAOT 2017), even if the client is the child. Costa et al. (2017) maintain that children can think about their situation, plan goals and actively participate in their rehabilitation. The idea that children can provide unique information about themselves is supported by literature (Sturgess et al. 2022). Research indicates that children can identify the activities and tasks that are challenging for them, and they can also identify those which are meaningful to them, not just to their parents (Galvin et al. 2010).

Missiuna and Pollock (2000) and Missiuna et al. (2006) found that children aged 5-to-9 years and 6-to-9 years respectively, who had a variety of disabilities, could effectively report on their ability to perform daily living activities. These same children could then prioritise goals for intervention, based on areas that were meaningful to them. In the first study (Missiuna and Pollock 2000) the occupational therapists administered the measures to children at home, while the second study (Missiuna et al. 2006) was conducted in a school setting. The PEGS (Pollock and Missiuna 2015) was used as a data collection measure in both studies. Ohl et al. (2015) conducted a similar study using the Child Occupational Self Assessment (COSA; Kramer et al. 2014). Findings showed that children aged 6 to 12 years could perceive their competence in activities of daily living and also assign a value to these activities. These assessments were performed at school or at home.

Vroland-Nordstrand et al.'s (2016) research has shown that not only can children identify functional, rehabilitation goals, but their goals may be more specific and reachable than goals, which are set by relevant others, such as their parents. Therefore, children are credible sources for identification of their treatment goals, thereby influencing their involvement in their OT intervention (Vroland-Nordstrand et al. 2016). Client-centred practice requires the active participation of the client in all the phases of OT treatment, including the identification of therapy goals. In paediatrics, therapists need to listen to the client and rely on instrumentation that provides the child and their family, a voice in the therapy process (Missiuna et al. 2006). Resources that enable their participation in the treatment goals are required in order for the child and family to be able to engage in client-centred practice (Ruggio et al. 2018). The information that is given to clients needs to be intelligibly presented, thus enabling them to engage in decision-making about their needs (Law et al. 1995), hence the need for client-centred, or more specifically, child-centred outcome measures.

2.11.1 Children's Views are Consistent

There is evidence to suggest that children can report reliably and consistently on their experiences (Riley 2004). Literature supports the view that children's perception of their competencies in everyday activities and the value that they assign to these activities are fairly consistent over a two-week period (Missiuna et al. 2006; Vroland-Nordstrand and Krumlinde-Sundholm 2012b; Ohl et al. 2015). This indicates that children are likely to remain committed to addressing a therapy goal two weeks later (Missiuna et al. 2006), since the choice of goals for intervention is found to be relatively stable (Vroland-Nordstrand and Krumlinde-Sundholm 2012b). Such consistency was in evidence when using the PEGS (Pollock and Missiuna 2015) tool (Missiuna et al. 2006; Vroland-Nordstrand and Krumlinde-Sundholm 2012b) and the COSA (Kramer et al. 2014) measure (Ohl et al. 2015).

2.12 Conclusion and Justification for this Study

This chapter has reviewed the literature related to client-centred and child-centred practice as it applies to paediatric OT. The areas that were explored included the main features of client-centred practice and challenges related to the application of this approach, the child's participation in SDM and in goal setting and the importance of addressing the child's view, apart from adults' concerns.

None of the reported research has been conducted in Malta and much of the literature is dated. Moreover, most of the studies described in this chapter focused on client-centred practice application in OT, with a paucity of literature on the paediatric area. Locally, there is no research, which addresses these issues in child-centred practice. This study sought to fill this lacuna.

The absence of children's voice in health and OT services reported in the literature highlights the importance for therapists to constantly reflect on their practice to ensure that they are adopting a client-centred or child-centred approach. Indeed, this study sought to understand whether paediatric occupational therapists in Malta fully understand the meaning and implications of a client-centred model of practice, when working with children, thus providing food for thought to Maltese paediatric occupational therapists. Given the lack of research on the involvement of children in goal setting and decision-making, this study also aimed to identify whether such components of child-centred practice are being implemented in Malta.

Chapter 3: Outcome Measurement in Paediatric Occupational Therapy

This chapter explains the factors that led to the demand for outcome measures within OT. It explains how outcome measures complement a client-centred and a child-centred approach. It also reviews some benefits of using outcome measures and some challenges that are related to the use of these tools. Self-reports are identified as potential child-centred outcome measures that can enhance the child's participation in the OT process. Finally, a number of child-centred outcome measures aligned with child-centred care, are explored.

3.1 The Development of Outcome Measures in Paediatric Occupational Therapy

Several factors in the health and social care sectors have instigated the need for continuous evaluation and documentation of treatment effectiveness in OT (Unsworth 2000; Corr and Siddons 2005; Doucet and Gutman 2013), that is to measure outcomes. Occupational therapists are being requested to validate and justify the services they provide. This is especially important during the economic rationalisation situation that health care has been facing, with therapists having to tackle recurrent challenges of limited funds, resources and access to services (Gupta and Taff 2015), and competing with other health care professionals (Doucet and Gutman 2013). Other health care changes that have contributed to this demand in the 1990s include the increase in number of persons with disabilities (Fisher and Short-De-Graf 1993; Law et al. 1998).

Moreover, occupational therapists are expected to provide efficient and cost-effective services (Costa and Lindenthal 2015). The drive to achieve a balance between effectiveness, quality and cost of services has created a focus on outcomes (Cohn and Cermak 1998; Fuller 2011). There is ample research about the importance of outcome measurement in OT in the 1990s and early 2000s with scantier literature in recent years, except for research related to the use of specific outcome measure tools. “Outcome measures are standardised tools, used to establish … change … in occupational performance over time" (Davenport and Underhill 2023, p. 43).

Outcome measurement is reported to prove of the impact of practice (Parker 2012) and the effectiveness of an intervention (Corr and Siddons 2005) since such tools can track changes in outcomes and evaluate whether the treatment goals were met (Laver-Fawcett and Cox 2021). Unsworth (2000) states that the use of outcome measures allows the clinicians to assess not only any positive change following intervention, but also whether the most effective treatment was provided. Furthermore, Laver-Fawcett and Cox (2021) argue that outcome measures can even demonstrate the general effectiveness of a service.

McLaren and Rodger (2003) highlight similar challenges that paediatric occupational therapists have been faced to be accountable for the treatment that they provide, both to the health care management and their clients. Therefore, measuring functional performance and intervention outcomes forms a vital part of paediatric clinical practice. The measurement of outcome has in fact been considered a means of addressing and ensuring accountability (Payne 2002).

Payne (2002) adds that the development and drive towards clinical governance have promoted evidence-based practice, largely characterised by outcome measurement. Clinical governance entails the maintenance of high standards of care whilst ensuring the quality of services (Wilks and Boniface 2004; National Health Service [NHS] 2021). Clinical governance shifts the responsibility for the standard of care to all practising professionals (Orton et al. 2022). Payne (2002) argues that outcome data can assist in monitoring the attainment of standards of care and informing development of guidelines through the identification of best practice. She adds that outcome data, together with clinical guidelines, can influence local and national health policies, by educating policymakers about the aims and applicability of OT services for various client populations, including paediatrics.

Additional advantages acquired by the use of outcome measure have been identified. Payne (2002) maintains that outcome measurement provides information that assists with monitoring the competency of staff and the identification of training needs. Besides the benefits to the OT profession, service users would also gain from the effective application of outcome measurement (Payne 2002).

The documentation of outcome data can be viewed as both a responsibility for that service and a way to demonstrate the credibility of a profession (Kielhofner and Forsyth 2001). Several scholars assert that occupational therapists should be careful in selecting the right outcome assessment, since the latter reflects the beliefs and assumptions about the desirable changes through intervention (Cohn and Cermak 1998; Klein et al. 2008; Romli et al. 2019). For a particular type of therapy to be developed and appreciated, it is important for therapists to document the impact of intervention on daily life (Kielhofner and Forsyth 2001).

The need for congruence between the OT's fundamental beliefs in human occupation and the data-collection process cannot be overstated (Fisher and Short-De-Graf 1993; Klein et al. 2008). Such congruence would demonstrate the profession's unique contribution (Klein et al. 2008). Since occupational therapists seek to improve occupational performance as an expected outcome of their intervention, then the main outcome measure in OT should focus on such a change in occupational performance (Backman 2005).

Research shows that occupational therapists tend to use non-standardised measures to document OT outcomes (Davis and Rodd 2014; Davenport and Underhill 2023) or to borrow outcome measure tools from other health professions (Romli et al. 2019). However, there are a number of problems associated with the use of non-standardised tools to measure client outcomes. Since such home-grown assessments lack reliability and validity (Laver-Fawcett and Cox 2021), the information gathered from such instruments does not contribute to the client outcomes data that can support the efficiency in terms of cost and time, and the effectiveness of OT practice. Moreover, it undermines the credibility and legitimacy of the services that are being provided (Doucet and Gutman 2013). Apart from home-grown tools, occupational therapists are encouraged to refrain from using measures that are borrowed from other disciplines if the latter do not measure OT outcomes (Doucet and Gutman 2013; Romli et al. 2019).

Given the greater focus on the client's role in intervention and decision-making regarding health care, the use of outcome measures to assess the quality of services acquires greater importance when using a client-centred approach (Parker 2012). Through the understanding of the children's and families' perspectives and the outcomes that are meaningful to them, occupational therapists can provide interventions that address clients' specific needs. This can provide further evidence on how OT is applicable to daily life (Payne 2002). Keller et al. (2005) claim that paediatric occupational therapists need valid and reliable measures that focus on the activities that are meaningful to children and increase participation in the assessment process and intervention planning (Keller et al. 2005).

Tam et al. (2008) recommend that measures used be individualised and promote full participation of children and their families in goal setting and in outcome evaluation. They argue that the use of such client-centred measures would raise motivation in children and their families to work on the identified goals. Such measures would also match the pre-requisites of child-centred care, as discussed in the previous chapter.

Furthermore, outcome measures need to be sensitive (Fisher and Short-DeGraf 1993; Pollock 1993; Dixon-Wood et al. 1999; Laver-Fawcett and Cox 2021) in order to capture the type and degree of expected change (Laver-Fawcett and Cox 2021) and represent the client's varying needs and conditions (Pollock 1993) and the potential change in children's perspectives as they develop (Dixon-Wood et al. 1999). The latter is particularly important in the paediatric area.

The previous chapter discussed how literature seems to indicate a concerning paucity of child-centred care practice. Dixon-Wood et al. (1999) argue that "an important source of resistance to extending the ideals of patient partnership to children is lack of good evidence about the outcomes." (p. 778). They suggest that children's perspectives be included in the evaluation of outcomes and that when using outcome measures, therapists need to keep in mind possible gradual changes in children's perceptions. No research studies were found to indicate whether this justification applies to contemporary paediatric OT practice or the Maltese context.

Despite the constant advocacy to use outcome measures, routine outcome measurement is not generally typical in OT (Colquhoun et al. 2010; Davenport and Underhill 2023). This could also apply to Malta, where to the researcher’s knowledge, routine outcome measurement is not standard practice across OT settings, including paediatric settings. Routine outcome measurement is defined as “the systematic use of a standardised outcome measure/s in clinical practice with every patient as a part of a standardised assessment practice guideline.” (Colquhoun et al. 2010, p. 49). Law (2003) reports an acceleration since the 1980s in the application of outcome measurement to support paediatric OT practice. However, several decades later, this is still not the case in Malta. No research studies concerning the use of outcome measures in paediatric OT in Malta is available, indicating an evidence gap in this area of practice.

3.2 Self-reports

An important foundation underpinning client-centred practice is the ability to listen to the clients, understand their needs and priorities and collaborate with them to achieve goals which address their concerns (CAOT 1997; Townsend et al. 2013). The previous chapter discussed how children tend not to be involved in setting their own treatment goals (Curtis et al. 2022; Pritchard et al. 2022) and that occupational therapists tend to set goals with parents or educators instead of the child (Vroland-Nordstrand and Krumlinde-Sundholm 2012; O’Connor et al. 2021).

Literature about the effectiveness of OT largely eschews the inclusion of children’s perception of their competence in completing daily activities (Cohn and DeMarinis 2016). Children’s experiences of OT and their perceived competence are vital to proof intervention effectiveness (Cohn and DeMarinis 2016). In order to assess what is important for clients, Brown and Bowen (1998) argue that the latter should be asked to identify and prioritise their needs. Then, clients can make the best choices about their health, once the necessary information is provided to them.

A client's subjective experience is important in OT (Corr and Siddons 2005). Collecting information directly from children, in this case, is vital for the therapist to design tailor-made treatment and measure meaningful outcomes aligned to children's priorities (Cohn and DeMarinis 2016). Child self-reports are the appropriate tools to involve the child for the application of client-centred practice (Keller and Kielhofner 2005; CAOT 2017).

Self-report assessments in OT seek to identify the client's needs and concerns (AOTA 2002; Kramer et al. 2010) to plan intervention (AOTA 2002) and generate meaningful goals (Kramer et al. 2010). They also measure client-reported change following intervention, thus evaluating effectiveness of the service (Kramer 2011). Self-reports allow the development of client-generated outcomes (Kramer et al. 2010). Self-reports scales are often in the format of a questionnaire, whereby clients can score their ability and satisfaction levels with performing an activity (Corr and Siddons 2005).

Client-directed assessment balances the power between the clinician and the client, giving the client, in this case the child, the opportunity for self-direction (Keller and Kielhofner 2005). Self-report is a means to gather information that is only known to the client (Sturgess et al. 2002). Involving clients in the assessment process is imperative as it:

- acknowledges the client's expertise regarding their unique challenges, placing the client at the focus of the decision-making process
- enables the client to participate in decisions related to the treatment that they are receiving
- increases autonomy, providing a sense of self-control (Hong et al. 2000)

Keller et al. (2005) note that through the involvement of young clients in assessment and intervention planning, paediatric occupational therapists are ideally positioned to nurture the children's self-determination. One way of fostering such self-determination and client-centred practice is through the use of self-assessment. Self-reports also offer the chance for children's decision-making skills to flourish (Keller et al. 2005), thus promoting young clients' personal development (Keller and Kielhofner 2005).

Missiuna et al. (2006) maintain that since children's involvement in judging their own competence influences both their motivation and their performance, self-reports are one means of achieving this. They add that children are more motivated to improve their performance when they reflect on their competence. This information can then be utilised for goal setting purposes.

The use of self-reports is thus seen to be vital in the OT process, highlighting the relationship between children's perceived self-efficacy and their participation, while stressing the impact that such participation has on children's health and wellbeing (Costa et al. 2017). Only with the use of valid and reliable tools, where the child is at least one of the direct informants, can the therapist obtain information about the child's sense of self-efficacy (Sturgess et al. 2002). In their systematic review, Tam et al. (2008) concluded that listening to children's voices in OT assessment and intervention promises to be a valuable and valid approach in a paediatric setting. This is congruent with UNCRC (UN 1989), which emphasises children's right to make their voice heard.

Green and Wilson (2008) note that a suitable outcome measure should address the child's perspective. Indeed, Law et al. (1994) remark that occupational performance does not consist solely of the client's ability to perform certain tasks, but also of the individual's satisfaction with the performance. Being aware of the unique perspectives of children with disabilities is important to ensure that programmes, treatments and services that are created effectively meet their specific needs (Harding et al. 2009).

OT philosophy is based on client-centred practice that emphasises the client's engagement in meaningful occupations (CAOT 2002; AOTA 2011), hence the importance of tools that assess children's meaningful occupations. Vroland-Nordstrand and Krumlinde-Sundholm (2012b) argue that acknowledging children's perspectives increases their cooperation and motivation to participate in OT intervention planning. Occupational performance is a key area of OT, so self-reports should direct focus on this area (Cordier et al. 2016).

Keller et al. (2005) highlight that the inclusion of children's perspectives in the assessment and treatment planning aligns with OT best practice and demonstrates respect for children with disabilities (Keller et al. 2005). Psychometrically sound client-directed assessments and outcome measures support evidence-based practice (Keller and Kielhofner 2005). Adaptations such as appropriate language for the questions used, use of pictures that provide concrete stimuli, and clear response options enhance the validity of these tools' outcomes (CAOT 2017).

The use of self-reports with children is reported to have gained traction. The literature supports the idea that children can provide valid information about themselves that is fairly stable over time (Missiuna and Pollock 2000; Sturgess et al. 2002; Missiuna et al. 2006; Galvin et al. 2010; Vroland-Nordstrand and Krumlinde-Sundholm 2012; Pritchard et al. 2022). A literature review by Sturgess et al. (2002) justified the use of self-report measures with children and provided extensive evidence on the features of such tools and effective ways to design these tools. A systematic review by Cordier et al. (2016) also encouraged the use of child-reports.

Some authors lament the lack of self-report tools that evaluate children's perspectives about their own experiences (Vroland-Nordstrand and Krumlinde-Sundholm 2012; Greco et al. 2017). Conversely, some other researchers cite several clinical instruments that were developed to measure participation outcomes in children and the children's perception of their preferred activities (Cohn and DeMarinis 2016). The increase in the development of self-report assessments for both research and clinical use is linked to the increase in the application of client-centred practice, which empowers clients - including children – to voice their concern (Sturgess et al. 2002).

Given the benefits associated with self-reports, occupational therapists should have access to such self-assessments that are adaptable and accessible to children of all abilities (Keller et al. 2005). There is scant research about the use of child self-reports and about the understanding of children's views in paediatric OT; a noticeable gap this current study seeks to address.

3.3 Child-Centred Outcome Measures

“Measuring what matters is in the eye of the beholder, and we need to assert what matters to our clients and our profession.” (Backman 2005, p. 260). An essential element of client-centred practice is that of assessing the client’s perception of their own abilities (Engel-Yeger et al. 2009), and this should not be any different in paediatrics. The literature clearly indicates that children are still struggling to have their voices heard in health care (Davies et al. 2022). It is not common practice to involve children in health-related decision-making and communications. Indeed, when children’s involvement is present, it tends to be limited or tokenistic, as adults take the main decisions (Davies et al. 2022). Moreover, children’s views on service evaluation are often excluded or replaced by parents’ (Antoniadou 2022). However, since adults’ views may significantly differ from children’s (Fayed and Kerr 2009; Schiariti et al. 2014; Costa and Lindenthal 2015; Costa et al. 2017), the former are no substitute for children’s unique voices (Söderbäck et al. 2011).

Several tools have been developed to facilitate children’s and their parents’ active involvement in goal setting (Brewer et al. 2014; Curtis et al. 2022). These include the PEGS (Pollock and Missiuna 2015), which enables children to rate their performance in daily activities and select activities that they would like to work on through the use of illustrated cards; the COSA (Kramer et al. 2014), a tool that provides information about the child’s competence and values; the COPM (Law et al. 2014), a client-centred outcome measure, enabling clients to identify and prioritise issues that affect the child’s participation in daily activities through a structured interview; the Paediatric Activity Card Sort (PACS; Mandich et al. 2004), a tool that identifies a child’s occupational profile; and the Goal Attainment Scaling (GAS; Kiresuk et al. 1994), a method of scoring the degree of achievement of a client’s individual goals. These tools will be discussed below. To date, no research has investigated the use of any of the aforementioned tools in Maltese paediatric OT practice.

A literature review was conducted by Tam et al. (2008) to identify and compare the clinical utility of individualised, client-centred outcome measures used in paediatric rehabilitation. The researchers identified five tools: the COPM supported by 28 studies, the GAS supported by 34 studies, the PEGS supported by two studies, the Target Complaints (TC) supported by one study and the PACS supported by one single instruction manual. The COPM and GAS have been used in various settings and within a wide age range. The tools that seemed to lend themselves to the child's direct participation in the goal setting process were the aforementioned PEGS and the PACS. The researchers found limited evidence to support the use of TC in paediatrics (Tam et al. 2008).

3.3.1 The Canadian Occupational Performance Measure (COPM)

The COPM (Law et al. 2014) is a client-reported outcome measure that allows occupational therapists to measure their intervention outcomes (Wilkins et al. 2001). It detects perceived changes in the client's self-reported occupational performance over time (Law et al. 2014), thus providing a measure of occupational performance changes throughout therapy (Pollock 1993). It was developed to reflect the occupation-focused CMOP (CAOT 1997; Law et al. 1998; Law et al. 2002) and embrace its philosophy (Pollock 1993; Tam et al. 2008). After 2007, the model was updated and henceforth referred to as the CMOP-E (Polatajko et al. 2013). This measure encompasses clients' roles and role expectations within their environment, thus ensuring the relevance of the identified challenges (Pollock 1993). The COPM is a measure of self-perception of occupational performance (Candler 2003) in the three areas of occupational functioning: self-care, productivity and leisure (McColl et al. 2000; Candler 2003), which are the three categories of the CMOP-E (Polatajko et al. 2013).

The COPM is an individualised outcome measure that was designed to be used specifically by occupational therapists (Sewell and Singh 2001). This measure was developed on the basis of client-centred concepts (Pollock 1993; Wilkins et al. 2001; Tam et al. 2008) and is considered "an excellent example of the application of the essence of the client-centred approach" (Sumsion 1993, p. 7). Indeed, this self-report recognises the client's responsibility for their own health and their therapeutic process (Pollock 1993). This is similar to the

CMOP, which underscores the need for clients to play an essential role in the therapeutic process in order to improve their performance in daily activities (CAOT 1997). When administering this measure, the therapist cooperates with the client in line with client-centred practice beliefs (Law et al. 2014)

The COPM can be used to support children in identifying their own needs. However, this tool was developed via research with adults (Verkerk et al. 2023). Although the manual suggests that the COPM be used with children from eight years of age (COPM 2024a) onwards, paediatric occupational therapists have long been reporting a lack of clear instructions on how to administer this outcome measure to children of such a young age (Verkerk et al. 2023), frequently questioning its applicability for children (COPM 2018) because of the level of abstract thought underpinning this outcome measure (Missiuna and Pollock 2000). To facilitate the use of COPM, Verkerk et al. (2023) recently conducted a study that presented specific instructions for therapists when administering the COPM to children. The instructions were informed by feedback from children, parents and occupational therapists. The COPM is considered a useful tool for adolescents (McGavin 1998).

Missiuna and Pollock (2000) note that the COPM can be adapted for children aged eight or nine, who can use it to set goals; however, they argue that younger children cannot participate in its administration (Missiuna et al. 2006). This shortcoming gave rise to the development of the PEGS (Pollock and Missiuna 2015), which will be discussed in the following section. Candler (2003) reported that the COPM can even be used with seven-year-old children. However, in their study, the COPM was administered to the child and a family member though the identified goals were family-goals, rather than the child's specific goals.

The COPM is more than an outcome measure; it is also a goal formulation tool (Law et al. 2014). Indeed, it can be used for goal setting with children (Verkerk et al. 2023). This measure is administered in five steps throughout a semi-structured interview. The client is encouraged to identify and discuss concerning activities and then asked to rate their importance. Cue cards are used to help clients with the ratings, whose scores range from one to ten (1 = not at all important and 10 = extremely important). The client then chooses the five most important occupational performance problems. Occupational performance problems refer to activities that a client needs to do, wants to do or is expected to do but cannot do, does not do or is dissatisfied with how they are done (Law et al. 2014).

In the final steps of the initial assessment, the clients identify their perception of their performance of the selected tasks and their satisfaction with their performance. Clients then rate their performance and satisfaction on a 10-point scale for each of these activities (where 1 = not able to do at all or not satisfied at all, and 10 = able to do it extremely well or extremely satisfied). Cue cards are used to assist with ratings at this stage. Two scores are therefore obtained from the COPM – the client's perceived efficacy in performance and the client's satisfaction with that performance, by summing the ratings in each respective area and dividing the figure by the number of problem areas identified. The goals of OT intervention can be based on the latter identified goals, and OT treatment is subsequently planned accordingly. After intervention, clients re-rate their performance and satisfaction with performance vis-à-vis these activities. The ratings at the start of intervention are subtracted from those of reassessment and the result provides a measure of the change in occupational performance. A difference of two or more points is considered to be clinically significant changes (Law et al. 2014).

The COPM is considered to be a generic outcome measure (Sewell and Singh 2001), which means that it is not diagnosis-specific (Pollock 1993). McColl et al.'s (2005) work also demonstrated the adaptability and flexibility of the COPM to various settings, situations, clients (regardless of disability, age and background) and purposes. However, they noted that the complexity of its application varies (McColl et al. 2005). The COPM's interviewing strategy, assessment language, or the scoring system can be potentially adjusted to take into account the client's development stage and cognitive or communication ability. For example, tangible stimuli such as pictures can be used (McColl et al. 2005).

The therapist may complete the COPM with a caregiver when clients cannot identify problem areas (as when the client is a young child) (Pollock 1993). Indeed, despite the fact that the COPM was initially designed as a self-report, this measure can be used as a proxy-report measure by, for example, administering it to parents (Laver-Fawcett and Cox 2021).

Therefore, in the case of small children, parents can express their viewpoint and identify their concerns (McGavin 1998). The parents would rate young children's performance (García-Grau et al. 2022). The most significant identified difficulties would then form the basis for determining therapeutic goals (McGavin 1998). However, the therapist must exercise care when the COPM is applied to parents. Pollock and McColl (1998) point out that "it is important, however, to distinguish between these individuals as proxies for the client and as the clients themselves." (p. 102). In this case, the therapist should bear in mind that the information collected would be predominantly the parents' view rather than the child's.

Several studies have used the COPM with parents of children (e.g., Lowe et al. 2006; Lowe et al. 2007; An and Palisano 2014). In their scoping review, Mathews et al. (2020) identified the COPM as an outcome measure and goal identification tool for children with disabilities between the ages of 2 and 7 years. In these studies, the COPM was administered to parents. In their systematic review, Calder et al. (2017) found a paucity of studies that reported use of outcome measure in the area of participation with children under 2 years of age. However, the COPM could be used with this age group.

Although several authors identify teachers as potential clients for the COPM (McColl et al. 2005; COPM 2024b), there are barely any studies that conducted the COPM with teachers or that provided details about the most practical way to apply this outcome measure with them, such as over the phone, in clinics or in schools.

The use of the COPM does not require specific training, and it is considered a time-efficient tool (Cusick et al. 2006). A Maltese version of the form is also available. A review of literature by Carswell et al. (2004) found that the COPM was used with a range of clients and problem areas, enabling the engagement of clients in therapy and facilitating client-centred practice and supporting outcomes research (Carswell et al. 2004). The use of this tool enhances collaborative goal setting (Brewer et al. 2014). Indeed, research has shown that the COPM is a flexible tool that can be adapted to various situations (McColl et al. 2005; Mathews et al. 2020). Another upside of the COPM is that it can be used for programme evaluation (McColl et al. 2005). Occupational therapists can use this tool to evaluate the effectiveness of programmes that they offer, such as consultation treatments, or group intervention.

Law et al. (2014) consider the COPM a standardised tool as it imposes specific methods and provides instructions on its administration; however, this measure is not norm-referenced. Indeed, this outcome measure acknowledges that occupational performance is an individual subjective experience (Wressle 2002; Wressle et al. 2002a). Numerous research studies have been conducted to demonstrate the validity, reliability and utility of the COPM. This tool was found to be valid, reliable and clinically useful in a variety of settings (Law et al. 2014).

3.3.2 The Perceived Efficacy and Goal Setting System (PEGS)

The PEGS (Pollock and Missiuna 2015) is a picture-based self-report that assesses the child's views of their own competence in everyday activities. This tool can be used with children with disabilities, who are chronologically or developmentally between 5 and 9 years of age, in different clinical and community settings (Missiuna and Pollock 2000; Missiuna et al. 2006). It can be used with children with different conditions and severity levels if they can formulate some kind of response.

The PEGS is a standardised instrument, but it is not a norm-referenced one. It tries to understand the subjective experience of children about their perceived self-efficacy and caregivers' view of children's competences (Costa et al. 2017). Indeed, this tool includes questionnaires for parents and for teachers, enabling the therapist to collect information from different sources and gather different perspectives about the child's occupational performance (Costa and Lindenthal 2015), and including each stakeholder's goals (Brewer et al. 2014).

The PEGS, which is conducted via a semi-structured interview, is described as child-friendly, since it uses pictorial cards to support dialogue and a child-appropriate language. This assessment is administered via a card-game, which improves the therapist's understanding of the child (Missiuna and Pollock 2000). The administration of the test itself helps to build a trustful therapeutic relationship, with the therapist listening to the children's lived experiences and learning what is important for them (Costa and Lindenthal 2015).

A two-step decision-making process is used, whereby the respondents indicate their perception of the child's performance (Pollock and Missiuna 2015). Paired picture cards showing a child that can successfully perform an activity, such as buttoning, together with another child experiencing problems performing this task, are used. Children are asked to indicate whether they feel more like the child experiencing difficulties ("not competent") or the child with no problems in performing that task ("competent"). Children are then guided to indicate whether they feel "a little" or "a lot" like that child. Children are reassured that there are no right or wrong answers. This system enables scoring of the perception of competence on a 4-point Likert scale, providing interval-scaled data, as well as qualitative information. The PEGS includes 24 daily activities on which children express how they view their competence. These activities are self-care, productivity/school and leisure activities that children typically perform at home, at school or in the community (Missiuna and Pollock 2000; Missuna et al. 2006). Additionally, the therapist can use an open item to ask the child about any other activity that is important to the child, in which the child is either experiencing challenges or a positive experience of self-efficacy intervention.

Parents and teachers follow the same two-step decision-making process. They are given the Parent or Teacher Questionnaire of the PEGS, each of which has corresponding items. They rate the child's competence for each daily activity (Missiuna and Pollock 2000). Further meaningful activities that they would like to be addressed in OT may be added (Costa et al. 2017). Parents can be asked to answer the Parent Questionnaire separately from the child, while the Teacher Questionnaire can be emailed to the child's teacher or sent by post. If necessary, parents or teachers can also be interviewed on the phone (Costa and Lindenthal 2015).

Besides being a screening tool and an assessment, the PEGS is also a goal setting tool (Costa and Lindenthal 2015), similar to the COPM (Law et al. 2014). It enables collaborative goal setting for OT services for children. All respondents, be they children, parents and teachers, are asked to select a maximum of four goals, prioritising four activities that the child is having difficulties with and that they would like to improve upon. They are also asked about the reasons for selecting these specific goals, thus setting their own intervention goals

(Missiuna and Pollock 2000). Therefore, the goals developed are occupation-based and relevant even for the child (Costa et al. 2017).

The PEGS has been described as a client-centred tool (Missiuna et al. 2004; Missiuna et al. 2006; Tam et al. 2008; Costa 2014; Costa and Lindenthal 2015; Costa et al. 2017; Ruggio et al. 2018). Indeed, it takes into account the perception of the child as well as their parents' and teachers'. This tool that involves both the child and significant others in goal setting (Missiuna and Pollock 2000), can be used to identify goals that are meaningful to the child (Costa et al. 2017). It explores the goals of all the clients involved (Costa et al. 2017), enabling a comparative analysis and adjustment of treatment goals (Ruggio et al. 2018). The PEGS' characteristics match the concepts underpinning client-centred practice (AOTA 2014), and child-centred care. This tool was in fact designed to involve children in the treatment planning process (Pollock and Missiuna 2015), thus defining the direction of OT intervention (Missiuna et al. 2006).

The PEGS is also congruent with the CMOP-E (Galvin et al. 2010). Several researchers have successfully used the PEGS in their studies (Missiuna et al. 2006; Galvin et al. 2010; Costa and Lindenthal 2015; Costa et al. 2017). No specific training is required to administer this test.

This tool, which was developed in Canada, is used in more than eight countries for both therapeutic and research purposes (Missiuna and Pollock 2000; Tam et al. 2008; Vroland-Nordstrand and Krumlinde-Sundholm 2012a; Vroland-Nordstrand and Krumlinde-Sundholm 2012b; Costa 2014). However, this outcome measure is not being used in Malta. The PEGS has been translated into different languages and culturally adapted to some others (e.g., Vroland-Nordstrand and Krumlinde-Sundholm 2012a; Costa 2014), but to date no such study has been conducted in Malta.

Missiuna et al. (2006) argue that by allowing collaborative goal setting with children, the PEGS enables them to take charge of their therapy process and, eventually, their own achievements. The PEGS was designed to be used mainly by occupational therapists working in the paediatric area (Pollock and Missiuna 2015).

3.3.3 The Goal Attainment Scaling (GAS)

The GAS (Kiresuk et al. 1994) is an individualised, criterion-referenced evaluation tool. It is considered to be a sensitive means to measure post-intervention individual goals (McLaren and Rodger 2003). Similar to the COPM (Law et al. 2014) and PEGS (Pollock and Missiuna 2015), the GAS can yield information about the extent of success of a treatment programme in meeting clients' needs (Brewer et al. 2014). According to Steenbeek et al. (2011), both the COPM and the GAS are being adopted as goal-based outcome measures in adult as well as in paediatric rehabilitation, and can demonstrate important changes, which are not captured by other standardised outcome tools, such as the Pediatric Evaluation of Disability Inventory (PEDI; Haley et al. 1992) and Gross Motor Function Measure (GMFM; Russell et al. 2002).

Since the GAS is a generic evaluation tool (Steenbeek 2010), it can be used with a variety of clients and conditions. It was initially developed for use in mental health services but has since then been utilised in a variety of settings (Kiresuk et al. 1994). This tool has gained traction in paediatrics. Indeed, a number of studies used the GAS in paediatric rehabilitation (King et al. 2000; Mailloux et al. 2007; Steenbeek et al. 2008; Steenbeek et al. 2010; Steenbeek et al. 2011; Harpster et al. 2019; May-Benson et al. 2021) or recommended it as an appropriate tool for paediatric rehabilitation (Steenbeek et al. 2007).

Indeed, the GAS has been successfully used in a variety of settings, including paediatrics (Chapleau 2015). In their systematic review Harpster et al. (2019) identified 52 studies that utilised the GAS as an outcome measure within paediatric rehabilitation. Their review highlighted the use of the GAS as a therapy outcome measure in the paediatric population. The GAS was found to be used with several conditions such as motor delay, autism, traumatic brain injury, sensory integration difficulties, cerebral palsy, ADHD and other developmental conditions. The children's age varied from four months to 19 years. Early intervention, sensory integration, occupational therapy following Botox and constraint-induced movement therapy were amongst the approaches used in the reviewed interventions (Harpster et al. 2019). Research supports the use of the GAS as an evaluation tool for treatment programmes and as a means of recording the progress of individual children towards identified goals (McLaren and Rodger 2003).

Each identified goal is scaled to form five levels of accomplishment in consultation with the relevant clients, such as the family or teacher and potentially even the child. The scaling includes the identification of an expected level of outcome or performance, two potential levels, which are less than expected and two others which are more than expected (Kiresuk et al. 1994). The ways of scaling differ as some researchers have experimented with the scale but it was originally done on a 5-point ordinal scale of - 2 to + 2, with the expected level of outcome being scored as 0, a much-more-than-expected goal attainment being scored as + 2, and a much-less-than-expected outcome was accorded the score of – 2 (Mailloux et al. 2007). The outcome scores are then converted to T-scores. Some positive features attributed to the GAS include: (1) its sensitivity to subtle changes; (2) its responsiveness or ability to detect significant change; (3) its content and inter-rater reliability; and (4) its content validity and construct validity (Steenbeek 2010).

Indeed, the process of the GAS typically begins with a client-centred interview, with the child or the parent asked to identify meaningful goals. The interview can be used with or instead of the administration of an individual assessment tool (Chapleau 2015). Key stakeholders or additional clients, such as parents and teachers, can be consulted when scaling and constructing the goals (McLaren and Rodger 2003). When the GAS is used in studies, however, the goals tend to be planned with the parents, not with the child (e.g., Löwing et al. 2009; Lowe et al. 2007; Mailloux et al. 2007; May-Benson et al. 2021), on the basis of parent-identified priorities.

Although the GAS could potentially be used with children, researchers tend to develop goals with parents (Cusick et al. 2006; Mailloux et al. 2007; Steenbeek et al. 2008) or goals are created by the therapists themselves (Steenbeek et al. 2008; Steenbeek et al. 2010; Steenbeek et al. 2011) rather than with the child. Unfortunately, children are rarely involved in the goal setting process (Tam et al. 2008). Cusick et al. (2006) compared the relative utility of the COPM and GAS; however, these tools were administered to parents and not to children themselves.

Paediatric occupational therapists frequently work with children, who may show minor improvements, which tend not to be detected on traditional standardised assessments. Such children include those with autism, cerebral palsy, and Down Syndrome, among others. Standardised tests may not be sensitive enough to detect changes; however, a child's slight improvement may still result in functional gains and the GAS may be a means of identifying and measuring these small gains (Mc Laren and Rodger 2003). Goals can be formulated to represent the functional performance vis-à-vis tasks that are relevant to the family. Parents can then observe and report on progress (May-Benson et al. 2021).

The GAS can be used in clinical settings, as well as in research, to assess whether an intervention was effective in meeting client-identified goals (Harpster et al. 2019). Training may be required for the GAS to be reliably administered (May-Benson et al. 2021). The GAS is not based on any specific language, so it could potentially be used in Maltese. Goals can even be set in Maltese, if necessary. The GAS-light version (King's College London 2024; Natspec 2024), an adapted version of the GAS, is a possibly less time-consuming option. However, no research was found to support the use of this adapted tool in practice.

Since the GAS is not a self-report; it cannot be considered child-centred unless it is used with another child-centred tool. Through this measure, the therapist can incorporate parents' and teachers' goals as well. Indeed, the use of more than one outcome measure has been recommended and carried out in a number of studies, as the following section shows.

3.3.4 GAS + COPM + PEGS

The GAS (Kiresuk et al. 1994) is frequently used to supplement data from other standardised outcome measures (McLaren and Rodger 2003). The GAS is both an alternative to standardised measures and an augmentation to standardised outcome measures (McLaren and Rodger 2003). McLaren and Rodger (2003) note that the GAS could be used with other aforementioned outcome measures, namely the COPM (Law et al. 2014) and the PEGS (Pollock and Missiuna 2015).

Novak et al. (2009) used the GAS together with COPM, with the GAS used to set goals based on areas identified by the COPM. Other research used both the COPM and the GAS (Cusick et al. 2006; Østensjø et al. 2008). However, these studies discuss mainly parents' role in goal setting rather that the child's (Pritchard-Wiart and Phelan 2018). Although using both tools is acknowledged to be highly time-consuming (Doig et al. 2010), doing so leads to specific and family-centred measurable outcomes (Evans-Rogers et al. 2015). Due to the considerable time required, further research is needed to implement the joint use of the COPM and the GAS (Mathews et al. 2020). McLaren and Rodger (2003) have also recommended the use of the GAS in conjunction with client-centred measures, such as the COPM or the PEGS.

Galvin et al. (2010) used both the PEGS and COPM in their study, depending on the child's age. Children aged 10 years and over completed the COPM, whereas younger ones were administered the PEGS. When children were unable to complete the PEGS or COPM independently, the COPM was administered to parents. In their scoping review, Curtis et al. (2022) found that the COPM and PEGS were the most commonly used tools for goal setting with children.

This study has also supported a range of outcome measures, which can be used with the child and the multiple clients that are typically involved, such as parents and teachers. These measures include the aforementioned PEGS, the COPM and the GAS. The selection of the tool depends on the child's age and abilities, including the child's cognitive and communication skills.

3.3.5 The Child Occupational Self Assessment (COSA)

The COSA (Kramer et al. 2014) is a self-report in which children rate their perceived personal competence and importance on 25 statements. It tackles a range of occupations that paediatric occupational therapists typically address (Keller and Kielhofner 2005; Keller et al. 2005), namely activities that children perform at home, at school and in the community (Kramer et al. 2010). The items belong to various areas of occupations, including self-care, play and leisure, and learning (Kramer et al. 2014). Studies have shown that it can be re-administered and used as an outcome measure, given that it is deemed sufficiently sensitive to detect change (Keller and Kielhofner 2005; Keller et al. 2005).

This outcome measure was designed to be used with children, who are between seven and eighteen (Kramer et al. 2014), and who have adequate cognitive abilities to self-reflect and plan (Ohl et al. 2015). However, Kramer et al. (2010) also used the COSA with six-year-old children.

This tool was developed to accommodate the need for a broad-spectrum child-directed OT assessment (Keller et al. 2005) to involve children in goal identification and outcome measurement (Kramer et al. 2010). The authors underscored the importance for occupational therapists to enable the development of self-determination in young clients, by supporting their learning of foundational skills, such as decision-making, self-mastery and problem-solving (Keller et al. 2005). The COSA was found to assist in children's identity clarification in an OT context (Keller and Kielhofner 2005) by empowering children to be involved in the OT process (Kramer et al. 2010; Ohl et al. 2015). The COSA was also found to be a client-directed assessment that provides information about the child's competence and values, which can in turn be used to inform OT intervention (Keller et al. 2005). Research shows that the COSA can capture children's views about their value and competence in meaningful daily activities and roles (Keller and Kielhofner 2005; Ohl et al. 2015).

Every item on the COSA is rated on two rating scales: the Occupational Competence scale and the Values scale (Kramer et al. 2010). It can be administered in three different ways, according to the child's abilities: (1) a paper-and-pencil form with different symbols and visual cues (faces and stars) to enhance the description of each rating category; (2) a paper-and-pencil form that does not include symbols or visual cues; and (3) a card-sort version with items placed on a separate card and each rating category (and visual cue) placed on a separate, larger rating card (Kramer et al. 2010; Kramer et al. 2014). The selection of the most appropriate format to be used with a particular child depends on the therapist's therapeutic reasoning (Kramer et al. 2014). Throughout its administration, the children are asked to pick the category that best describes their feelings, while being reassured that there is no right or wrong answer (Kramer et al. 2010).

The COSA is based on the Model of Human Occupation[6] (MOHO; Kielhofner 2008), which served the theoretical foundation that shaped the content of the COSA (Kramer et al. 2014). Instead of producing a score, therapists who administer the COSA use MOHO theory to interpret the results and then decide on the most relevant means to communicate that interpretation to significant others (University of Illinois 2023).

The COSA is described as a client-centred assessment tool (Kramer et al. 2014); however, it can also be considered a child-centred tool, since it is administered to children and encourages children's participation in the OT process. Moreover, the variety of formats and modifications in the administration of COSA provides children having a range of abilities with the opportunity to demonstrate their strengths and needs (Kramer et al. 2014).

This tool can be used by occupational therapists and other professionals who would like to understand children's self-perceptions of their abilities (Kramer et al. 2014). The COSA is not a standardised assessment but a theory-driven and evidence-based assessment method (Kramer et al. 2014). This tool provides additional benefits, including the building of rapport between the therapist and the child, and the facilitation of communication between children, their parents and other professionals (Kramer et al. 2014).

3.3.6 The Paediatric Activity Card Sort (PACS)

The PACS (Mandich et al. 2004) is a paediatric self-report, which was designed to be used as an occupation-based assessment or research tool to identify a child's occupational profile (Mandich et al. 2004). It consists of photographic cards that the therapist uses to identify the child's level of occupational engagement. This tool was designed to be used with children aged five to fourteen. The PACS can be used with clients with any diagnosis if the child has

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[6] The MOHO is an OT model of practice. Within the MOHO, occupations are viewed as being associated with motivations, patterns and behaviours. This model conceptualises humans as made up of three interrelated elements: volition (the drive for occupations), habituation (the mechanism through which occupations are structured into routines) and performance capacity (the mental and physical attributes that support proficient occupational performance) (Kielhofner 2008).

an approximate developmental age of four years and can respond to the pictures and questions (Mandich et al. 2004).

The PACS is described as a client-centred and individualised measure. Children choose and sort photographic cards based on the frequency with which they performed the activities shown on the cards. They are asked to choose the five most important activities they are currently performing and the five they would like to do, need to do, or are expected to do most (Tam et al. 2008). The involvement of the child in the assessment makes this a child-centred one.

The PACS comprises 75 cards, which the authors describe as falling into four categories: personal care, school/productivity, hobbies/social activities and sports. A blank card is also available in each category to encourage the child to identify other activities that are not on the photographs. Information from the PACS can assist the therapist in goal setting, in intervention planning, and in documenting change (Mandich et al. 2004). The tool can act as an outcome indicator of the child's participation (Tam et al. 2008). The PACS is not norm-referenced. It draws within-child comparisons using children as their own control. Although the PACS was designed to be used with children, it can, in rare instances, be used with caregivers. However, the authors warn that in such a case the results would only be approximations of the child's needs or desires (Mandich et al. 2004).

The PACS was designed to be used by occupational therapists (Mandich et al. 2004). The authors emphasise that when using this tool, therapists should embrace a client-centred philosophy with a focus on occupation-based practice (Mandich et al. 2004). Unfortunately, there is scant research on this tool.

3.4 Psychometric Properties

In order to inform assessment and treatment planning, it is crucial to thoroughly evaluate the quality of the reported psychometric properties of any measures that are used in practice (Cordier et al. 2016). When discussing psychometric properties "one is implicitly referring to the two cornerstones of accurate measurement: reliability and validity" (Cronin and Mossman 2024, p. 86). To ensure their soundness and rigour, OT measures, tests and instruments must have substantial reliability and validity evidence published about them (Lugton et al. 2020). Such information would enable the occupational therapist to make informed decisions about the robustness of the measure and its suitability for their practice (Laver-Fawcett and Cox 2021).

Validity is the extent to which a tool measures what it was intended to measure (Laver-Fawcett and Cox 2021). When research shows that a test is successful in measuring what it was designed to measure, the test is deemed valid (Ottenbacher 1997; Laver-Fawcett and Cox 2021). Validity necessitates both response or relevance and accuracy (Ottenbacher 1997).

The *reliability* of a measure is defined as its capacity to reproduce consistent responses when it is repeated, such as over time or by different raters (de Clive-Lowe 1996; Ottenbacher 1997), provided that there is no real change in the client (Law et al. 2014). If a reliable measure is used, the therapist would obtain the same score every time the tool is used under identical conditions (Laver-Fawcett and Cox 2021). This psychometric aspect is particularly relevant when dealing with outcome measures, as the occupational therapist would retest a client on an assessment given before treatment to determine any possible change in function, in order to assess the efficacy of the intervention provided. It is, therefore, critical that variations in a client's test performance are unaffected by the rater or the time period (Laver-Fawcett and Cox 2021). A test's *reliability coefficient* serves to gauge the reliability of the tool in delivering consistent results over time. Typically, reliability is represented by a correlation coefficient, ranging from - 1.0 to + 1.0. The more reliable the test, the closer its reliability coefficient is to + 1.0 (Laver-Fawcett and Cox 2021).

There are various types of reliability, such as test-retest reliability and inter-rater reliability, and validity, such as content validity and construct validity that should be considered in an outcome measure. Table 1 defines some key aspects of validity and reliability. Each of these is essential when evaluating the quality of an outcome measure.

In order to support holistic interventions for children, occupational therapists are expected to select self-report measures with evidence of validity, reliability and clinical utility (Law et al. 2005; Brown et al. 2014). Occupational therapists may feel powerless over several variables pertaining to service delivery in the rapidly evolving health care environment. Nevertheless, they are still responsible for interpreting assessment procedures and developing treatment plans. Practitioners need to ensure that their clients receive the best possible assessment and care by having access to research data on validity, reliability and sensitivity (Ottenbacher 1997).

Table 1. Definitions and description of common types of validity and reliability of an outcome measure

Type	***Definition and Description***
Content validity	Content validity is the extent to which a test assesses what it is intended to measure based on the suitability of its content (Laver-Fawcett and Cox 2021). When experts concur that the entire domain or content of the construct has been measured, content validity is strengthened (Law et al. 2014). Therefore, content validity is related to the degree of rigour with which test items have been collected, reviewed, and chosen (Laver-Fawcett and Cox 2021). The instrument's content should be logically related to the concept, with items being pertinent and representational of every domain that could be indicative of the concept (Ottenbacher 1997). Clemson et al. (1999) used a Content Validity Index (CVI) to calculate the percentage agreement of experts. The CVI is computed by dividing the number of test items that are judged by experts to have content validity by the total number of test items. The level suggested when utilising a panel of ten or more judges is CVI > 0.78, which is what some test developers adopted as their individual item cut-off (Clemson et al. 1999).
Construct validity	Construct validity is the degree to which items meant to measure the same construct converge to measure the construct (Romero Ayuso and Kramer 2009). It is related to the extent to which an assessment can be claimed to measure the theoretical concepts it was intended to measure (Ottenbacher 1997; Laver-Fawcett and Cox 2021), assuming that the relevant concepts are ingrained in theory (Ottenbacher 1997). When the index score favourably correlates with another measure of the same concept, the construct validity of that tool is validated (Law et al. 2014).
Face validity	Face validity addresses the issue of whether the test appears to be testing the areas that it claims to test from the perspective of the client themselves, in this case the child or the parents. It examines whether the test is acceptable to the clients (Laver-Fawcett and Cox 2021).

Type	***Definition and Description***
Face validity (cont.)	This aspect of validity is very relevant to child-centred and client-centred practice since it takes into account the experience of the children or the clients. Face validity is the extent to which the tool seems to adequately reflect the construct to be measured and is closely related to clinical utility (Laver-Fawcett and Cox 2021).
Clinical utility	A test's usefulness in a clinical setting is not guaranteed, even if it is well-standardised, valid, and reliable. Clinical utility encompasses test characteristics including administration time, score interpretation, ease of use, reasonable cost, acceptability, training needs, and portability. It is the tool's overall usefulness in a clinical setting (Laver-Fawcett and Cox 2021).
Test-retest reliability	Test-retest reliability shows how consistent the scores are over time (Ottenbacher 1997; Laver-Fawcett and Cox 2021). A correlation coefficient of 0.70 or above is considered as an acceptable value for test-retest reliability (Benson and Clark 1982; Paiva et al. 2014).
Inter-rater reliability	Inter-rater reliability refers to the extent of agreement between different raters administering the test (Ottenbacher 1997; Laver-Fawcett and Cox 2021). A correlation coefficient of 0.90 or above is considered to be an acceptable value for inter-rater reliability (Gwet 2014).
Internal consistency	A test's internal consistency measures how closely related its items are to one another. A high level of internal consistency indicates that the items are closely linked and are likely to measure the same construct (Ottenbacher 1997). A value of 0.70 is considered to be reasonable for internal consistency (Tabachnick and Fidel 1996).

Type	***Definition and Description***
Responsiveness and sensitivity	Responsiveness refers to the degree to which changes in scores are related to actual clinical changes in the construct being measured over time (Cusick et al. 2007). Sensitivity to clinical change is another crucial psychometric feature that occupational therapists need to consider in order to determine the effectiveness of their intervention, apart from research that supports other aspects of validity and reliability (Laver-Fawcett and Cox 2021). Therapists should be aware that a test is more sensitive to clinical change the larger its effect size is (Laver-Fawcett and Cox 2021). An effect size of 0.8 or more is deemed large, 0.5 is regarded as a moderate size, while 0.2 or less is considered a small effect size (Sullivan and Feinn 2012).

3.4.1 Psychometric Properties of the COPM

Validation of the COPM (Law et al. 2014) is reported to be ongoing (Law et al. 2014). Several researchers constantly add to the comprehensive knowledge on the COPM’s reliability, validity, responsiveness and utility. A range of clients with varied disabilities and from different countries were included in the COPM’s psychometric studies, demonstrating the wide range of application of the COPM (Law et al. 2014).

Two research studies (Verkerk et al. 2006; Cusick et al. 2007) specifically addressed psychometric properties of the COPM in paediatrics; however, these researchers administered the COPM to parents and not to children themselves. Verkerk et al. (2006) examined the reproducibility and validity of the Dutch version of the COPM. Regarding inter-rater reliability, 80% of the problems which were prioritised in the first interview were also highlighted in the second interview. They found no systematic differences in the average scores for performance and satisfaction of the prioritised problems in both interviews. For performance ratings, the limits of agreement were -2.4 to +2.3 (*đ* – 0.7, SD 1.2), and for satisfaction scores, they were -2.3 to +2.6 (*đ* – 0.18, SD 1.2) (Verkerk et al. 2006).

The COPM was compared with the Pediatric Evaluation of Disability Inventory (Dutch Version) (Haley et al. 1992) and a quality of life questionnaire in order to study construct validity. The findings support the hypothesis that the issues with occupational performance found by the COPM are overlapping with items on the questionnaires used to assess the underlying constructs of independent functioning (50%) life satisfaction, and intrinsically satisfying occupational performance (39%). Problems identified by parents on the COPM that had no comparable items on the other tests addressed varied activities, which were not specifically addressed in these other compared tests. Verification of criterion validity was established by having 71% of the problems identified in an open-ended question, also pinpointed as prioritised problems on the COPM (Verkerk et al. 2006).

Cusick et al. (2007) adapted the COPM for use with very young children, with the parents acting as proxies. Overall results indicate that the modified COPM retained many of the robust aspects of the original COPM. Internal consistency reliability was acceptable for both Performance (0.73) and Satisfaction (0.82) scales. Good construct validity was evidenced by the high Cronbach alpha scores. Proxies deemed the content of occupations and the rating approach valid, thus confirming content validity. Moreover, significant pre-post scores and moderate correlations ($r_s = 0.35 – 0.49$, $p = 0.05$) with GAS (Kiresuk et al. 1994) scores showed responsiveness to change in clinical status (Cusick et al. 2007). Cusick et al. (2006) also compared the COPM with the GAS when used in paediatric rehabilitation. The COPM was found to be a sensitive tool to measure change withing groups. In terms of administration, development, and training the COPM was found to be more time-efficient.

Law et al. (2014) report that the general consensus is that the COPM can be repeated with consistent results. Internal consistent reliability has also been demonstrated to fall within a reasonable range (Law et al. 2014). Research with a wide range of clients, including paediatrics, has consistently demonstrated test-retest reliability to exceed the acceptable range (Sewell and Singh 2001; Cup et al. 2003; Pan et al. 2003; Eyssen et al. 2005; Verkerk et al. 2006; Cusick et al. 2007). Test retest reliability in the aforementioned studies ranged from $r = 0.84 - 0.85$ to $r = 0.90 - 0.92$, with an interclass correlation ranging from ICC = 0.67 - 0.69 to ICC = 0.73 - 0.83.

The COPM has also undergone evaluations for various validity categories, such as content, construct, criterion, concurrent, convergent, divergent and discriminant validity, across a range of contexts and groups, including paediatrics (Law et al. 2014). These studies include Chan and Lee (1997), McColl et al. (2000), Ripat et al. (2001), Dedding et al. (2004), apart from aforementioned studies.

Furthermore, additional research looked at the clinical utility of the COPM (McColl et al. 2000; Carpenter et al. 2001; Ripat et al. 2001; Wressle et al. 2002a; Wressle et al. 2002b; Cusick et al. 2007; Colquhoun et al. 2010; Gustafsson et al. 2012). A scoping review by Ryan et al. (2024) found only one study (Verkerk et al. 2021) that showed good clinical utility for the COPM when this is used with child self-respondents. No research featuring child self-respondents was found that examined the COPM's reliability, validity or responsiveness.

3.4.2 Psychometric Properties of the PEGS

Some of the research on the psychometrics of the PEGS (Pollock and Missiuna 2015) was conducted on the initial version of the test, the All About Me (AAM; Missiuna 1998), which served as the foundation for the development of the PEGS. Missiuna (1998) calculated internal consistency of the AAM, whereby Cronbach's alpha reliability coefficient for the total measure was very good (0.91), while that for both scales was good (0.85). Missiuna (1998) also found a correlation ranging from 0.54 to 0.80 between the AAM and the Pictorial Scale of Perceived Competence and Social Acceptance (PCSA; Harter and Pike 1984), indicating moderate to good level of concurrent validity.

In order to demonstrate construct validity, Missiuna (1998) compared the results of the AAM with the scores from the Bruininks-Oseretsky Test of Motor Proficiency (Bruininks 1978), the Developmental Test of Visual-Motor Integration (VMI; Beery 1989) and the IQ estimate of the short form of the Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler 1974), to show the relationship between children's perceptions and their actual motor competence. With Pearson product-moment correlations ranging from an *r* of 0.56 to 0.73, the results showed highly significant correlations between the motor measures and each subscale together with the scale total of the AAM. On the contrary, correlations with IQ were unsurprisingly non-significant.

Klein and Magill-Evans (1998) examined the test-retest reliability of the AAM, finding no significant difference and adequate test-retest reliability between the total scores ($r = 0.77$) and the fine motor ($r = 0.79$) and gross motor ($r = 0.76$) subscales. Regarding concurrent validity, Klein and Magill-Evans (1998) found a correlation between the scores of the AAM and the PCSA, with the highest correlations being found between the AAM-Total score and the PSCA competence factor score ($r = 0.80$) for time 1.

An additional validity indicator is the PEGS's capacity to distinguish between children with and without disabilities. Children with motor impairments (Developmental Coordination Disorder [DCD]) were compared with their age-matched peers without motor impairments on the AAM, during the creation of the PEGS (Missiuna 1998). Children in the DCD group had

AAM mean scores that were two to three standard deviations lower than those of the age-matched group. Paired t-tests yielded a highly significant difference ($p < 0.001$) between the groups, proving that AAM could distinguish between children who had motor deficits and those who did not (Missiuna 1998).

"No matter how well developed the psychometric properties of a test; it must also be clinically useful to be of value" (Pollock and Missiuna 2015, p. 65). Clinical utility of the PEGS was confirmed by Missiuna et al. (2006), whereby therapists completed a clinical utility questionnaire, apart from attending group meetings to give their feedback on the PEGS. Additionally, the application of the PEGS in various countries was investigated. Indeed, research has shown that the PEGS is valid for use with children with disabilities in a variety of cultures and countries, including Brazil, Australia, Israel, Norway, Sweden and the United Kingdom (Missiuna et al. 2010).

Vroland-Nordstrand's (2008) study illustrated the clinical utility for the Swedish version of the PEGS. The study also demonstrated cross-cultural application, showing that the PEGS is valid on content in Sweden. Similarly, in Vroland-Nordstrand and Krumlinde-Sundholm's (2012a) study, all the therapists felt that the content of the Swedish PEGS was suitable to paediatric rehabilitation settings. Research showed that the Swedish version of the PEGS has good content validity (Vroland-Nordstrand and Krumlinde-Sundholm 2012a). The Swedish PEGS also demonstrated acceptable stability in children's perceived competence/non-competence in performing daily tasks across test-retest administrations. An absolute agreement ranging from 71% to 100% was found on 22 of the 25 PEGS items (Vroland-Nordstrand and Krumlinde-Sundholm 2012b). Test-retest reliability was more varied when the four-point scale was used. In the latter case, the absolute agreement varied from 33% to 100%. Moderate to good weighted kappa values between 0.50 and 0.88 were shown on 18 of the 25 items, whilst poor to fair agreement was demonstrated in the remaining items (Vroland-Nordstrand and Krumlinde-Sundholm 2012b). A study by Vroland-Nordstrand et al. (2016), which used the Swedish version of the PEGS pre and post intervention, showed that the PEGS is responsive to change, although it was not explicitly described as such.

In her Master’s thesis, Lin (2010) examined validation of the Chinese PEGS when used with children with DCD. Optimal internal consistency was found in the DCD group for both children (*r* = 0.87) and caregivers (*r* = 0.85). Lower, but acceptable values were obtained for children (*r* = 0.75) and caregivers (*r* = 0.79) in the normal group. The findings also provide evidence of discriminative validity, whereby the Chinese PEGS could distinguish between children with and without motor difficulties (Lin 2010). Translation and cross-cultural adaptation of the PEGS for its use in German-speaking countries was also carried out by Costa (2014). This included field-testing of the AG-PEGS version (Costa 2014).

Ruggio et al. (2018) examined the validity and reliability for the use of the PEGS with Brazilian children. Regarding test-retest reliability, at least one coinciding goal was identified by 100% of the children on retest, with one child identifying the same goals on both occasions. This result was less stable than other previous studies (Missiuna et al. 2006; Vroland-Nordstrand and Krumlinde-Sundholm 2012b). The latter studied children with disabilities, in contrast to Ruggio et al. (2018), who researched only typically developing children. Having difficulties may intensify the child’s challenges, thus affecting the selection of specific goals (Ruggio et al. 2018). When examining internal consistency of the PEGS-Brazil test, Ruggio et al. (2018) obtained a satisfactory Cronbach’s α coefficient value of 0.81, 0.70 and 0.88 for the child, caregiver and teacher questionnaires, respectively (Ruggio et al. 2018).

Similarly, Nobre et al. (2023) investigated the use of the PEGS with Brazilian children. When examining test-retest reliability, they found a percentage agreement ranging from 76% to 92%, with an alpha for polychoric correlation ranging between α 0.71 to α 0.77, thus showing adequate internal consistency. Therapists in this study reported that the items on the Brazilian version of the PEGS were very clear and pertinent, thus providing proof for content validity (content validity coefficient ranging from 98.4% to 100%; Gwet's agreement coefficient ranging from 0.85 to 1.00, $p < 0.001$).

Nobre et al. (2023) reported that adequate discriminant validity was also shown on the Heterotrait-Monotrait ratio test (self-care and productivity [value = 0.76]; self-care and leisure [value = 0.57], productivity and leisure [value = 0.76]). However, one should note that the sample in this study only included typically developing children.

Miguel et al. (2016) translated and adapted the PEGS for use with Portuguese children. A reasonable value was obtained for internal consistency of the children's scale ($\alpha = 0.72$). When test-retest reliability was examined, Miguel et al. (2016) found a significant correlation for the PEGS total score ($r_s = 0.85$, $p = 0.00$) and for the gross motor ($r_s = 0.82$, $p = 0.00$) and fine motor ($r_s = 0.74$, $p = 0.00$) items. Ferreira et al. (2022, as cited in Nobre 2023) also found that the Portuguese version of PEGS' internal consistency was good ($\alpha = 0.79$). The original article could not be accessed since it was not written in English.

Cordier et al. (2016) conducted a systematic review on literature about the psychometric properties of child-report measures of occupational performance. The methodological quality of the included studies was assessed using the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) taxonomy of measurement properties and definitions for health-related patient-reported outcomes (Mokkink et al. 2010a; Mokkink et al. 2010b). This was followed by an evaluation of the actual quality of the psychometric properties of the tools, according to Terwee et al.'s (2007) criteria.

In their systematic review, Cordier et al. (2016) note that the PEGS had some studies of good methodological quality, about its psychometric properties although the rating of these studies for psychometric quality criteria was not optimal. The PEGS had good to excellent quality of studies for reliability and for internal consistency. However, in the absence of studies about the PEGS' measurement error, further research for a more comprehensive view of the PEGS' reliability was recommended.

Evidence of studies at a good or excellent level of quality on hypothesis testing was also found in this systematic review. Nonetheless, Cordier et al. (2016) underscored the need for further studies to evaluate the test's content validity, criterion validity and structural validity. Cordier et al. (2016) stated that the PEGS was properly translated and adapted for different cultures, whilst noting that the quality of studies on cross-cultural validity was excellent. It is worth noting that some of the available studies on the PEGS were not included in Cordier et al.'s (2016) systematic review.

3.4.3 Psychometric Properties of the GAS

The validity (Bowman et al. 2015), reliability (May-Benson et al. 2021) and utility of GAS (Kiresuk et al. 1994) with specific client populations (Rockwood et al. 2003; Bowman et al. 2015; May-Benson et al. 2021; Logan et al. 2022) were all examined in a number of reviews.

Palisano (1993) found evidence of content validity, as the criterion for content validity was met by 77% to 88% of the therapists. Concurrent validity was not supported. Regarding interrater reliability, there was an 88% agreement, with the kappa coefficient being 0.75. Responsiveness of the GAS was also supported. Palisano (1993) recommends that similar research be replicated among therapists and with children of different ages and disabilities, before the results are generalised.

Cusick et al. (2006) compared the GAS with the COPM (Law et al. 2014) when used in paediatric rehabilitation. Despite COPM's many benefits, the GAS was found to offer more flexibility, which could make it a suitable outcome measure if the service or programme's objectives align with family-directed goals.

Hurn et al. (2006) conducted a systematic review to examine the reliability, validity and sensitivity of the GAS. They found evidence of validity, namely substantial evidence for congruent validity, limited evidence for concurrent validity, limited work with positive results on predictive validity and one study that examined construct validity with positive results. This systematic review showed ample evidence for the sensitivity of GAS. A number of studies that support inter-rater reliability of GAS with a range of client populations and settings were also found (Hurn et al. 2006). The authors recommend further research before reaching any definitive conclusions.

A study by Marson (2009) showed that the level of rater reliability for GAS weights was acceptable (Kendall's *W* coefficient = 0.832). Similarly, in May-Benson et al.'s (2021) study on GAS inter-rater reliability, agreement was found for 78% of the goals, with an adequate intra-class correlation (ICC = 0.70) for the total score. Shankar et al.'s (2020) systematic review also showed evidence of interrater reliability; however, this review focused mainly on validity evidence.

In their systematic review, Shankar et al. (2020) identified a number of articles about the validity and reliability of the GAS. However, they also point out a few gaps in the body of research supporting the commonly accepted GAS across disciplines. Their review highlights gaps in the validity evidence for the GAS and encourages researchers to address how validation procedures can support the numerous assertions made about this tool.

In another systematic review, Cheema et al. (2024) state that the GAS is a relevant measure in paediatrics. In order to examine GAS' responsiveness, they compiled Cohen's *d* values from every study that was part of their review. Cohen's *d* values varied from -0.015 to 2.562, and the median effect size was 0.52. Four studies showed small effect sizes (e.g., between 0.1 and 0.4), whereas the majority showed medium to high effect sizes (e.g., between 0.5 and 0.8).

A limitation about GAS research is that most studies examining validity and reliability of the GAS used only experienced GAS-trained professionals (Palisano 1993; Steenbeek et al. 2007), which may not accurately reflect the use of GAS by the average therapist in clinical OT practice (May-Benson et al. 2021). Moreover, similar to Ryan et al.'s (2024) scoping review, this literature review did not identify any research that discussed the GAS' responsiveness, validity, or reliability when used with child self-respondents. Indeed all the aforementioned studies mentioned used the GAS with parents and not with children.

A significant limitation of GAS is its reliance on the ability of the therapist to create meaningful, valid and reliable scales (Krasny-Pacini et al. 2016). There is a need for more standardisation to address challenges to the validity and reliability of GAS stemming from the inconsistencies present in both its application and reporting (Logan et al. 2022). Training was recommended to ensure standardisation of the application of the GAS as a self-reporting outcome measure and to improve the reliability of the results (Logan et al. 2024). Bias can be mitigated and GAS validity and reliability can also be strengthened through the use of GAS quality appraisal criteria (Krasny-Pacini et al. 2015).

3.4.4 Psychometric Properties of the COSA

Keller et al. (2005) examined the psychometric properties for the COSA (Kramer et al. 2014). The overall findings indicate that the COSA includes two unidimensional measures that assess occupational competence and value. Every item of the Competence scale fits the Rash Rating Scale model, while there was only one misfitting item on the Values scale. Keller et al.'s (2005) results showed that the COSA was not sensitive enough to discriminate among the children who were administered the test. They provided recommendations to improve the rating scales.

A follow-up study by Keller and Kielhofner (2005) aimed to improve the psychometric qualities of the COSA, based on the analysis of Keller et al.'s (2005) research. The sensitivity and reliability of the COSA were enhanced by extending the initial three-point scale to four response categories. The reliability of the Competence items increased from 0.74 in the prior study to 0.85 in this one. The reliability of the Values items increased to 0.82 from the initial study's 0.78. Finally, there was an improvement in participant reliability on both scales: with a rise from 0.72 to 0.88 in the Competence scale and an increase to 0.91 from 0.80 in the Values scale. The COSA could differentiate the responders into distinct groups. Keller and Kielhofner (2005) recommended further research on the psychometric properties of the COSA and its clinical utility when used as an outcome measure.

These findings were followed by Kramer et al. (2010), who researched the validity of the COSA by analysing a larger sample following revision of the test's original version. Their results showed good content, structural and substantive validity of the COSA, evidenced by the unidimensionality evaluation and the item and child fit statistics. More than 85% of children responded consistently. Further proof of substantive validity is offered by this study's theoretically meaningful item hierarchies. Both the reported COSA competence and values, and the degree of fit, showed variations with some demographic and assessment administration variables, thus putting external validity into question. This study provided evidence to support the validity of interpreting the majority of children's COSA responses as indicators of occupational competence and value for daily tasks (Kramer et al. 2010). In another study, Kramer (2011) provided some evidence about the social validity of the COSA.

Ohl et al. (2015) investigated the test–retest reliability of the COSA. The intraclass correlation coefficient (ICC) showed good test-retest reliability for total Competence and Value scores ($ICC_{2,1} = 0.72 – 0.77$), whilst the reliability across category scores ($ICC_{2,1} = 0.44 – 0.78$) was poor to good. These results indicate that, over a short time, the children's perceptions of their own skills and the importance they attached to their daily activities were reasonably stable. Given the unpredictability of emotions vis-à-vis physical and cognitive performance, unsurprisingly the Emotional Regulation Skills category had the lowest ICCs for both Competence ($ICC_{2,1} = 0.44$) and Value ($ICC_{2,1} = 0.58$) scores.

The COSA was translated and used in different countries. Romero Ayuso and Kramer (2009) investigated the psychometric properties of the Spanish version of the COSA with children with ADHD. They found excellent internal consistency for the occupational Competence ($\alpha = 0.91$; $p = 0.05$) and Values ($\alpha = 0.92$; $p = 0.05$) scale. The COSA was found to consistently measure the intended constructs, and acceptable construct validity was found. Items converged to measure each construct, as seen by the majority of each scale's items having correlations with several items from the same scale. Additionally, the two constructs being measured by the COSA seemed to be distinct because only a small number of items were shown to correlate with items from the opposite scale (Romero Ayuso and Kramer 2009).

The COSA was included in Cordier et al.'s (2016) review. Regarding reliability, internal consistency was found to be detailed for the COSA; however, the quality of the research was rated as fair. For hypothesis testing, the evidence of available studies was reported to be of poor or fair quality level. Although cross-cultural validity was reported, studies about translation and cultural adaptation were found to be of limited quality. Moreover, the COSA was rated as having only one psychometric characteristic (structural validity) with moderate positive support, apart from obtaining ratings of indeterminate or conflicting levels of evidence (Cordier et al. 2016).

In Cordier et al.'s (2016) systematic review, the quality of the studies on the COSA was reported to be relatively weak. This review did not find evidence of content validity. Future studies on the COSA were recommended to obtain more information about the psychometric properties of this tool, including further evidence on internal consistency, reliability, measurement error, content validity, construct validity and criterion validity, and to increase the generalisability of the results. It is worth noting that not all available COSA studies were included in this review.

3.4.5 Psychometric Properties of the PACS

The PACS (Mandich et al. 2004) manual provides preliminary validity and reliability data, supporting the use of this tool, whereby a number of studies, which were used in the creation of the PACS are reported. The latter are mainly Master's theses. A sample of 13 children was used for the PACS item validation process and the findings showed that the participants had an 86% occupational involvement in the activities (Mandich et al. 2024). The impact of the child's age on their responses was also examined, revealing that there were differences in the activity patterns of the various age groups, indicating that the PACS was age-group sensitive (Mandich et al. 2024).

Lugton et al. (2020) investigated the convergent validity between three children's self-report play and leisure activity interest scales measures, namely the PACS, the Children's Assessment of Participation and Enjoyment, and Preferences for Activities of Children (CAPE/PAC; King et al. 2004) and the Kid Play Profile (KiPP; Henry 2000). Significant correlations were found, generally at a moderate level between a number of the CAPE scales and certain PACS domains. For instance, the PACS School/Productivity and the CAPE Diversity were significantly associated ($r_s = 0.387$, $p = < 0.01$). A moderately positive correlation was registered between the PACS Hobbies/Social Activity and the CAPE Diversity ($r_s = 0.526$, $p = < 0.01$) and Intensity ($r_s = 0.402$, $p = < 0.01$) domain.

Furthermore, Lugton et al.'s (2020) findings showed that, apart from physical activities, all PAC domains and the PACS Hobbies/Social Activities had a moderately strong correlation. A moderately significant correlation between the PAC Skill-Based and Self-Improvement Activities scale and the PACS Hobbies/Social Activities scale was also obtained. A moderate level of significant correlation was observed between some aspects of the KiPP and half of the PACS domains. There was no correlation between any KiPP domain and the PACS Personal Care domain, since personal care activities are not included in the KiPP activities. Lugton et al. (2020) recommend further studies with a larger sample to enable generalisation of the results. Research that examines structural validity and cross-cultural validity, in line with COSMIN principles, was also suggested (Lugton et al. 2020).

Jutzi et al. (2023) created the e-PACS, an alternate electronic online version of the PACS, and examined whether this version is a reliable alternative to the original version. The agreement between the paper-based version and the e-PACS was assessed using Cohen's kappa findings, which varied from К = 0.75 to К = 1. The combined mean of all kappa values indicated very good agreement (К = 0.88, 95% CI [0.84 – 0.93]) between the e-PACS and the paper-based PACS (Jutzi et al. 2023). This study was conducted with a very small sample (n = 7). Further research with a larger sample is required to ensure generalisation of results.

Published studies on the PACS are limited (Tam et al. 2008; Lugton et al. 2020). Indeed, similar to previous reviews (Tam et al. 2008), this literature review found scant literature evaluating the psychometric properties of the PACS. According to Calley et al. (2012), there is inadequate data about the validity and reliability of the PACS for usage with children with cerebral palsy. Chien et al. (2013) similarly found insufficient evidence to support the criterion-related validity of the PACS. Additionally, Chien et al. (2014) report that the validity of the PACS is greatly restricted by the limited sample used in its development.

Several limitations can be identified in the available research on all the aforementioned child-centred outcome measures. Most studies used convenience sampling. Several of these child-report measures of occupational measures were developed with small sample sizes (< 300 children) and/or validated with modest sample sizes (Cordier et al. 2016), limiting their generalisability to a wider population.

Different studies used different tests to examine the psychometric properties of these tests, making the task of comparing results a challenging one. Additionally, the rigour of the processes used to translate some of these measures varied across translations. Of particular significance for this study is the absence of research about the face validity of these tests. Given that the child's and parents' perspective is fundamental in the application of a child-centred or a client-centred approach, face validity studies for child-centred outcome measures are essential.

No other systematic review that analysed the methodological qualities and the quality of the psychometric properties of child self-reports besides that of Cordier et al. (2016) was found. A limitation of the latter review was that responsiveness, an important quality for outcome measures, was outside the scope of this review and thus not included. A scoping review about child-led goal setting and evaluation tools for children with disabilities was conducted by Ryan et al. (2024). Further rigorous research was recommended in this area. Research to evaluate the psychometric qualities of child-report measures of occupational performance and to upgrade the psychometric qualities of already existing tools is required. Such research should ideally use a larger normative sample to improve generalisability.

Research on child-led goal-setting and evaluation methods and instruments used by children is scarce. The scope of previous systematic studies on goal setting involving children is restricted to a particular goal setting instrument, such as the GAS (Kiresuk et al. 1994; Harpster et al. 2019) or the COPM (Law et al. 2014; Ohno et al. 2021; McColl et al. 2023). Several reviews have been undertaken on goal-setting in a particular paediatric group, such as children with autism (McColl et al. 2023) or motor disabilities (Pritchard-Wiart and Phelan 2018). Further systematic reviews are required to obtain conceptual clarity regarding the features of and procedures for child-led goal setting when used with a wide range of children (Ryan et al. 2024). This would enhance evidence-based practice related to child-centred and client-centred care. Such research would also enable occupational therapist to select the best available measure that meets a particular client's needs.

3.5 Challenges Related to the Use of Outcome Measures

There are a several challenges related to the use of outcome measures. Whilst acknowledging that some aspects of OT might be difficult to be measured, Doucet and Gutman (2013) argue that "measurement is nevertheless critical for the survival of the profession" (p. 8). These researchers argue that therapists would be doing a disservice to the profession if they considered OT as an unmeasurable art. The use of reliable and valid tools is imperative to demonstrate the client's progress by measuring objective and measurable outcomes of intervention (Doucet and Gutman 2013).

Indeed, it is an ongoing challenge for occupational therapists to be proficient enough to identify which instrument to use to measure OT services. The underlying concepts of outcome measures are similar to those in standardised assessments; the difference lies in that an outcome measure needs to be able to demonstrate any change following intervention (Corr and Siddons 2005) and such tools need to be able to evaluate change (Payne 2002). On the other hand, the main aim of assessment is "to gain a clear picture of the individual to develop an intervention plan that will result in improved, or maintained, function, participation, and enhanced quality of life." (Laver-Fawcett and Cox 2021 p. 1).

The ability of occupational therapists to measure the effects of their services can be influenced by several factors (Bowman 2006). Duncan and Murray (2012) maintain that the degree of organisational and peer support that is provided to clinicians to advance their work, and their level of expertise and confidence in utilising outcome measures influence their routine use of outcome measures. Occupational therapists constantly face challenges to integrate effective measurement into their practice. Although the principles of measurement are widely understood, making outcome measurement a regular part of the daily OT routine is nonetheless challenging (Law 2003). No research has investigated the challenges that Maltese paediatric occupational therapists may encounter when trying to measure the effectiveness of their interventions. This study sought to address these literature gaps.

3.6 Conclusion

For a child-centred approach to be authentic, there needs to be child involvement and engagement at all intervention levels. However, a recent scoping review (Antoniadou 2022) showed that while several strategies were being employed to involve children at the assessment and goal setting levels, no strategies were found regarding the engagement of children in result evaluation or outcome measurement. It is well known that children can evaluate results since they know their needs, wishes and priorities best (Curtis et al. 2022).

OT services are unique, vis-à-vis other health care services. Indeed they pose the constant challenge to show the efficacy of intervention, highlighting the distinctive contribution that occupational therapists provide in complementing the work of other team members (Klein et al. 2008). Evidence of the unique contribution of OT services can only be provided via the use of outcome measures demonstrating OT-specific assessment and treatment goals (Klein et al. 2008).

This chapter has provided a historical overview of outcome measures in paediatric OT and has highlighted the importance of the use of self-reports to support child-centred practice. A number of child-centred outcome measures were also reviewed. A literature gap, which examines the use of child-centred outcome measures and the factors influencing their use in Maltese paediatric OT practice, was identified, suggesting that this is an under-researched topic. Therefore, this study sought explore the factors that affect the use of child-centred outcome measures in Malta.

Part Two: Research Design

This part of the thesis deals with the methodological considerations of this research. **Chapter 4** discusses the methodology that was selected for this study, that is, action research and, more specifically, participatory action research. **Chapter 5** explains the methods that were employed to conduct the study, including the data analysis.

Chapter 4: Methodology of the Enquiry

This chapter outlines the philosophical and theoretical background to action research and more specifically, to participatory action research. It provides details about the methodology and research design. The main aim of this chapter is to explain the rationale behind the methodology of this study.

To reiterate, the aim of this research was to identify and explore factors that facilitate and/or inhibit a measurable, child-centred OT practice in Malta. This chapter starts with a justification for the methodology chosen, with a view to outlining my philosophical stance. It then describes the characteristics of action research, linking them to this study. The foundations of action research as a methodology ensues, followed by an explanation of the rationale for adopting a participatory action research approach. The chapter concludes with a description of the specific characteristics of participatory action research and its application in this enquiry.

Rather than explore current practice as a snapshot through traditional methodologies, action research, or more specifically, a participatory action research approach, was deemed the most appropriate methodology as it is ideally suited to provide a means for a collaborative and critical review of current practice, and potentially improve such practice. I sought to explore the issues of child-centred outcome measures in the hope that such research would provide recommendations to ultimately develop and improve local paediatric OT practice.

4.1 Approaches to Research

Prior to settling on action research, I explored a variety of alternative methodologies, wanting to find a methodology that was congruent with OT's core values and beliefs. This would ensure that the outcomes of the study would align with the professional experiences of the local paediatric occupational therapists. Moreover, I wanted to choose a methodology that would be easily understood and that the therapists would perceive as relevant, thus motivating to participate in the research and develop their practice. Occupational therapists collaborate with others in order to deliver the highest quality care (AOTA 2021). They enable people to do the things that they need and want to do (WFOT 2018). In addition to the inherent emphasis on collaboration, the process of action research, namely that of identifying common problems and trying to solve them (Swantz 2015), resembles the OT process that therapists use in their daily practice. This makes action research an attractive methodology, which may also involve local occupational therapists in the process.

There is ample research about child-centred outcome measures; however, I was interested in the local situation and the experience of local therapists. After considering a variety of possible options, I opted to conduct a study with the occupational therapists themselves, using action research as a methodology for this study. Action research was selected since an important value of action research is that it respects the knowledge and experience that people possess and posits that participants are capable of understanding and addressing the situations that they find themselves in (Brydon-Miller et al. 2003).

Additionally, action research was chosen for this study, since this research style has been recommended as being ideally conducive to changing and improving workplace practice (Hart and Bond 1995; Winter and Munn-Giddings 2001) and is widely "adopted by health care practitioners who would like to develop aspects of their practice and that of their organisations" (Williamson 2012c, p. 9). Moreover, the findings that are generated through action research are meaningful and useful to clinicians (Meyer 2000). Action research will, therefore, be discussed in greater detail below. Such a discussion includes the relationship of action research to the epistemology that influenced this study, as well as its relationship with the approach that was adopted for this enquiry.

Research approaches are typically described as coming from a quantitative or a qualitative approach. These two methodological approaches are frequently viewed as differing in how research is thought about and applied (Williamson 2012c; Braun and Clarke 2013; Bryman 2016). The epistemological and ontological foundations of the quantitative and qualitative approach vary (Williamson 2012b; Bryman 2016). Research literature defines terms such as epistemology and ontology in conflicting ways (Carter and Little 2007). A basic distinction between the different epistemological and ontological positions is whether reality and the social world are external to us and are *discovered* through research or whether these are created by humans in the research process (Braun and Clarke 2013; Bryman 2016). These concepts will be elucidated and the approach that was adopted in this study will then be discussed.

4.1.1 Ontology

Ontology is concerned with the study of being (Braun and Clarke 2013; Braun et al. 2017) and the underlying nature of reality (Nicholas and Hatchcoat 2014). It refers to the belief of what exists in the world (Coleman 2015) and addresses questions about the relationship between the world and human understandings and interpretations of the world (Braun and Clarke 2013; Braun et al. 2017). The different view of reality may inform action research and the methodologies that are employed (Nicholas and Hatchcoat 2014).

Relativism is an ontological position, which suggests there is not a single, correct version of truth or reality (Braun and Clarke 2013; Braun et al. 2017). Instead, relativists argue that there are multiple realities. These representations of reality are actively constructed by human beings and they are strongly related to the contexts in which they occur (Koshy et al. 2011; Braun and Clarke 2013; Coleman 2015; Braun et al. 2017). Hence, “there are *knowledges*, rather than knowledge” (Braun and Clarke 2013, p. 30). This is in contrast with realism, an ontological position that suggests there is a single, true reality that researchers can discover (Braun and Clarke 2013). Relativists believe that all versions of reality are equally valuable (Braun and Clarke 2013). Such an ontology underpins most qualitative research as well as action research, including my research study.

4.1.2 Epistemology

Epistemology refers to the theory of knowledge (Carter and Little 2007; Braun and Clarke 2013; Braun et al. 2017), concerned as it is with what is deemed acceptable and valid knowledge (Bryman 2016; Braun and Clarke 2013; Braun et al. 2017,). Therefore, it also determines how we go about obtaining or generating meaningful knowledge (Braun and Clarke 2013; Coleman 2015; Braun et al. 2017).

How the researcher views the participant when collecting and analysing data depends on the epistemology that is embraced (Carter and Little 2007). Such epistemological considerations tend to be related to whether the researcher is interested in taking a natural science approach (mostly that of positivism) vis-à-vis following an interpretivist one (Bryman 2016). A brief discussion on positivism and interpretivism in relation to the applicability of this research follows.

Positivism is an epistemological position which affirms that the social world can and should be researched by applying the principles and methods of the natural sciences. Positivism is often regarded as 'an objective' value-free approach to research. Researchers adopting a positivist approach view themselves as detached from the object being studied in order to attain 'objective truth' (Crotty 1998; Greenwood and Levin 2007; Tekin and Kotaman 2013; Bryman 2016).

Positivism is a theoretical position that is based on the belief that the world, or reality, exists independently of the people who are trying to research it. It posits that if researchers use rigorous methods for observing it, they can discover the real truth (Coleman 2015; Braun et al. 2017). This epistemology does not align with my research and justification for this incompatibility is debated further on.

On the other hand, the theoretical perspective of interpretivism posits that every individual constructs their own reality, since reality is subjective and relativist (Crotty 1998; Bryman 2016). This epistemology was developed by writers who called into question the idea that the social world can be studied using the scientific model and the principles of natural sciences (Williamson et al. 2012; Tekin and Kotaman 2013; Bryman 2016). These writers believed that the social sciences are fundamentally different from the natural sciences and that culture and values are essential. Consequently, a different research procedure is required to study the social world. Social reality is viewed as involving complex interactions and cannot be studied through a cause-and-effect relationship (Tekin and Kotaman 2013). Interpretivism is concerned with the meaning that arises from social interactions (Koshy et al. 2011; Tekin and Kotaman 2013). Data are situated and dependent on the context in which they occur (Koshy et al. 2011). Social reality is viewed as being meaningful to human beings, so it needs to be interpreted from the persons' point of view (Bryman 2016). People's interpretations are considered to be solid knowledge and are regarded as the main data (Mac Naughton and Hughes 2008). This was the case with this study, which was interested in the occupational therapists' interpretations of issues related to child-centred outcome measures.

Interpretivists believe that 'insiders' are more knowledgeable and they can better understand their respective social world than outsiders, even if the latter are experienced researchers (Crotty 1998). Insiders are researchers who form part of the communities that they are researching, whereas outsiders are researchers, who are not members of the groups that are being researched (Braun and Clarke 2013). In this study, as an occupational therapist working in the paediatric area and who worked with this team, I was an insider. Further discussion about the concept of insider can be found in the following chapter (Methods).

Interpretivism is based on principles of hermeneutics, which refers to the interpretation and understanding of human action, their thoughts and ideas (Mac Naughton and Hughes 2008). Weber's (1984-1920) definition of *Verstehen* (understanding) is also related to this approach (Crotty 1998). In this enquiry, I tried to understand (verstehen) the feelings and experiences of the paediatric occupational therapists, using a small scale study as is commonly done when adopting the interpretivist approach.

In contrast with positivism, the interpretivist approach is subjective. It only deals with the present situation, trying to explain and solve current issues and rejecting the idea of objectivity (Greenwood and Levin 2007; Tekin and Kotaman 2013). If one were to draw an imaginary line ranging from objectivism to subjectivism, one would place the positivist paradigm on the extreme objectivist side, with interpretivism located on the opposite part of the continuum (Tekin and Kotaman 2013). This study aligns with the interpretivist or subjective end of the continuum.

4.1.3 Action research and interpretivism

Action research chimes with the qualitative, interpretive paradigm. This is mostly due to the fact that action research is based "on a participatory and democratic relationship between researcher and participants" (Williamson 2012b, p. 35). According to positivism, the researcher should distance themselves from the phenomenon under scrutiny. However, this is not the case in action research. Instead, action research participants are also researchers (Tekin and Kotaman 2013).

Similar to interpretivists, action researchers believe that knowledge is socially constructed and that our realities are built socially as we experience reality and understand the same reality in different ways (Morton-Cooper 2000), whilst acknowledging that research is situated within a framework of values.

Action research draws on interpretivism mostly when the aim of the research is that of professional change, as was the case in this study, which sought to explore factors related to client-centred outcome measures. This runs counter to action research for social change, the latter drawing more on critical theory (Mac Naughton and Hughes 2008).

> In action research for professional change, … individuals … become curious about their daily practice; they think openly about their daily practice by using hermeneutic reasoning to identify and interpret 'wise' practice; and then they work to increase the 'wisdom' of their daily practice. (Mac Naughton and Hughes 2008, p. 105).

Another feature of action research, which is congruent with the interpretivist paradigm, is the researcher's equal status with participants. Such power relationships will be further discussed in the Methods chapter (Chapter 5).

Just like interpretivists, action researchers engage in a thorough evaluation of the perception of participants, be they practitioners or patients. This paradigm is adopted when the researcher indulges in empathic understanding. What the participants say, as well as how the action researchers interpret what they say and do, is considered an essential part of knowledge creation (Koshy et al. 2011).

Moreover, similar data collection methods are used by interpretivists and action researchers (Tekin and Kotaman 2013). Interpretivists tend to use mostly qualitative methods (Williamson et al. 2012; Bryman 2016) as was the case with this study, since the former are flexible (Braun and Clarke 2013) and suitable for understanding complex context-related issues (Carcary 2009). When qualitative research methods are used, the theoretical and conceptual frameworks may be refined or redefined throughout the research process as it is inductive (Betts et al. 1996). In this study, I used action research groups to collect the data as described in detail in the Methods chapter (Chapter 5).

4.1.4 Action research and qualitative research

Indeed, most authors state that action research tends to employ predominantly qualitative methods such as observation, in-depth interviews, focus groups and field notes (Meyer 2000; Bradbury 2010; Koshy et al. 2011; Williamson 2012b). Moreover, similar to qualitative research, action research is deeply contextualised in the (local) knowledge of the participants (Bradbury 2010). The action researcher uses qualitative data to study participants' interactions and behaviours, in their natural settings, such as hospitals or clinics (Koshy et al. 2011).

Similar to qualitative researchers, action researchers view reality as being meaningfully constructed through the interpretations of the researchers and as being constantly changing and not as something that is objective, external and independent (Bryman, 2016; Koshy et al. 2011). Similarly, in action research, the data collected depends on the subjective narrations from the participants who are in a specific context (Koshy et al. 2011).

Not only do qualitative researchers acknowledge the researcher's values, views and assumptions, but this subjectivity is considered a strength (Braun et al. 2017). Similarly, the action researcher does not aim for objectivity in order to conduct a valid study (Tekin and Kotaman 2013). Action research, in fact, challenges the positivistic view that research should be objective and value-free so as to be credible (Brydon-Miller et al. 2003). While quantitative researchers seek objectivity, detachment of the researcher and control, action researchers are more concerned about the relevance of the research and the resultant professional or social change. The validity of the study is determined by the participants themselves, during the actual application of the research (Brydon-Miller et al. 2003).

The main concept underlying my research study was that of client-centred, or more specifically, child-centred practice. I was concerned about what this concept meant for the occupational therapists who would be applying this approach. My research sought to identify and explore factors that facilitate or inhibit the use of child-centred outcome measures, by understanding the therapists' experiences. To that end, the research sought to explore the attitudes, and to understand the practice, experience and the perception of the occupational therapists within the context of paediatric OT. Given the nature of enquiry, which is based on OT, a qualitative research study was deemed the most suitable approach to design this research on, so as to address the research questions.

In that respect the main justification for the use of a qualitative research design stemmed from my research questions and objectives. Additionally, occupational therapists have generally used qualitative methodologies to research issues about OT practice, and such methodologies are considered congruent with the profession's philosophical orientation (Hammell 2002). Qualitative methods also chime with a client-centred philosophy. They can help OT researchers identify how OT practice and service delivery can meet the clients' needs, thus being ideally suited to develop client-centred practice in OT (Hammell 2001).

Indeed, the methodology that was adopted for this study was shaped by interpretivist epistemology and relativistic ontology. Epistemology, ontology as well as the methodology that the researcher adopts are instrumental in shaping the human need to discover, understand and change our environment (Coleman 2015).

4.2 Development of Action Research

The history of action research is complex and dates back to at least the beginning of the twentieth century (Kemmis et al. 2014). It is described as a research method that emerged from a wide range of fields (Brydon-Miller et al. 2003). There are traits of action research in John Dewey's philosophical and educational work, just as one can also find elements of action research in the labour-organising traditions in Europe and in the US (Brydon-Miller et al. 2003).

Dewey believed that democracy developed through humans' active participation in understanding their own social world, rather than by having powerful outsiders imposing solutions on them. He underscored the constant involvement of all levels of society in their social improvement for democracy to flourish, and the inseparability of thought from action. These ideas led to his proposal of an action approach to science when conducting research, emphasising that this is intimately linked to democracy and chiming with our current perception of action research (Greenwood and Levin 2007). Indeed, action research stemmed from a pragmatic attempt to connect democracy and research (Nielson and Nielson 2006).

Scholars disagree about the founder of action research. Both John Collier (Neilsen 2006; Bradbury 2015) and social psychologist Kurt Lewin (Adelman 1993; Holter and Schwartz-Barcott 1993; Brydon-Miller et al. 2003; Nielson and Nielson 2006; Bradbury 2010; Williamson 2012c; Tekin and Kotaman 2013) have been cited as the founder. However, despite different views of the identity of the founding father, it can be said with certainty that whereas Collier's action research version addressed the democratic collaboration to solve essential social issues, Lewin's version was more science-oriented (Neilsen 2006). There is, however, consensus between Collier and Lewin that the main aims of action research were to instigate a change in practice and to create or refine theory. These aims remain two key features of action research to date (Holter and Schwartz-Barcott 1993).

Lewin developed a new role for the researcher which contrasted with that of traditional research. Rather than considering researchers as distant, objective observers, he suggested that researchers should participate in the research process and that they should be involved in finding a solution to practical problems (Greenwood and Levin 2007; Williamson 2012c). Lewin's work is considered to be an essential foundation of what is referred to as action research today (Greenwood and Levin 2007).

In its early stages, action research was still very much grounded in the positivistic epistemology. Since positivism was predominant in American social sciences in the 1940s, action research had to conform to such methodological philosophies. The British version of action research that emerged later in the 1970s rejected the positivistic research methodology and endorsed an interpretive epistemology (Carr 2006). Moreover, the early forms of action research were less collaborative than subsequent developments. Action research started to change following the 1968's democratic movements, whereby new approaches such as participatory action research, characterised by clear emancipatory intentions, started to develop (Boog 2003).

Sol Tax, an American anthropologist, created action anthropology, an approach that is concerned with social justice (Coghlan and Brydon-Miller 2014). He encouraged collaboration with the relevant stakeholders while following a democratic process. Action research efforts were also supported by the Tavistock Institute of Human Relations, where social science is applied to contemporary problems (The Tavistock Institute 2020). Research at this institute was based on the work of British, Norwegian and Australian researchers. Such work initially flowed into Britain and Scandinavia before spreading to Germany, Denmark and Sweden (Brydon-Miller et al. 2003).

The development of action research continued. The Highlander Folk School was founded by Myles Horton and his co-researchers in Tennessee, and focused on social justice leadership. Action research was promoted by a number of other scholars, including Budd Hall, Paulo Freire, Orlando Fals-Borda, Marja-Liisa Swantz, in order to address social injustice and community change (Brydon-Miller et al. 2003). This work was also advocated by other researchers, such as Reg Revans, William Torbert, John Heron, Chris Argyris, Donald Schön and Peter Reason, in a vast range of organisations, both in the public and private sector (Brydon-Miller et al. 2003). Efforts to trigger positive social changes have been an integral constituent of all action research since the 1970s. Such emancipatory or liberation concerns remain essential components of action research (Boog 2003; Bradbury 2015). These concepts also underpinned this research study.

4.3 Action Research – a 3rd Paradigm?

Williamson (2012c) argues that although action research shares some similarities with the two main research traditions, it does not fit perfectly with any of these. Action research has, in fact, been described as a 'new paradigm' (Williamson 2012b, p. 31) or a 'third paradigm' (Williamson 2012b, p. 37), since it looks at research from a different perspective. Such differences include the closeness between the researcher and the participants, and the involvement of the participants in order to apply change (Holter and Schwartz-Barcott 1993; Williamson 2012b). Bradbury (2010) maintains that although action research is quite similar to qualitative research in its tendency to use qualitative techniques, qualitative research can be described as research *about* practice, whilst action research is research *with* practitioners.

Moreover, in quantitative and in most qualitative research, the researcher is an 'outsider' to the research context (Williamson 2012b). On the other hand, in action research, the researchers tend to be insiders, who attempt to create positive change for themselves as well as for the participants who share the same social concerns (Williamson 2012b). Although in some qualitative research, such as insider autoethnography, the researcher is an insider, any changes that are expected are mostly related to construction of the self on the part of the researcher (Maydell 2010). This is opposed to action research, where changes are expected to occur to both the researcher and the participants of the study. The issues of change related to action research will also be further explored below.

There has been an increase in the application of action research in health care. This may be attributed to the fact that action research is driven by the final aim of enhancing patient care

(Koshy et al. 2011). This goal is consistent with that of health clinicians who, similar to action researchers, collaborate to improve patient care (Bellman 2012a). The latter is achieved by integrating education, research and clinical practice (Williamson et al. 2012). It is particularly relevant for practitioners, who work directly with patients, to effect change (Williamson et al. 2012).

Being such a practical and collaborative approach, action research can be very useful to health professionals. It can be used to apply evidence-based changes to practice or to implement new government initiatives or else to further develop a service (Koshy et al. 2011).

"Action research is not easily defined. It is a style of research rather than a specific method" (Meyer 2000, p. 178). Different authors define action research in different ways and there is no universally accepted definition (Koshy et al. 2011). "Action research is the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding." (Winter and Munn-Giddings 2001, p. 8). It is:

> …an approach employed by practitioners for improving practice as part of the process of change. The research is context-bound and participative. It is a continuous learning process in which the researcher learns and also shares the newly generated knowledge with those who may benefit from it. (Koshy et al. 2011, p. 9).

This definition reflects the ideas and process underpinning my research study. The main features of action research and their link to this study will be further explored below.

4.3.1 Action Research - Linked to Practice

Action research tries to bridge the gap between theory, research and practice (Holter and Schwartz-Barcott 1993). To that end, it values the knowledge that one gathers from experience, stressing the need to develop one's understanding (Winter and Munn-Giddings 2001). Rather than being a separate, technical and specialised undertaking, action research is intimately linked to practice (Winter and Munn-Giddings 2001) and is conducted in the participants' own context and situation (Koshy et al. 2011). Action research does not have to be considered an interruption of work but a way to enhance the development of the work that is already being performed (Winter and Munn-Giddings 2001). This was the case with this research study, as the enquiry was conducted at the occupational therapists' place of work, and during working hours (with approval from management). Action research helps clinicians to improve their own practice, which in turn leads to an improvement in their own working environments as well as those of service users (Koshy et al. 2011).

Therefore, action research cannot be regarded as a temporary quick-fix solution to solve issues in practice. On the contrary, it encourages clinicians to question the literature and challenges them to provide a justification for the decisions that they take based on theories, which result from practice itself (Morton-Cooper 2000).

4.3.2 Action Research - Participation

In action research, the practitioners are involved, together with the researcher, in the identification of the problems, in designing any plans of action and in implementing such action (Holter and Schwartz-Barcott 1993) in order to improve their clinical or social world (Williamson 2012b). Such an involvement of both researchers and participants contrasts with other paradigms in which researchers are seen as neutral observers, detached from what is being investigated (Holter and Schwartz-Barcott 1993).

The involvement of people, who are directly related to the situation which is being investigated, is critical in action research (Hart and Bond 1995; Meyer 2000). This is especially the case in health care services (Winter and Munn-Giddings 2001). All those who have an interest in the project should have a say in it (Mac Naughton and Hughes 2008). The former can include both clinicians and service-users (Winter and Munn-Giddings 2001). This concept was applied in this study, whereby all the paediatric occupational therapists who could potentially use child-centred outcome measures were invited to participate in this enquiry. The initial plan of this study was to include service users too; however, the study evolved and the time needed for collaboration with the therapists did not allow room for participation with the clients, given the time constraints to complete this PhD. However, it is the clients who will, it is hoped, ultimately benefit from the outcome of this study.

In order for action research to succeed, the participants should feel the need to change and should accept to have an active role in the research (Meyer 2000). Identifying areas for improvement is considered to be the first step of an action research study, and this typically becomes the topic of the action research project (Mac Naughton and Hughes 2008). In this study, the need for further research on child-centred outcome measure had been expressed by the occupational therapists (participants) themselves, during previous OT professional meetings related to the adoption of the CMOP-E model. The Introduction chapter has shone a light on this model.

The commitment that is expected from participants in action research differs from that of traditional research and would typically require more than the simple answering of a question or the acceptance to be observed (Meyer 2000). That is why people who participate in action research are referred to as participants, as is done in most qualitative research, and not as subjects (Morton-Cooper 2000). Not only does action research help practitioners identify their problems, but it enables them to identify suitable solutions to improve or resolve them (Hart and Bond 1995; Morton-Cooper 2000; Koshy et al. 2011) in their own context (Williamson 2012b), as was the case in this study.

Therefore, since the aim of this research is to uncover what is important for occupational therapists, this further motivates their active participation with a view to resolving the problem (Hart and Bond 1995), making the research itself and the findings more meaningful for these participants (Meyer 2000), and instilling a sense of ownership among those, who are involved in the research (Winter and Munn-Giddings 2001).

As noted above, action research has always been described as research that is conducted *with* people not *on* people (Bellman 2012a; Coleman 2015). Indeed, the action researcher acknowledges the right for people to be involved in changing their current situation and shaping their future (Coleman 2015). Collaborative work is therefore fundamental in action research as it ensures success of the project (Koshy et al. 2011). Since participants are regarded as equals, action research has been described as being democratic (Meyer 2000; Morton-Cooper 2000; Williamson 2012c; Bradbury 2015). The researcher still acts as a facilitator, but the democratic spirit is shown in the collaboration that is inherent in this approach to research.

4.3.3 Action Research - Initiation of Change and Development of New Knowledge

Another distinctive difference is the fact that action research is mostly a process of action as opposed to a process of description (Winter and Munn Giddings 2001). Descriptive research, for example, seeks to describe a situation, which the researcher assumes will remain stable during the observation and writing of the report. Conversely, action research aims not only to further understand a situation, which participants are involved in, but also tries to transform some things. The same action research proceeds to describe the learning that results from such a change (Winter and Munn-Giddings 2001).

Action research is widely recognised as a method used to manage change in health care (Koshy et al. 2011; Williamson 2012a). Such changes vary and can occur at different levels. Change may involve personal changes within the individual or changes within the organisation and the community (Hart and Bond 1995; Brydon-Miller et al. 2003; Williamson 2012a). An organisation may revise its underlying assumptions; clinicians may change their personal values or there can be a change in the running of the organisation. The problem that participants identify and their collaboration throughout the project will determine the type of change that takes place (Holter and Schwartz-Barcott 1993). Throughout the action research process, the researcher and the practitioners simultaneously change as a result of their interaction, and the results obtained are regarded as the outcome of such interaction (Tekin and Kotaman 2013). Following an action research project, the organisation under study is somewhat different that it was before (Morton-Cooper 2000). In this study, the change was mostly related to the learnings that took place, foremost among which was increased awareness of different child–centred outcome measures.

Indeed, apart from improving practice, action research is concerned with the generation of new knowledge, both of which are relevant goals in health care settings (Williamson 2012b). Action research collects and analyses data as is done in traditional research. However, a process of reflection is ongoing throughout the study. The findings are then shared with practitioners, and any actions are refined based on these findings and reflections (Koshy et al. 2011). The research skills that are used to collect the data are utilised to offer a positive contribution to the setting where action research is conducted (Bradbury 2015).

Any change in practice in action research can only occur after the participants find new ways to think about it. This change in thinking is common in action research. The research encourages participants to think differently. Action research typically results in a change in knowledge by making the participants question their knowledge and their current practice (Mac Naughton and Hughes 2008). The change in understanding is a prerequisite for any subsequent change in practice (Winter and Munn-Giddings 2001). Therefore, action research produces change and creates new knowledge (Williamson 2012c).

During action research, participants tend to discover issues that they were not aware of (Morton-Cooper 2000; Williamson 2012a). The newly generated knowledge can be either theoretical or conceptual (Williamson 2012a). The development of theory is indeed a final goal of action research (Holter and Schwartz-Barcott 1993). It is worth noting that the emphasis of action research process is not on producing new knowledge for knowledge's sake but to lead to some form of improvement, be it an overall improvement in the organisation or a solution to a practical issue identified by participants (Gaventa and Cornwall 2015). In this study, the knowledge was related to suitable child-centred outcome measures for the service under scrutiny, as well as to the factors that facilitate and/or inhibit their use in practice.

Therefore, knowledge and action are a means to an end, namely that of generating change and creating knowledge (Gaventa and Cornwall 2015). The action research process is an iterative one featuring researchers and practitioners collaborating in a flow of activities. One cannot change a situation unless one tries to understand it better, and once this happens change is more likely to be initiated (Williamson 2012c). Knowledge is created through action, and by reflecting on this knowledge further action is generated (Gaventa and Cornwall 2015).

Given that action research involves research-in-action, there cannot be a separation between theory and action. The challenge for the action researcher is, therefore, to ensure that the change happens, while reflecting on it as it occurs, so as to further develop theory inductively, thus adding to the body of knowledge (Coghlan and Brannick 2014). Given that in action research the participants are co-researchers, they contribute to improve their practical situation and to develop further knowledge related to their practice (Gaventa and Cornwall 2015). Such learning opportunities lead to the professional development of all co-researchers (Koshy et al. 2011).

4.3.4 Action research - Blurring of Participant and Researcher

Contrary to traditional research, the action researcher is involved in the research, alongside participants (Williamson 2012c). This closeness between the researcher and the participants has been critiqued as promoting bias and as being subjective. However, researchers' involvement and their collaboration with participants is what makes action research unique (Williamson 2012b) and radically differs from the idea of a detached researcher acting as an outsider observer aloof from the people being investigated (Holter and Schwartz-Barcott 1993). This "proximity and shared understanding with participants is a goal" (Williamson 2012c, p. 21).

Action research was developed as a challenge to traditional research, which stresses the separation between the researcher and the participants. Action research enables the researcher to be in close contact with the situation under scrutiny. Indeed, such direct access is of paramount importance in practical disciplines (Holter and Schwartz-Barcott 1993), such as OT.

Questions have been raised about the generalisability of action research projects (Koshy et al. 2011). However, the key upside of action research is not generalisability, but the fact that any changes that take place are directly relevant to the practice context. In action research, it is the resolution of the problem identified in the original context that is a priority; generalisation of the findings is not the main aim (Morrison and Lilford 2001) Generalisability will be further discussed in the following chapter - Methods.

To summarise, action research has a number of characteristics which distinguish it from other types of research. It was considered to be suitable for this study, since it is based on the collaboration between the researcher and the participants; it aims to resolve practical problems, leading to a change in practice and the development of new knowledge (Holter and Schwartz-Barcott 1993). The results are always relevant to the specific environment where the research is conducted (Mac Naughton and Hughes 2008). The latter would ensure that the outcomes would be relevant for the local paediatric OT service.

Achieving clinical governance in health care is a constant challenge (Veenstra et al. 2017). Action research can be an effective means for clinicians to evaluate and reflect on their practice, with a view to improving it. Therefore, action research serves to enhance the quality of the health services that are provided (Koshy et al. 2011) and which considers all the relevant stakeholders (Morton-Cooper 2000). Managers can also use the action research approach to develop new services (Williamson et al. 2012).

4.3.5 Types of Action Research

Action research is not a single research methodology. It comes in a variety of forms in practice, with the latter having a common approach to research (Brydon-Miller et al. 2003; Cassell and Johnson 2006). An over-use of the term “action research”, to refer to methods of research conduction, occasionally without uncovering the basic principles underlying action research, has been reported. Consequently some confusion persists about the true nature of action research (Reason and Bradbury 2001; Barton et al. 2009).

Action research “is in many ways the precursor of all the action enquiry strategies and participatory human enquiry strategies” (Bray et al. 2000, p. 31). The various research strategies emerged from action research. Different authors subdivide action research in different ways. Bray et al. (2000) divide action research into six approaches: collaborative enquiry, appreciative enquiry, participatory action research, action science, action enquiry and action learning. Conversely, Reason (1994) cites three main approaches, namely cooperative enquiry, participatory action research and action enquiry. A brief description of these types of action research can be found in Table 2. After a comprehensive examination of each of these approaches, the participatory action research approach was selected for this study. This approach will, therefore, be discussed in detail. Such justification for the choice of methodology will also be dealt with in detail below.

Holter and Schwartz-Barcott (1993) divide action research into distinct approaches. They divide action research into three approaches: the technical collaborative approach, the mutual collaborative approach and the enhancement approach. These are further described in Table 3 below.

Table 2. Types of action research

Type of action research	Description
Collaborative Enquiry	The main aim of this research is the production of knowledge. Through their lived experiences, participants create a new meaning about the world (Bray et al. 2000).
Appreciative Enquiry	The focus of the research is not only problem-driven but tries to create a new organisational and social context (Coghlan and Brannick 2014).
Action science	The aim is to understand and act on what is responsible for individuals to create outcomes that they do not want to intentionally create (Bray et al. 2000).
Action enquiry	This research is based on reflection in action, that is, being aware of how one's thoughts and feelings affect one's behaviour (Bray et al. 2000).
Action learning	In this research, each member tries to resolve problems that they bring to the group. Members of the group help one another by asking questions and they learn from their own actions. The group may also discuss and reflect on a common problem (Bray et al. 2000).
Cooperative Enquiry	This research involves two or more people, who reach an issue through their experience. They go through cycles of experience and reflection acting as co-subjects in the experience phases and co-researchers in the reflection phases (Heron 1996).
Participatory Action Research	The aim of this research is to achieve change at individual and societal level (Bray et al. 2000). This is the type of action research that was employed in this study.

Table 3. Different approaches to action research (Holter and Schwartz-Barcott 1993)

Action Research Approach	**Description**
Technical collaborative approach	The researcher identifies the problem and the intervention that will be applied. The theoretical framework is also pre-set by the researcher. Participants only assist with the facilitation and the application of this intervention. Following such a research approach, there is a sudden change in practice. However, the effect is short-term as old practices re-emerge once the enthusiasm of clinicians fades (Holter and Schwartz-Barcott 1993).
The mutual collaborative approach	The researcher identifies the problem and potential solutions with the participants. The changes last more than in the previous approach. However, such changes depend on participants, who were directly included in the research. Therefore, they only last while the same persons are there, and start to fade when these same individuals leave or new staff members join the organisation (Holter and Schwartz-Barcott 1993).
The enhancement approach	This differs from the previous two approaches. The researcher encourages participants to reflect on their practice, assisting them in questioning their values, assumptions and the tacit beliefs underlying their practice. The researchers facilitates the reflection on both a personal and an organisational level, and any incongruences are identified. The changes that emerge from this approach tend to be more long-lasting as a new culture of practice emerges and the changes are both personal as well as cultural (Holter and Schwartz-Barcott 1993). This is the approach that was used for this research study.

4.4 Participatory Action Research

After a thorough evaluation of the different action research types, a participatory action research methodology was found to be the best fit with my study. This is because participatory action research aims to achieve change (Williamson 2012c), both at the individual and societal levels (Bray et al. 2000). In this study, change occurred at the individual and organisational levels. Participatory action research has an important role to play and is increasingly being used in health care (Baum et al. 2006; Williamson 2012c). It also seeks to change practice and to understand the organisation members' needs (Baum et al. 2006; Williamson 2012c).

Other forms of action research did not fit with my study. For example, Reason's (1988) co-operative enquiry method and Bray et al.'s (2020) collaborative enquiry entail close collaboration between the researcher and participants in all the stages of research, including reflecting on the experience and making sense of it. This does not reflect my study, since the participants could not be fully involved in every stage of the research, such as the final detailed data analysis. In this study, the participants were given the opportunity to discuss the preliminary analysis that occurred after each action group. However, they were not included in the final data analysis.

Although participatory action research has been used and valued in OT (Cockburn and Trentham 2002; Letts 2003; Suarez-Balcazar et al. 2005; Wimpenny 2013; Bennett et al. 2016; Crabtree et al. 2016; Schwartz 2019), there is limited research about its use within paediatrics (Galheigo et al. 2019; Mc Quiddy et al 2019). Moreover, no research could be found about child-centred outcome measures. Besides, no local participatory action research studies have been conducted in OT.

Participatory action research was also chosen because it was compatible with the participatory nature of this research project and chimed with my intention to empower the occupational therapists to identify the factors influencing the use of child-centred outcome measures in practice. Being the researcher, I acted as a facilitator of change, while working in partnership with therapists, thus matching the participatory action research approach.

My final aim was to have any recommendations from this study being applied in practice. The direct involvement and collaboration of the organisation members, in this case the occupational therapists, would help to ensure that they would be more committed towards any appropriate change and that it would also make it more likely for them to inform and accept the change. Moreover, such participation would increase the chance that any change resulting from this research would be implemented (Glasson et al. 2008).

Additionally, besides being deemed a suitable approach due to its focus on problem solving (Bray et al. 2000) participatory action research was chosen for its ability to assist with the development of population-centred health services (Loewenson et al. 2014). In my case, the final aim was to enhance child-centred OT practice, through the use of child-centred outcome measures. Participatory action research also challenges inequalities by involving individuals who act to improve their situation (Baum et al. 2006). In my study I tried to apply this, firstly by involving therapists and then indirectly by aiming to improve the paediatric OT service in such a way that children would eventually be involved in the assessment or measuring of outcomes, through the use of child-centred outcome measures. Unfortunately, service users could not be directly involved in this study, due to time limitations, although the original research plan included children and their parents. The evolution of this participatory action research is further described in Appendix A.

Most of the concepts of participatory action research resemble those of action research. In participatory action research there is full collaboration between the researcher and the members of the organisation (Greenwood et al. 1993), as the latter are actively involved in studying and transforming their own organisation (Greenwood et al. 1993; Baum et al. 2006).

Change is inherent in participatory action research. Participatory action researchers try to improve the organisation as well as participants' lives (Williamson 2012c). Through participatory action research, participants question their old ways of working and create new ways of practising (Koch and Kralik, 2006). Although change is essential, generation of new knowledge is also regarded as important (Williamson 2012c). The latter was the case with this study. Both the researcher and participants go through a process of self-reflection to better understand and improve their situation. The action is elicited from reflection, and both of these are influenced by the local context in which the research is taking place (Baum et al. 2006). The participants analyse the collected data and then decide on the action to pursue. This is followed by further research of the resulting action, leading to an iterative cycle of reflection and action. This cyclical process was followed in my study and will be further discussed below.

Another crucial feature that results from this type of research is, therefore, the constant growth and learning (Greenwood et al. 1993; Koch and Kralik 2006). Learning occurs for the members of the organisation as well as for the researcher (Greenwood et al. 1993: Koch and Kralik 2006). Both the researcher and participants build on their knowledge by identifying common problems and trying to solve them (Swantz 2015).

Participatory action researchers acknowledge that participants are intelligent and are knowledgeable (Greenwood et al. 1993; Loewenson et al. 2014). Practical experience is also recognised as being highly valuable (Reason 1994; Loewenson et al. 2014). Participatory action researchers believe that the inclusion of the organisation members and the knowledge that they contribute will help to develop participants and researchers (Greenwood et al. 1993). Such growth, learning and development of occupational therapists, including the researcher, was considered to be an essential feature of this study.

Participatory action research stresses the emancipatory aspect that is fundamental to action research (Williamson 2012c). Empowerment is a vital concept in participatory action research (Reason 1994; Baum et al. 1996). Participatory action research gives particular consideration to power relationships, whereby the power is consciously shared between participants and the researcher, thus empowering the organisation members (Baum et al. 2006). Therefore, when clinicians engage in participatory action research, they are enabled to control their own practice (Glasson et al. 2008). There is a blurring of the roles and the participants eventually become co-researchers and partners in the research process.

Participants can be involved in the selection of the topic, in the collection and analysis of the data and in determining the actions that need to be taken based on the findings (Baum et al. 2006). Therefore, participants, be they clinicians or clients, gain power over the practices of their organisation and the knowledge that is produced (Baum et al. 2006). Such knowledge is produced democratically (Greenwood et al. 1993). Since the participants are actively involved in the research process (Baum et al. 2006), they contribute in ensuring the quality of the findings, and enhancing the trustworthiness of the information.

The broad topic of this enquiry was selected by participants, as aforementioned. As a researcher doing my PhD, I initially came out with the title and aims of the study. However, there were a number of changes made, following collaboration and consultation with the participants. Participants' feedback induced a change in the title and aims of the study. The participants were also involved in the data collection and in preliminary analysis. Such an involvement will be further described in the Methods chapter (Chapter 5).

4.4.1 Participation as an Emergent Process

One can rarely achieve a complete participatory action research since most research situations do not permit it (Greenwood et al. 1993). Unlike other more static approaches, in participatory action research the data and information are closely associated with the context (Baum et al. 2006). Moreover, a participatory action research project depends on the participants' involvement, and not all participants may be willing to exert the same level of commitment (Meyer 2000; Bellman et al. 2012). Organisation members' willingness to be involved in the research fluctuates, meaning that the participatory level that can be achieved cannot be predicted (Baum et al. 2006).

> No one may mandate in advance that a particular research process will become a fully developed participatory action research project. Participation is a process that must be generated. It begins with participatory intent and continues by building participatory processes into the activity within the limits set by the participants and the conditions. To view participation as something that can be imposed is both naïve and morally suspect. (Greenwood et al. 1993, p. 76).

Participatory action research is a process that emerges over time. It is not typically fully present at the very initial stages of the research. Therefore, participatory action research can be placed on a continuum, ranging from “expert research” to participatory action research (Greenwood et al. 1993). On one end of the continuum, the researcher has full control over the research, whereas on the other end, there is full collaboration between the researcher and the members of the organisation under scrutiny (Greenwood et al. 1993). My study evolved and became more participatory as it went along. Initially, it was my PhD, and as a researcher participants may have seen me as the expert. However, this changed throughout the study, as participants became more involved and started to share ownership of the research.

Participation is, therefore, a component of research that can always be improved. A researcher, who is interested in participatory action research, needs to engage in a continual evaluation of the level of participation being achieved in that specific context. Even in cases where full participation cannot be achieved, the researcher can always work towards improving the participation level. The responsibility to develop the participatory dimension is ongoing (Greenwood et al. 1993). This was the case with my study.

4.5 Conclusion

This chapter has discussed action research as a research methodology. In summary, action research has some specific characteristics aiming to change and improve the situation under investigation; improve social or organisational practice; and create new knowledge. Importantly, the changes and improvement are specific to the context under scrutiny (Mac Naughton and Hughes 2008).

Participatory action research was chosen as the specific action research methodology for this research study. Participatory action research enables clinicians to bring innovation to the services that they offer (Glasson et al. 2008). It can also contribute to development of practices and health policy (Loewenson et al. 2014). This chapter has explored how participatory action research aligns with this research study. The empowerment that is inherent in participatory action research, together with the participatory nature of this approach (Glasson et al. 2008), made this a particularly suitable methodology to explore the factors that affect the use of child-centred outcome measures in Maltese OT practice.

Chapter 5: Methods: Conducting the Research

This chapter explains in detail the practical application of participatory action research in this enquiry and the procedures used to collect the data. It also explores the opportunities, challenges and dilemmas that were encountered during the research process as well as information on how the data were analysed.

This chapter may falsely give the impression that the research design was a linear, predefined one, with decisions and steps being determined *a priori*. This was not the case, as such an approach would contradict the nature of participatory action research. Although the broad focus was planned at the beginning, research questions and objectives have emerged and evolved throughout the study (see Appendix A), based on the study's data collection and data analysis as well as the literature.

5.1 Overview of the Research Study

5.1.1 Study Setting and Research Participants

Having the 'right type' of participants in research groups is essential (Morgan 1998b). When planning to carry out research groups, participants should be chosen from a population which is relevant to the research question (Krueger and Casey 2015; Stewart and Shamdasani 2015). The idea was that such participants - in my case paediatric occupational therapists working in Malta - would be sufficiently knowledgeable about the paediatric OT practice in Malta to be able to provide appropriate information that would help answer the research question.

Therefore, purposive sampling was used to select the participants for this study. I chose the paediatric OT department from all the OT departments and services that are offered in the public health sector in Malta, since the large majority of paediatric occupational therapists worked there. Purposive sampling is commonly used in qualitative research (Wu Suen et al.

2014; Palinkas et al. 2015), whereby the researcher carefully selects a particular group of people based on the aims of the project (Morgan 1998b; Wu Suen et al. 2014) and on their specific characteristics or experience to answer the research questions (Braun and Clarke 2013) relevant to the study. I used purposive sampling "with the expectation that each participant will provide unique and rich information of value to the study" (Wu Suen et al. 2014, p. 111). This setting will be referred to as the OT Department (unless otherwise indicated). The inclusion and exclusion criteria were developed in relation to the literature review, aims of the study and following discussion with my supervisors.

The broad inclusion criteria for the participants were the following:

- Occupational therapists who were working at the paediatric OT Department in Malta at the time of the study;
- Participants had to be able to speak in Maltese or English.

The exclusion criteria were the following:

- Occupational therapists who were not familiar with the Maltese or English language
- Paediatric occupational therapists working in the private sector
- Occupational therapists whose caseloads included some paediatric cases, but who did not work in the paediatric OT Department

5.1.2 Research Participants – the Group

Approval to carry out this research was obtained from Cardiff University's Research Governance and Ethics Committee in December 2016 and from the University of Malta's Research Ethics Committee in February 2017. Permission to conduct the study and to access participants was also obtained from the Professional Lead for OT Services in Malta and the management of the OT departments. Copies of these approvals and samples of permission letters can be found in Appendix B, C and D.

In the initial stage of this action research, referred to by Bellman (2012a) as the preparatory and assessment stage, I liaised with the management of the OT service in Malta as well as the management of the OT department, emphasising this research's alignment with the national OT vision, in order to gain their support. Having the support from relevant managers is key to the success of an action research project (Winter and Munn-Giddings 2001).

All the paediatric occupational therapists in Malta, who worked in the public health sector, met the inclusion criteria. This included 15 occupational therapists who worked at the paediatric OT department in Malta and another two occupational therapists who worked in Gozo. As the lead researcher, I was also a paediatric occupational therapist working in Gozo. Being the initiating researcher and a co-worker, I distributed a letter of invitation (Appendix E) to each occupational therapist, together with a participant information sheet (Appendix F) and a consent form (Appendix G), in October 2017. If interested in participating, the therapists were asked to return the signed consent form to me, either by post (in a self-addressed envelope provided to them) or by emailing me a scanned copy of it. They could ask questions before deciding whether to accept or not. All the paediatric occupational therapists who were invited accepted to participate. I exercised care to ensure that none of the therapists felt obliged to join the study if they did not wish to. Further details about this can be found in the Ethics and Governance section below.

It was agreed that any new occupational therapists who would join this paediatric OT team throughout the study would be invited to participate. A newly appointed paediatric OT manager was invited and she joined the study during one of the action groups. Morton-Cooper (2000) encourages researchers to allow such occasional participation, since these "onlookers" may be able to spot any shortcomings in the project and they may provide a new viewpoint (Morton-Cooper 2000, p. 62). Two other occupational therapists, who were also new members of the team, were invited and they joined the study from action research group 4 and group 5 respectively, in September and October 2018. Hence, a total of 20 OTs (n=20), in addition to the researcher, participated in this study.

Since participatory action research involves a collaboration between the researcher and the study participants (Greenwood et al. 1993), the participants act more like co-researchers than subjects of research (Winter and Munn-Giddings 2001; Mac Naughton and Hughes

2008). Therefore, the participating occupational therapists performed the role of co-researchers (Reep 2018). Being a participatory action research, all the participants were on an equal footing. Such equality of participation could still permit different participants to have different assignments to complete (Mac Naughton and Hughes 2008), for example, it was only me who acted as a facilitator.

This research involved eight action research groups with the participants. Further details about these action research groups, together with the justification for the use of such groups is provided below. A timeline of the various stages of data collection can be found in Appendix H.

5.1.3 Justification of Methods

The consensus among action researchers is that this style of research is not dependent on a special data gathering method (Holter and Schwartz-Barcott 1993). In fact, action research can include a range of data collection methods (Baum et al. 2006; Coghlan and Brannick 2014). Action research differs however, in that there is shared participation by the researcher and the participants (Morton-Cooper 2000).

Chiu (2003, p. 166) states that:

> Although action research invariably permits the use of a wide range of methods to bring about desirable changes, group processes are central because of their potential in engaging participants in research activities.

In action research, the choice of methods is strongly influenced by the cultural norms and the context in which the research is conducted. Additionally, the participants' usual ways of practising need to be considered (Morton-Cooper 2000). In my case, the occupational therapists were used to discussing professional issues and future ways of working together as a group. Therefore, I felt that action groups would be ideally suited as data collection methods. "By taking advantage of existing arrangements you are more likely to encourage active participation." (Morton-Cooper 2000, p. 70). This was the case in this study.

Different authors use different words to describe research groups used in action research. Koshy et al. (2011) refer to such group meetings as action research groups; Reagon and Boniface (2013) and Boniface et al. (2015) refer to them as action research groups or action research meetings. A similar terminology to that of Reagon and Boniface (2013) and Boniface et al. (2015) was used in this research. In this study, data were collected mainly through a number of action research meetings or research cycles, which were characterised by ongoing discussions and reflections (Koshy et al. 2011). The participants were included in the data collection and preliminary data analysis.

Action research groups are powered by an action research cycle which combines enquiry, intervention and evaluation (Hart and Bond 1995). This is similar to the OT process (AOTA 2020) that the occupational therapists are used to, namely assessing a client, conducting the intervention and evaluating any progress. Such a similarity further justified the use of action research groups.

Group discussions can promote the development of clinical services (Krueger and Casey 2015) as was the case in this study. They tap into a wide range and forms of understanding (Kitzinger 1994), gathering participants' opinions and perceptions about the particular issue or service (Krueger and Casey 2015) and increasing understanding of their beliefs and experiences (Morgan 1998a). Group discussions can also be a quick and time-saving way to gather the viewpoints of the participants (Koshy et al. 2011). Of particular importance is that such an understanding would be obtained from the same staff, who would be implementing the programme or service (Krueger and Casey 2015).

A group discussion enables the researcher to discuss a variety of topics, including those which the research team has limited knowledge about. There is communication among the group members as well as between the researcher and participants, giving participants a sense of being listened to (Morgan 1998a). If managed appropriately, a group conveys a sense of friendliness (Morgan 1998a). Hence, participants tend to feel less threatened in a group (Koshy et al. 2011) and they may be more willing to express any conflicting views or discuss controversial subjects (Kitzinger 1994; Koshy et al. 2011). The communication and interaction between group members form the foundation for the exploration and development of the research topic (Parker 2012).

The researcher, on the other hand, can acquire invaluable insights into the group or social process (Kitzinger 1994) and about the language that the participants use to talk about the research subject (Krueger and Casey 2015). The organisation members can also provide their perspectives on researchers' goals and they can provide feedback and suggestions about how to reach the study's aims (Morgan 1998a). Groups also create the right environment for participants to identify and discuss barriers and facilitators to practice (Krueger and Casey 2015). Therefore, action research groups seemed to be a perfect fit for my research.

However, this selected data collection method has its downsides. Group discussions depend on the researcher/facilitator's skills for their success. There may also be power issues which undermine the contribution of some group members. Some members may also be too unassertive to challenge the views of the majority (Koshy et al. 2011) where appropriate. Consequently, group sessions may be dominated by particularly vocal participants. The strategies that I have adopted to overcome these possible limitations are discussed below. Following a thorough analysis of all of the above-mentioned issues, action research groups were confirmed as the methods that best fit the aims of this action research.

5.2 Ethics and Governance

In action research, the researchers are already ethically responsible for their colleagues or as a service provider towards the service-user (Winter and Munn-Giddings 2001). The code of ethics that I am bound by as an occupational therapist is embodied in the ethical research course of action (Bellman 2012b). Action research is therefore an amplification of these same ethical relations, such as respecting rights, ensuring well-being, preventing harm and respecting confidentiality (Winter and Munn-Giddings 2001), assuring informed consent, integrity, and providing participants with the right to withdraw from the study. Apart from these principles, there are two other ethical considerations which are specific to action research: the provision of power and ownership of the research to the participants (Bellman

2012b). Some of these ethical issues, in addition to others such as the management of pre-existing and ongoing relationships and issues related to insider researchers will be discussed further throughout this chapter. This section will describe specific issues related to ethics and governance.

Action research may be relatively lengthy due to its cyclical nature; it may take more time and resources than other research methods (Williamson 2012b). Another particular issue was that in action research one would expect change since the action is constantly informed by the data collected and their analysis (Koshy et al. 2011). Therefore, I was alert to any new ethical issues that might arise throughout the research process so that I could promptly deal with them.

Throughout this study I was aware that some boundaries may be blurred as a result of my multiple role as a lead researcher, colleague and a clinician. When action researchers have a prolonged relationship the with participants, as was the case with my study, the participants might feel obliged to help the researcher 'succeed' (Trondsen and Sandaunet 2009). I could feel this at some particular points throughout my study and I took pains to obviate this potential bias from undermining the trustworthiness of this action research.

Since I was conducting this research in my own organisations there were additional ethical issues that I had to manage. I had the responsibility to offer a quality service as an occupational therapist whilst simultaneously performing my researcher role and contributing to generate knowledge (Coghlan and Brannick 2014). I was also aware that my research could add to my participants' workloads and that this could undermine the quality of the delivery of OT services (Morton-Cooper 2000). Therefore, I minimised the time that the participants would need to allocate outside the action research groups.

Given that all of the team participated in this study, I took account of the differences in opinions between colleagues and I was also aware of the hierarchical structure within the OT department, with participants having managerial and/or supervisory responsibility for some others.

5.2.1 Informed Consent

The participant information sheet consisted of jargon-free information about the purpose and nature of the research. This included their potential role in the study, its possible duration and any possible benefits or disadvantages. Permission for audio recording of meetings was obtained from the participants. Moreover, I provided my contact details and the participants were encouraged to broach any concerns regarding the study with me at any time.

An ethical action researcher should empower participants to believe that they can instigate change; however, participants should be allowed to decide whether they want to create such change (Mac Naughton and Hughes 2008). All participants were therefore informed that participation in this study was voluntary and that if they accepted to take part, they could withdraw from the study at any time, without fear or prejudice and without giving any reason. They were informed that if they decided to withdraw, they could ask for any unanalysed information they would have offered to be destroyed. I ensured that the participants were not pressurised by myself or by the management to participate in this study. Participants were assured that the decision not to take part, or to withdraw their participation including data collected, would not affect their situation or employment, or any other service that they received from the OT Department. Morrow (2009) recommends that participants should have at least 24 hours to decide whether they would like to participate. In this case, occupational therapists were given around 3 weeks to consider their willingness to participate in this project.

Since the method evolved throughout the research process, hence when obtaining informed consent, research participants could not be told everything that might happen or what was to be expected of them at the start. In the initial stages I only had a vague idea of what participation in this study entailed; however, I highlighted the need to be committed to such an undertaking. The participants were also informed that they could participate in a flexible way. Although commitment to the study was be expected, the participants were not bound to attend each meeting.

Since all of the occupational therapists were recruited in this study and the enquiry discussed issues related to OT practice, the action research meetings and the OT practice were not always clearly separated. However, the decision of participants to opt out would have been respected. The participants may have encountered difficulties to decline the offer to participate as they may have been concerned about their colleagues' reactions and their feelings of exclusion from professional discussions and learning. I carefully monitored any concerns about engagement in this enquiry and ensured that the action research meetings were clearly demarcated as separate from their work meetings. All the information collected was used solely for this research study.

5.2.2 Confidentiality

Confidentiality and anonymity should be given special attention in participatory action research studies. The issue of confidentiality was discussed at the start of the group meetings and the participants were asked not to disclose information about their colleagues outside of the groups.

The fact that the participants knew each other had a direct effect on confidentiality. Any details that co-researchers reveal in such research groups can have long-lasting consequences, even after the research is terminated (Morgan 1998b). Therefore, privacy was a main concern due to the participants' ongoing relationships. The participants were sharing the information not only with the researcher but also with their colleagues (Morgan 1998a). The concern is related to self-disclosure, that is, "the amount that people reveal about themselves in the course of a conversation" (Morgan 1998a, p. 90). Participants risk revealing more than they would have liked to. Therefore, I was alert for any potential over-disclosure, since the latter would pose a serious threat to privacy. In the case of over-disclosure by one of the participants, other participants may consider it "safe" to include their own disclosures (Morgan 1998a). I was vigilant to avoid any invasion of privacy and minimised any other stressful situations for the participants by discussing this in advance. Planning in advance also enabled me to recognise such potentially stressful situations and prevent co-researchers from saying something that they cannot take back (Morgan 1998a).

Action researchers who conduct small-scale studies, as was the case with my research, need to be cautious about the possibility for people and events to be recognised (Koshy et al. 2011). Malta's small size increases the risk that the setting will be identified. Moreover, given that this is an insider research, there is the risk that once the author of the study is known, the setting would be easily discovered (Toy-Cronin 2018). Therefore, I decided that I would not try to conceal the site of my study, as attempts to do so were likely to be unsuccessful. I concentrated on protecting the identity of my co-researchers instead. A number of measures were taken to ensure this.

In cases such as this study, one cannot achieve anonymity since the participants can be easily traceable through the research setting and the researcher (author). Banegas and Villacañas de Castro (2015) even argue that anonymity may be a delusion in an action research study, due to the context-specific nature of this research. I explained that participants will not be anonymous; however, all the data that was collected during the action research groups could not be traced to any particular therapist. Pseudonyms replaced the co-researchers' names in the transcripts. The names and identities of participants were unrecognisable. I kept the details about the co-researcher's identities separate from the data which I collected from them. Moreover, since the majority of participants were females, I changed the gender of the male pseudonyms, referring to all the participants as females, so the two male participants could not be identified.

All the data collected were stored and treated with confidentiality (Koshy et al. 2011). All the recorded data were stored on my personal computer, and its access was restricted by a password known only to me. All data were stored in a locked filing cabinet, which was only accessible to me. Raw data (i.e. the transcripts and recordings of meetings) will be stored for five years following completion of the study and will then be destroyed.

5.2.3 Mitigating Risks

There were no discernible physical risks for myself as a researcher or for the participants. This research study took place at the OT Department, the therapists' workplace. Any potential risks involved were therefore everyday risks. The greater risk to the participants was that of self-disclosure.

It was not anticipated that the participants would experience any potential distress or discomfort in any session but given the nature of the study, I aimed to avoid raising any overly sensitive issues and aimed to create a respectful and encouraging atmosphere. The group meetings were carefully conducted so that any tensions or anxieties would be harmoniously resolved, and I accepted responsibility to provide whatever support I could, should this become necessary. Acceptable behaviours were also discussed as part of the negotiated ground rules. These ground rules will be further discussed below.

Although not expected, if participation in this study became distressing, the participants could contact the Employee Support Programme (ESP) services, which provide free psychological or emotional support to public employees at no financial cost on the participant's part. I was also prepared to use distress facilitation (Bray et al. 2000), should the need arise. Any clashes of ideas were promptly addressed and resolved, to prevent the problem from festering and souring interpersonal relationships (Bray et al. 2000).

There was no direct benefit to the participants, who took part in this study and the participants were not remunerated. However, following their participation in this study, the participants were more knowledgeable about action research. Hopefully through their involvement in this study they have gained or built upon their skills as co-researchers. Participants stood to gain in terms of personal development and empowerment through their engagement in a potential change (Solomon 2018). The participants were informed that participation in this study would contribute to the development of the OT service in Malta and Gozo, and potentially wider.

5.2.4 Insider and Outsider Considerations for the Researcher

All the participants "not only … [knew] each other, but they … [were] often familiar with the values, habits, and interests of their colleagues" (Krueger and Casey 2015, p. 223).

In this study I was mostly an insider. An insider refers to a researcher who is conducting action research in the same organisation in which one works or is a member of (Braun and Clarke 2013; Coghlan and Brannick 2014; Fleming 2018). On one hand, I was an insider because I was a paediatric occupational therapist working in the public health care system, similar to the other participants, and I also knew all the participants on a professional basis. Moreover, I was a colleague for the two participants who worked in Gozo and an ex-colleague for the senior participants from Malta. On the other hand, I could also be considered as an outsider for the majority of the participants because I was not part of the OT team in Malta.

Since I shared membership with my participants there was a degree of proximity and shared understanding, which is an important goal of action research (Williamson 2012c). Being an insider is considered to be an advantage for a number of reasons. Firstly, an insider researcher is familiar with the setting and is therefore in a better position to develop the connection required to conducting the study (e.g., gaining permissions, recruiting participants, etc.,) (Tekin and Kotaman 2013). As an insider researcher I was investigating my own work practices that I was familiar with (Kemmis et al., 2014). The *a priori* knowledge that I had as an insider researcher enabled me to develop my research questions based on the issues that needed to be investigated, ensuring that the findings would be significant for my organisation (Fleming 2018).

Another advantage of being a facilitator for my own organisation was my familiarity with the system and with its culture (Coghlan and Brannick 2014), enabling me to get up to speed on relevant issues almost immediately (Morgan 1998d). I could also understand very quickly the context of my research (Fleming 2018). I could observe what was going on in the group without drawing attention to myself (Coghlan and Brannick 2014). Such familiarisation also proved to be valuable for data analysis (Morgan 1998d). Additionally, being familiar with the work pressures and internal sources of conflict I could steer the discussion clear of these and ensure that my action research groups would not become platforms used by the participants to vent their existing frustrations (Morton-Cooper 2000). Moreover, it was less likely for me to misunderstand my participants' responses (Fleming 2018).

Being an insider action researcher I was an instrument for dynamic change, whereby I could lead change from inside my own organisation (Coghlan and Shani 2015). An upside of being an internal staff was that members would use the research findings. Since the participants were involved in this same study, they are more likely to remember and apply the findings in different ways (Morgan 1998d).

Whilst being an insider researcher proved to be beneficial in different ways, there were a number of challenges that I had to deal with. An insider researcher requires a specific set of skills and abilities (Coghlan and Shani 2015). Being close to the data can make the researcher assume that they know the strengths and limitations of the organisation (Bellman 2012a). However, taking for granted the implicit patterns and consistencies that I was expecting to be present in the data (Fleming 2018) could have bred overconfidence and misled me in probing less than I would have done, had I been an outsider. Action researchers are indeed often criticised for subjectivity since they are not independent of the situation being researched (Williamson 2012b).

Being part of the culture makes it more difficult for researchers to evaluate and critique it (Coghlan and Brannick 2014). It was a continuous challenge for me to "get attuned to the assumptions and limits that … [I] often unconsciously embrace[d]" (Morgan 1998d, p. 39). The first step for me, however, was to acknowledge such a potential limitation (Morgan 1998d). This study sought to further develop paediatric OT practice in Malta but I had vested interest as a researcher as it served to complete my PhD. These two aims could have been in conflict, hence the need to be constantly reflexive.

Preunderstanding is "the challenge for insider action researcher … to develop a spirit of inquiry in familiar situations where things are taken for granted (Coghlan and Shani 2015, p. 49). Preunderstanding refers to the knowledge, insight and experience that one has before engaging in an enquiry (Coghlan and Shani 2015). As an insider-researcher I had to get closer to the OT department, whilst simultaneously distancing myself from it to be able to observe critically and allow change to happen (Coghlan and Shani 2015), what Delamont et al. (2010) refer to as making the familiar strange. In order to achieve this in practice, I regularly questioned my own assumptions.

Journaling enabled me to reflect about and acquire insight into my preunderstanding. Recording my experiences, thoughts and feelings as these evolved allowed me to identify any gaps between what I thought I knew and what I actually knew. I meticulously analysed the evidence that I was being presented with as I was researching a familiar setting, avoiding the pitfall of taking my assumptions for granted. Discussing my analysis of the data with my supervisors, both during the preliminary stage as well as during the final data analysis, helped to ensure that I enquired and probed what was familiar to me (Coghlan and Shani 2008).

Since I was conducting this research in my own organisation, a relevant issue that I had to deal with was the conflict of interest in my role as an organisational member (colleague or manager) vis-à-vis that of a researcher (Williamson 2012a). This is referred to as role duality (Coghlan and Shani 2015). My role as an occupational therapist and member of the organisation demanded my active commitment and total involvement, whilst my role as an action researcher required a more detached and reflective position. Managing both roles can be challenging and confusing (Coghlan and Brannick 2014) especially in situations of high workloads (Coghlan and Shani 2015). Such a role conflict occasionally made me experience role detachment (Adler and Adler 1987), when I felt that I did not belong to any of the two roles. I kept a research diary, also known as reflective journal (Koshy et al. 2011) and found this helpful in exploring role duality (Coghlan and Brannick 2014).

5.2.5 Issues of Power

Since I was conducting research in my own organisation, I had to consider a number of power relationships (Coghlan and Brannick 2014). These included the relationships between the therapists, who were heading the service and the other therapists. I also had to manage the relationship between myself (as a researcher and as a head of department) and the two therapists, whom I managed, and the relationship between myself and the therapists as my ex-colleagues or peers, some of whom were even old friends. I found the reflective journal to be a "valuable tool for coping with and exploring political and ethical issues" (Coghlan and Brannick 2014, p. 158) regarding such power relationships.

The occupational therapists, who served as co-researchers in this study ranged from basic graduates to more senior staff. Ideally, a supervisor should not be the facilitator of a research group (Morgan 1998a), since some of the participants may not feel at ease, but in this case there was no alternative. Power-related issues might have inhibited some participants (Krueger and Casey 2015). It was indeed a challenge to effectively manage a group of participants with different levels of formal and informal power during these action research groups. However, the involvement of all levels of staff, including the more senior staff in research increases the likelihood of support for the implementation of the changes decided upon during the project (Hart and Bond 1995).

There were occasional instances where the participants were looking towards me as the facilitator, possibly checking whether they were on the right track (Bray et al. 2000, p. 67). Having been a lecturer, I had previously taught some of my participants. Moreover, I had been a clinical specialist in the past. Given these previous positions and my present role of researcher, I was aware of running the risk of being regarded as an ‘expert’ by my co-researchers and forced into a leadership role. To minimise this risk, I exercised meticulous care to make the whole research process as collaborative as possible (Boniface 2001), occasionally reminding the participants that every opinion would be respected (Boniface et al. 2015).

Participatory action research was deemed the most appropriate methodology for this inquiry to address power issues. Participatory action research is, indeed, regarded as ideally suited to overcome power imbalances (Grant et al 2008). Furthermore, I addressed power issues by being reflexive throughout the whole enquiry and by following the strategies recommended by Grant et al (2008), namely, reflecting on power positions and discussing these with my participants; considering this research as a learning opportunity for all; explaining the research process; and encouraging my co-researchers’ participation.

5.3 Conducting the Research

Action research involves cycles of reflection and action (Winter and Munn-Giddings 2001) in order to create meaningful change (Mac Naughton and Hughes 2008). The action research cycles occur when members of the organisation agree to observe and record their practice, critically reflect on these observations, meet to discuss these reflections and plan on actions to take based on the conclusions reached from such meetings and interactions (Winter and Munn-Giddings 2001). The participants were involved in decisions concerning the focus of the work.

5.3.1 Method of Data Collection

Data were collected mainly through a number of action group meetings or research cycles. I met with the co-researchers on eight different occasions (eight action research groups) over a 14-month period between November 2017 and January 2019. Each action research group lasted between 60 and 90 minutes. Following their acceptance to participate in the study, I sent an email to the participants, and we found a suitable date for all, and thus scheduled the first action research group. Dates for subsequent action group meetings were always planned together with the participants, since such meetings should always be conducted when convenient for the participants (Krueger and Casey 2015). On the majority of cases this was carried out at the end of the previous action research group. Prior to each meeting, I emailed to all the participants a reminder about the date and time of the meeting. At times, action research meetings had to be rescheduled due to annual leaves, sickness or shortage of staff.

As aforementioned, all the action group meetings were held at the OT Department, since most participants worked there. This made it easier for the participants to attend the meetings. Stewart and Shamdasani (2015) suggest that holding groups at the participants' place of work increases the likelihood of participation, while Morgan (1998a) argues that if participants are genuinely interested in the research topic, the place where the groups are held is immaterial. The action group meetings were held during working hours, as preferred by the participants and approved by management.

The meetings were held in a quiet space, a large therapy room, with access to restrooms. I arranged the chairs in a circle, so that each co-researcher, including myself, could make eye contact with all the other members, thus creating an ideal seating for group discourse. Such a seating arrangement also decreases the likelihood of a participant monopolising the group discourse (Stewart and Shamdasani 2015). I provided light refreshments at each action group meeting to create a relaxed and informal atmosphere.

There is no consensus about the optimal size of research groups in action research. Different researchers have recommended a wide gamut of optimal sizes, ranging from 6 to 8 participants in focus groups (Morgan 1998a) and 8 to 12 persons (Stewart and Shamdasani 2015) to as few as 3 and as many as 14 participants, excluding researchers (Gill et al. 2008). Smaller groups inevitably make for a poor or narrow discussion (Stewart and Shamdasani 2015). Conversely, larger groups lend themselves to a wider discussion but pose challenges as the facilitator may struggle to moderate such groups (Krueger and Casey 2015; Stewart and Shamdasani 2015). Moreover, participants might have to compete with more assertive persons to share their experiences (Krueger and Casey 2015).

However, Morgan (1998b) acknowledges that there are times when having a large research group would be the only possible option. This is especially the case when the researcher uses pre-existing groups, as was the case with my research. Chiu (2003) states that in participatory action research, the local conditions will influence the sizes of the groups. The size of my groups ranged from 14 to 17, since not all the participants could attend all meetings. Similarly, other researchers have managed research groups with a relatively large number of participants ranging from a maximum of 25 occupational therapists (Parker 2012) to a minimum of 16 (Boniface 2002; Boniface et al. 2008).

I raised the issue of being a large group with the participants and offered the possibility of dividing the group into two smaller groups. The idea was to have two groups, similar to Wong's (2018) study, "with each group functioning independently of the others, but with a mechanism in place for communicating and sharing the learning among them" (Bray et al.

2000, p. 60). However, the participants opted for one larger group since they were used to discussing issues related to professional practice as one whole group. They agreed that they would consider splitting the group into two should they encounter any difficulties or should the moderation of the group become challenging. However, the group size was manageable, obviating the need to split the group.

The participants were used to carrying out staff meetings and professional meetings as one large group and the self-imposed discipline that they were used to during their regular meetings ensured a well-functioning group discussion for my research. Other factors that helped the group discussion despite the large size to proceed smoothly was the participants' keen interest in the topic and in each other's contributions and their mutual familiarity. Having a larger group was also considered to be advantageous for a number of reasons. Firstly, a large group may create a lively discussion (Morgan 1998b). Secondly, it is always ideal to over-recruit to avoid having to cancel the session in case only a few people turn up (Stewart and Shamdasani 2015).

All the action group meetings were digitally recorded and transcribed verbatim by myself. Being both the interviewer and the transcriber helped me avoid some of the pitfalls of transcribing, mostly transcription errors (Easton et al. 2000). I recorded each session using a Dictaphone and the Smart Recorder application on my tablet as a backup. The duplicate recording was deleted after the completion of data analysis. The audio recording served as a way to capture "the lived experience" of the action research group (Bray et al. 2000, p. 90). Transcription served as a means for me to re-familiarise myself with the data. The recordings were then dated and stored securely.

At the beginning of each meeting each participant said their name and something about themselves, such as their favourite food or colour for recording and voice-identification purposes. Stewart and Shamdasani (2015) recommend that group members share such "nonintimate personal facts" (p. 103) at the introduction of group research meetings as a way to build further rapport in the group.

On their first attendance for an action group meeting, the participants were asked to fill out a short demographic characteristics form (see Appendix I). This is typically done when the researcher refuses to discuss such information within the group (Krueger and Casey 2015). These data are shown in Table 4. The fact that the participants were from different grades and with varied experience ensured that the findings of this project would be culturally valid and valued (Morton-Cooper 2000). Having such breadth and variety of views is also considered to be critical for successful collaboration (Bray et al. 2000).

Table 4. Demographic details of the occupational therapists who participated in this study*

Variable	**Quantity/frequency**
No. of years working as an occupational therapist	Average: 12 years Range: 3 years to 30 years
No. of years working in paediatrics	Average: 8 Range: 3 months to 20 years
Highest qualification	Masters (n=10) Bachelors of Science (n=8) Diploma (n=2)
Grades	1 Senior Allied Health Practitioner (Scale 6**) 4 Allied Health Practitioners (Scale 7**) 5 Senior Allied Health Professionals (Scale 8**) 9 Allied Health Professionals (Scale 9**) 1 Allied Health Professionals (Scale 10**)
Gender	18 Females 2 Males

*The researcher is not included in this table.
** This salary scale system is used in the local public service stream to indicate seniority. The smaller the scale number, the higher the seniority.

The first meeting was conducted in Maltese as it felt more natural to do so. Following transcription, I translated the data of this group from Maltese to English. However, I was concerned because at times it was difficult to translate some concepts and ideas from one language to the other. I also feared the “lost in translation” issue. Finding a balance between valuing meaning and obtaining conceptual equivalence was particularly challenging (Regmi et al. 2010). Therefore, on the second action group meeting I proposed carrying out the discussions in English. The participants agreed to do so. The use of English would ensure that no important information would be lost in translation (Morgan 1998c) and direct quotes could be used more accurately.

English is the other official language for Malta, besides Maltese, and all the participants were bilingual. As the facilitator for these groups, I was fluent in both languages. I explained that the participants could use Maltese if they felt more comfortable to speak in their mother tongue to ensure that their linguistic expression would faithfully reproduce their views (Morgan 1998c). Following transcription of each action research group, I translated any data in Maltese into English. An extract from these transcripts can be found in Appendix J.

We decided that non-research related group communication (i.e., communication in between meetings) between us would be conducted mainly by email. I ensured that all participants were kept up to date with what was being discussed in the groups. The regular contact with the participants, including the contact made through emails between each action group meeting, served to nurture my relationship with them (Morton-Cooper 2000).

Prior to starting the action research groups I performed an initial review of the literature about the relevant topics, including client-centred practice, child-centred practice, outcome measures and child-centred outcome measures. Such a literature review is typically done by the researcher and it serves “an introduction to the study topic for what would be co-researchers.” (Morton-Cooper 2000, p. 37).

I prepared a plan with some guidelines of what I would go through during each action group meeting, before each session, and drafted some points for discussion. The literature review shaped the key discussion questions for the action group meetings. A draft of an interview schedule should ideally be shared for feedback and review (Morgan 1998c), so I shared my questions for each group in advance with my supervisors. These points of discussion were not meant to be followed strictly, as participatory action research excludes any form of imposition. Indeed, I kept adapting my points of discussion on the go, to handle new or unexpected information (Stewart and Shamdasani 2015). With the exception of the first group meeting, discussion in each group was largely informed by what was discussed in the previous group. The action group plan always included an introduction to the current meeting and a summary of the analysis of the previous group (applicable from action group 2 onwards). A sample of these plans and probing questions or points for discussion can be found in Appendix K and L respectively.

During discussions, I let the participants build the discussion based on each other's comments (Stewart and Shamdasani 2015) and I only intervened when further clarifications were required, when I needed to probe for further detail and depth or follow up, or when the debate ended. Some degree of direction and structure was occasionally required to draw out reticent co-researchers (Stewart and Shamdasani 2015). I was determined to learn from my co-researchers. However, I needed to strike a balance between hearing what the participants had to say and getting them to discuss relevant issues (Morgan 1998a).

I concluded each group with a brief summary of the main issues that were discussed during that session. While delivering this summary, I noted the participants' body language, for indications of agreement, hesitation or confusion (Morgan 1998d). The participants were then asked about the adequacy of that summary, using what is typically referred to as the summary question (Morgan 1998c; Krueger and Casey 2015). The aim was to elicit any additional views or experiences that participants wished to share. I reminded the participants that all of their views would be useful for analysis. Such a summary was also found to be useful in the successive analysis process (Morgan 1998d). I invited the co-researchers for comments, amendments or corrections about this summary, thus involving them in the preliminary analysis process.

During each action group meeting, we collectively decided what actions to follow and what areas needed further reflection, for discussion at the next meeting. At the very end of each action group sessions, I recapitulated the action that we had just discussed. These tasks or actions were an integral part of the action phases, since this was an action research study. Reflection was conducted before (between) the sessions as well as during the action research groups. The participants were allowed to set priorities for this research, in line with participatory action research (Loewenson et al. 2014).

Coloured markers, Post-it notes and large blank sheets of paper were used in action group 4 and 5 to create a visual representation of what was discussed, thus generating a lively atmosphere among the research group (Stewart and Shamdasani 2015). These charts also captured the main points discussed and allowed the participants to use them as a visual cue during the discussion (Krueger and Casey 2015). The charts were then collected and added to the data for analysis.

I took notes of key points during every action group meeting, together with occasional complete statements from the co-researchers to serve as a reminder for me about points and issues to be discussed and explored later (Morgan 1998d). I used the reflective journal to record my reflections about what happened during this action research study, their influence on this research and any gradual changes in the study (Bray et al. 2000). Samples from this reflective journal can be found in Appendix M. The reflective journal, which "helps to keep the research context sensitive" (Morton-Cooper 2000, p. 72), contributed to reflexivity in this enquiry. Reflexivity is further discussed below. Further details of the action research groups, which were the main source of data collection follows.

5.3.2 Action Research Meetings

Action research group 1, which was a search conference (Wilks and Boniface 2004), was held in November 2017. This search conference served to set the scene for this research by providing an opportunity for the co-researchers to discuss the research topic, thus involving themselves in this study (Wilks and Boniface 2004).

During the search conference, I welcomed the co-researchers and described the action research methodology that would be used since the co-researchers were not familiar with this methodology. I introduced this study by explaining in detail the latest model of practice that was being implemented in the Maltese OT profession, namely the CMOP-E, guiding OT practice in Malta. I also explained the study's purpose as researchers should be clear about the aim of the groups (Krueger and Casey 2015).

The overall plan for this research study was explained. I highlighted that action research is led by the co-researchers and that the focus and direction of the research are liable to change given the inquiring and unpredictable nature of action research. My role as a researcher was also explained, mainly that I would be acting more like a facilitator on an equal footing rather than a 'leader' controlling the study. I ensured that my co-researchers were aware of the role that they had in generating research data. As co-researchers they would be shaping the research (Mac Naughton and Hughes 2008).

I explained the possible benefits that this research might have on the service that they were providing as occupational therapists. Ground rules (Morton-Cooper 2000; Koshy et al. 2011; Williamson 2012b, Duncan 2015; Stewart and Shamdasani 2015) for behaviour regarding mutual expectations, confidentiality, way of speaking, respect for all members, co-researcher participation, keeping time, listening to each other and equality between all members were established and discussed with the co-researchers. These ground rules, which were outlined before every meeting, are key to developing and maintaining trust and respect for all co-researchers (Koshy et al. 2011). I highlighted the need for every participant to actively contribute to the discussions and to listen empathetically to their fellow co-researchers without talking at the same time, since such a conversation would then be difficult to transcribe. The demands that action research makes on co-researchers are more complex than those required by other types of research (Morton-Cooper 2000). Therefore, it was essential for the participants to understand their roles in this study.

In this first action group meeting, I then introduced the topics of discussion related to this study, namely outcomes, outcome measures, client-centredness and child-centredness according to the plan mentioned in the section above. Then I encouraged my co-researchers to start reflecting about the issues. The ideas discussed in this first action group meeting were used to prompt the discussion in the following group session and each group discussion activated the successive one. Table 5 summarises the main topics of discussions during each action research group. As one can note from this table, this research process was a recursive one. This is often the case in qualitative research, whereby, the process "often involves going sideways and backwards, as well as forwards, to reach the answers you're looking for." (Braun and Clarke 2013, p. 16).

Table 5. Topics of discussion in the action research groups

Action research group	**Topic of discussion**
1	Introduction on outcomes
	Introduction on outcome measures
	Introduction on client-centredness
	Introduction on child-centredness
2	Client-centredness in paediatric OT
	Who is the client?
	Factors that affect the application of client-centred practice
	Involvement of the child, parents and the school in OT practice
	Challenges related to the application of child-centred and client-centred practice
3	Current level of child-centred practice in OT practice
	Satisfaction with the current way of practice
	Listening to the voice of the child
	How does an outcome measure fit in our current practice?
	Ideal properties of an outcome measure
	Current assessment tools and outcome measures
4	Review of individual outcome measure tools
5	Review of individual outcome measure tools
6	Comparing and contrasting outcome measure tools
7	Factors related to the use of outcome measures
8	Factors related to the use of child-centred outcome measures
	Recommendations for practice

At the outset, we were unsure how many action groups would be needed. Data collection stopped when saturation point was reached, identified when I kept gathering repetitive information (O'Sullivan and Hocking 2013). Saturation, which describes "the point where you have heard the range of ideas and aren't getting new information" (Krueger and Casey 2015, p. 23) started to be reached at around action group 7. Once saturation is reached continuing to collect data becomes pointless (Morgan 1998b; Morton-Cooper 2000). Besides saturation, there was an agreement with the co-researchers about having reached an end point. Together with the co-researchers a concluding session, action group 8, was then planned.

All of the eight action research groups, which were carried out, formed the action research 'cycle' for this study, whereby a group of OT colleagues (the co-researchers) agreed and planned to observe and take note of their practice, critically reflected on their observations, met to discuss these reflections and formulated a plan for future work. This was based on the conclusions that they drew from these reflections (Winter and Munn-Giddings 2001).

I thanked my co-researchers both personally and in writing (by email) after every action group meeting.

5.3.3 The Role of the Researcher and Group Facilitation

As a group facilitator, I moderated all the group discussions. I had had some experience with running discussion groups in clinical practice with occupational therapists. Effective facilitation is fundamental for successful action research. Facilitation has to be planned and requires skills (Bellman and Webster 2012). I had gained such skills during previous roles that I had performed in my OT and lecturer career. I had experience in managing varied groups, including a wide range of patients, undergraduate and postgraduate students, and OT team meetings. Consequently, I was adept at managing a number of people in a group setting. Indeed, I managed to strike a happy balance between having a plan and being sufficiently flexible enough to allow my co-researchers to set priorities.

My role as a facilitator of the group was mainly that of enabling participants to come together as a group and depict a scene of what is currently happening as well as to critically examine what was accepted to be able to envisage possibilities for the future. To that end, there was a need to shed light on the participants' wide range of perspectives (Solomon 2018). Stinger (2007) recommends that an agreement on the action to be taken can only occur once the differing perspectives are discussed. Schön (1991) further adds that one needs to offer a context, which would enable us to make sense of the current situation, and this would form the basis for reflection and planning for the following cycles.

Stringer (2007) underscores that the researcher should act as a catalyst to help participants communicate their problems and support them as they try to identify successful solutions. Although participants will inevitably perceive the researcher to be skilled, approachable, resourceful and supportive, they should facilitate without assuming expertise. I tried to follow these principles during my facilitation of the action research groups.

I tried to foster an open, relaxed, comfortable and non-threatening atmosphere. The aim of these action research groups was to promote self-disclosure among the participants (Krueger and Casey 2015) and having a "safe communication space" (Bellman 2012a) was essential to enable such self-disclosure. I explained that there was no right or wrong answer and encouraged all the co-researchers to actively participate in the discussion. Some of the therapists' contributions were initially scant: "For some individuals, self-disclosure comes easily—it is natural and comfortable. But for others, it is difficult and requires trust, effort, courage" (Krueger and Casey 2015, p. 4). To encourage participation, I used different techniques such as providing eye contact to make reticent participants feel at ease. However, I exercised meticulous care to respect these participants' occasional reluctance to open up (Krueger and Casey 2015).

I observed the participants' nonverbal communication such as facial expressions, gestures and tone of voice to get an inkling of their hidden feelings (Stewart and Shamdasani 2015). Through the careful use of nonverbal communication, such as eye contact or facial expression, I could also encourage shy respondents to speak or others to hold back on comments (Morgan 1998d). This enabled a more balanced participation within the group (Stewart and Shamdasani 2015). When some participants were overly quiet, I asked them directly to air their views (Krueger and Casey 2015; Fox 2017). At other times, I did not prompt individual participants but simply observed the group dynamics instead (Fox 2017).

Moreover, when I was transcribing the action group meetings I reviewed the level of collaboration and engagement of the participants to avoid reporting only the views of dominant ones. Indeed, whenever an unassertive participant's view was cut short by the group I made a conscious effort to revisit those themes during the following action research groups and ask for other perspectives (Reep 2018).

Facilitation was essential for the success of this enquiry. Heron (1999) describes three modes of facilitation:

- The hierarchical mode – where the learning process is directed by the facilitator, who has full power over the group. The facilitator leads the groups and thinks and acts on behalf of the group.
- The co-operative mode – where power is shared between the facilitator and the group. The facilitator guides the group and collaborates with them.
- The autonomous mode – where freedom is granted to the group to find their own way. The facilitator does not intervene and gives space for the group to direct their own learning.

I was minded to use the co-operative and autonomous modes of facilitation for this research. However, there were instances where I adopted the hierarchical mode as when I introduced the topics of discussion or concluded each action research meeting. There were also times when I had to play the role of the devil's advocate in order to prompt the participants, as recommended by Heron (1999).

I tried to be non-directive by allowing the discussion to progress naturally as long as it did not digress. My role as a facilitator included that of clarifying co-researchers' responses, asking follow-up questions and, where appropriate, probing for greater depth and detail. Probes, such as asking why or how were used for clarity and to elicit additional information (Morgan 1998d; Stewart and Shamdasani 2015). Probes also served to indicate that as a researcher I was interested in complex replies (Stewart and Shamdasani 2015). I challenged the participants to discuss any inconsistencies emerging between them (Kitzinger 1994).

I took pains to ask open-ended questions, as they allowed the participants to feel free to elaborate and contribute with as much information as they wanted to give (Stewart and Shamdasani 2015). Such questions also reveal the participants' point of view rather than the facilitator's (Morgan 1998c). Closed-ended questions, which tend to be more restrictive, were avoided, where possible. I also tried to use neutral questions rather than directed (loaded) ones (Stewart and Shamdasani 2015). My intent, as a moderator, was to facilitate the discussion without leading it (Gill et al. 2008).

I conscientiously controlled my personal reactions and held back my opinions. This skill improved with each action group. Feedback from my supervisors, following their review of each of the group transcripts, helped me to listen with sensitivity and focus on empathising with the participants' perceptions. This was particularly hard when my views did not chime with the participants' (Krueger and Casey 2015). Additionally, I listened to the audio-recordings to see how I facilitated the groups and reflected on the transcripts to learn from my own mistakes (Morgan 1998d), and hone my facilitation skills.

Cross-talk often happened when the discussion became animated. Maltese people tend to be loud (Reljic 2014) and such crosstalk is typically observed in other group discussions in the Maltese context. I restated the ground rules for speaking, at the start of every new session, such as emphasising the importance of not talking over each other.

To relieve the tension stemming from work I made good use of my sense of humour, an essential element in such groups (Morgan 1998d) since it can be "a powerful bonding agent, particularly when it is spontaneous and not at anyone's expense" (Morgan 1998d, p. 43). A smile to the participants also helped to initiate a conversation, while delivering warmth and empathy (Krueger and Casey 2015). Additionally, a group "vote" was used once, when deciding about a potential child-centred outcome measure, in action research group 6. Such a vote can "elevate the group energy and provide a basis for continued elaborated discussion" (Stewart and Shamdasani 2015, p. 73).

Another technique that I used to facilitate these action research groups, especially in the final groups, is the five-second pause (Morgan 1998d; Krueger and Casey 2015). This pause is used after a question by the moderator, after a participant's comment or when participants do not reply. Initially, I tended to shift too quickly from one topic to another. However, using such a short pause generated more responses, especially when combined with eye-contact from the facilitator (Morgan 1998d; Krueger and Casey 2015).

5.3.4 Group Dynamics

Issues related to group dynamics were considered by me as the lead researcher. Group dynamics is "the process of interaction within a set of people" (Morgan 1998a, p. 10).

The participants were a group of co-workers, who inevitable knew each other well (Morgan 1998a). Conducting research with pre-existing groups, which are "clusters of people who already knew each other through living, working or socialising together" (Kitzinger 1994, p. 105) proved to have its advantages and disadvantages. Working with pre-existing groups helped me to better understand the context as it allowed me to "tap into *fragments* of interactions" (Kitzinger 1994, p. 105) which were similar to the data that might have been gathered by participant observation (Kitzinger 1994). The fact that the participants could easily relate to each other favours the discussion as they feel comfortable with challenging each other (Gill et al. 2008).

Conducting participatory action research within a single-discipline department, with participants who share their work practices and who were already familiar with each other was also deemed to be more manageable (Bennett et al. 2016). Krueger and Casey (2015) report that they always choose participants who have something in common, arguing that participants participate more actively in discussions if they perceive themselves to share commonalities, such as occupation, which was the case in this study. Homogeneity within compatible groups generates more open communication than heterogeneous groups (Stewart and Shamdasani 2015).

The effective interactions I managed to encourage included both sharing of experiences as well as challenging each other (Kitzinger 1994). Indeed, the occupational therapists succeeded in taking on the co-researchers' role and moved the research into new and unplanned directions, as is expected in participatory action research.

5.4 Rigour and Trustworthiness

Quality is important in any research study but is particularly fundamental in action research (Marshall and Reason 2007). Cypress (2017) argues that while aspects of validity and reliability might apply to both quantitative and qualitative research, these two terms might not be enough to describe the quality of qualitative research and that the terms "rigour" and "trustworthiness" might be more appropriate to qualitative research. Trustworthiness is described as the "quality, authenticity, and truthfulness of findings of qualitative research" (Cypress 2017, p. 254). Rigour can be achieved by ensuring credibility, transferability, dependability and confirmability (Lincoln and Guba 1985). Koch and Kralik (2006) argue that in participatory action research rigour and quality are co-dependent. Several researchers argue that demonstrating the rigorousness of an enquiry is a key challenge for action researchers (Touboulic 2014).

Credibility is the extent to which the researcher followed processes that allow the reader to trust the report (Williamson 2012b). In this study, credibility was achieved through the prolonged contact with participants. Having been present for all action research meetings ensured that I had a prolonged period of collaboration with my co-researchers. Through my direct involvement in the organisation that I was investigating, it was easier for me to build or enhance my rapport with the participants. As an insider researcher, I could have a better understanding of the contextual issues, thus further enhancing credibility (Fleming 2018). To that end, I acknowledged who I am and how I might have influenced the research process in my write-up (Fleming 2018). The credibility was also demonstrated through the use of participants' quotes to illuminate my themes and findings.

Since I emailed a summary of the transcribed discussion and preliminary analysis to the co-researchers for member checking, the latter could, therefore, check this information for accuracy and completeness (Williamson 2012b). They could also contact the researcher if they disagreed with what was written. Moreover, since this preliminary analysis was discussed during the action research groups, participants could contest this analysis during the same groups. Therefore, this practice served as an insider verification measure (Morton-Cooper 2000). Such a process demonstrates the collaborative and transparent attributes of action research (Koshy et al. 2011).

Transferability was ensured by using a purposive sampling method and by providing a thorough description of the co-researchers and their work setting (Cypress 2017). I ensured that the transcription of the audio-recording was done verbatim. Moreover, I gave a detailed description of how the analysis was conducted.

Coghlan and Brannick (2014) recommend that an insider-researcher recruit an "external facilitator" (p. 135) to assist in making sense of the experience and that "an academic supervisor may play this role" (p. 135). This was the case in my study. My supervisors assisted me in making sense of the data I was collecting. I performed a peer review of my data analysis with my supervisors and this helped to inform theme development, whilst guarding against the potential for lone researcher bias. Sharing my data interpretation with my supervisors served to challenge the robustness of any emerging themes (Cutliffe and McKenna 1999). Peer review is considered to be a vital part of action research (Morton-Cooper 2000). Validating my findings with my supervisors also ensured dependability. As an insider researcher, it was critical for me to fully acknowledge and describe my position within the context of this research. Whereas the latter enhanced dependability, I was also aware that it created some ethical problems related to confidentiality.

To achieve confirmability, I kept a reflective journal throughout the research process, as noted above. I kept notes and used regular documentation about the steps taken and data collection method used throughout the study. Such an audit trail also included documentation of the data analysis methodology (Cypress 2017) and a description of decisions taken throughout this project (Carcary 2009). An audit trail is a common strategy used in qualitative research to ensure trustworthiness (Carcary 2009). The audit trail of my actions and the research process also addressed dependability. Moreover, I was constantly aware of my role as a researcher and "sole instrument of this study" (Cypress 2017, p. 259). I regularly reflected on whether the collected information was an accurate representation of reality and whether its accuracy could be questioned (Sagor 2000). To that end I checked that the transcriptions and the translation were accurate as far as possible. I acknowledged that some meaning may have been lost in translating from Maltese into English. Being reflexive throughout also helped to improve the rigour of the study (Koshy et al. 2011). Reflexivity "involves having researchers reflect on their own process and how it impacts their understanding" (Bray et al. 2000, p. 76). Reflexivity also refers to the researchers' active engagement in critical self-reflection about their own biases (Cypress 2017). Consideration of researcher bias is another important element to ensure rigour. Through reflexivity I was conscious of my own beliefs, personal views, assumptions and biases although I was aware that these could not be completely eliminated (Cypress 2017).

Action researchers continually engage in reflexivity, by reflecting on their actions and behaviour vis-à-vis the co-researcher and the research process (Williamson 2012b). The action and reflection cycles in action research also need to be reflexive about how change is taking place, as well as about the effects that the researcher's presence is having on this change (Bradbury 2010). Being reflexive is an essential requirement in order for researchers to take a participatory view of the world and for them to be able to observe how inquiry and action results in the co-creation of knowledge (O'Brien and Moules 2007). The philosophical approach of action research, a critically reflexive research model is both client-centred and linked to practice (Morton-Cooper 2000). Such a critically reflexive approach will then result in changing one's typical ways of practice and the researcher's and co-researchers' view of the world (Morton-Cooper 2000).

The reflective journal helped me learn to reflect on my preunderstanding. Journaling also revealed the limits of my knowledge in light of my closeness to the issues and the organisation (Coghlan and Brannick 2014). Moreover, in order to further ensure trustworthiness I used pseudonyms for my co-researchers but not for myself. This clarifies to the reader the identity of the major contributor to the theories discussed (Wong 2018).

Touboulic (2014) notes that action researchers need to find a way to balance rigour and the relevance of the study. This would enable them to identify practical solutions to address the identified problems, while ensuring that the research produced passes muster in the vast academic world. The main criticism levelled at action research is that since the researcher is so deeply embedded in the context, the findings of action research cannot be widely generalised (Touboulic 2014).

The knowledge that is developed through action research can be useful in contexts other than those from which it emerged. However, Greenwood and Levin (2007) argue that the transfer of this knowledge is not achieved through mere generalisation of this knowledge, as this transfer depends on the awareness of the contextual features of the location in which the research was undertaken, carefully evaluating the new context where knowledge will be applied, and assessing whether the two contexts are sufficiently congruent in terms of their structures and processes (Greenwood and Levin 2007). If the findings of an action research project cannot be validly applied to another context, they can still be considered valuable if they had resolved the problems in the original context (Morrison and Lilford 2001).

This enquiry took place in the local paediatric OT department and the methods that were used were not designed to be replicable by others. However, my intention was to work with the local occupational therapists to achieve ‘internal credibility’ (Williamson 2012b, p. 39), with a direct link to the local context. I was, however, expecting that the findings of this research would develop new understanding about the use of child-centred outcome measures, which would be relevant and transferable to other similar paediatric OT services.

5.5 Data Analysis

This section describes how the collected data were analysed. Action research is still a work in progress and establishing itself as a research method. Although there is ample information about the use and dynamics of action research, there is a notable paucity of discourse regarding how action researchers should manage and analyse their data (Wong 2018).

Action research is an iterative cycle of action and reflection, so data are jointly analysed by the co-researchers during the reflection phase. Since the reflection phase is an essential part of the action research process, one can argue that action research may be regarded as a self-analysing research method with minimal need for additional steps of analysis (Wong 2018).

Nonetheless, I wanted to find a method to systematically analyse and present my findings in a more robust way. After extensive background reading and ongoing discussions with my supervisors, I opted to use reflexive thematic analysis (TA; Braun and Clark 2019a; Braun and Clark 2022). This section starts by describing TA. It then provides the rationale underpinning the use of this method, and then describes in detail the steps taken to analyse the data. The preliminary analysis process is also described.

5.5.1 Reflexive Thematic Analysis

TA "is a method for developing, analysing and interpreting patterns across a qualitative dataset, which involves systematic processes of data coding to develop themes." (Braun and Clarke 2022, p. 4). When using TA the researcher tries to identify potentially intriguing issues (Braun and Clarke 2006) and focuses on finding meaning in the data (Braun and Clarke 2006; Braun and Clarke 2012). TA is a helpful research tool that can provide a comprehensive and in-depth description of the data (Braun and Clarke 2006).

Although TA tends to be referred to as one method, there are various ways of conducting TA (Braun and Clarke 2022). I have specifically selected reflexive TA (Braun and Clarke 2019; Braun and Clarke 2022) to find the patterns of meaning and to code data for this research study. "Reflexive TA offers a particular orientation to, and form of, TA." (Braun and Clarke 2022, p. 9). The core of reflexive TA is the researcher's subjectivity and skills, as in any qualitative research (Braun and Clarke 2022). Indeed, the presence of a reflexive researcher is what distinguishes reflexive TA from other forms of TA (Braun and Clarke 2019).

5.5.2 Rationale for the Use of Reflexive Thematic Analysis

Since reflexive TA largely shares the same values as qualitative research in general, namely the recognition of the subjectivity of the researcher, the iterative coding processes and the significance of the engagement with, and reflection on, the data (Braun and Clarke 2022), I anticipated that it would be a suitable method to analyse my data. Moreover, I felt that the inherent reflexive nature of reflexive TA resonated with the action research methodology I had adopted. An action researcher continually engages in reflexivity (Williamson 2012b). Although this reflexive TA approach was used at the last stage of my research study, that is, after the collection of data from the eight action research groups, I was reflexive throughout the whole study. Being reflexive is key to taking a participatory view of the world and observing how inquiry and action result in the co-creation of knowledge (O'Brien and Moules 2007).

As a reflexive researcher, I was aware of the philosophical and theoretical assumptions that informed my research. I also took pains to become aware of my values and assumptions (Braun and Clarke 2022). Awareness of the researcher's positionality is essential in qualitative research (Holmes 2020), particularly so in action research (Coghlan and Brydon-Miller 2014).

Unlike other forms of data analysis, such as grounded theory and interpretative phenomenological analysis), Braun and Clarke's TA is considered to be independent of theory and epistemology, thus being applicable to a variety of research methods (Braun and Clarke 2006; Clarke and Braun 2013) and within a wide range of ontological and epistemological considerations (Bryne 2022). This flexibility, one of the undoubted strengths of this qualitative data analysis method (Braun and Clarke 2006; Braun and Clarke 2012; Braun and Clarke 2022), was one of the main reasons why I chose TA.

In their study, Campbell et al. (2021) have found reflexive TA to be compatible with their commitment to interpretivism, which is the epistemology that I was following. Bryne (2022) has also highlighted the alignment of reflexive TA with interpretivism. I felt that reflexive TA chimed with the theoretical and conceptual assumptions of my study, and would enable me to analyse the qualitative data which was collected in a way that respects the subjectivity of participants' narratives.

Furthermore, TA has been described as being a particularly useful approach for qualitative health research (Braun and Clarke 2014) with a significant potential application in participatory action research (Braun and Clarke 2012; Solomon 2018; Braun and Clarke 2022). For the aforementioned reasons, this data analysis method was deemed the most appropriate for my research study.

5.5.3 Preliminary analysis

All action group meetings were recorded and transcribed verbatim as soon as possible afterwards. Data analysis started in the early stages of my data collection process, more specifically after the first action research group. I had initially attempted to thematically analyse each group as they were running, according to Braun and Clarke (2006)'s thematic analysis. I started with coding of group 1 but this proved to be very time-consuming and too detailed for reporting back to the participants, and for participants to engage in. I therefore decided to conduct a preliminary analysis between groups and a detailed thematic analysis at the end of the data collection.

While ideally co-researchers should be involved in all the steps related to the data analysis, I was aware that in practice most research situations do not allow this (Greenwood et al. 1993). Given the constraints I was working under, there is a limit to the extent to which participation can be extended. As was pointed out in the Methodology chapter, "To view participation as something that can be imposed is both naïve and morally suspect." (Greenwood et al. 1993, p. 176).

The amount of time my co-researchers could dedicate to the analysis was constrained by their work commitments and shortage of staff. Moreover, this was my PhD and it was more important for me than it was to the participants who had other work-related duties. Therefore, being the initiator of this enquiry, I felt responsible for conducting the preliminary analysis and then involving the co-researchers to discuss them. Indeed, Morton-Cooper

(2000) explains how an action researcher should take into account any local pressures in the action research process. Hence, in light of my co-researchers' high work load, we collectively agreed that I would just send them the summary of my preliminary analysis rather than the full transcript.

Indeed, following each group meeting I conducted an initial analysis of the transcript and summarised the main themes and actions emerging from each session. I was aware that my own 'construction of knowledge' (Gray 2022, p. 756) differed from that of my co-researchers, whose interpretations of the issues discussed did not necessarily align with mine (Reep 2018). Therefore, the preliminary analysis was fed back to the co-researchers in different ways, to ensure that a consensus was reached about the interpretation of the data and the way forward.

Firstly, I emailed this summary to each co-researcher so they could do the checking prior to the next meeting. Sending a summary of what was discussed after each group to the participants served to validate the discussion with them and added to the credibility of the research. I encouraged participants to read this summary before the following meeting when feedback would be discussed. A sample of an action research group summary can be found in Appendix N. Secondly, the key ideas that came out of this analysis were used to kick-start the discussion in the following action group meeting. The co-researchers were free to disagree and contest any of the researcher's interpretations that did not match their opinions and they were asked to elaborate on the findings they found meaningful.

The main objective of this preliminary analysis was to identify the necessary changes and negotiate the actions co-researchers were willing or motivated to take (Reep 2018). Moreover, the summary and preliminary analysis served as an efficient way to recapitulate the topics discussed in previous groups, particularly to any participants who had missed the previous session or new participants, providing us with an opportunity to further develop our ideas (Boniface 2001). Additionally, this preliminary analysis process served as the initiator for the reflection phase.

Therefore, data collection and preliminary data analysis occurred concurrently. Findings from the preliminary analysis of each action research group served to inform the decisions about the next stage of the research (Meyer 2000). Such a “formative style of research is thus responsive to events as they naturally occur in the field and frequently entails collaborative spirals of planning, acting, observing, reflecting, and re-planning ” (Meyer 2000, p. 178). Similarly, Kemmis et al. (2014) describe the action research process as a spiral of self-reflection cycles (see Figure 1), consisting of:

- planning a change,
- acting and observing the process and the results of change,
- reflecting on these processes and changes, and
- re-planning and repeating the whole cycle

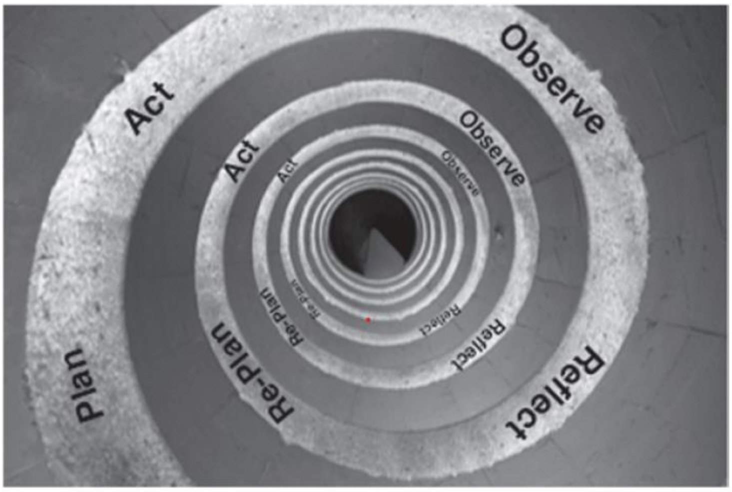


Figure 1. The action research spiral (Kemmis et al. 2014)

The collected data consisted of audio recordings, transcripts, summaries of the sessions, charts, researcher’s notes and the research diary. Having such a wide range of data collection sources enabled me to have a deeper and broader view (Koshy et al. 2011).

5.5.4 The Process of Reflexive Thematic Analysis

Following the completion of all the eight action research groups, I conducted a more thorough analysis of the collective data using TA. The analysis of this participatory action research followed the six phases of reflexive TA described by Braun and Clarke (2022), which are summarised in Table 6. Although I will be describing one phase after the other, it is important to note that I did not follow these phases rigidly, in a linear way. Indeed, Braun and Clarke (2022) have deliberately, used the term "phases" instead of "steps" in order to show the recursive process that this data analysis method entails. One does not necessarily have to complete a phase before moving on to the following one (Clarke and Braun 2013). In fact, I often had to move backwards, or even in circles, as I progressed throughout this iterative data analysis process.

Table 6. Six phases of reflexive thematic analysis (Campbell et al. 2021; Braun and Clarke 2022)

Phase	**Description**
1. Familiarising yourself with the dataset	Transcribing; reading and re-reading data line by line; taking notes
2. Coding	Labelling meaningful aspects of the data across the dataset, using codes
3. Generating initial themes	Sorting codes into potential themes
4. Developing and reviewing themes	Reviewing the entire dataset and checking on the quality of the themes
5. Refining, defining and naming themes	Refining the themes and identifying the story of each theme
6. Writing up	Presenting an account of the story told by the data

5.5.4.1. Phase 1: Familiarisation with the dataset

In this phase, researchers immerse themselves into the data to become familiar with its contents (Braun and Clarke 2006; Braun and Clarke 2012; Clarke and Braun 2013). Being the researcher, I have collected all the data myself. The time that I spent transcribing the audio-recorded data, and doing any necessary translations (from Maltese into English) was regarded as a critical step since it assisted with the interpretation of data (Bird 2005) by increasing my familiarisation with the data. Afterwards I read and re-read the transcripts and translations line by line, listening to the audio-recordings, while taking notes of any ideas

(Braun and Clarke 2006; Braun and Clarke 2012; Clarke and Braun 2013). This engagement with the data enabled me to develop a deeper understanding of my dataset. I also highlighted parts of the data which seemed related to the research question. Such note-taking helped me in starting to read “the words actively, analytically, and critically, and starting to think about what the data mean.” (Braun and Clarke 2012, p .61).

5.5.4.2 Phase 2: Coding

In this phase, codes were generated from the data. Coding is done by creating short but meaningful labels for parts of the data that seem to be potentially relevant to the research question (Braun and Clarke 2006; Clarke and Braun 2013). I worked systematically through my dataset to identify data that seemed potentially interesting or relevant to my research question. Once a chunk of data was identified for coding, the code was written down and the corresponding text was marked. More than one code was occasionally assigned to the same portion of data, text was coded once or more than once, or it may have been left uncoded if the text was irrelevant to the research question. All of the latter three options are acceptable in reflexive TA (Braun and Clarke 2006; Braun and Clarke 2012). The various types of codes used will be described further below.

In this study, I first coded a hard-copy (printed) of each action group transcript. This was done by highlighting a part of the text and writing the name of the respective code next to it. The coded portions of text included some surrounding data, as recommended by Braun and Clarke (2006). I went through both the original transcript as well as the translated version in order to ensure that the participants’ meaning was preserved. Each coded transcript was then reviewed, revised and the process was repeated, with the codes being inserted on an electronic version of the transcript. Subsequently each data set was reviewed twice, thus increasing thoroughness and rigour of the data analysis process (Braun and Clarke 2022). I shared my initial coding framework with my supervisors. Such collaboration helped in developing a richer and more complex insights into the data and to enhance reflexivity (Braun and Clarke 2022) and protect against potential lone researcher bias. This coding process was followed for each action research group transcript.

Before I began coding, I had no list or set ideas of what codes were going to be developed. The codes evolved throughout the coding process, reflecting good reflexive TA (Braun and Clarke 2022). The fact that my subjectivity as a researcher shaped the coding process is valued in reflexive TA (Braun and Clarke 2022).

Coding in this study was conducted at both a descriptive and/or interpretive level. Descriptive codes give a direct summary of an extract of data, while remaining faithful to the language and meanings of the participants, and the content of the data (Braun and Clarke 2012). Such codes that capture the explicit or surface meaning are also called semantic codes. In contrast, interpretive codes, also known as latent codes, focus more on an implicit or conceptual level of meaning, transcending the participants' expressions (Braun and Clarke 2012; Campbell et al. 2021; Braun and Clarke 2022). In latent coding, researchers may base these meanings on their own theoretical and conceptual frameworks (Campbell et al. 2021) as was done in this study. Being a beginner in coding, I initially produced descriptive or semantic codes, though eventually I became more adept at latent coding as the ability to generate interpretive or latent coding improves with experience (Braun and Clarke 2012; Braun and Clarke 2022). Table 7 shows an example of some descriptive and interpretive codes.

There are two main approaches to data coding and analysis, - an inductive approach and a deductive approach. An inductive approach is a bottom-up approach, whereby the resulting codes and themes are elicited from the data content. In contrast, a deductive approach is a top-down approach, whereby the researcher bases coding and analysis on ideas and concepts that they bring to the data (Braun and Clarke 2012). The analysis in this study included a combination of both approaches, as in most research (Braun and Clarke 2012) given that pure induction is very hard to achieve (Braun and Clarke 2022). A literature search was conducted in preparation for the research proposal as well as while carrying out the action research groups, to inform the probing questions that were used to guide the action research groups' discussion. However, I took pains to elicit themes from the collected data, without allowing myself to be influenced by the literature or by my previous knowledge. Figures 2 and 3 show two coded data extracts.

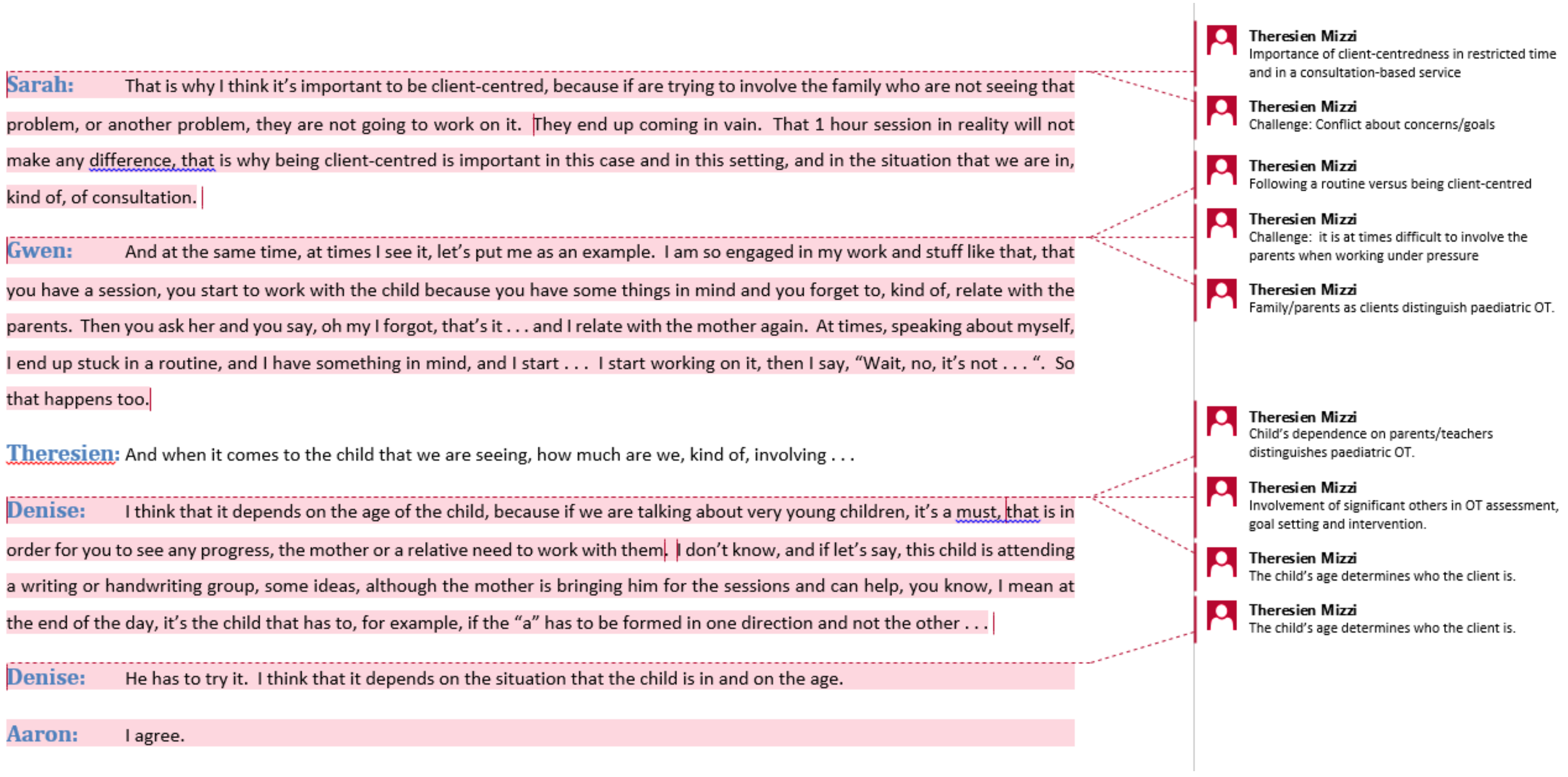
Table 7. Examples of descriptive and interpretive codes

Theme: Child-centredness / client-centredness: Rhetoric or reality	
Descriptive codes	*Interpretive codes*
Children are not being treated as clients and they are not included in goal setting	Working on the parents' goals and not addressing the child's makes the OTs feel that 'something isn't quite right'
OTs tend to be very regimental and there is too much focus on academics	Applying the same goals for all children breaches fundamental OT principles
Outcome measures should ideally be filled in by OTs for it not to be subjective	Are we understanding client-centredness?
An outcome measure should be objectively scored	OTs are dissatisfied with the way that intervention is being provided
	Subjectivity is seen as a negative thing
	Contradiction with being holistic
	Contradictions about client-centredness

5.5.4.3 Phase 3: Generating initial themes

In this phase the researcher reviews the coded data and checks for commonalities between the codes (Braun and Clarke 2006; Braun and Clarke 2012). I examined the relationships between codes and sorted the various codes into potential themes and subthemes, by grouping codes with similar features. "A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set." (Braun and Clarke 2006, p. 82). Since each theme had a central organising concept (Braun and Clarke 2022) I could determine whether or not a particular code fitted within it.

The process of searching for themes is shaped by the researcher's judgement (Braun and Clarke 2006). Indeed, such a process is an "active" one, since these themes have to be generated by the researcher, rather than discovered in the data (Braun and Clarke 2022, p. 35). While working on identifying themes, I re-examined the original transcripts, and I tried to use as much of an inductive approach as possible, to ensure that the themes reflected the participants’ views, rather than my expectations or any pre-conceived theories that I had. The importance of themes was not measured on the basis of recurring patterns but on their relevance to OT practice.



Sarah: That is why I think it's important to be client-centred, because if are trying to involve the family who are not seeing that problem, or another problem, they are not going to work on it. They end up coming in vain. That 1 hour session in reality will not make any difference, that is why being client-centred is important in this case and in this setting, and in the situation that we are in, kind of, of consultation.

Gwen: And at the same time, at times I see it, let's put me as an example. I am so engaged in my work and stuff like that, that you have a session, you start to work with the child because you have some things in mind and you forget to, kind of, relate with the parents. Then you ask her and you say, oh my I forgot, that's it . . . and I relate with the mother again. At times, speaking about myself, I end up stuck in a routine, and I have something in mind, and I start . . . I start working on it, then I say, "Wait, no, it's not . . . ". So that happens too.

Theresien: And when it comes to the child that we are seeing, how much are we, kind of, involving . . .

Denise: I think that it depends on the age of the child, because if we are talking about very young children, it's a must, that is in order for you to see any progress, the mother or a relative need to work with them. I don't know, and if let's say, this child is attending a writing or handwriting group, some ideas, although the mother is bringing him for the sessions and can help, you know, I mean at the end of the day, it's the child that has to, for example, if the "a" has to be formed in one direction and not the other . . .

Denise: He has to try it. I think that it depends on the situation that the child is in and on the age.

Aaron: I agree.

Theresien Mizzi
Importance of client-centredness in restricted time and in a consultation-based service

Theresien Mizzi
Challenge: Conflict about concerns/goals

Theresien Mizzi
Following a routine versus being client-centred

Theresien Mizzi
Challenge: it is at times difficult to involve the parents when working under pressure

Theresien Mizzi
Family/parents as clients distinguish paediatric OT.

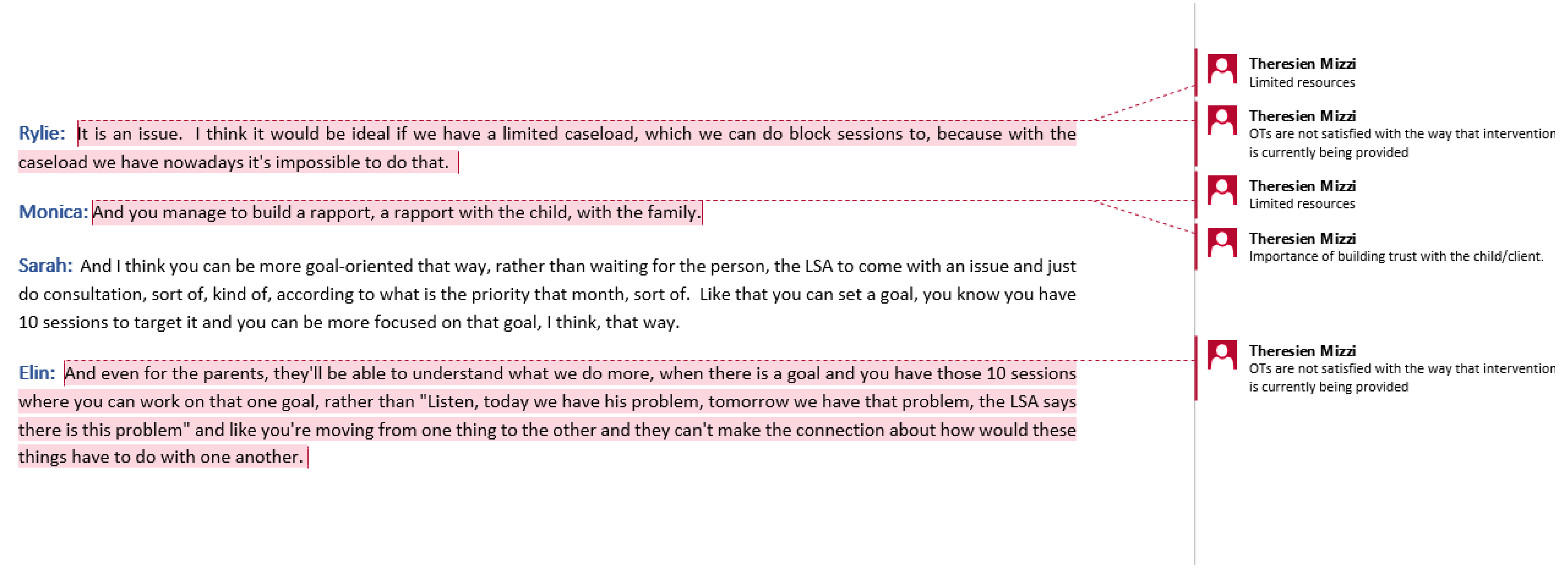
Theresien Mizzi
Child's dependence on parents/teachers distinguishes paediatric OT.

Theresien Mizzi
Involvement of significant others in OT assessment, goal setting and intervention.

Theresien Mizzi
The child's age determines who the client is.

Theresien Mizzi
The child's age determines who the client is.

Figure 2. A coded data extract from action research group 1



Rylie: It is an issue. I think it would be ideal if we have a limited caseload, which we can do block sessions to, because with the caseload we have nowadays it's impossible to do that.

Monica: And you manage to build a rapport, a rapport with the child, with the family.

Sarah: And I think you can be more goal-oriented that way, rather than waiting for the person, the LSA to come with an issue and just do consultation, sort of, kind of, according to what is the priority that month, sort of. Like that you can set a goal, you know you have 10 sessions to target it and you can be more focused on that goal, I think, that way.

Elin: And even for the parents, they'll be able to understand what we do more, when there is a goal and you have those 10 sessions where you can work on that one goal, rather than "Listen, today we have his problem, tomorrow we have that problem, the LSA says there is this problem" and like you're moving from one thing to the other and they can't make the connection about how would these things have to do with one another.

Theresien Mizzi
Limited resources

Theresien Mizzi
OTs are not satisfied with the way that intervention is currently being provided

Theresien Mizzi
Limited resources

Theresien Mizzi
Importance of building trust with the child/client.

Theresien Mizzi
OTs are not satisfied with the way that intervention is currently being provided

Figure 3. A coded data extract from action research group 8

I used mind-maps as a visual representation to help with sorting of the different codes into logical, coherent themes. I initially produced a mind-map for each action research group. These mind maps evolved as I worked on the construction of themes. A copy of the mind-maps for all of the groups can be found in Appendix O.

I reviewed the datasets and codes of each action research group and identified themes for each group. The datasets and codes of all action research groups were then collectively reviewed to identify shared meanings. Rigour was enhanced through the "systematic engagement with meaning and patterning across the entire dataset" (Braun and Clarke 2022, p. 54), thus ensuring that themes were founded on a sound and meticulous analysis. A final mind-map for all the themes from the collective groups was then produced. Appendix P displays the thematic maps for the collective groups.

At the end of this phase, I ended up with a list of the main themes and sub-themes, together with all of the portions of data relevant to each theme (Braun and Clarke 2006). The themes that I identified at this stage were provisional as my constant engagement with the data led to changes in the generated themes. The preliminary themes and their related codes were shared with my supervisors.

5.5.4.4 Phase 4: Developing and reviewing themes

In this phase the researcher refines the themes that were developed in Phase three (Braun and Clarke 2022). To that end, I re-engaged with all the coded portions of the data as well as the full data set. I checked whether there were enough data to support each provisional theme. This review included blending two themes in one theme (e.g., "Professional Identity" and "OT Identity in Paediatrics" were blended into one theme, "Concepts around professional identity") and splitting a broad theme into two separate ones (e.g., "Conceptualising the 'client' in paediatrics" was split in "Conceptualising the 'client' in paediatrics" and "Child-centredness / client-centredness: rhetoric or reality?").

I was aiming for a rich and detailed analysis that addressed my research question. Themes or subthemes unrelated to my research question were discarded. At this stage, I also started to consider “the relationship between the themes, and existing knowledge, and/or practice in … [the] research field, and the wider context of … [the] research.” (Braun and Clarke 2022, p. 35). Following such a review, I became more knowledgeable about the different themes, how they related together, as well as the information that they provided about the data.

5.5.4.5 Phase 5: Refining, defining and naming themes

In this phase, the researcher defines and refines the themes (Braun and Clarke 2006) and conducts a detailed analysis of each theme and subtheme. I identified the fundamental qualities of each theme and determined what part or feature of the data was being captured by each of them, thus fine-tuning my analysis. This was followed by the creation of a pithy, striking and informative name for each theme (Clarke and Braun 2013). I also wrote a brief summary for each theme and subtheme. Once again, the data were interpreted and linked to the research question (Braun and Clarke 2012).

Being an action research study, with eight action group meetings, I initially refined and defined the themes and subthemes that came out of each group. This was followed by a collective review analysis of all the themes from all groups. Table 8 shows the main themes and subthemes that were generated by this analysis. Apart from my immersion and engagement with the data, I took pains to produce a good quality analysis by “giving the analysis some distance” (Braun and Clarke 2022, p. 8). This was achieved by taking an occasional break from the analysis process.

5.5.4.6 Phase 6: Writing up

In thematic analysis, writing is an essential characteristic of the analytic process, as is most qualitative research (Clarke and Braun 2013) and is interlaced with analysis (Braun and Clarke 2012). Although the production of the report is being considered the final phase, one should note that in qualitative research writing occurs throughout the entire analysis (Braun and Clarke 2012). The write-up of the analysis should produce a comprehensive, rational, clear and well-organised account of the story about the data, which holds the reader’s attention (Clarke and Braun 2013).

Table 8. List of themes and subthemes

Theme 1 **Conceptualising the ‘client’ in paediatrics**	
	Subthemes Challenges of child communication Children’s insight on and awareness about their own difficulties Conflict between the goals set by the child, parents and professionals
Theme 2 **Child-centredness / client-centredness: Rhetoric or reality?**	
	Subthemes Perceived challenges for the delivery of a child-centred / client-centred practice Prerequisites for the delivery of a child-centred / client-centred service and attributes of such a service
Theme 3 **Occupational therapists’ understanding of outcomes and outcome measures**	
	Subthemes Occupational therapists’ perception of the qualities and attributes of outcomes / outcome measures Occupational therapists’ perception of the qualities and attributes of OT-specific outcomes / outcome measures Occupational therapists’ perception of the qualities and attributes of paediatric OT-specific outcomes / outcome measures
Theme 4 **Applying child-centred outcome measures**	
	Subthemes Current OT practice in this setting (with respect to outcome measures) Perceived benefits for using an outcome measure Prerequisites for the use of a child-centred outcome measure Perceived challenges for the use of a child-centred outcome measure in this setting
Theme 5 **Child-centred outcome measures for paediatric OT practice in Malta**	
	Subthemes The suitability of the PEGS as an outcome measure for this service The suitability of the PACS as an outcome measure for this service The suitability of the COSA as an outcome measure for this service The suitability of the COPM as an outcome measure for this service The suitability of the GAS as an outcome measure for this service
Theme 6 **Challenges around professional identity**	

The reporting and the discussion of the themes can be found in the Findings and Discussion Chapters. When reporting my findings, I included extracts of the data in my report, in order to corroborate the themes within the data. The story that I tell to address my research question is also contextualised vis-à-vis the literature and OT practice in the Discussion chapter. Given that the themes overlapped across action research groups and continued to evolve with subsequent groups, they were collectively considered in both the Findings and Discussion chapters. The evolution of themes from one action research group to the following one will be further described in The Evolution of Themes chapter (Chapter 6).

5.6 Conclusion

This chapter described the process of this participatory action research. Participatory action research was selected as the methodology for this research study since it can empower the local paediatric occupational therapists to collaborate in learning and develop their own practice. As a researcher, I participated in this study with my co-researchers. Data were gathered mainly through eight action research groups with occupational therapists, who acted as co-researchers. There were cycles of action and reflection and each group informed the following one.

This enquiry was based in the local paediatric OT setting with the aim of improving the development of local OT practice. This research sought to widen the knowledge about child-centred outcome measures. This chapter has explained the data analysis process that I followed to finally tell a coherent and compelling story about the findings that address my research question. I used reflexive TA (Braun and Clarke 2022) to achieve this. Further information about the findings, and the interpretation of these findings will be discussed in the following chapters.

Part Three: Findings

This part of the thesis presents the findings of this study. **Chapter 6** gives an overview of the evolution of themes. **Chapter 7** presents the findings vis-à-vis client-centred and child-centred practice whereas **Chapter 8** then presents the findings related to outcome measures.

Chapter 6: The Evolution of Themes

This section describes the evolution of the themes. I used reflexive thematic analysis (Braun and Clarke 2022) to explore the patterns across the datasets. Six themes, shown in Figure 4 below emerged from the collective data. This section gives an overview of each theme, which will then be discussed in more detail and will be illustrated by original quotations in the following chapters.

Figure 4. Themes that emerged from this research

Some of the themes were further divided into sub-themes. The sub-themes for these themes are shown in Figure 5. These sub-themes will be discussed in the subsequent chapters. Data were collected through eight action research groups. All the aforementioned themes emerged from more than one group, as will be described below.

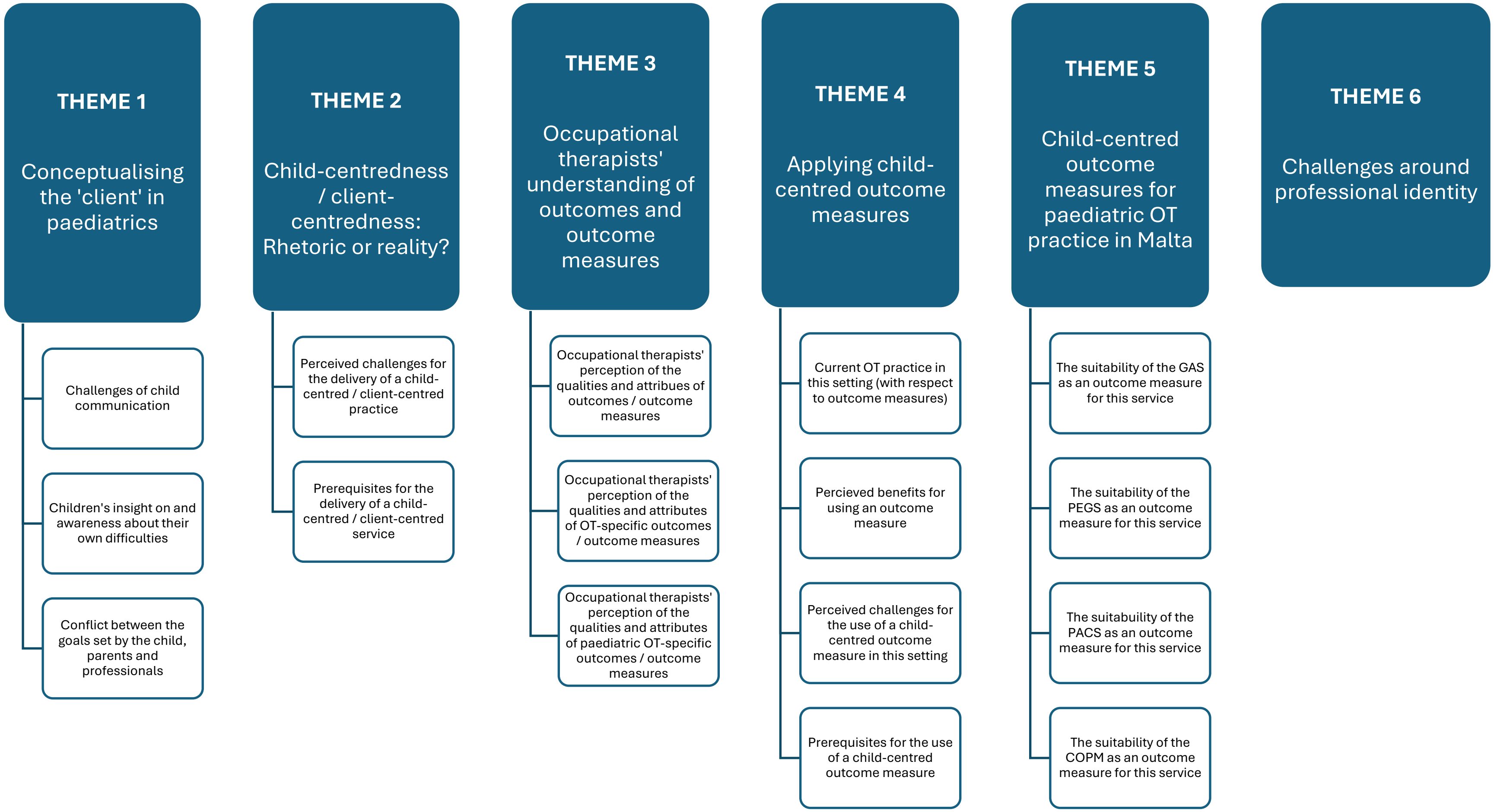


Figure 5. List of themes and subthemes

6.1 Theme 1: Conceptualising the ‘Client’ in Paediatrics

This theme discusses the conceptualisation of who the client is in paediatric OT practice. It deals with issues about the application of child-centred practice and addresses the dilemma of whether the client is the child or whether the term includes significant others, for example, the parents and/or the teachers. Therefore, it explores the conundrum of whether one should talk about child-centred practice or client-centred practice. This theme also explores other issues related to having children as clients and to some challenges that may result from this. The latter include challenges that are related to obtaining information from a child, the lack of insight and awareness that children might have about their difficulties, and the conflicts stemming from differences in goals.

This theme started to emerge in action group one, where all of the related issues were briefly discussed. It then continued to evolve in all the following groups. Issues related to the potential lack of insight that children may have, were mentioned mostly in action group one. In groups one and two, issues related to challenges associated with child communication, together with the conflict that tends to occur between the goals set by the child, parents and professionals, featured more prominently. The theme of conflicting goals was reiterated in the remaining groups, together with the need to work with the parents and significant others rather than solely with the child.

6.2 Theme 2: Child-Centredness / Client-Centredness: Rhetoric or Reality?

This theme relates to the level of application of child-centred/client-centred practice in the setting where the study was conducted. It raised questions about the actual application and delivery of a child-centred / client-centred service in practice; some essential features of such a type of service delivery; and other general challenges posed by the attempt to apply child-centred / client-centred practice.

Some issues related to this theme were discussed in the first group and were then further developed in all groups, except for group five.

6.3 Theme 3: Occupational Therapists' Understanding of Outcomes and Outcome Measures.

This theme examines how occupational therapists define the terms 'outcomes' and 'outcome measures'. It encompassed the properties that the therapists assign to outcome measures. It also incorporates qualities of OT-specific outcomes and outcome measures, as well as paediatric OT-specific outcome measures.

This theme emerged from all action research groups. It started to develop in action group one and continued to evolve in each of the following action research group. Culmination of this theme was reached in action groups four and five, whereby following discussions in previous action research groups, therapists were more knowledgeable and could further identify specific features related to outcome measures. These include features related to validity and reliability of such measures.

6.4 Theme 4: Applying Child-Centred Outcome Measures

This theme deals with a range of issues vis-à-vis the application of a child-centred outcome measure in practice. It investigates the current OT practice in this setting, with respect to the use of outcome measures and the potential benefits of such measures. Moreover, this theme incorporates prerequisites and perceived challenges related to the use of a child-centred outcome measure. This theme first emerged in group three and continued to develop in all the subsequent groups.

6.5 Theme 5: Child-Centred Outcome Measures for Paediatric Occupational Therapy Practice in Malta

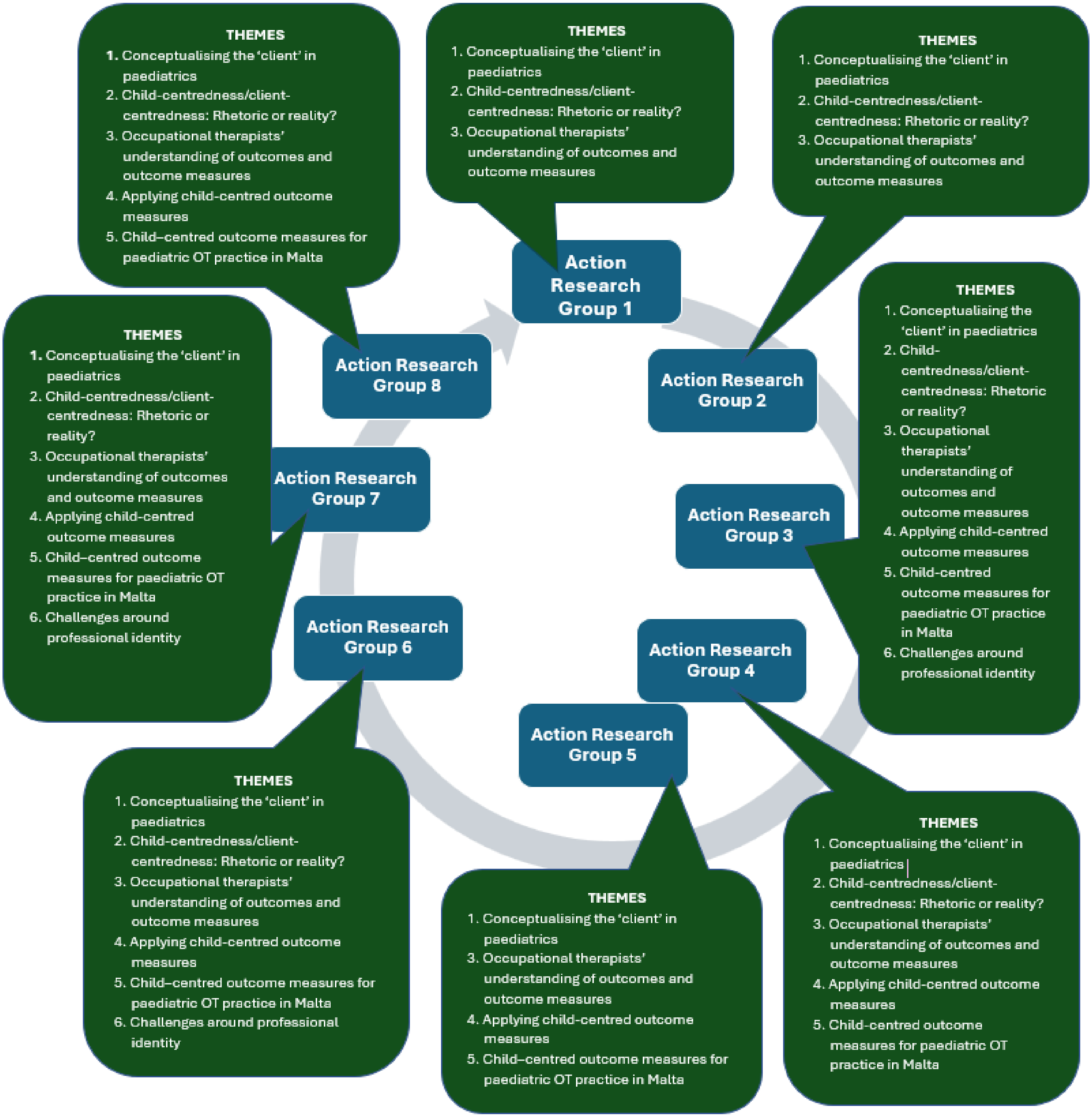
This theme concerns child-centred outcome measures that could be employed in Malta. The OTs started to identify and discuss such measures in action research group three. These were further discussed in groups four and five as the therapists reviewed a number of child-centred outcome measures. The suitability of some outcome measures was looked into in groups six and seven.

6.6 Theme 6: Challenges around Professional Identity

This theme discusses issues related to OT professional identity and largely explores the perception of participants on how third parties view the OT profession. This theme firstly emerged in action research group one and was further developed in groups three, six, seven and eight.

6.7 Conclusion

This section gave an overview of the themes that emerged from the data and it showed how the themes evolved through the process of the action groups. The development of themes throughout the eight research groups is summarised in Figure 6, which depicts the action group from where the themes evolved. Each of the above-mentioned themes are expanded in the following two chapters. Chapter 7 discusses the findings related to client-centred and child-centred practice, while chapter 8 deals with the findings related to outcome measurement.



Action Research Group 1

THEMES
1. Conceptualising the 'client' in paediatrics
2. Child-centredness/client-centredness: Rhetoric or reality?
3. Occupational therapists' understanding of outcomes and outcome measures

Action Research Group 2

THEMES
1. Conceptualising the 'client' in paediatrics
2. Child-centredness/client-centredness: Rhetoric or reality?
3. Occupational therapists' understanding of outcomes and outcome measures

Action Research Group 3

THEMES
1. Conceptualising the 'client' in paediatrics
2. Child-centredness/client-centredness: Rhetoric or reality?
3. Occupational therapists' understanding of outcomes and outcome measures
4. Applying child-centred outcome measures
5. Child-centred outcome measures for paediatric OT practice in Malta
6. Challenges around professional identity

Action Research Group 4

THEMES
1. Conceptualising the 'client' in paediatrics
2. Child-centredness/client-centredness: Rhetoric or reality?
3. Occupational therapists' understanding of outcomes and outcome measures
4. Applying child-centred outcome measures
5. Child-centred outcome measures for paediatric OT practice in Malta

Action Research Group 5

THEMES
1. Conceptualising the 'client' in paediatrics
3. Occupational therapists' understanding of outcomes and outcome measures
4. Applying child-centred outcome measures
5. Child–centred outcome measures for paediatric OT practice in Malta

Action Research Group 6

THEMES
1. Conceptualising the 'client' in paediatrics
2. Child-centredness/client-centredness: Rhetoric or reality?
3. Occupational therapists' understanding of outcomes and outcome measures
4. Applying child-centred outcome measures
5. Child–centred outcome measures for paediatric OT practice in Malta
6. Challenges around professional identity

Action Research Group 7

THEMES
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5. Child–centred outcome measures for paediatric OT practice in Malta
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Action Research Group 8

THEMES
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Figure 6. Themes emerging from each action research group

Chapter 7: Findings Related to Client-Centred and Child-Centred Practice

Six themes were identified from the data analysis. This chapter presents the findings under Themes 1 and 2, and their subthemes, which are related to client-centred and child-centred concepts and practice.

Participants' quotes are used to illustrate the findings. The specific action research group and page number on the transcript for such quotes are included to support the credibility of the findings. Themes three to six will be discussed in the following chapter.

7.1: Conceptualising the 'Client' in Paediatric Occupational Therapy

This first theme concerns the nature of the client in paediatric OT practice. Since this study focused on client-centredness, or more specifically, child-centred outcome measures, the concept of client-centredness proved to be fundamental to my research question.

The consensus among participants was that it is crucial for occupational therapists to understand who the client is. Indeed, identifying the client is important "t*o set goals with the client. Goal setting should be done with the client so we need to see who the client is, to set goals and work towards them."* (Sarah, Action Group [AG] 2, p. 4). Identifying the needs of each client is especially important given that different 'clients' may have different goals and priorities.

> *I think it's important [to understand who the client is] because sometimes the children's goals and the parents' goals differ. . .The parents see one type of problem and the children who have insight . . .[may] see a different aspect of the problem.* (Rory, AG 2, p. 4)

Additionally, the participants agreed that identifying who the client is enables the therapist to design a tailor-made intervention for the client, formulate specific programmes and provide OT recommendations,

> *. . .because the intervention needs to be tailor-made for the client. So not knowing who the client is . . .it [OT intervention] won't be tailor made for the client, so I believe that's the most important thing, the first thing we need to be aware of.* (Rylie, AG 2, p. 4)

However, the findings in this study suggest that the complexity of client-centredness in a paediatric setting poses serious challenges to identifying who the client is. Age was mentioned as being a contributory factor to these multilayered challenges, since paediatric settings cater for children who are under 16 years of age.

The challenge is *"mainly because they [the children] are minors . . .They need to be cared for because they are minors, so you need to speak to their parents, their teachers, [and] their family"* (Maya, AG 2, p. 9).

> *If you have an older client you would go with the goals or with the priorities highlighted by the older client. But because we have a minor you'd have to listen to the child and the parents as well.* (Ruby, AG 2, p. 6)

The participants acknowledged that "i*t is difficult to have [just] one client in this setting"* (Sarah*,* AG 2, p. 7) and this *"makes it more difficult to be client-centred."* (Rowan, AG 1, p. 32). Participants emphasised that the client *"cannot be just the child"* (Jade, AG 1, p. 32) and that the therapist *"cannot . . .work . . .only with the child"*. (Sarah, AG 2, p. 20). The participants noted that the parents and the school need to be involved too. The findings clearly indicate that in paediatric OT practice, one cannot separate parents from the child. Indeed, the participants explained how the child's dependence on parents and teachers, distinguishes paediatric OT from other disciplines.

> *One of the differences that there is between us [paediatric occupational therapists] and maybe other occupational therapists, is parental concerns . . .[and] teacher's*

> *concerns . . .We do not simply look at the child's difficulty . . .but we are also addressing the parents and the teachers of this child and how we could maybe help depending on their concerns.* (Reese, AG 1, p. 8)

Therefore, parents are regarded *"as clients too. Sometimes both the school . . .[and] the parents . . .need our help. So they're all clients. And even if I'm setting goals with them, to me they're the clients, per se."* (Elaine, AG 2, p. 20). *"The client in our case, like we said. . ., are both [the child and the parents]"* (Rory, AG 3, p. 3). It is therefore clear that in a paediatric setting, *"the client . . .can be a lot of people."* (Alianna, AG 2, p. 6).

Four participants identified *"the family"* (Jade, Monica, Rory, Reese, AG 1, pp. 8-9) as the client in paediatric OT. However, the client can also be *"whoever is supporting [the child and who] will be working with him, so the family, and even to a certain extent the school, that is, the teacher [and] the Learning Support Assistant."* (Rory, AG 1, pp. 8-9). Indeed, some participants added that the client occasionally might not be the parents or the teacher. Instead, the client might even be "*a social worker, who is trying to put goals together"* (Elin, AG 2, p. 23). It can be "*the grandmother, [with whom the child] spends most of the time"* (Rory, AG 2, p. 23). It can also be another *"primary caregiver or the person with responsibility [such as] a nun . . .or someone who . . .[has] more insight that the parents . . .[if the latter have] low cognitive abilities . . .[This person might be] creating the goals for the child".* (Elin, AG 2, p. 23) .

The findings convey the complexity around deciding the identity of the client in a paediatric setting. All participants appeared to agree that *"the child is the primary client"* (Jade, AG 2, p. 21), and that the parents and the teachers are *"secondary clients"* (Rory, AG 2, p. 21). One participant suggested that *"initially it is the child that is primarily the main client"* (Faith, AG 2, p. 6). Therefore, as the OT involves the parents and teachers, whom the child is dependent on*, "the school and the parents will end up as clients as well"* (Faith, AG 2, p. 6). "*Ideally all three parties [referring to the child, parents and teachers] are involved initially, but it's difficult to do [so]."* (Rylie, AG 2, p. 18). Another participant described the nature of the interrelationship that needs to be present between the different parties involved, as being *"like a triangle, the [child], the parents, and the school together."* (Jade, AG 1, p. 15).

Ruby felt that the school was more of "*an environment that needs to be assessed and analysed according to the needs of the child . . .unless there are cases . . .where the parents . . .do not understand . . .the needs of the child"* (Ruby, AG 2, pp. 18-19), or in cases where the OT cannot get the necessary information from the parents as the child's concerns are school-related. She warned that OTs *"have to deal with the parents first, before dealing with the school, legally."* (Ruby, AG 2, pp. 18-19).

7.1.1 Challenges of Child Communication

This subtheme is mainly related to challenges that therapists encounter when trying to obtain information from a child, mostly during assessment. A client-centred and occupation-based evaluation process is expected to revolve around identifying the client' needs and wishes, so the client needs to be involved in decision-making.

The participants reported that children who are referred to OT generally have various difficulties and present with complex problems, which affect the child's development, including their communication and cognitive abilities. These children, for example, children with autism, may be non-verbal. The participants remarked that such children may have difficulties in expressing themselves, in voicing their concerns and/or in setting their goals with therapists. In a paediatric setting,

> *. . .it's difficult for the child to come up with a goal on his own, especially when the child is still young and does not have certain reasoning. And after all, the children that come here are children who have difficulties, not children [who are typically developing].* (Reese, AG 1, pp. 25-26)

The participants reported that it is quite challenging for them to know what non-verbal children want from therapy. The participants identified different techniques or adapted assessment methods that they used as occupational therapists, to obtain the information from a child. For example, the therapist may make therapeutic use of the self as such a technique. The participants explained how this is performed by being aware of the language that is used and how the therapist interacts with the child. This enables the therapist to build a rapport with the child to make the child feel at ease and motivated to participate in the OT session.

The participants highlighted the variety of ways in which the occupational therapist interacts with the child to discover their preferences, depending on each child's specific needs. Participants insisted that this interaction was performed during intervention rather than during assessment. *"Even in terms of what goals you set, it does make a difference knowing the child and what they're interested in."* (Elin, AG 2, p. 5). The general consensus among participants was that they found it challenging to use different ways and adaptations to elicit information from a child on a daily basis.

Moreover, the participants were concerned that even though adaptations may be provided, some children might still be unable to express their needs and identify their priorities. Given the challenges related to communicating with the child, participants perceived parents as being important information givers, especially for non-verbal children. Moreover, the participants acknowledged parents' role as being essential advocates for their children.

> *Most of the children that I see are on the autism spectrum. The first thing that I start from, is to build some trust with the child, because if I don't have that, we would not achieve anything. So, the first thing that I do if the child can speak to me, which is not the case most of the time, . . .[is asking] the parents, 'Listen, what does the child like to play with at home?' and 'What is the thing that drives him the most, that motivates him?' and generally the parents would know. They would tell you for example, 'things that he can spin' . . .repetitive play.* (Reese, AG 1, p. 20)

Trust can therefore be seen as an important component of client-centred, or child-centred practice. The participants noted that they tried to build trust with the child to form a therapeutic relationship with them. One participant also noted that if the therapeutic rapport with the child is based on trust, the child might be more likely to provide the information that the therapist requires during assessment, such as the child's concerns or occupational challenges (given that the child has the cognitive abilities to do so). The participants acknowledged the need for occupational therapists to question whether they were allowing children to voice their concerns and to decide areas for improvement they wanted to work on in therapy.

7.1.2: Children's Insight into and Awareness about their Own Difficulties

This subtheme concerns the extent of insight into and awareness of their own problems. *"There may be some children who have insight to their problems, and . . .[other] children who don't have."* (Reese, AG 1, pp. 11-12) A child's self-awareness and insight *"depends on the age, the IQ level . . .[and the] cognitive skills"* (Reese, AG 1, pp. 11-12) of the child. The latter factors were identified by a number of participants as the main determinants of a child's acquisition of insight.

Different participants had different opinions on various pre-teen age groups, which they felt might pose particular challenges in terms of self-awareness. The consensus was that the age groups that posed the severest challenges were three- to five-year olds, under-eight children or under-12 children. However, following various discussions there was a consensus that insight and self-awareness improve by the age of eight in typically developing children. "B*y eight [years of age], they have the cognitive ability to self-examine. Children lower than eight do not have . . .that ability"* (Ruby, AG 2, p. 15). The participants explained how children, who are referred to OT, generally have cognitive difficulties or complex diagnoses, which affect their cognitive abilities. Consequently, these children may not be aware of their difficulties.

Some participants believed that as they grow up, children start to compare themselves with their peers and they become more aware of their difficulties. These participants viewed young children as being more aware of difficulties that they can actually "see", such as coordination difficulties, than of other "hidden" difficulties, such as a limited attention span. Participants agreed that as children with good cognitive skills get older, they become more aware of academic difficulties, such as handwriting problems. One participant shared her personal childhood experience of having insight into her own participation challenges, whereas another participant referred to an older child, whose good verbal skills helped her graphically describe her sensory processing difficulties:

> *You get some powerful statements sometimes, from children . . .I had recently a seven- year old,. . .[who] had very good verbal communication skills, . . .her description of how sensory processing issues are hurting her, [and] affecting her, they were really powerful, and they struck me.* (Faith, AG 2, pp. 13-14)

Therefore, while parent involvement was seen as being important for the younger child, participants agreed that older children need to be more involved in the assessment process. *"If you have a 10-, or 11-year old you can involve him . . .more, so that he gives more input to the situation, as if he owns the situation."* (Rylie*,* AG 1, p. 9). The consensus among participants was the older the children, the more insight they would typically have and the more adept they are at participating in the sessions, including participating in information gathering during assessment.

The participants seemed to indicate that the child's insight and awareness, which are affected by the child's age and their cognitive abilities, can determine whether the child can be regarded as the 'main client' (as Faith described it) or not. Age in fact, poses a challenge to client-centredness, or more specifically child-centredness. The participants argued that it is challenging to treat young children as the main clients and to set goals with them. "*It is difficult for the child to come up with a goal on his own, especially when the child is still young and does not have certain* reasoning" (Reese, AG 1, pp. 25-26). They believe that when self-awareness is absent, the parents would need to be more involved.

7.1.3: Conflict between the Goals Set by the Child, Parents and Professionals

The participants acknowledged that allowing clients to set their own goals is fundamental for client-centred practice. The data indicated that incongruence exists between the goals set by the child, the parents, the teachers and/or the occupational therapists themselves. This subtheme deals with the goal conflict that occurs between these various parties or potential clients. The conflict in goals arises at different levels, such as between the child and the parents; between the child and the teacher; between the therapist and the parents; between the therapist and the teacher; between the child and the therapist; or between parents and teacher.

The participants pointed out that “*the worst case is when the mother and father do not agree [on what the OT should work on]”* (Reese, AG 1, p. 42). One of the participants even added that the conflict can occur between different caregivers, such as between a grandparent and an aunt, who may accompany the child for different OT sessions. Each of these caregivers may have different goals. Such a conflict was reported to occur mostly with the very young (i.e., children under three years of age).

The participants discussed how the therapist has to take into account,

> *. . .everyone's concerns because everyone . . .[views] a different angle of the issue. The . . .child is seeing one angle, the teachers are seeing their angle, the parents or the guardians are seeing another angle . . .So you have to see everyone's [concern] . . .Every stakeholder has a bit of right, in their own way, because different people see different aspects of the problem.* (Alianna, AG 2, p. 5)

The challenge resulting from goal conflict featured to different extents in all of the action research groups. The participants felt that such a conflict in goals was probably more complex in a paediatric OT setting, vis-à-vis other OT settings. One participant compared the challenge resulting from the disagreement over priorities or concerns that occur in a paediatric setting to that of a geriatric setting. She noted that with an older adult as a client, even if the latter is non-verbal, there is typically a main carer that the therapist would liaise with. However, in paediatrics there are:

> *… schools, . . .doctors, . . .parents, all of them have different goals that they have to work on because they are in different settings, . . .[and] that's where it becomes more complex . . .[In paediatric OT] it's ten different people who can guide you in ten different directions, so you would have to figure out which one the child needs most, which is difficult.* (Elin, AG 2, pp. 9-10)

Another participant compared the paediatric setting to an acute hand therapy unit:

> *[In a paediatric setting] there are so many people involved. You've got the parents, the mother, the father, the teacher. When you're working in another setting, let's say in an acute setting with a hand injury and you've got this man who's coming for therapy for the hand injury, it's mainly him, because he knows his own concerns, . . .and you're sort of working with him. In this setting, there are so many other elements that need to be taken in consideration.* (Rylie, AG 2, p. 9)

The participants indicated that different concerns and goals between parents and children might stem from different priorities and the lack of insight into and awareness of a potential problem by the children. One participant asked,

> *How many children are aware of their difficulties?" . . .On the average I see, that they don't really see an issue . . .[but this contrasts with the parents' response] . . .which is a complete opposite. And then, what do you do then?* (Monica, AG 6, p. 5)

Participants generally agreed that parents and teachers seemed more concerned about children's handwriting and other academic difficulties than the children themselves, who fretted mostly about self-care.

> *Generally, . . .parents have more of an educational framework in their mind, . . .[and] they're more geared towards education, whereas a child or an older child would go for more things related to self-care for example, because it's something that they're experiencing personally and they have a difficulty with.* (Elin, AG 2, p. 5)

The participants noted that children also tended to prefer working on play activities and activities involving gross motor skills during OT sessions, rather than academic tasks, such as writing. Nevertheless, handwriting was reported to be the main reason for OT referral.

> *The child may not keep up with his peer [in writing], but as such . . .only a few kids would be affected by this. It's more [important to] the parents, because they want . . .[their children] to write neater, to keep up for exams, or [to] the teachers.* (Elaine,

> AG 1, p. 13). *"It depends on how much [writing] is of a concern for the child . . .and most of the time, as we were saying, it's not.* (Ruby, AG 1, p. 13)

One of the participants described a clinical scenario to exemplify this issue of goal conflict between the child and the parents. The therapist tried to rationalise the parent's behaviour for choosing a different goal to that of the child, while reflecting on what she might do in such a circumstance:

> *We have a particular case, an 8-year old . . .[who was] always fed by his mother. . .We tried to teach him how to eat, [but] learning to eat is not his goal, so he wasn't even interested. . .I don't blame the parent who would like to find some way in which he [her son] could eat on his own. Obviously, if it were my son I would do the same, but at the same time I understand the . . .child's perspective.* (Rylie, AG 1, p. 27)

Feelings of frustration featured prominently in all narratives, when there was a conflict in goals.

> *And even what to focus on. It's very difficult . . .You've got a parent, you've got a teacher, you've got [the child] . . .so the parent is saying one thing, the teacher is saying another, they don't agree with each other, so it's like, it's too varied.* (Elin, AG 3, p. 19)

Participants indicated that conflicting goals set by the child, the therapist, parents, teachers and society undermined their ability to be client-centred with children. Consequently, the participants questioned whose concerns and goals they should follow when there are conflicts.

> *Especially as we were saying, if the goals of the different stakeholders don't match . . .the problem . . .to be client centred [is] . . .who are you going to follow? . . .Whose goals are you going to try and tackle . . .if they are not matching?* (Sarah, AG 2, p. 9)

This dilemma loomed large in participants' minds as they strove to decide the identity of the primary client: *"It all boils down to who will we consider as our client . . .The parent or the children?"* (Elaine, AG 1, pp. 22-23).

Participants suggested that being client-centred entails negotiating a balance between the child and the parents. *"Maybe here, for us to be client-centred, [that] means that we find a leeway between the two of them . . .We should not give more importance to one or the other."* (Elaine, AG 1, pp. 30-31). One participant recommended that the therapist can:

> *. . .give choices to empower them [the children] . . .although you're working on parents' goals . . .you can give choices between activities, etc. And sometimes, the hardest thing is . . .when they [the children] are non-verbal . . .[in such cases the therapist] observe[s] their behaviour. If you see that the goal that the parents set is further increasing frustration or [challenging] behaviour . . .we have to negotiate with the parent . . .*(Faith, AG 2, p. 11)

Participants admitted that they struggled to reach a consensus between different parties. They expressed familiarity with this difficulty but expressed their concern that their difficulties would be exacerbated, should their practice become a more child-centred or client-centred one.

7.2: Child-Centredness / Client-Centredness: Rhetoric or Reality?

This second theme discusses the level of application of child-centred or client-centred practice in the setting where the study was conducted. The challenges and prerequisites for the implementation of such a service are also addressed.

Throughout the study the participants affirmed the importance of being child-centred and client-centred. However, they were simultaneously making statements that did not seem to resonate with their practice, creating a sense of dissonance.

A particular issue that seemed to run counter to client-centred practice was the fact that subjectivity was seen as a negative thing, whereas the client's subjective experience is typically considered the heart and soul of client-centred practice (Sumsion 1993; Law et al. 1995; Sumsion 2000). Indeed, when discussing the desirable properties in an outcome measure, the participants initially stated that "*it's important that it [the outcome measure] won't be subjective . . .because [if] parents and teachers [are] filling in [the outcome measure, it] can become subjective*" (Rylie, AG 3, p. 8). The participants seemed to be concerned about the fact that questions, criteria or scoring options on an outcome measure may be misinterpreted, and so to avoid this, they opted for having the therapist filling in the outcome measure instead. "*If we had an outcome measure, I think that we should be doing [it]*" (Elin, AG 3, p. 15). According to the participants, this option would make the whole procedure less subjective.

Participants repeatedly affirmed that client-centredness and holistic practice are inextricably linked. However, whilst participants emphasised the importance of being holistic and taking in "*the whole picture*" (Monica, AG 1, p. 38), two participants suggested that being in a health setting, they should not address educational issues. They suggested that the occupational therapists in this setting should "*focus more on the self-help and the play [areas, only], so that . . .[they would be able to provide a] more focused intervention . . .focusing on . . .occupations [which] are health-related, because we [the therapists] have to do with the health sector"* (Reese, AG 7, p. 29). These two participants added that other occupational therapists who work in the education sector would then "*take more care of the education part*" (Reese, AG 7, p. 29), "*focusing more on school-based issues*" (Sarah, AG 7, p. 29). This was seen as a way of solving the lack of *"resources, [including limited] human resources [and limited] space*". (Reese, AG 7, p. 29) that they were experiencing.

However, another participant saw through the discrepancy, and was highly critical of dissociating health issues from educational ones as this "*would defeat the purpose of the holistic approach per se*" (Marcelle, AG 7, p. 29). The issue of a holistic approach was a concern for some of the participants as it was seen as being interlinked with child-centred and client-centred practice. Elin claimed that having different therapists focusing on different areas does not mean that one "*is not holistic . . .but you're a bit more specific in your* *intervention*" (Elin, AG 7, p. 30). This statement was deemed contradictory by some participants, who rejected such a recommendation. Moreover, failing to address educational issues also contradicts the participants' assertion that teachers can in fact be considered as extended clients in paediatric OT practice, as discussed under Theme 1.

One participant suggested that a child should get different occupational therapists to address different issues, having "*a person for this difficulty, a person for that difficulty*" (Elin, AG 7, p. 31). However, another participant criticised this suggestion, pointing out that in such a scenario, "*the parents [would] start to get confused*" (Sarah, AG 7, p. 31). Indeed, on a number of occasions, the participants lamented how confounding it can be for the parents to have a number of professionals working with the child, fearing that different professionals may be giving mixed messages to parents. They deemed such fragmented practice as incongruent with client-centred concepts.

Arguably, some of the findings suggest that a clear understanding of what constitutes client-centred practice is lacking. One such instance was when one of the participants complained that after a number of sessions, clients (referring mostly to the parents) tended to identify a different concern that the therapist should work on, once they came to the point of discharge. The expectation was that the client would be discharged after a pre-determined number of sessions. "*I would say that he will have 10 sessions and that when we solve this issue he will be discharged.*" (Maya, AG 7, p. 24). This same participant gave a clinical example from her caseload, whereby the child had:

> *. . .started school . . .[and] the pre-writing [area] was not a concern because her [the mother's] main concern was toileting at that stage. Once he [the child] was toilet-trained this was not a concern anymore, so she found another concern.* (Maya, AG 7, p. 24)

The participant argued that the therapist would then "*need to re-start all over again*" (Maya, AG 7, p. 23). This was mostly seen as being a ploy used by parents "*just not to get discharged*" from OT services (Maya, AG 7, p. 24). Such reasoning seemed to contradict the idea that in client-centred practice, the intervention needs to constantly address the client's concerns and needs, which might change over time. Furthermore, having a pre-determined number of sessions may not align with client-centred practice, since not all clients would require the same amount of time to reach their goals.

Another instance of a discrepancy between participants' perceptions of what they thought they were doing and what they actually did, arose when the participants explained how they tried to discover what activities the child preferred to play with, by asking parents or by observing the child during free play. They stated that they tried "*to involve the child [during OT sessions] and to do activities that are meaningful for him*" (Reese, AG 1, p. 21). However, this intervention sought to reach the therapist's goals and not the child's (client's) goals. "*I am doing something that is meaningful for him, but I am achieving what I want, with things that are meaningful for him*" (Reese, AG 1, p. 21). Another participant described how this is at times unwittingly done.

> *Unconsciously we work on their [the children's] likings, after all. It's true that we are achieving our goals, the goals that we would have set with the parents, but at the same time, the activity, if you realise that he likes it you're going to work with it.* (Monica, AG 1, p. 17)

Such behaviour was seen as being client-centred, especially when working with a non-verbal child, such as a child with autism.

> *I will work on those activities that he [the child] likes. Eventually, I will start to use these activities for my benefit. For example, if I want to increase his sitting tolerance I will alternate between an activity that he likes and something that is maybe a bit more challenging. That is, I would be setting my goals, but at the same time I am putting the child first as well.* (Reese, AG 1, p. 20)

Although the ultimate aim of such practice seemed to be a genuine one, no reference was made to the therapist's attempt to try to include the child in goal setting. The participants considered it important to discover what was meaningful for the child in terms of what will be used during the session but they admitted that they were not trying to find out the child's goals. Indeed, one of the participants stated that although the therapists occasionally tried to involve children, the latter were not involved in all the stages of the OT process.

> *Still, I feel, speaking about myself, that . . .the children are more involved in that one hour session per se . . .I don't feel that we really involve them [the children] in goal setting and concerns. I feel that it is more the parents that we involve*. (Elaine, AG 1, p. 21)

Indeed, the findings clearly indicate that children are not being treated as clients and they are not included in goal setting. Such practice contradicts participants' stated belief that the child is the main client, as discussed under Theme 1.

In fact, most participants specifically stated that only the parents' goals were being addressed. "*At times it's like we take the children for granted, it's like we automatically ask the parents*" (Melody, AG 1, p. 11). "*We are focusing mostly on the parents' goals*" (Sarah, AG 2, p. 21). Some participants explained how they "*really underestimate the children . . .in particular those who are non-verbal*" (Melody, AG 1, p. 15). They mentioned that occasionally when the therapist worked on the parents' goals the non-verbal child would indicate that the latter were not meaningful for him. The child would then end up being "*disregarded*" (Melody, AG 1, p. 11). Ignoring the child violates the principles of child-centred practice.

The participants argued that whether they were being client-centred or not depended on whether it is the child or parent, who is considered the client. This issue was discussed under Theme 1. The findings seem to indicate that in some respects, the service is client-centred but not child-centred. This is because the parents' goals are addressed, not those of the child.

> *That's what I meant when I said that we are not client-centred. Now it's either the client group that we coincidentally have and that we see, because we see children between three and five and most of them have ASD [autism], so it's difficult as long as you don't have someone with Aspergers [high-functioning Autism] and you would*

> *know exactly. So it is very difficult with these children to ask them and . . .to set goals from the information that these children would have given you, due to either them being still young or because of their condition*. (Rylie, AG 1, p. 21)

The participants doubted how much they were allowing the children to voice their concerns and to decide what they wanted to work on in therapy. The participants showed concern that they "*are not even giving these children ever a choice and . . .a voice . . .in these things*" (Elaine, AG 1, p. 23). "*The voice is there. You have to allow them to use it*" (Melody, AG 1, p. 39). Some participants admitted that children were being involved in the OT session but not in goal setting and not even verbal children were being asked about their concerns/goals or about what they would like to work on. "*That is why I see it as if we're underestimating the child after all . . .[and] we're not giving him [the child] the opportunity*" (Monica, AG 1, p. 39).

One participant seemed to be suggesting that one might be client-centred or child-centred at some levels of the intervention but not at others.

> *I think, mostly, setting the goals would have to be with the adult, with the parent, with the teacher. Then to implement it, we have to then be more client-centred towards the child . . .knowing the interests so that you can get to the goal that the parent wants . . .to motivate the child to work . . .you know, so that is the way, I think, we need to be client-centred . . .in the way we maybe implement the goals*. (Elaine, AG 2, p. 10)

It was evident that deep down participants yearned to be child-centred. However, the way this notion was being applied in practice did not fully align with child-centred care.

> *At least you make it fun so that they [the children] are motivated to work on that [parents'] goal, rather than just imposing something on them and forcing them to do something, which is sometimes what people do. So that [is] where child-centred[ness] comes in, where . . .you are not completely child-centred because you can't really work on a goal the child has set, but at least working in a fun way where they enjoy

> *therapy to get to that goal . . .that their parents, or the school want . . ., that would be, sort of being child-centred, I feel, at this point* (Elin, AG 2, pp. 10-11)

The participants concluded that parents and/or parents and teachers were being treated as the main clients in the service that was being provided. This conclusion indicated that in practice the service is client-centred but probably not so child-centred. Such practice also belies participants' belief that the child should be the main client. The participants noted that parents and teachers were more concerned about children's handwriting and other academic difficulties than the children themselves. It was evident to them that children preferred play activities and activities that involve gross motor skills rather than academic tasks. However, the latter are what the therapists ended up working on during OT intervention, since they were addressing goals set by adults. One participant commented that the OTs tended to be "*so regimental*" and overly focused on academics. The participant added that "*there are children who don't have any difficulties but they are [simply] not interested in school*" (Gwen, AG 1, p. 28).

The participants expressed concern that if given a choice, the children might not choose to address academic issues. The participants felt that the service that they were providing was probably more meaningful to the parents than to the child, since only the parents' concerns/goals were being addressed. They felt that consequently, the need for OT was only felt by the parents and not by the child. They added that if children were treated as the main clients, they would probably not feel the need for the OT service that was being offered at that time. "*We would not see half of them [the children], or even three fourths*" (Arona, AG 1, p. 23).

The fact that one of the participants wistfully reported that they, as occupational therapists "*have to work on the mother's [goals], but with something that the child likes*" (Melody, AG 1, p. 41) shows that participants harboured a feeling of inadequacy and lack of belief in their practice. There was a conviction that working on the parents' goals without addressing those of the child was not the correct way to practise. Another participant gave an example of a former client of hers, a 9-year-old child, who was able to communicate well. The therapist would work on the mother's goals and this child would tell the therapist "*Why do I* *have to come here? I know my writing is horrendous and I think that's how it will remain*" (Rory, AG 2, p. 15).

The participants themselves cited some additional aspects of their services, which in their view did not align with child-centred or client-centred care. They reported that group intervention was being offered to some of the children, rather than individual sessions and that the therapists themselves were "*not a hundred percent satisfied*" with this (Faith, AG 3, p. 3-4). The participants were aware of the difficulty of reaching specific individual goals through group-based intervention.

> *It's nice to be client-centred and do individual goals with the child, but realistically [some of the children are seen] in groups. Well, it is useless sort of, to do specific goals, individual goals with the child, when all I have to offer is a group treatment!* (Faith, AG 3, pp. 3-4)

"*The ideal would be that if he [the child] has a problem . . .I target that in an individual session*" (Rylie, AG 4, p. 21). The participants were aware that the client may identify a goal or "*highlight a difficulty that we are unable to help with*" because of this (Rylie, AG 7, p. 11).

One participant expressed frustration that they could not help the parents and or child, since they could not provide the specific individual attention that the child required. She explained how she would have to tell parents "*We can offer you A, B, C, D. If the problem is E . . .for that, I can't really help you, good bye*" (Monica, AG 6, p. 8). Monica expressed how "*annoying*" that is for them. Another participant added that "*as a therapist, you don't feel very, very satisfied with the service you're giving, when a parent feels like you're just moving them along to the next service*" (Elin, AG 8, p. 9).

Whilst client-centred practice is based on the relationship between the therapist and the client, the participants regretted that they could not build a rapport with either the child or the parents. Participants attributed this to the low frequency of appointments. "*From our end, we don't really have consistency, here, to build that rapport*" (Elin, AG8, p.9). They claimed that it would be ideal for them to "*manage to build a rapport, a rapport with the child [and] with the family*" (Monica, AG 8, p. 4).

The consensus among participants was that applying the same goals for all children breaches fundamental OT principles, including child-centred and client-centred care. This was mostly reported to occur at schools and not at the OT clinic. Having "*the same goals [for the different children goes] against all our [values]*" (Monica, AG 1, p. 16).

Another participant also criticised her occasional tendency to end up following a routine, which she thought violated the principles of client-centred practice. "*I am so engaged in my work . . .at times . . .I end up stuck in a routine . . .then I say 'Wait, no, it's not [the way to go]*" (Gwen, AG 1, p. 19)

7.2.1: Perceived Challenges for the Delivery of a Child-Centred / Client-Centred Service

This subtheme relates to the challenges cited by participants when they tried to deliver a child-centred or client-centred service. The participants argued that the application of a child-centred or client-centred practice was particularly challenging in a paediatric OT setting, when compared to other OT settings.

The participants noted how in paediatrics, the child, who is considered to be the main client, never asks to be referred to OT, unlike in other OT settings. It is the parents or the teachers who ask for the child to be referred. One participant gave the example of a child who is referred to OT for handwriting issues. "*For this child, it's not him who would be seeing a difficulty in handwriting, and he comes here [to OT], so even from there it's not client-centred*" (Jade, AG 1, p. 31).

A child's unawareness of why they were referred to OT was seen as a challenge. "Sometimes, [when] the children who are referred here, . . .are asked 'Why did you come here? What is your concern?', sometimes they don't know how to answer" (Jade, AG2, p.8). They added that “The child does not know why [he] is coming to therapy . . .He was assessed and all, he came for the group sessions and yet, he doesn’t know why he was there for” (Arona, AG 2, p. 21).

The participants seemed to be confusing the children’s ability to identify the reason for referral with the ability to, or possibility for, identifying any concerns that they might harbour. The latter is what typically occurs in child-centred assessments. No reference was made to the use of child-centred assessments or outcome measures. No client-centred tools were being used with the parents or teachers either. This will be elaborated further under Theme 4.

The fact that at times, not even the parents may be aware of why their children were referred to OT, was perceived as an additional challenge. In such cases, it would be either the school, who would have referred the child, occasionally without discussing the referral with the parents, or the child would have been automatically referred as part of the organisation’s referral system. The therapists feel that how a child is referred to OT may have an impact on client-centredness.

Another identified challenge was the child’s parents’ low insight or being in denial about the child’s difficulties, so they may not identify the same goals as the therapists. An additional barrier to being client-centred, or namely, child-centred is the fact that children “*are minors. So . . .that is an issue why in our setting it's a bit more difficult to be client-centred*” (Rylie, AG 2, p. 23). The participants explained how children, who are referred to OT, tend to have complex problems which may affect the child’s development. These children may be non-verbal and they may also have cognitive difficulties. This was seen as exacerbating the challenge of being child-centred. This was once again linked to these children’s unawareness of their own difficulties and inability to identify their concerns. The participants also identified difficulties with obtaining information from very young children or from children with severe disabilities.

The participants felt strongly that limited resources were adversely affecting the delivery of a child-centred or client-centred care. The resources cited by participants include human resources, which was deemed a major challenge, time, equipment and facilities. "*Ultimately there are not enough people [occupational therapists] for the amount of children who need a service or who are referred*" (Elin, AG 7, pp. 31-32).

The participants reported that they were currently unable to provide the frequency of intervention that the child needs. Consequently, they admitted that they were mostly delivering a consultation-based service, and involving the parents and teachers as the main clients more than the children themselves. Moreover, due to the limited number of staff, the occupational therapists had to resort to group intervention to meet the demands for service, struggling to reach specific individual goals through group-based intervention.

The consensus among participants was that child-centred or client-centred practice was more time-consuming, so they lamented their limited preparation of child-centred activities and rushed therapeutic interventions stemming from time constraints.

> *I have an hour . . .I got [some activities which] I found with me for the session . . .[and] I have to work with the activities that I got now and that's it . . .If [the child] . . .is not interested in any of these, how will I get to see what he wants and how will I get to know what he likes?* (Monica, AG 1, p. 29)

The participants lamented the limited time available to select a variety of preferred activities for the child. "*Even just simply having to prepare a colouring sheet that you know he [the child] likes . . .[and that] he will be interested in . . .even that takes time*" (Elaine, AG 1, p. 40).

One of the participants highlighted the importance of getting to "*know your children well*" for the delivery of a client-centred service and child-centred outcomes to build a good rapport with the child during the assessment. However, this was felt to be "*a bit impossible at the moment*" due to the low staff-to-patient ratio (Maya, AG 7, p. 25). The therapist needs time "*to get to know more about the child*" (Melody, AG 1, p. 40). Currently two hours are allotted for assessment but the participants thought that this was not enough. "*The amount of human resources when compared to the demand, is very low, so I cannot afford spending more than two hours to carry out an assessment*" (Rylie, AG 3, p. 18). These time constraints limit the time needed to acquire information and build good rapport with parents and teachers as well.

One participant claimed that she felt that "*the child becomes the client . . .during the intervention*" (Arona, AG 2, p. 21) and not during the assessment, since the therapist has some more time to interact directly with the child during some of the group sessions, when compared to the more limited time available at the assessment stage. Despite the disadvantages cited regarding group intervention, the groups are offered more frequently (usually once a week) than the consultation sessions, thus allowing the therapist to build a better rapport with the child.

The participants also lamented the difficulty of involving even the parents when they were working under pressure, as they ended up planning and conducting the intervention based on what the therapist thinks would be helpful for the child. Therefore, parents' concerns might not be addressed. Moreover, the participants reported not having enough time to meet as a team with the other professionals, who would be working with the child. Collaboration and communication were deemed to be important for the delivery of child-centred and client-centred care.

Additionally, the participants complained that the limited choice of activities and equipment available could restrict the service that they provided. The participants strongly criticised the restrictive therapy environment. Participants reported problems with letting the children that they were working with play freely since the clinic space had to be shared with a number of therapists and their respective children (clients). The participants complained that they could not assess some personal activities of daily living, such as feeding and dressing, due to the lack of privacy and lack of equipment or space available. These constraints were identified as important areas that occupational therapists should address. "*It's not really appropriate [to work on dressing] in this [these] rooms, because people come in and out of the room all the time*" (Maya, AG 3, p. 18). A split service, that is omitting three important OT areas, namely play, feeding and dressing, cannot be considered a child-centred or a client-centred one.

The participants were highly critical of "*the [limited] set-up and the equipment that we [they] have*" (Ruby, AG 8, p. 14), insisting that the lack of space and equipment hindered their attempt to provide a specific type of intervention for some children. Issues related to privacy were also reported. The participants were particularly frustrated that "*the changes that . . .[were] made [to improve the physical environment] . . .[did not] help . . .but [instead they created further problems]*" (Monica, AG 7, p. 26). Such changes included the installation of vertical blinds to separate a large room into cubicle-like spaces, which were reportedly made without consultation with the therapists. Such a solution was "*imposed, without thinking about how this is going to affect the child, the parents, [and] the therapists*" (Elin, AG 8, p. 16). The aim was to address privacy issues, but the vertical blinds only address "*visual privacy*" (Rylie, AG 7, p. 27). One participant recounted an episode where she had a session with a child in one cubicle and the child's mother could identify her neighbour, whose child was being seen in another cubicle, by listening to the neighbour's voice. Another therapist added, "*Or you hear something like 'That boy is more severe than mine, no?'*" (Monica, AG 7, p. 27).

This scenario was seen as a serious breach of privacy, which the participants identified as running counter to child-centred or client-centred practice. "*There is research against it that you shouldn't put flicking curtains for children with autism and we put them?*" (Gwen, AG 7, p. 26). Another participant added:

> *I have an obsession with the curtains we have . . .and I really want to chop them off . . .My child [client] gets into it, he then bangs his head against the wall because he tried to get into the curtain*. (Monica, AG 7, p. 26)

Another two participants cited two instances of parents, who were able to share their real concerns, after a number of OT sessions, only when an appropriate room was available. The participants reported how parents may refuse to open up and share their personal problems, because of their fear of being overheard by other persons in a setting that does not inspire confidentiality.

Another point that was mentioned regarding the lack of privacy was the inappropriate storage of equipment used during the OT sessions. At the time of the study, equipment was stored in one of the clinics.

> *Storage should be a room in itself. You cannot go over other people's sessions, just to get the toys you need. It's rude. I can't help it. I have to [do it], but it's rude . . .[What] if that's the moment the person has just started to open up on something and someone barges in [to get some equipment from the room]?* (Monica, AG 8, p. 16)

Apart from limited resources, participants acknowledged that it is a challenge to be client-centred in a team of other members, who do not necessarily share the same values. They were referring mostly to the educational setting, where the same goals were being set for different children. The participants believed that "*How much client-centred you can be, depends on other professionals too*" (Ruby, AG 1, p. 35) "*and [on] how client-centred other professionals are*" (Gwen, AG 1, p. 36).

Finally, one of the greatest challenges to the application of a child-centred or client-centred practice is the perception that change is beyond participants' control. "*They are not things that we can control*" (Melody, AG 3, p. 5); "*It's the system*" (Sherly, AG 3, p. 5). The participants were fatalistic, believing that it was beyond their control, since they were not being involved in decision-making regarding the service that was being offered.

One participant felt that it would be easier to start a new paediatric OT service "*from scratch*" based on child-centred and client-centred principles, rather than applying these principles to their service, stating that "*at this point, we are so swimming in deep seas*" (Monica, AG 7, p. 22). This participant felt that therapists were being "*looked upon as if we were resisting anything new*", rejecting this accusation and adding that there were a number of issues that needed to be addressed before the implementation of a child-centred or client-centred service can be made. She added that "*this situation is very sad*" as they "*would like to make it so much better*" (Monica, AG 7, p. 23) though she was doubtful given that some fundamentals were missing.

7.2.2: Prerequisites for the Delivery of a Child-Centred / Client-Centred Service and Attributes of Such a Service

This subtheme describes some requirements that the participants identified to be necessary for the delivery of a sound child-centred or client-centred service. It includes characteristics which the participants associated with child-centred or client-centred practice.

As aforementioned, the participants acknowledged the need for therapists to be clear about the identity of the client. “*Which goal are you going to start [addressing] first, the child’s [or] the parents . . .? That is why it's important to know who is the client*” (Melody, AG 2, p. 6). Whilst participants believed that the child is the main client, they acknowledged that the therapist cannot work solely with the child. The parents or possibly the teachers would also need to be involved, as clients. “*You have to work with them, but for the benefit of the client, of the child*” (Faith, AG 2, p. 19)

Since the general consensus among participants was that the child should be considered the main client, they concurred that the child should be included in goal setting. They explained how the therapist should try to involve the child as much as possible, even if the child is non-verbal or very young. Therefore, there is a need for appropriate assessment tools which can be used with the range of clients that are seen in a paediatric OT setting. Furthermore, the participants agreed that the intervention needs to be specifically designed for the client, for it to be considered as child-centred or client-centred. The participants insisted they should work on what they, as therapists, think is important for the child rather than impose their agenda on the child. “*If you don’t work on . . .what he [the child] likes finally, you will never see a result*” (Monica, AG 1, p. 27). The participants agreed that OT intervention should be based on the child’s “*needs and . . .wishes*” (Sarah, AG 2, p. 4). Addressing the child’s goals and what is important and meaningful for the child, would promote child-centred and client-centred care, and also enable OT intervention to achieve favourable outcomes.

The participants recommended that the therapist, parents, teachers and the child collaborate and work towards the same goal. When the goals are different, the therapist needs to take on board all parties involved. In order to be client-centred, the participants recommended that a balance be sought between the child's goals and desires, and those of parents and teachers.

An additional requisite that was cited was sufficient time. The participants recommended that more time be allocated at assessment stage to get to know the child. More than two sessions may be needed to see both the child's and parents' concerns. If need be, there should also be time to collect information from the school. "*During the first session the child will not have a good rapport with you that he will be at ease to say his concerns, difficulties, etc.,*" (Faith, AG 3, p. 6). The participants reported that more time is required to be dedicated solely to the child, to build "*that level of rapport with the child [since the latter] takes time [and] for them to trust you to give you . . .information that maybe is opposite to their parents'*"" (Elin, AG 2, p. 15). One participant even recommended that less time be given to parents on initial assessment, "*allocating that time to the child*" (Sarah, AG 2, p. 7), thus enabling therapists to be more child-centred.

However, some participants acknowledged that apart from children, parents also need:

> *more time …to open up . . .[and to feel] comfortable to speak to me about certain things . . .You should not be limited to your stopwatch, which says one hour and that's it . . .You need to have the flexibility to be able to spend time on the parents who need it more . . .*(Elin, AG 8, p. 19)

Some participants suggested that in order to maximise both child-centred and client-centred practice, the parents could possibly be interviewed on their own (without the child being present). The parents might need to disclose issues which would not be appropriate to discuss in front of the child. Indeed, building a rapport with the parents was identified as equally important. More time was also recommended for the therapist to be able to plan an OT session and use the activities planned "*as opposed to [using] what you find at that time*" (Elin, AG 8, p. 26).

Besides time, the participants recommended additional OT staff to meet the demand for services. They explained how at the time of the study there were "*not enough people for the* *amount of children who need[ed] a service or who are[were] referred*" (Elin, AG 7, pp. 31-32).

The participants believed that to ensure client-centred service, it should be left to the parents to decide whether they would like their child to be referred to OT services, rather than having the child automatically referred to OT as part of a referral-to-all-services protocol. Since all participants were convinced that a good therapeutic rapport with the client is an integral part of a client-centred services, they believed that the parents would be more willing to engage with the therapist and participate in the OT process if they feel the need for the services, vis-à-vis when they are forced to receive services. The issue of possible self-referral was mentioned by one of the participants as being more client-centred than the current system, which is overly based on the medical model.

The participants believed that client-centredness should ideally be a continuous process across services. "*Ideally client-centredness should continue. It should not start and stop*" (Rylie, AG 1, p. 16). However, there were occasions when client-centredness was being found not to be continuous across the same OT process that is being provided, such as having children or clients included in the intervention but not in the assessment or goal setting part of the process.

The participants identified the need to deliver one-to-one sessions to the children that they see, to be able to target their needs. They also noted the importance of having a suitable environment to allow the therapist to set the goals with the child during assessment. *"On assessment I think you need . . .an environment that is going to stimulate the child further to . . .bring out . . .his goals*" (Sarah, AG 3, p. 4). A suitable environment was also recommended for intervention, mostly for privacy's sake. Privacy was indeed seen as being fundamental. Different OT sessions should ideally not be conducted in a shared room. Having a private area would allow the therapist to assess and work on personal activities of daily living (ADLs), such as dressing, if the latter are a concern for the child or the parent. Such an environment would also allow the parents to discuss sensitive problems with the therapist. Moreover, the participants indicated that there is a need for better equipment and resources so they would be well equipped to address the needs that are identified by the clients.

Furthermore, one of the participants suggested that having the opportunity to observe the child in his setting would provide “*much more fruitful information*” and enhance child-centred or client-centred practice. “*The ideal observation of the child would be in his setting, not in a clinical setting. [It can be the] home [or] school . . .or where the concerns are*” (Rylie, AG 8, p. 15). The participants mentioned how children behave differently in different environments. If there was more time available, the therapists would be ideally placed to observe the child in different contexts and provide intervention and recommendations accordingly.

The consensus was that the service needs to be built on honesty. Honesty was identified as missing in other paediatric health or education services, which the participants have classified as not being child-centred or client-centred. A specific reference was made to being honest when delivering information to the carers of the child, including the breaking of bad news.

Finally, the participants recommended “*a vision for paediatric [OT] services in Malta*” (Rory, AG 3, p. 4). Moreover, the participants noted the interlinking of different services, such as “*social services, school-based services, and all services have to . . .work together*” (Rory, AG 3, p. 4). The participants criticised the lack of cooperation and lamented the lack of vision for the OT department.

> *I see that as the main challenge, the fact that our service is not well defined. We are trying to be everything, trying to fit everyone and everything, and . . .there is not a lot of planning in that regard*. (Ruby, AG 8, p. 28)

7.3 Conclusion

This chapter has addressed issues related to child-centredness and client-centredness practice. The findings of Theme 1 have indicated a lack of clarity regarding the identity of the client in a paediatric OT setting. The issue of client-centredness was found to be more complex in this area. In addition to the child, who may be considered the primary client, the participants remarked that the parents and the teachers also need to be involved. In fact, having significant others as clients, apart from the child, distinguishes paediatric OT from OT intervention in other settings.

The participants mentioned communication challenges, issues related to age and complex disabilities, as well as parental expectations, that all impact the ability to be client-centred or child-centred. The findings, therefore, indicate that being client-centred can be more challenging in a paediatric setting than in another OT setting. Occupational therapists are on the horns of a dilemma about who should be regarded as the primary client. This is especially the case when the goals of the various clients are in conflict.

This chapter has also explored some contradictions between what is considered to be ideal practice and what is actually being carried out in relation to the delivery of a child-centred and client-centred service. Findings from Theme 2 addressed challenges that participants were perceiving to be limiting the delivery of a child-centred or client-centred practice and the prerequisites that the participants identified as being important to allow such practice. Despite the current limitations, being child-centred and client-centred was seen by all the participants as being of utmost importance.

Chapter 8: Findings Related to Outcome Measures

This chapter discusses the themes related to outcome measures. It addresses the therapists' understanding of outcome measures and their perception of the qualities and attributes of outcome measures. It looks at the current application of child-centred outcome measures in the setting where the study was carried out, outlining the participants' perceived benefits, challenges and prerequisites related to the use of such tools. Finally, a number of child-centred outcome measures are reviewed, in terms of their applicability to this paediatric service.

8.1 Occupational Therapists' Understanding of Outcomes and Outcome measures

This theme describes how the participants define outcomes and outcome measures and the properties that they assign to outcome measures. It also incorporates qualities of occupational therapy-specific outcomes and outcome measures, and those that are specific to paediatric occupational therapy. The findings related to these issues are discussed under three respective subthemes.

8.1.1 Occupational Therapists' Perception of the Qualities and Attributes of Outcomes/Outcome Measures

This subtheme explores the characteristics that participants associated with outcomes and outcome measures, and deals with their understanding on these matters. It outlines some of the ideal properties that the therapists identified as being important for an outcome measure for this paediatric setting.

The participants described outcomes as a form of measurement of intervention. An outcome was described as being "*a result*" (Reese, AG 1, p. 5), "*a result of something . . .[that the OT would] have worked on*" (Sarah, AG 1, p. 6). There seemed to be consensus that a measurement should be taken "*before and after*" (Sage, AG 1, p. 6) any intervention. "*I think that there should be a baseline before, so that you can compare*" (Gwen, AG 1, p. 6) .

A similar description was given to an outcome measure. The participants noted that the outcome measure should be one that the therapist can "*repeat*" (Jade, AG 4, p. 4; Ruby, AG 4, p. 4), meaning that it can be re-administered after intervention. The participants provided several examples of how an outcome measure can be re-administered. Some showed a preference for solely measuring the area that was targeted during the intervention on re-assessment, be it, for example, "*handwriting*" or "*ADL*" (Melody, AG 3, p. 11). On other occasions the participants indicated that the whole outcome measure would be repeated once the intervention is completed.

An outcome measure was seen by one of the participants as laying the foundation for future work with the child. While on one hand participants were stating that an outcome measure is designed to be repeated, on the other hand, one of the participants believed that they could possibly use such a tool "*for assessment purposes only, not as an outcome measure*" with children who are over 5 years old (Faith, AG 6, p. 12). This shows that there may not be a clear understanding of what an outcome measure is, with possible conceptual confusion between assessment and outcome measures. This same participant also suggested that the outcome measure "*can be used as a screening tool*" (Faith, AG 6, p. 15).

Different forms of outcome measures were deemed feasible. The participants explained how an outcome measure can be in the form of "*interviews, questionnaires [or] observations*" (Elin, AG 3, p. 9). Participants noted that an outcome measure in the form of questionnaires could also be filled in by the parents or teachers, recognising that an outcome measure should take "*into consideration the parents' and teacher's views*" (Melody, AG 5, p. 22). Concurring that an outcome measure should be client-centred, participants acknowledged that self-reports, which are filled in by the clients themselves including children, would render such tools client-centred or child-centred.

A number of participants suggested that an outcome measure could be completed, or "*fill[ed] in . . .by the parents and the teachers . . .after . . .a block of intervention sessions*", thus preventing the administration of the outcome measure from being "*be a burden for the service*" (Maya, AG 3, p. 8). Another participant suggested that the outcome measure can be completed by the children themselves, after receiving OT intervention. Various forms of self-reports were identified as potential client-centred or child-centred outcome measures, although some of the recommendations that followed were not congruent with child-centred or client-centred concepts. These discrepancies will be addressed below.

Melody (AG 3, p. 9) highlighted the importance of a clear, intelligible and easy-to-be-filled-in tool, if parents will be completing the outcome measure. She noted that it might be easier for the parents to answer questions related to the child's general participation in ADLs rather than more detailed observations, such as the child's pencil grip.

Five participants (Jade and Rylie, AG 7, p 7; Monica AG 7, p. 8; Rylie and Monica, AG 8, p. 22; Melody and Sarah, AG 8, p. 22) added that outcome measures should use lay terms and "*not so technical words*" (Jade, AG 7, p. 7). This would enable children with disabilities to be assessed and parents with a limited educational background to complete such measures, thus making the outcome measure more child-friendly and client-friendly.

"*Hands-on*" was mentioned as another way of measuring outcomes. "*Before we mentioned hands-on as one of the properties and hands on is that we see the child doing it [the activity being assessed]*" (Melody, AG 4, p. 16). The degree to which such an outcome measure would meet child-centred or client-centred principles is debatable. Indeed, participants themselves had serious doubts about this, since such methods exclude the client's views. There seemed to be consensus regarding the idea that a therapist-administered hands-on outcome measure might fall short of being child-centred and the two options were actually seen as being on a different end of a continuum: "*If it is child-centred, or . . .if it is hands on*" (Faith, AG 4, p. 3).

Given that occupational therapists work mostly with children who have disabilities, the participants noted how an outcome measure should ideally be suitable or adaptable for use with children with various disabilities, including cognitive difficulties. One such adaptation that was mentioned was the use of visuals. "*It would be good . . .[for the outcome measure]* *to have pictures*" (Elin, AG 4, p. 32) especially "*real pictures*" (Melody, AG 5, p. 24). This would make the outcome measure more "*adaptable for . . .different client groups*" (Elin, AG 7, p. 4).

Additionally, the participants noted how an outcome measure should be applicable to different contexts or settings so that it could provide information from different contexts , namely home and school, thus making the tool more versatile. The participants also mentioned the possibility of having different outcome measures to provide choice when the most suitable one for a given situation is to be selected.

Standardisation was seen to be a crucial component. The participants reported that they would always look for the "*psychometric properties*" of an outcome measure before using it (Rory, AG 5, p. 7). Indeed, two specific features that participants closely associated with an outcome measure were "*reliability and validity*" (Rylie, AG 4, p. 2; Melody, AG 4, p. 29).

The participants emphasised that an ideal outcome measure for their service should be scored and "*maybe having numbers*" (Maya, AG 3, p. 9). Most participants seemed to be aiming for a norm-referenced outcome measure, so the therapist "*can score actually according to . . .[the child's] age*" (Denise, AG 3, p. 13). Expecting "*normative data*" (Ruby, AG 4, p. 3) may indicate the lack of understanding of client-centredness, given the difficulty of comparing a child's or client's unique values and goals to any norms. This view contrasted sharply with another participant's belief in individualised child-specific outcome measures. The latter aligns with child-centred and client-centred practice.

Regarding scoring, the participants expected an outcome measure to be objective. However, the findings seemed to indicate some therapists' poor and confused understanding of the terms "objective" and "subjective" together with reliability issues. The participants seemed to be mostly concerned with the ability of the tool to provide a reliable score, although this was not always labelled as such. The way in which they used the term "subjective" seemed to be more related to reliability. Some of the non-subjective features that were expected to merge from the outcome measures fly in the face of certain child-centred or client-centred concepts that the participants themselves had identified elsewhere throughout the discussions. These contradictions (e.g. negatively viewing subjectivity) were discussed under Theme 2. The findings indicate a constant preoccupation with the need for therapists to obtain accurate information. One participant recommended that the outcome measure be "*very specific*" and that it address a "*very observable behaviour that cannot be misinterpreted*" (Elin, AG 3, p. 15).

Participants' concern about possible incongruity between parents' and teachers' views makes therapists feel undecided about what they should do when an outcome measure is administered to both. "*At times the parents tell me something, I go to school and it's a totally different child. So how can I base my outcomes of therapy on what the parent is saying?*" (Elaine, AG 3, p. 15). Another participant mentioned clinical scenarios when the parents might become more aware of the child's difficulties as they progress through therapy. "*So what do I do with my outcome measure? Initially she [the parent] told me that he [the child] was able to do . . .[a particular activity]. Is it going to show that my therapy is causing a regression?*" (Elin, AG 3, p. 15). Feelings of frustration featured prominently in participants' narratives. The solution that was proposed for this dilemma was that the therapist "*should be doing the outcome measure*" (Elin, AG 3, p. 15). Once again, this recommendation runs counter to having self-reports, and violates other principles of client-centred care.

The uncertainty, stemming from the presence of different concerns expressed by different parties was strongly in evidence. This indecisiveness apparently supported a possible lack of understanding of what being client-centred entails, as discussed under Theme 2.

The "*time to administer*" the outcome measure was considered to be particularly important too (Taylor, AG 4, p. 2). "*A quick . . .outcome measure, not [a] lengthy [one] . . .Ideally it would be an outcome measure that collects information but in a quick manner, so it's not too time consuming*" (Rylie, AG 3, p. 8). Another relevant factor that was considered essential was "*how easy it is to score and to administer*" (Elin, AG 4, p. 2) the tool. Moreover, the interpretation of the scores was also expected to be easy. Two participants highlighted the importance of "*clear and concise [scoring sheets]*" (Sarah, AG 4, p. 3; Melody, AG 5, p. 23).

Participants also recognised the need for an outcome measure to be based on assessing activities culturally relevant to Maltese clients (e.g., skiing is not assessed since it does not snow in Malta). They also recommended that ideally the outcome measure should be translated into Maltese or at least administered in Maltese *ad hoc* by the therapist.

Lastly, the participants recommended that the affordability of an outcome measure should be considered. "*The cost*" was seen as an important feature of an outcome measure, given limited resources (Faith, AG 4, p. 3). The need for training was also seen to be a key feature that a therapist should keep in mind, before considering the use of a specific outcome measure as this will impact the overall cost.

8.1.2 Occupational Therapists' Perception of the Qualities and Attributes of Occupational Therapy -Specific Outcomes / Outcome Measures

This subtheme deals with qualities, which the therapists attributed to outcomes and outcome measures that are specific to OT. Firstly, the participants demanded that the outcome measure be primarily "*in line with the CMOP[-E] model*" (Melody, AG 5, p. 24). This is the overarching OT model that was adopted by Maltese OT practice. All the participants agreed that OT-specific outcome measures should address functional performance. Various words were used to describe this feature, including "*function*" (Monica and Sage, AG 1, p. 6; Maya, AG 3, p. 8), "*occupation*" (Elaine, AG 1, p. 6), and "*level of activity*" (Monica, AG 1, p. 6). "*The ultimate aim is always the function*" (Rylie, AG 3, p. 11) since this "*is what makes us occupational therapists*" (Rylie, AG 7, p. 21).

The participants noted that an OT outcome measure might also address performance components and skills that are related to function, but the therapist should always "*start with function*" (Elin, AG 7, p. 28). One participant warned that focusing too much on the performance skills might lead to confusion about the OT's role. This issue will be discussed under Theme 6.

8.1.3 Occupational Therapists' Perception of the Qualities and Attributes of Paediatric Occupational Therapy-Specific Outcomes/Outcome Measures

This subtheme describes the qualities which the therapists attributed to outcome measures that are specific to paediatric OT. The most important feature discussed was the outcome measure's suitability to be used with a child, mainly whether it resembles a self-report, which can be filled in by the children themselves, independently or with assistance. Since in paediatric OT practice the therapist cannot work solely with the child, participants also identified the need for the outcome measure to be able to collect information from the parents and possibly teachers too.

Moreover, the participants claimed that paediatric OT outcome measures should look at the child's "*performance [both] at home and at school*" (Faith, AG 1, p. 6). The outcome measure would address the "*everyday things, like independence, self-help skills . . .the activities of daily living [and] the life of the child*" (Arona, AG 1, p. 6). Since children develop as they age, one participant noted that paediatric outcome measures should be able to address "*how he [the child] is functioning according to his age*" (Denise, AG 1, p. 7). Similarly, another participant highlighted the importance of a developmental approach: "*What we look at, is more the occupational development of the child, from when he is born until he is still called a child*" (Ruby, AG 1, p. 7).

Since play "*is a primary occupation for a child*" (Ruby, AG 1, p. 7), "*play . . .is one of the main areas that needs to be tackled*" when working with a child (Maya, AG 2, pp. 13-14) and in the measurement of outcomes. Nevertheless, some participants noted that in practice, the therapists tended to focus mostly on the child's academic performance, ignoring play and other areas. "*Play does not exist, leisure does not exist, family does not exist. Nothing. Just being able to progress at school!*" (Elaine, AG 1, p. 29). One of the participants explained how by addressing play, the therapist can even use the information obtained from the measure to educate the parents or teachers about this area. Most participants explained how allowing the child to participate in free play would also enable the therapist to "*observe what he [the child] likes . . .[and what] he prefers . . .so you try to include these things during* *the intervention sessions*" (Maya, AG 2, p. 12). Consequently, OT practice would be more child-centred.

Last but not least, the issue of holism was mentioned regarding attributes of a paediatric OT outcome measure. The participants stated that outcome measures should look at the child as a whole and should address "*the child's life*" (Arona, AG1, p. 7). Paediatric occupational therapists "*see the child globally*" (Monica, AG 1, p. 25). Since OT outcome measures should be holistic, one participant explained that outcome measures should also address the child's participation in sports and similar physical activities, which tend are often overlooked. Additionally, the participants highlighted the importance of addressing the child's social interaction in a paediatric outcome measure, such as the child's "*interaction with his parents, with other children at school [and] with his siblings*" (Ruby, AG 1, p. 7). "*When we say occupational therapy and function, there is a lot we need to focus on. . .It includes education, play and self-help*" (Reese, AG 7, p. 29).

8.2 Applying Child-Centred Outcome Measures

This theme deals with a range of issues related to the application of a child-centred or client-centred outcome measure. It looks at the current OT practice in this setting, with respect to the use of outcome measures, and the potential benefits of such measures. Moreover, this theme incorporates perceived challenges and prerequisites related to the use of a child-centred or client-centred outcome measure.

8.2.1 Current Occupational Therapy Practice in this Setting (with Respect to Outcome Measures)

The participants reported that at the time of the study the outcome of OT intervention was not actually being measured. "*There is no[thing] formal*" (Rylie, AG 3, p. 11). According to the participants, no formal or standardised outcome measure was being used. "*Documentation helps to remember obviously how the child started and how he progressed, but it's not something standardised*" (Sarah, AG 3, p. 12). On some occasions, such as in handwriting groups, non-formal pre- and post-intervention methods (such as copying a sentence to observe handwriting) were used to observe the outcomes. Clinical observations were also occasionally used (for example, after sensorimotor groups).

With younger children, the therapists informally ask the parents how children are functioning. Such "*parental interviews*" (Rylie, AG 3, p. 17) are used mostly to collect information and not necessarily to measure the outcomes:

> [When issues] *are related to the school, you do a school visit at the beginning of the year, you attend the IEP [Individual Education Plan], and you set certain goals with the teacher, LSA [Learning Support Assistant], INCO [Inclusive Education Coordinator] and . . .[other school professionals], and then at the end of the year they have another IEP and you see the goals, you see whether they were achieved or not*. (Reese, AG 3, p. 18)

Participants added that standardised assessments were occasionally administered to the children, but these were not used as outcome measures, that is, they were only used as part of the OT assessment and not re-administered after intervention. "*It's mainly being done to assess not as an outcome measure*" (Maya, AG 3, p. 13). The findings seemed to indicate a possible confusion between the concepts of assessment (standardised assessments) and outcome measure. Some of the participants mentioned the DASH[7] (Barnett et al. 2007), Movement ABC[8] (Henderson et al. 2007) and the Peabody[9] (Folio and Fewell 2000) as being outcome measures. Tellingly, another participant argued that "*I don't think that these are outcome measures*" (Rory, AG 3, p. 14).

Moreover, none of the said tools which were available at the setting, at the time of the study, measured function or occupational performance. Although the participants identified function as being an important area that outcome measures should address (as discussed in

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[7] The Detailed Assessment of Speed of Handwriting, known as the DASH, assesses speed and legibility of a child's handwriting.

[8] The Movement Assessment Battery for Children, known as the Movement ABC, assesses a child's motor impairment.

[9] The Peabody Developmental Motor Scales, known as the Peabody, assesses a child's gross and fine motor skills.

Theme 3), the participants acknowledged that this was not being addressed at the time. "*Focusing on occupation . . .is important [but] we do not practise it now*" (Rylie, AG 7, p. 21).

Moreover, the tools available lack the properties or characteristics that were identified by the participants themselves. Indeed, following discussion, the participants acknowledged that they "*cannot measure the outcomes of therapy with these kinds of tools*" (Elaine, AG 3, p. 15).

8.2.2 Perceived Benefits for Using an Outcome Measure

The participants agreed that the use of an outcome measure can benefit the OT service. The participants seemed to agree that "*an outcome measure is always a plus*" (Rory, AG 3, pp. 6-7). The need for OT services to be more efficient was highlighted by participants. The use of an outcome measure could assist the participants to achieve this aim.

"*With an outcome measure you can actually measure the quality of work*" (Gwen, AG 3, p. 6). The participants described how an outcome measure can also assist with auditing and to prove the effectiveness of OT. Moreover, it can justify the need for additional services or human resources - a shortcoming cited in all action group meetings and discussed in the previous chapter. "*It would help even auditing and asking for more services, for more human resources*" (Rory, AG 3, pp. 6-7).

A client-centred outcome measure can help in identifying the occupational issues that are important for the client. "*It would give you what is important*" (Ruby, AG 6, p. 15), "*what is important*" (Arona, AG 6, p. 15). A client-centred outcome measure would also "*direct us to what the parents and what the teacher wants*" (Rylie, AG 6, p. 15). Having a child-centred outcome measure would direct the therapist to address only those areas that are meaningful for the client and "*that will be time efficient*" (Rylie, AG 6, p. 15), thus eventually saving time.

The participants were aware that the use of an outcome measure "*could help with goal setting*" (Elin, AG 8, p. 28). The participants mentioned how a child-centred or client-centred outcome measure can assist them is focusing on function. “*In relation to setting goals, it [the outcome measure] can help [for the goals] to be more occupation-based*” (Elin, AG 8, p. 26).

An outcome measure was also thought to improve the assessment process. Clients “*will just get a good assessment*” (Maya, AG 6, p. 10). The participants spoke highly of the fact that the therapist would be better placed to add recommendations, since the latter would be child-/client-specific. However, this benefit was associated only with situations when the outcome measure is used on assessment only. “*It would not be for intervention, but just to do proper recommendations*” (Maya, AG 6, p. 10). This contradicts the participant’s own description of the outcome measure as being used before and after intervention.

The use of an outcome measure was also thought to assist in planning intervention services and in setting criteria for participation in groups. Children could be placed in groups depending on the concerns that result when the outcome measure is administered. This would lead to “*more uniformity*” among the children, who are in a group intervention session, since children in a particular group would have similar difficulties (Rylie, AG 6, p. 11). “*There are situation[s] where we cannot offer [a specific service that the child needs] . . .but at least what we offer would be better*” (Rylie, AG 6, p. 11). Furthermore, using a good outcome measure was thought to identify clients who are truly in need of OT services, by identifying those with participation challenges.

8.2.3 Perceived Challenges for the Use of a Child-Centred or Client-Centred Outcome Measure in this Setting

The participants identified a number of challenges that they felt could affect the use of a child-centred outcome measure and possibly even a client-centred one.

The participants questioned the suitability of using an outcome measure for the current service that was being provided. “*The work pressures that we are under . . .might make it harder for us to use it*” (Gwen, AG 3, p. 6). Moreover, doubts were cast about the largely consultative nature of the service being offered to young children and the low frequency of sessions. The participants seemed to believe that progress depended solely on providing children with one-to-one intervention and not on consultation at a low frequency. They felt that a child's progress might stem from other interventions or due to the work of carers or other professionals and not as a result of the OT intervention being provided. The participants noted that they might be measuring "*the child's improvement . . .[and] not [changes due to] the therapy that we are doing*" (Elaine, AG 3, p. 14). This was seen as a challenge. The participants seemed disappointed that an outcome measure might not indicate what caused the improvement, be it the OT intervention or any other external factor.

> *I think that because of the lack of resources and the frequency that we see the children [with], it is very difficult to have an outcome measure at this stage because you are very dependent on what the parents do at home or what the school does . . .so there are a lot of variables that are not under your control. So how can you really have an outcome if you are on a consultation basis and the people [that] you are consulting with . . .are not carrying [out the] . . .treatment [that you recommended]? . . .Maybe at this stage it is difficult to have an outcome when the frequency of sessions is not block.* (Elin, AG 3, p. 8)

One participant cast doubt about the feasibility of having the outcome measure administered to each client, attributing this to the possibility that some clients might not register any improvement with intervention. This raises questions about this participant's understanding of outcome measures. "*I think it will be very unrealistic to expect that every person has this outcome measure and that every person is going to improve*" (Elin, AG 3, p. 15).

The participants were aware that group intervention cannot "*be that specific*" to address individual child-centred or client-centred goals (Melody, AG 4, pp. 18-19). This quotation puts this issue in a nutshell:

> *We offer only groups for 5 pluses, one of the biggest concerns would be that the assessment [outcome measure] would highlight a difficulty that we are unable to*

> *help with. So that would put a very bad light on the service per se, so it will . . .be working against us*. (Rylie, AG 7, p. 11)

The participants discussed how the use of an outcome measure could help therapists identify important areas of concern for the child (and family), though they discounted the possibility of addressing these concerns in group intervention, since groups tend to target general issues rather than specific individual concerns. They discussed a clinical example: "*Let's say . . .[the outcome measure] will highlight . . .[that the child] has difficulty with cutlery and only a session [one of the series of group session] will focus on that"* (Faith, AG 4, p. 19). Participants were concerned that only one or a few sessions might end up being relevant for a child, if they would qualify for group therapy services, as opposed to one-to-one sessions. *"If someone has a problem with the use of cutlery, what am I going to do? List him for the ADL [group] programme and out of 10 sessions . . .only two of them would be really relevant to him?*" (Rylie, AG 4, p. 19). "*It would not be worth it for him [the child] to come just for two sessions*" (Rory, AG 4, p. 20).

One participant considered it a "*waste of time*" to do an outcome measure if they were to send the children for group intervention, where their specific needs might not be met (Arona, AG 6, p. 6). According to the participants, "*the fact . . .that there are no individual sessions [for the over 5 years' age group] does not make it so . . .practical and useful here at the moment*" (Rylie, AG 4, p. 19). When confronted with the fact that in the absence of an outcome measure, they were already identifying issues during assessment, which they could not directly address, the participants warned that the use of a child-centred or client-centred outcome measure would exacerbate such problems.

The fact that parents were not always aware of why they were referred to OT was seen by the participants as an additional challenge to the implementation of an outcome measure. The participants reported that some children are referred to OT by the school. When therapists ask the parents about their concerns, during assessment, some common replies that the therapists receive are: *" 'I do not see a problem' or 'I have no concerns' "* (Monica, AG 6, p. 8).

The participants highlighted that some parents encounter difficulties in identifying their child's occupational concerns. The participants seemed to be concerned about parents' inability to voice their concern, believing that some parents might require more prompting for them to "*open up and say what concerns them. If you prompt them you can narrow down . . .their concern into an occupation-based problem*" (Faith, AG 8, p. 17). Findings seemed to indicate that to ensure a client-centred outcome measure, some participants were expecting parents to have their concerns ready at hand and lose no time in sharing them directly with the OT. Participants seemed to be unaware of the fact that a child-centred or client-centred outcome measure may in fact help parents or children identify their concern, since it would address different functional areas and the questions asked would be relatively easy for the parent (or even child) to understand.

The consensus among participants was that the limited resources they were experiencing may affect the implementation of a child-centred and client-centred outcome measure. The limitations were described in terms of human resources, time, large caseloads, and the environment. Another cited constraint was the lack of outcome measures available in this setting.

The time factor in the use of resources was a major concern. Indeed, the participants stressed the importance of quick administration of an outcome measure. Concerns were raised about the use of an outcome measure as it "*may take more time than we actually have*" (Gwen, AG 7, p. 5). The participants felt that for them time was of the essence.

With regards to the application of a client-centred outcome measure, the consensus was that to be client-centred an outcome measure has to take into account "secondary clients", such as teachers. The participants lamented the difficulty they encountered in obtaining feedback from the school and teachers and problems faced to fill in the outcome measure during summer, since school would be closed in summer. One participant also added that once schools re-opened, the child would have a new teacher, who would need time to get to know the child first before filling in outcome measure, thus making therapists lose precious time to start the OT process.

The participants noted that the successful use of an outcome measure in the form of a questionnaire or self-report depends on the person who completes in. The participants had some negative experiences regarding the use of questionnaires, as the latter were occasionally not returned to the therapists. Moreover, some parents or teachers might leave sections empty and the therapist would have to contact them again to complete the missing parts. This was seen by participants as another obstacle to the proper completion of the outcome measure, because of time constraints.

Nonetheless, the completion of a child-centred or client-centred outcome measure, especially self-reports, is:

> *. . .very dependent on the . . .skills and the personality of the parent and the child. We find parents who are all in and they would know the child inside out . . .With those type of parents this [the use of a self-report outcome measure] would be perfect. But there are parents who are really passive, who ended up here [because they were referred against their will]*. (Rylie, AG 7, p. 18)

Language was identified to be another potential barrier. The parents and/or the child might not be able to understand English and they might not be able to communicate in Maltese either. Outcome measures tend to be in English and not all measures can be translated into Maltese. Participants reported that in such cases it is challenging for the child or the client to complete the outcome measure and for the therapist to help them identify the goals.

The participants also cited the barriers posed by illiteracy and low levels of education that might hinder the attempts of parents or carers to complete a questionnaire. Although some outcome measures have client-friendly versions, "*there will still be a group of people who would find it hard [to complete them]*" (Sarah, AG 7, p. 12).

There seems to be a fear that the use of a child-centred or client-centred outcome measure may encourage clients to change the goals that they would like to work on. The following is a clinical example that was provided by one of the participants.

> *In summer the parents are concerned about toileting, but then when he [the child] is at school and his LSA . . .[accepts] to change his nappy . . .toileting does not become an issue anymore. Then it is socialising with other children or the fact that he is not sitting down during class*. (Elin, AG 8, p. 28)

Indeed, one participant expressed concern about possible changes in parents' own goals that might impact the number of sessions that the child needs to work on the said goals. She complained that if a new goal was identified along the way, the therapist would need to start working on a different goal, even if she was close to discharge. Such a worry runs counter to the emphasis that a child-centred or client-centred service lays on addressing what is relevant and meaningful to the client, which can change over time.

> *If there was more of a system . . .in place . . .then the parent knows that she is coming here because of a particular concern and we want to keep working on this. If you [the parent] need another, if you [the parent] has a different concern, you can either be referred to a different unit or I can speak to the therapist [in school] as well, to give her feedback . . .so she does not have to start everything from [scratch]*. (Elin, AG 8, p. 28)

As was also noted in Theme 2, participants expressed feelings of helplessness to control change. This inability to control change was considered a challenge since the participants seemed to believe that "*there is little that we can do*" (Elin, AG 8, p. 9). Elin added that "*as a singular person, there is little to nothing that I can do about it*". Such feelings of powerlessness may limit the amount of effort that the participants may make to introduce an outcome measure in their setting.

The participants felt that the service was ill prepared for the use of an outcome measure unless some changes were effected.

> *We do not have a stable ground at all . . .People are pulling and pulling pieces out of us all the time. Our foundations are constantly crumbling. So yes, that [the use of an outcome measure] is a very good idea, but the thing is 'Are we ready for it?'. I do not*

> *know. There are so many issues underlying that needs to be solved prior to [being able to use an outcome measure]*. (Monica, AG 7, p. 21)

8.2.4 Prerequisites for the Use of a Child-Centred Outcome Measure

The participants thought that a number of factors need to be in place in order to enable the use of an outcome measure in a given setting.

The participants underscored the need for time to build a rapport with the child or the parents, which would facilitate the use an outcome measure with them. The therapist needs to build trust mostly with the child, so that the latter would feel free to express their concerns or difficulties. The child needs to "*be at ease to say his concerns [or] difficulties*" (Faith, AG 3, p. 6). The participants highlighted the need of sufficient time to implement child-centred and client-centred outcome measures, as building trust and creating a welcoming, warm milieu takes time.

There needs to be enough time to administer the outcome measure to other "secondary" clients, such as the parents and teachers. Some participants strongly suggested that the OT should dedicate some time solely for the child, with some other time dedicated solely to the parents. Whereas participants argued that more time was required for the clients to disclose their concerns, Faith disagreed that it was merely a matter of time, arguing that therapists should consider changing their approach with clients, instead of complaining about time constraints:

> *I do not think it is an issue of time, because let's say we have one hour, two hours, and they [the clients] do not open up because we do not have enough time. If you go to a doctor you have about . . .10 to 15 minutes [yet] they [clients] open up [about] everything . . .I think it is also the way of changing our mentality and our approach [that matters]*. (Faith, AG 8, p. 18)

The participants felt that more time should be allocated to the child's assessment in order to be able to administer a child-centred outcome measure, since the therapist has "*to complete* *it with them*" (Rory, AG 7, p. 10). More time might also be needed if the therapists were to help parents complete their questionnaire. One of the participants suggested that OT assistants might be trained to help illiterate or semi-illiterate parents fill in the outcome measure questionnaire.

Apart from time, the participants emphasised the importance of creating an appropriate environment for both the child and parents that is congenial for therapists' administration of the outcome measure so that goals can be accurately identified. The environment should be sufficiently welcoming and inviting to encourage the client to open up with the therapist and to identify the goals. The participants stressed the need for enough privacy to allow the practice of ADLs, including dressing and the discussion of personal issues and personal goals.

The participants stressed that therapists need to be aware that children with disabilities may have difficulties to formulate goals, and that an outcome measure should address and enable this. The participants remarked that before therapists can opt for the selection of a particular outcome measure, they need to check the client's age group to be covered by the service, or part of the service, and ensure an age-appropriate outcome measure. A particular concern aired by participants was the difficulty in finding a child-centred outcome measure that can be used with very young children. When the participants were going through different outcome measures, they could note that child-centred outcome measures tend to be used with ages 5 and upwards. Such measures would not meet the therapists' needs since "*most of our client group is younger*" (Ruby, AG 4, p. 17). No such measures could be found for younger children. The participants seemed to be uncertain as to the type of outcome measure that would be relevant to their setting, finding it quite challenging to identify a single measure. This issue will be further discussed in Theme 5.

It was also noted that therapists need to be aware of the materials required to use a specific outcome measure, and ensure that such materials are available, before opting to select it for the service. Another important pre-requisite that was mentioned was that the therapists need to consider "*whether the staff requires training to administer the test [outcome measure]*" (Jade, AG 4, p. 4). If that is the case, the participants recommended provision of accessible and affordable training. Some tests also require specific "*user qualifications*" (Sarah, AG 4, p. 11).

There seemed to be consensus that the feasibility of an outcome measure hinged on fundamental changes being made to their service. The use of outcome measures would be possible "*as long as it is not an addition"* to what they were already using (Monica, AG 3, p. 7). "*For it to be successful . . .it has to be instead of what we already have. Adding to it [what is already being done] will be difficult*" (Rylie, AG 3, p. 7). The participants were recommending the outcome measure as a replacement of some dispensable parts of practice, instead of an addition to what was being done. "*Something has got to give*" (Monica, AG 3, p. 7).

Indeed, following discussions the participants concluded that their current assessment process needs to change to accommodate the use of an outcome measure. This includes "*how to structure our evaluation, interview, etc.*" (Faith, AG 8, pp. 18-19) as well as other aforementioned recommendations. "*The way that we do the assessment has to change . . .we cannot do what we do and that [the new outcome measure]*" (Melody, AG 7, p. 14). "*Maybe we can change the way that we do the assessment and just use [the new outcome measure] instead of adding it to what we already do*" (Elaine, AG 3, p. 7). Doing so "*would be more feasible*" (Monica, AG 3, p. 7). Regarding the assessment process, participants explained that they were referring to the informal assessment form being used at the time of the study.

More importantly, Ruby recommended that the success of the implementation of an outcome measure necessitated a change in how the therapists "*approach a problem . . .a change in the mindset*" (Ruby, AG 6, p. 7). In that respect, Ruby stressed that therapists would need to be prepared to "*rely on what the parents and the child say*" (Ruby, AG 6, p. 7) if they wanted this new practice to be child-centred or client-centred.

Additionally, the participants discussed how the assessments that were currently being used measured mostly performance skills. Therefore, the use of a child-centred or client-centred outcome measure that addressed function would automatically result in a radical change in practice. “*That is why it is a change*” (Ruby, AG 6, p. 14). The participants debated how the standardised assessments that were being used to measure performance components would not necessarily be phased out; however, the therapists would “*not start with those”* (Ruby, AG 6, p. 14). The participants recommended that the outcome measure be used first and then if the occupational therapist needed to assess further, other standardised assessments that focus on performance components would be used.

The participants agreed on the need for a “*cultural shift*” (Elin, AG 7, p. 22) towards focusing on occupational performance and participation. Such a shift was viewed as being essential for both other professionals but maybe, more importantly, for the therapists themselves as well. The fact that the occupational therapists should “*focus on function*” was undisputed (Marcelle, AG 7, p. 28).

8.3 Child-Centred Outcome Measures for Paediatric Occupational Therapy Practice in Malta

This theme deals with the suitability of a number of outcome measures to the paediatric OT service in Malta. It incorporates the views that participants held about a number of outcome measures that met most of the criteria, which were identified by the participants themselves, and which were discussed under Theme 3.

During action research group 3, the group agreed that they would bring any outcome measures that were available for action research group 4, so that the group would appraise them together. In preparation for this session, I conducted a thorough literature search for potential child-centred outcome measures, including an in-depth critique of such tests. Apart from the databases, I used the backward and forward snowballing, which was explained in the literature search strategy. I considered the three areas recommended by Unsworth (2000), namely suitability for the population; meeting needs and being standardised, and also followed the guidelines for selecting tests and test critique by Laver-Fawcett (2007). I focused on outcome measures that seemed to address most of the areas that were identified by the participants in the previous action group meetings.

Being familiar with resources available in the OT departments in Malta and Gozo, I was aware of the local unavailability of such tools. I could therefore anticipate that the participants would not bring any outcome measure with them for the following group meeting. I was not expecting participants to purchase any tool personally. Therefore, I purchased the outcome measures that emerged from the literature search, namely the PEGS (Pollock and Missiuna 2015), the COSA (Kramer et al. 2014), the PACS (Mandich et al. 2004), and COPM (Law et al. 2014). I also purchased a book about the use of GAS (Kiresuk et al. 1994) since the latter does not involve an actual test kit with manual, unlike the other measures. I also brought journal articles about the aforementioned outcome measures. The participants then discussed these tools and pored over literature during the following action research group meetings.

The findings about the various outcome measure are summarised in Table 9. The table was a joint-effort and was developed during the action research groups by participants. A more detailed discussion of these outcome measures follows.

Table 9. Summary of discussion about outcome measures – November 2018

Properties	**Outcome Measures**				
	PEGS (Pollock and Missiuna 2015)	**PACS** (Mandich et al. 2004)	**COSA** (Kramer et al. 2014)	**COPM** (Law et al. 2014)	**GAS** (Kiresuk et al. 1994)
Aim	To enable young children with disabilities to self-report their perceived competence in everyday activities & to set goals for intervention	To assist the therapist in determining the child's level of occupational engagement & can be used for goal setting & intervention planning	To capture youths' perceptions regarding their sense of competence & the importance of everyday activities	To detect change in a client's self-reported occupational performance over time	To provide a method for individualised goal setting & treatment evaluation
Age range	5 to 9 years (developmental age of 5)	5 to 14 years (developmental age of 4)	7 to 18 years	8+	Any age (but needs to be used together with another child-friendly tool to identify the child's concerns)
Addresses other ages	x	x	X	√ Can be administered to parents of very young children	√ Can be administered to parents of very young children

Properties	Outcome Measures				
	PEGS	**PACS**	**COSA**	**COPM**	**GAS**
Addresses function	√	√	√	√	√
Areas assessed	• Self-care • Productivity & School • Leisure	• Personal Care • School / Productivity • Hobbies & social activities • Sports	• Self-care • Play & Leisure • Learning	• Self-care • Productivity • Leisure	Any
Reliable & valid	√	X No published information about validity & reliability	√	√	√ Reliability improves if therapists are trained Validity improves if therapists use another standardised measure on which to base their goals
Self-report	√	√	√	√	X Can be used with another self-report or an informal set of questions

Properties	**Outcome Measures**				
	PEGS	**PACS**	**COSA**	**COPM**	**GAS**
Easy to administer	√	√	√	√ There is also an App version	X One needs to use a formal or informal tool or set of questions to identify the client's needs The therapist needs to formulate a goal
Easy to score	√	√	√	√	√
Time	20 to 30 min to administer Caregiver & educator questionnaire: 5 to 10 min to complete Scoring & summarising the scores & goals from all 3 measures take about 10 min	20 – 25 min to administer	20 mins for the Rating Form (questionnaire) version The Card Sort version may require a longer time	20 to 40 minutes to administer (12 min if it is used strictly to identify & rate occupational performance problems)	Completing a GAS assessment usually takes between 20 – 45 min
Easy to interpret	√	√	√	√	√

Properties	Outcome Measures				
	PEGS	PACS	COSA	COPM	GAS
Materials needed	Manual, Cards, Forms to be photocopied from manual	Manual, Forms, Cards	Manual, which is available as an e-version, Forms to be printed from manual	Manual, Forms, Number line cards	Nil
Environment/ context where it can be used	Any	Any	Any	Any	Any
Client-centred	√	√	√	√	√
Child-centred	√	√	√	√ When it is administered to the child	√ Only if it is carried out following an interview with the child
Looks at Parents' & Teacher's view	√ Includes a separate form for parents & teachers similar to that of the child's	x	X	√ Can be administered to the parents & teachers	√ One can set goals with parents & teachers
Hands on (observation of the skill)	X	x	X	X	x

Properties	**Outcome Measures**				
	PEGS	**PACS**	**COSA**	**COPM**	**GAS**
Can be used with children with disabilities	√ Can be used with any disability as long as the child is able to formulate some kind of response Includes research for use with a wide variety of diagnoses	√ Can be used with any diagnosis as long as the child has an approximate developmental age of 4 & can respond to pictures & questions	√	X Can be administered to parents of children with disabilities (including those with severe disabilities)	X Can be administered to parents of children with disabilities (including those with severe disabilities)
Standardised/ normative data	X	x	X	X	x
Scoring sheet clear/concise	√	√	√	√	N/A One can develop a GAS form to record the goals & measure the outcomes
Cost & shipping	€82 plus shipping	€112 plus shipping	€35 (downloadable, so no shipping is required)	€26 (E-version Manual + 100 forms) €36 plus shipping (paper version)	X (price for any training)

Properties	Outcome Measures				
	PEGS	**PACS**	**COSA**	**COPM**	**GAS**
				€0.10 per measure (COPM Web-App)	
Staff training to administer	No training	No training	No training	No training	Yes, requires training
Can be repeated for re-assessment	√	√	√	√	√
Language. Can be used in Maltese?	√	√	√	√ Maltese version of the scoring form available	√
In line with CMOP-E	√	√	Preferably to be used with MOHO	√	√
Culturally appropriate	√	X A relatively large number of pictures are not culturally appropriate	√	√	√
Real pictures vs drawings	Drawings	Real pics	N/A	N/A	N/A

Properties	**Outcome Measures**				
	PEGS	**PACS**	**COSA**	**COPM**	**GAS**
			Cards or questionnaires with words (some have stars/smileys)	Number line (1-10) Can be adapted with smileys or stars	
Research about its use in paediatrics	√	Limited	√	√ (mostly when used with parents)	√ (mostly when used with parents)
Others				FAQ on manual: "*How can I take the time to do a COPM with my clients? I have a really high caseload & just don't have the time.* The COPM should save you time in the long run. It may take more time initially, but by clearly focusing your intervention on issues that are important to the client, you will reduce excess assessments, have a	Can be used to evaluate outcomes of individual or groups session as a whole Can be used to measure outcomes of a service You would need to have another self-report or a set of questions to use as guidelines for interviewing the child or the parents/teachers

Properties	**Outcome Measures**				
	PEGS	**PACS**	**COSA**	**COPM**	**GAS**
				more goal-directed treatment plan, & should have higher client motivation to participate. The COPM can often replace some of the intake procedures you do now" (Law et al. 2014, p. 46)	
Combination of assessments	Authors & other researchers recommend that this be used with the COPM	Authors recommend that this be used with COPM	Authors recommend that this be used with GAS	Researchers recommend that this be used with the PEGS (for the younger population)	Can be used together with any other assessment / tool

8.3.1 The Suitability of the PEGS as an Outcome Measure for this Service

The PEGS (Pollock and Missiuna 2015) was found to be "*very client-centred*" (Rylie, AG 4, p. 17) and "*child-friendly as well*" (Jade, AG 7, p. 4). Indeed, it was designed as a self-report. The participants warmed to the fact that the PEGS is adapted to be used with young children. This outcome measure is aligned to the CMOP-E.

The participants spoke highly of how the PEGS addresses the parents and teachers, as well as the child. This outcome measure includes cards that can be used with the child, and questionnaires, which can be completed by parents and the teacher. Through the PEGS, one can "*get feedback from different environments, just with one tool*" (Monica, AG 7, p. 4), enabling the therapist to "*get a lot of information from one source*" (Gwen, AG 7, p. 5). Moreover, the participants felt that it was easy to administer and to score. They thought this measure was "*quite easy to use*" (Elin, AG 7, p. 4) and "*easy to go by*" (Monica, AG 7, p. 4).

The PEGS is also "*adaptable for many different client groups*" and this makes it an attractive tool to use (Elin, AG 7, p. 4). It can be used with children with disabilities as long as the child is able to formulate some kind of response. Moreover, the PEGS can be applied in various settings or contexts. The participants felt that this outcome measure was culturally appropriate. Another important feature was that the PEGS "*is very occupation-based*" (Elin, AG 7, p. 5).

The validity and reliability of PEGS was also viewed as positive. This outcome measure does not require any particular training for therapists to administer it. The PEGS possessed most of the qualities and attributes that were identified by the participants as being important for a child-centred or client-centred outcome measure for their service.

Participants spoke very favourably of the PEGS:
"*I really like the PEGS*" (Monica, AG 6, p. 5) and
"*I think that I would go for the PEGS*" (Faith, AG 6, p. 2).

The participants agreed that the PEGS was a child-centred outcome measure that they could use for children who are 5 to 9 years old (developmental age of 5 years) and who do not have severe disabilities. This self-report would be administered to the children themselves. It can also be administered to parents and teachers of these children. This would enable the delivery of a child-centred as well as a client-centred service.

8.3.2 The Suitability of the PACS as an Outcome Measure for this Service

The participants discussed how the PACS (Mandich et al. 2004) addresses function. This outcome measure is also a self-report, so it was agreed that it can be considered to be child-centred. However, the therapists felt that this outcome measure is not client-centred, since it does not address the parents' or teachers' views. This tool was seen as being easy to administer and score. The fact that the PACS can be administered to a child with various disabilities as long as the child has an approximate developmental age of 4 years and can respond to pictures and questions, was seen as a positive thing. However, therapists were concerned because no published information could be found about this outcome measure's validity or reliability.

Although participants agreed that the PACS met a lot of desirable criteria, they felt that this outcome measure was "not culturally appropriate" (Rory, AG 4, p. 26). This tool includes picture cards. A number of pictures or activities assessed on this measure were seen to be irrelevant to Malta. For example, some of the pictures showed children climbing trees when trees are conspicuous by their relative absence in Malta. Another non-culturally-relevant item that the participants pointed out was snowboarding. Moreover, the participants noted that the children on the pictures looked very much 'American' rather than Maltese and this might not go down well with Maltese children if it were to be administered to them.

Although the participants spoke favourably of the use of real pictures rather than drawings in this outcome measure, they did not like the actual pictures that were used. "*Those pictures are really ugly! Sorry*" (Elin, AG 4, p. 31). One of the participants reported that the pictures looked old. "*To be honest, even their faces. Some of the children look sad*" (Gwen, AG 4, p. 32). Consequently, they concluded that this outcome measure was "*not child-friendly*" for Maltese children after all (Elin, AG 4, p. 31). The participants dismissed this outcome measure as unsuitable for their service.

8.3.3 The Suitability of the COSA as an Outcome Measure for this Service

The participants discussed another self-report, the COSA (Kramer et al. 2014). This outcome measure, which addresses function, was perceived to be easy to score and administer. The participants spoke highly of the validity and reliability of this tool. Although the COSA can be used with children, the participants showed some concern about the fact that children need to be 7 years of age and over in order to qualify to use the COSA.

There was a consensus that this outcome measure addresses function and does not require any specialised training to be administered. However, the participants objected to the fact that this outcome measure was designed to be used with the MOHO and not the CMOP-E. The COSA requires the use of the MOHO as a theoretical framework to review and interpret responses on this measure, whereas participants were unfamiliar with this model of practice. Moreover, they did not feel that such a tool would suit their service needs because of the absences of an accompanying parent or teacher version.

8.3.4 The Suitability of the COPM as an Outcome Measure for this Service

The COPM (Law et al. 2014) was seen by the participants as being fit for purpose as it aligns the CMOP-E. Some positive features that were identified include the focus on function, the fact that it requires no specific training to be administered and the extensive research that shows that this tool is valid and reliable. The participants felt that this outcome measure is relatively easy to administer and they liked the fact that there is even an application for scoring, so it can be administered and scored from a tablet or smart phone. Additionally, participants discovered the availability of a Maltese version of the scoring form available, thus seen as culturally appropriate.

The participants noted how the COPM can be used with various clients including parents and teachers, if the latter attend OT sessions or if the therapist were to conduct intervention in schools. The participants did not discuss the fact that the therapist needs to administer this outcome measure through an interview, as opposed to the PEGS (Pollock and Missiuna 2015) for example, that allows parents and teachers to complete the questionnaire on their own. The COPM can also be administered to older children, but not to those who are younger than 8 years of age. This was seen as a concern, given that most children, who are referred to the service under scrutiny, are indeed younger. Indeed, participants were concerned because this outcome measure cannot be used with young children.
"*Performance, satisfaction and importance . . .it is very hard for a child*" (Ruby, AG 5, p. 16).
"*It is abstract*" (Ruby, AG 5, p. 17).

Therefore, this outcome measure was seen as a client-centred one but it might not address the child-centred requirements that are expected at this service. The participants were very much aware that not all children would be able to complete a self-report outcome measure, especially those who are at a developmental level younger than 5 years of age, or those who have severe disabilities. The COPM was therefore identified as a potential client-centred outcome measure for this service. It can be used with parents of children who are younger than five or who have significant disabilities. The COPM can also be administered to teachers and to children who are too old for the PEGS.

8.3.5 The Suitability of the GAS as an Outcome Measure for this Service

The GAS (Kiresuk et al. 1994) was described as being an outcome measure that can address function and other goals that are meaningful for the client. The potential for validity and reliability was viewed as a positive attribute. The participants discovered how they could improve the reliability of this tool if they were trained on the use of this tool and that validity can be enhanced if they were to use another standardised measure on which to base their goals. The former need for training was seen as a potential challenge, since the latter would hinge on resources available, especially regarding costs.

The participants noted that the GAS is not in the form of a self-report, so it cannot be regarded as a child-centred outcome measure. Although theoretically it can be used with any age, it needs to be used together with another child-centred tool to identify the child's concern in a child-centred way. The participants discussed how the GAS can be used for children with disabilities; however, it is mainly administered to parents of these children and not to the children themselves. Goals could also be set with the teacher.

One positive thing that the participants noted about the GAS is that it can be administered in Maltese so it would be "*easy to apply to Malta*" (Melody, AG 5, p. 24). The GAS was indeed described as being a "*very good*" tool (Ruby, AG 6, p. 2) and was seen to be culturally-relevant. Moreover, the GAS goals are "*in line with the CMOP[-E]*" (Melody, AG 5, p. 24).

The participants commented that the GAS could be a suitable tool to measure the goals at the end of intervention. The participants liked the fact that the GAS enables the clients to set their goals of intervention. Moreover, they noted that unlike the COPM (Law et al. 2014), the GAS helps the therapist write specific goals. The possibility of setting goals in Maltese was perceived as positive.

The GAS can be considered to be culturally appropriate if it is used with an appropriate formal or informal tool or set of questions to identify the client's needs. An additional advantage that the participants could identify was the fact that the GAS can be used to evaluate the outcomes of both individuals or a whole group. Furthermore, the participants added that it can be used with a wide range of ages and conditions, hence, its potential suitability for the service.

The GAS was perceived as a potential client-centred outcome measure for this service. The participants suggested that the GAS can be used with the PEGS (Pollock and Missiuna 2015). *"It [the PEGS] is very client-centred [child-centred] so we get the client-centredness [that] is missing from the GAS goals from the PEGS*" (Rylie, AG 6, p. 5). The participants noted that the GAS goals can also be used with the COPM. The use of the GAS-light, which is a shorter version of the GAS, was also considered.

8.4 Challenges around Professional Identity

This last theme deals with issues that the participants brought up during the action group meetings, and that are related to the professional identity as occupational therapists. Professional identity issues were found to be potentially influenced by the use of outcome measures.

The findings indicate that the participants feel that there is a lack of awareness about OT and about the role of the occupational therapist. *"People do not know what we do and how we do it and why we do it"* (Elin, AG 3, p. 19). The participants explained how clients seemed not to understand how OT can help with the problems they were encountering. *"You would explain what OT is . . .[but] they would not know how to fit in their concerns within our domain"* (Ruby, AG 6, p. 7). One participant noted that some of the clients referred to them had a number of *"issues affecting the child's occupations . . .[yet, the parents are unable] to voice . . .their concern"* (Ruby, AG 6, p. 7). This is reported to be more of an issue, when the parents are sent for OT services by the school, vis-à-vis when they themselves seek the service.

> *"It's the understanding of our role. You can explain it in several ways, but sometimes you don't really get it across, so you might get some bias in the answers back, because they're thinking one thing and you're trying to refer to something else"* (Monica, AG 7, p. 6).

People seem not to *"know what we really really do"* (Reilly, AG 7, p. 22). The participants were concerned that this lack of awareness might impact the way in which outcome measures are filled in.

Findings indicate that the lack of awareness of what OT is about is found at different levels. This starts with other professionals, notably medical doctors, who refer children for OT service for reasons other than participation challenges. For example, participants reported that children could be referred because of a particular diagnosis, irrespective of whether or not they have functional challenges. Lack of awareness was also noted in other professionals, who might expect that OT would or should address issues which might not necessarily be within our profession remit. "*There is a very big discrepancy between the expectations of entities and what we actually do*" (Rylie, AG 7, p. 22). Additionally, lack of awareness is seen in the clients who receive OT intervention, mostly parents, but also teachers. The participants gave a number of clinical examples of parents' lack of awareness of OT.

Throughout the action research group discussions, participants often underscored the importance of raising awareness of what OT is about. However, they thought that there were more severe challenges that need to be addressed first, foremost among which is the lack of resources. There is a need for "*more awareness in the profession, but we are so little in numbers and . . .we have so many other issues that we are trying to cope with, that awareness is the last thing on our minds*" (Gwen, AG 7, p. 22).

The participants were cognisant that if there was more awareness, they would stop receiving inappropriate referrals and this might save time, which is always at a premium. If only children with functional difficulties were referred to the service, the resources can be focused on those who most need the service. Referring bodies "*need to know what occupational therapy is*" (Michaela, AG 8, p. 11).

One of the participants highlighted that occupational therapists should focus on participation even at the assessment stage and when using outcome measures, so that clients would better understand the role of the occupational therapist. This participant was critical about collecting mostly information related to performance components, as it "*is not good to for us to show what our role is*" (Monica, AG 3, p. 9). The participant added that such practice of privileging performance components might even confuse therapists' clients.

“*Aiming towards those [function], would show more what we are talking about*” (Monica, AG 3, p. 9).

The participants acknowledged that it is crucial for therapists to focus on function but noted that such practice was not always being implemented. “*Focusing on occupation is what makes us OTs, so it is important. We do not practise it now, but that is what makes us OTs. . .So our ultimate aim is to improve functional performance in occupation*” (Rylie, AG 7, p. 21). Although on paper occupational therapists had adopted the CMOP-E as a model to guide their practice, this was not being actually done in practice and the enthusiastic adoption of such a model seemed more like paying lip service to the idea of a child-centred outcome than actually practising it.

The consensus among participants was that if the occupational therapist was addressing performance skills, therapists needed to clearly “*explain how particular skills are related to that function*” (Elin, AG 7, p. 28). The participants added that the therapist might work on performance skills, but the aim should always be to improve functional performance. One participant gave a clinical example of how paediatric occupational therapists address sensory issues when they work with “*a child who does not participate in an activity because of tactile sensitivity or tactile defensiveness [so] . . .with therapy, the child gets used to the activity and participates . . .more*” (Reese, AG 1, p. 7).

The participants acknowledged that “*occupational therapy is so vast, that . . .every difficulty can be referred [to] as [being] an occupation-based [one]*” (Faith, AG 8, p. 11). This compounds the challenge of making people more aware of what OT is and clarifying what lies within the remit of OT and what lies outside it.

The participants suggested that in paediatrics it is common for therapists to have to address a number of areas to improve a particular function. A clinical example of trying to achieve a handwriting goal was given, whereby the therapists would have to work on sitting posture and pencil grip in order to reach the goal. The participants’ concern was the discrepancy between the therapist’s goals for the child and the parents’. Once again, this exacerbates the confusion about the OT’s role.

Another issue that was discussed by participants was the feeling that being part a multidisciplinary setting, they seemed to have lost their identity of being a Paediatric OT Department. They had to abide by some policies of the overall setting, which, according to participants, did not always match what was best for the OT profession. "*We are not* [redacted] *[name of the paediatric health organisation, which their department forms part of], we are the Paediatric OT department*" (Faith, AG 8, p. 27). Participants also regretted that their work as occupational therapists was not being sufficiently appreciated. "*I think that professionally, we are under-appreciated*" (Elin, AG 8, p. 8). The participants felt a need to showcase the unique contribution that the OT profession can give to the multidisciplinary team that they work with and to society in general. They highlighted that a child-centred and client-centred outcome measure which is focused on occupations and participation can help all parties to reach the goal of becoming a better version of themselves.

8.5 Conclusion

This chapter has discussed the four themes that were related to the application of child-centred and client-centred outcome measures and factors that impact such practice. It started with a discussion of the properties that the participants associated with outcomes and outcome measures, including paediatric OT-specific outcome measures. Moreover, this chapter has outlined the current practice regarding these measures. The benefits and challenges that were identified by the participants in relation to the use of outcome measures were also reviewed. This was followed by the prerequisites that, according to participants, needed to be in place to enable the use of a child-centred or client-centred outcome measure in this setting. Furthermore, the suitability of a number of outcome measures for the paediatric OT service in Malta was discussed.

Finally, a number of issues related to our professional identity as occupational therapists and their impact on the use of outcome measure was addressed. These issues were mostly related to the lack of awareness of OT and the need of a 'cultural shift' towards focusing on occupational performance and participation.

Part Four: The Application of a Measurable Child-Centred and Client-Centred Occupational Therapy Service

This part of the thesis discusses the application of a measurable child-centred and client-centred OT service. **Chapter 9** presents the discussion of the findings and ends with the limitations and strengths of the research. **Chapter 10** deals with turning the rhetoric into reality. It presents the conclusion of the study, proposes a number of recommendations and delves into the implications for OT practice and research.

Chapter 9 - Discussion of the Findings

The discussion chapter is divided into two main parts. The first part deals with issues around the conceptualisation of the client in paediatrics, the understanding of which is essential to the eventual delivery of a child-centred and client-centred service. It also addresses the application of client-centredness and child-centredness, including a reflection on whether current practice reflects paediatric occupational therapists' client-centred and child-centred beliefs. Therefore, in this section the accent is on the study's first objective.

The second part deals with outcome measures and their application vis-à-vis child-centred practice. It highlights some ideal properties and potential child-centred and client-centred outcome measures that would meet the needs of the Maltese paediatric OT service. This section therefore discusses the second and third objectives of the study, and the evaluation part of the first objective. Finally, this chapter addresses this research's limitations and strengths.

9.1 Applying a Child-Centred and a Client-Centred Service

9.1.1 Conceptualising the Client – Who is the Client in Paediatric Occupational Therapy?

The findings of this study prompted the need to reconsider what is meant by the term 'client' in paediatric OT. The nature of client-centred intervention in a paediatric setting is complex. The client must be properly identified before the start of any OT intervention (Sumsion 1993). The study participants repeatedly highlighted how crucial it is for them to understand who the client is but simultaneously how challenging such an endeavour is, in their area of practice. Indeed, the conceptualisation of identify of the client, is renowned for being "the most significant challenge" that occupational therapists working in paediatrics have to face (Stewart and Cameron 2006, p. 158).

It is critical to remember that OT clients are not necessarily a single individual (Sumsion 1993; Law et al. 1995; AOTA 2020). In paediatrics, the client can be the family (Hanna and Rodger 2002), namely the parents, or the teacher (Wilkins et al. 2001; Missiuna et al. 2006).

Significant others would need to be involved for multiple reasons. The age of children, who receive services at the OT department, varies from 0 to 16 years. This client group, therefore, includes very young children who still count on their parents, and children who might have significant cognitive or communication difficulties. When clients have poor insight into their abilities or problems, or when there are communication difficulties, therapists have to rely on proxies (Laver-Fawcett and Cox 2021). Moreover, Coyne et al. (2016) note that one cannot understand the child in isolation from the family, as all family members are interdependent and interconnected. Family engagement is also essential for the implementation and progress of the child's intervention plan (An and Palisano 2014).

Furthermore, since the caregivers may be encountering difficulties to fulfil their needs and improve their own wellbeing, they themselves may also require OT support (Schiariti et al. 2014). Consequently, in paediatrics, the client cannot be solely the child. The number of clients may be further increased if the parents have poor insight or have cognitive difficulties themselves, so other carers or professionals would need to step in to support the parents, apart from the child. Such a need to involve a number of family members presents an additional complication (Schwellnus et al. 2015).

This complexity distinguishes paediatric OT practice from other OT areas. Although participants in this study acknowledged that they cannot work solely with the child, they seemed to agree that the child should be considered the "main client" and that therapists need to place the child first and adopt a child-centred approach. Pritchard-Wiart et al. (2019) referred to intervention based on goals identified by the child as a 'child first' approach. The child's engagement is a key aspect of this approach, whilst the parents and therapists can still actively participate in goal setting.

A number of authors have supported the use of child-centred care, which aligned with participants' recommendations. Coyne et al. (2016) note that in paediatric health care, interventions need to be "reframed through a child-centred lens" (p. 495). Using a child-centred care approach, the rights of the child as delineated by the UNCRC Article 12 (UN 1989), are acknowledged and reaffirmed (Coyne et al. 2016). The child is treated as the main client, receiving respect, provided with adequate space, and being enabled to participate in decision-making, together with the parents and health care providers. Children are given the opportunity to be actively engaged (Coyne et al. 2016) and their specific needs are addressed. Although the child belongs to a family, the child is regarded as the “key and active agent in the partnership” (Coyne et al. 2016, p. 496). Moreover, when both the parents and the teachers need to be involved, the consensus amongst participants was that the parents should be given priority.

Similar to Wilkins et al.’s (2001) findings, concerns regarding which clients (children) would benefit from a client-centred approach were expressed by some participants, who cast doubts on various clients' capacity to actively participate in their own treatment. This concern was frequently associated with individuals who had language challenges, cognitive issues, or poor insight. Age and insight were in fact regarded as the two main determinants of who the ‘main client’ is. Participants viewed older children who have good cognitive abilities as good candidates for being considered the main clients. Indeed, participants sustained that the family members or the educators frequently ended up being the occupational therapist's main clientele. Wilkins et al. (2001) indicate that the family member as a client may be the most appropriate option in certain circumstances, whilst dealing with the family member rather than the specified client may be just simpler in other circumstances. Unfortunately, such an issue was not debated in this study.

A number of treatment approaches have been developed to address the delivery of intervention with children. These include a family-centred approach and a child-centred approach. The primary distinction between these approaches is whether or not the child and/or family receive priority in the provision of care (Foster and Shields 2020). The assumption that one type of approach would be “a good fit for all” (Foster and Shields 2020, p. 153) is unrealistic (Shields, 2015; Uniacke et al. 2018). International specialists are currently debating whether these models are in the best interests of the child, person, and/or family, or not (Foster and Shields 2020).

Foster and Shields (2020, p. 154) argue that:

> … the child is not a separate being, nor a forefront to the family unit as a whole, and the family as a 'whole unit' is not forefront to the child's psychosocial physical and emotional health-care needs.

Foster and Shields (2020) note that family-centred care and child-centred care are interrelated and that the iterative interaction between these two is mutually beneficial. These researchers propose a Child and Family Centred Care (CFCC) that would incorporate both perspectives and that would enable beneficial health outcomes that respect the legal rights of the child, parents and family (WHO 1986; Carter et al. 2014; Coyne et al. 2016; United Nations Children's Fund [UNICEF] 2024).

Similarly, Costa and Lindenthal (2015) recommended the use of a "systems-oriented approach"(p. 17) in health care, whereby the perspectives of both the client and their proxies would be taken into account. This would impact the selection of suitable techniques and tools for evaluation and intervention.

In OT, the definition of client is, in fact, frequently changed to refer to the family as the client, so decision-making in therapy is subsequently transferred to them (Baum 1998; Pollock and McColl 1998; Sumsion 1999). Moats (2007) points out that the literature does not explore how this shift occurs and the extent to which the original client remains involved. Although Moats (2007) was referring mostly to older adults, the same issues are encountered in paediatrics. Moats (2007) remarks how some of the interviewed therapists believed that they were using a client-centred approach with the new 'client' (the family), while simultaneously addressing the original client's concerns. However, she notes that this transfer occasionally results in the total exclusion of the original client from the decision-making process, thus weakening and even possibly distorting the aim of client-centred practice (Moats 2007). Such a concern was also expressed by participants in this study, who reported that in practice they tended to address mostly parents' or teachers' concerns, the latter also being considered as their clients, while ignoring the child's goals or priorities.

The terms "child-centred" and "client-centred" are frequently used interchangeably when referring to approaches that involve working with children and their parents (Palisano 2006).

This was also the case in this study. Indeed, participants occasionally referred to the child as the client and at other times they referred to parents/family or teachers as clients. The term "family-centred" was never used. The fact that teachers were regarded as clients might explain why the term "client-centred practice" was invariably used by participants instead of "family-centred".

Following such a broad definition of "client", that includes the child's family and significant others, it is difficult for therapists to determine who the main recipient of their services is (Stewart and Cameron 2006). Given the complexity surrounding the identity of the client, the researcher thought fit to use the terms "client-centred" and "child-centred" conjointly throughout the write up of this thesis.

9.1.2 Factors that Affect the Implementation of a Client-Centred / Child-Centred Practice

A number of studies were conducted to identify the factors that influence the application of a client-centred approach in several areas of practice, within OT (Sumsion and Smyth 2000; Wilkins et al. 2001; Sumsion 2005; Sumsion and Lencucha 2007; Sumsion and Lencucha 2009; Kjellberg et al. 2012) as well as in general health care areas (e.g., Gondek et al. (2006) in mental health and Boland et al. (2019) in paediatrics).

Whilst some obstacles and facilitators that were identified in this study were similar to other studies performed in the OT field, some issues related to goal setting and shared decision-making are more specific to the paediatric area (Boland et al. 2019). Health decision-making in paediatrics differs from that of adults for several reasons. Children's involvement in shared decision-making is influenced by their developmental level. As a result, it is quite challenging to decide the extent of involvement that would be appropriate for each specific child. There is also the issue of multiple clients. This section will address the barriers and facilitators for the implementation of both a client-centred and a child-centred approach.

9.1.2.1 Barriers to Client-Centred and Child-Centred Practice

It is widely acknowledged that the implementation of a client-centred practice is a challenging task (Law et al. 1995; Sumsion 2006a). The participants in this study identified several factors, which they felt would impede the application of a client-centred or a child-centred approach. Various authors categorise barriers as arising from three main sources, namely the client, the therapist and the organisation/system (Law et al. 1995; Wilkins et al. 2001). Similarly, challenges at each of the latter levels were highlighted in this study.

At the level of the client

The extent of client-centredness may be affected by the clients themselves, who may act as barriers (Law et al. 1995). The first barrier is related to the attempt to solve the dilemma, as referred by participants, of who the client is. Goal setting is fundamental for paediatric rehabilitation (Pritchard-Wiart and Phelan 2018) and a client-centred intervention needs to target the client (CAOT 2002). However, as already discussed, the participants emphasised the impossibility of doing this if they are not sure who the client is.

The findings indicate that age offers a particular challenge to the application of a client-centred, and especially a child-centred approach. The participants underscored the difficulty of setting goals with young children as the main clients. The age at which children can make their own decisions is crucial (Stewart and Cameron 2006). Children require quite varied types of partnerships and assistance for such partnerships, depending on their age (Dixon-Woods et al. 1999).

As the findings have indicated, seeking out, hearing, and acting upon children's opinions, might not always be easy in real life (Savage and Callery 2007). There are issues even in the policies which are meant to ensure children’s rights. Savage and Callery (2007) argue that the UNCRC (UN 1989) contains conflicting views about children’s rights, thus posing practical challenges to building relationships with children. For instance, according to Article 12.1, a child's right to be heard necessitates an evaluation of their ability to adopt a viewpoint, considering the child’s age and maturity. However, rather than focusing on competency, assessments of children's ability to express opinions are usually based on the child’s age.

This issue features in observational research on paediatric clinic consultations, which found that children's age significantly determined their inclusion in conversations and that older children were more likely to receive direct attention than younger ones (Silverman 1987; Tates and Meeuwesen 2000; Tates et al. 2002). Similarly, in their qualitative study, O'Connor et al. (2021) found that a child's inclusion in decision-making hinged on the child's age. Such reliance on age denies younger children a voice, preventing them from gaining experience and improving decision-making skills (Coyne 2006).

A client-centred relationship starts with the therapist obtaining information from the clients about what they need or want to do (Baum 1998). A child-centred way needs to be conducted with the child. However, a significant proportion of the children referred to paediatric OT services present with several difficulties and complex issues, the latter adversely affecting their communication. Some of the children are non-verbal, including some children with autism. The participants noted that it is challenging for them to know what these children want from therapy.

Similarly, clients with cognitive limitations have been identified as posing an arduous challenge to the implementation of client-centred care (Law et al. 1995). It may be particularly difficult for someone with cognitive impairments to meet the cognitive demands necessary for self-reporting (Kramer and Schwartz 2017; Greenberg et al. 2020). It is commonly assumed by therapists that children may find it challenging to recognise and express the things that are most important to them (Galvin et al. 2010) and to accurately report on issues that would lay the foundation for the therapeutic agenda (McColl et al. 2005). This is especially the case if children have cognitive or language difficulties (Galvin et al. 2010).

Coyne (2006) correspondingly found that some professionals perceived the child's potential involvement in health decisions as hinging on the child's cognitive ability. "Consequently, health professional's communication behaviour may reflect recognition of children's cognitive abilities rather than their competence to understand" (Coyne 2006, p. 68). In order to counteract this, Pritchard et al. (2022) urged therapists to prioritise the child's

engagement, in order to mitigate the influence of therapists' understanding of the child's capability to engage in the goal setting process.
Moats (2007) is highly critical of the way client-centred practice literature in occupational therapy (e.g., Law et al. 1995) addresses cognitive impairment as an all-or-nothing situation, suggesting that a client is either competent in decision-making, or not, which is not the case.

The participants mentioned another related challenge, namely their perception that children tend to have low insight and poor self-efficacy. Clients' insight into participation difficulties is another issue that frequently arises in paediatric practice (Stewart and Cameron 2006). Lack of insight was considered to be the most arduous challenge by occupational therapists in Sumsion and Lencucha's (2007) study and described as being "a second issue frequently raised" by Pollock and McColl (1998).

The participants were concerned about how they could be child-centred with children who cannot fully participate in goal setting and shared decision-making due to poor self-efficacy. Participation was felt to be particularly important at the assessment stage. The client-centred assessment methods discussed here depend on the clients' analysis and articulation of their problems with occupational performance (Pollock and McColl 1998). A significant portion of children, who are referred to OT have complex diagnoses, which adversely affect their cognitive abilities. Others might be too young and would not have developed self-efficacy yet. The participants believed that the absence of self-awareness calls for more parental involvement.

Although research shows that children over the age of five can rate their ability to perform a task (Missiuna and Pollock 2000; Missiuna et al. 2006; Vroland-Nordstrand and Krumlinde-Sundholm 2012; Costa and Lindenthal 2015; Vroland-Nordstrand et al. 2016) this literature does not address self-efficacy for the very severely disabled children, especially those who might have poor cognitive and communication abilities. The participants explained how challenges related to cognitive problems and lack of insight are not only encountered with children, but with the parents.

Kjellberg et al. (2012) researched occupational therapists' perceptions of participation barriers. The main obstacle that was identified in their study was therapists' belief that clients could not engage in therapy. Clients were perceived as being unable to identify their problems or identify goals. Kjellberg et al. (2012) remarked that "The therapists' **perception** that their clients lacked the ability to engage in and take control of the treatment process was striking" (p. 425). Similar beliefs, which conflict with OT values and beliefs, were expressed by participants in this study. Echoing participants in this study, participants in Wilkins et al.'s (2001) study identified the 'right client' as being one who has good insight, and good cognitive and problem-solving skills. Nonetheless, as noted by participants in this study, most patients in need of paediatric OT lack these traits.

As aforementioned, participants identified several practical challenges when trying to include children in decision-making and goal setting. Curtis et al. (2022) highlight that most of the research focuses on school-age children, with limited research on children younger than 5 years. Their scoping review did not identify specific formal strategies that could encourage children to participate in goal setting. They also commented on how groups of children are excluded from studies related to the involvement of children in occupational therapy, based on their cognitive and communication abilities. Although the participants did not directly identify this barrier, similar concerns emerged following reflection on the data.

Although studies related to shared decision-making, goal setting, and child's rights-based approaches include children with disabilities, children with severe conditions tend to be excluded. For example, Missiuna and Pollock (2000) and Missiuna et al. (2006) included children with various neurodevelopmental problems, aged 5 to 8 years or 6 to 9 years respectively, whose receptive language was at or above a 5-year old functioning level, and who could make a choice between two options. Children who did not meet the latter criteria were excluded. Similarly, Costa and Lindenthal's (2015) study included children with a range of neurodevelopmental disabilities and other health impairments. However, children who did not meet the criteria of having a developmental competency in passive and active language above 5 years developmental age, the capability of reflecting on their ability, and the ability to make a choice between two options, were excluded.

In their scoping review on goal setting, Pritchard-Wiart and Phelan (2018) included articles related to research with children with physical or motor disabilities but omitted those which were conducted with children, who had neurobehavioural diagnoses such as autism, following their anticipation that goal setting targets and procedures with such children could differ substantially. O'Connor et al.'s (2021) study also included children aged 6 to 12 years, whose motor difficulties were impacting school performance and who could easily communicate their ideas. These authors acknowledged this limitation.

The age range, cognitive ability to cooperate, developmental level in receptive language, or ability to choose between options have been typically stated as inclusion criteria for non-observational research in this area. These criteria appear to capture some of the perceived difficulties in using a child-centred approach and associated instruments with certain paediatric groups due to age, communication or cognition (Curtis et al. 2022), in line with the challenges identified by the participants in this study.

Therefore, as Hodgetts and Park (2017) point out, most children, who require rehabilitation in the setting where the research took place, including mainly children with autism, are not represented in the published studies. According to estimates, between one-third and half of the children with autism have co-occurring intellectual disability (Centers for Disease Control and Prevention 2010), and about one-third of those with autism are only marginally verbal (Tager-Flusberg and Kasari 2013). Literature on child-centred care seems to overlook the very young children and those with severe disability or significant communication difficulties. Indeed, research that involves young children with autism, and which seeks to take a client-centred view point (even though this is not always explicitly stated) typically sets goals and administers outcome measures with the parents and not the child (e.g., Schaaf et al. 2012; Schaaf et al. 2014; Omairi et al. 2022).

Another factor that the therapist felt was hindering their application of a client-centred and child-centred approach was the setting of potentially conflicting goals. This was perceived to be a main concern. The participants acknowledged that the challenge of goal conflict may be more common in the paediatric area, vis-à-vis other OT areas, given the multiple clients and complexity associated with this sector.

The resulting relationships due to multiple clients may be complex (Dixon-Woods et al. 1999). Kramer et al. (2012b) refer to the relationship between the child, the parent and the professional as a "tridactic relationship" (p. 49), whereas Gagné-Trudel et al. (2024) refer to the resulting complex relationship when working with various family members as a multidirectional one. Moreover, the teacher is typically involved (Missiuna et al. 2006; Costa et al. 2017).

It was evident that the challenge of trying to provide a service to various clients, whose goals may vary was generating feelings of frustration. The participants felt that they were in a dilemma about whose goals they should focus on. They felt that this uncertainty hindered their ability to be client-centred with children, i.e. to be child-centred. The participants also expressed their unease at working with the child on a parent-identified goal, if the goal is not meaningful for the child.

Such participants' concerns related to potential multiple clients chime with findings in the literature about services in the paediatric context (McGavin 1998; Dixon-Woods et al. 1999; Wilkins et al. 2001; Kramer et al. 2009). In this study, this uncertainty was compounded by the difficulty of deciding over the identity of the client. Participants noted that should there be an easy answer to this conundrum, the therapist would proceed accordingly, addressing and focusing on the "client's" goals. Similarly, the discrepancy between the therapists' and clients' goals was seen as posing an arduous challenge for occupational therapists in some other studies (Wilkins et al. 2001; Sumsion and Lencucha 2007; Sumsion and Smyth 2020).

Literature has corroborated the aforementioned differences in priorities between the parents and the child, or among the child, parents and teachers (McGain 1998; Missiuna et al. 2006; Schiariti et al. 2014; Costa et al. 2017; Ruggio et al. 2018). Consistent with research, the participants reported that while parents and teachers are mostly concerned about handwriting and academic issues (Missiuna and Pollock 2000; Costa et al. 2017), children are more concerned about other areas, such as leisure (Missiuna and Pollock 2000; Galvin et al. 2010), sports (Galvin et al. 2010) or self-care (Missiuna and Pollock 2000; Galvin et al. 2010; Costa et al. 2017).

The disparity between the children's and parents' or teachers' views can be attributed to various reasons. Missiuna et al. (2006) note how since children are observed in relatively different contexts by parents and teachers, there may be significant differences in the way the child performs in each of those contexts. Moreover, teachers might also compare children to a ready-made peer group (Missiuna et al. 2006). Additionally, new learning experiences significantly impact children's goal selection (Pollock and Missiuna 2015). Moreover, in children with typical development, such experiences may vary every day (Ruggio et al. 2018).

Other possible reasons for the mismatch between the children's and their parents' perspective could stem from the child's developmental stage, which leads to a different expectation of competence from parents (Schiariti et al. 2014). Congruent with Schiariti et al.'s (2014) findings, participants reported that children tend to prioritise issues that directly affect them, such as their present skills, whereas parents tend to worry more about their child's future. Finally, a child's identified issues or goals may be impacted by their upbringing and experience with having a disability. Children may accept their disability and adapt to it, so they might not think of themselves as different from other children. Consequently, this influences their perspective on participation (Schiariti et al. 2014).

Although there seemed to be an understanding that every client's opinion is valid, nevertheless, in this study, the inconsistency in goals was occasionally attributed to low insight or denial, which may not necessarily be the case. Differences between the child's and parents' goals were attributed to lack of insight on the child's part, while differences between the parents' and therapists' goals were related to possible lack of insight or denial by parents. This difference in goals should not prevent therapists from being client-centred, although the limited literature that is available on how to deal with these dilemmas (McGavin 1998) should be acknowledged.

Given this challenge, researchers (Missiuna et al. 2006; Costa et al. 2017) emphasise the importance of unravelling the various clients' perception so that the goals and priorities of treatment can subsequently be discussed and coordinated. Kramer et al. (2012b) underscore the importance of collaboration between the child, parents and therapist to reach a shared understanding of the desired outcome of the intervention. If possible, therapists should obtain formal and informal information from various proxy sources, such as parents and teachers). Laver-Fawcett and Cox (2021) note that therapists must be aware of these potential discrepancies in goals in order to assess the reliability and value of the proxy's report.

Costa et al. (2017) argue that children’s goals should be recognised and addressed even if they diverge from those of their parents or teachers. Similarly, Kramer et al. (2012b) sustain that therapists need to be ready to settle differences between children's and their parents' intervention goals, and balancing their professional goals with their client’s goals (Kramer et al. 2012b). Taking into account the viewpoints of both children and their parents about areas of participation is also important (Schiariti et al. 2014). A ‘child first’ approach is recommended by Pritchard-Wiart et al. (2019), allowing children to choose goals that are to be discussed., thus allowing the active participation of the parents and professionals, whilst ensuring maximum child engagement. Aligning with the participants, Costa et al. (2017) identify this task of coordinating goals as a challenging and complex but essential one for therapists.

According to both the literature and participants in this study, client-centredness is easy to practise when the client and the therapist are in agreement. However, this approach is tested in the presence of disagreement (McColl et al. 2005). Therapists and families may have different views about the child since they have diverse areas of expertise (An and Palisano 2014); hence, the varying goals that they set for the child.

One of the challenges that participants encountered relates to the engagement of parents in the intervention process. Some researchers (An and Palisano 2014; D’Arrigo et al. 2017) acknowledge that the engagement of the family can be challenging. The engagement of both the parent and the child is complex and is interdependent. Children may be willing to engage but their participation depends on parental involvement, since it is ultimately the parents who seek OT intervention for their child. Likewise, a parent may be involved, but their child may not be motivated to participate (D’Arrigo et al. 2017).

In a paediatric setting the child never asks to be referred to the service. As it is the adults (parents or educators) who refer the child, the latter might not even know why they were referred. The participants noted that children might be seen to be ‘forced’ to attend for a service the latter deem unnecessary, thus violating client-centred principles.
Similar concerns were reported by the children themselves in O’Connor et al.’s (2021) study, where one child explained that he was attending OT services simply to humour his mother. While some children were excited to go to therapy, others were reluctant but they did not have a choice (O’Connor et al. 2021). The participants reported an even worse scenario when parents were unaware of the reason for their child’s referral to OT. This might have an impact on client-centredness.

Participants also discussed difficulties they experienced with informing the clients that they were referred to OT, thus hampering their efforts to build a good rapport with the client. This chimes with the difficulties experienced by therapists in Sumsion and Lencucha’s (2009) study, where clients’ unawareness that they were referred to OT undermined therapists’ efforts to relate with the client. Another issue cited by participants with regards to the referral system was the lack of awareness of the occupational therapist’s role in this system. This finding was also consistent with Sumsion and Lencucha’s (2009).

At the level of the therapist

Other barriers to client-centred practice could stem from the therapist. Although therapists did not directly identify these obstacles, they emerged following reflection on the data. A challenge that could be noted was the uneasiness that accompanies the transfer of additional control or power to the client. This challenge was also identified by Law et al. (1995) as a process that undermines the conventional perception of the therapist as an expert.

This finding matches Duggan’s (2005) study, which found that occupational therapists had their work cut out to relinquish control over the therapy process. Similar to this study, Duggan (2005) noted that therapists’ keen interest in discussing workplace-related issues, such as workload and the necessity to be involved in departmental decision-making were testimony to their need for control. It appears that occupational therapists must feel in charge of their workplace to feel effective (Duggan 2005), as was the case in this study.

The feeling that change is beyond the therapists' control emerged as a major challenge. However, despite appearances, one participant disagreed that therapists resisted change. Instead, participants blamed the system, believing that there was not much they could do. A feeling of fatalism and disempowerment was evident. Another participant noted that it would be easier to start a service from scratch, based on client-centred and child-centred principles than modify the existing system. Coyne's (2013) study yielded similar findings, regarding participants' feeling of powerlessness to implement change. Sumsion (2006a) remarks that some therapists may find it impossible to overcome the obstacles posed by a shift to client-centred intervention since some fear change.

In accordance with Sumsion and Lencucha's (2009) findings, the participants in this study perceived that the client-centred approach and the OT role were not well understood. Similar to Wilkins et al.'s (2001) findings, "it was obvious that client-centred practice … was not well defined or understood" even among the participants themselves (p. 76). The same can be said of child-centred practice.

At the level of the system

Besides the restraints at the level of the client and therapists, the findings uncovered barriers at the level of the system or organisation. Such barriers were also identified by the literature as limiting client-centred (Wilkins et al. 2001; Kjellberg et al. 2012) and child-centred (Pritchard-Wiart and Phelan 2018) practice. Apart from the client and the therapist, the context where they practise plays a key role in how client-centred practice is implemented (Gupta and Taff 2015).

The findings of this study also showed that in the absence of shared values by all team members, participants were finding it challenging to be client-centred. Such a challenge is widely recognised in the literature (Sumsion 1993; Law et al. 1995; Duggan 2005; Sumsion 2006a; Sumsion and Lencucha 2007; Sumsion and Lencucha 2009). The single efforts of occupational therapists are unlikely to be effective if other teams lack the knowledge and the will to apply it (Sumsion 1993). In line with previous findings (Law et al. 1995; Duggan 2005; Sumsion 2006a; Sumsion and Lencucha 2009), participants perceived working in a more directive team, which is dominated by the medical model, as an obstacle to the implementation of client-centred practice.

Limited human resources, time constraints, insufficient equipment and restricted facilities were also seen by participants as a hindrance to the delivery of a client-centred or child-centred approach. Such a concern is similarly reported in the literature (Hayes et al. 2019). The participants lamented that the limited human resources available could not meet the demands of the services. The low staff-to-patient ratio did not leave enough time to get to know the client, the parents, let alone the child. Times allocated for sessions were limited (in terms of actual session duration as well as frequency and total number of sessions that can be provided to each client).

A consultation-based service was being provided instead of a direct-service. Consultation is recognised as a service delivery mode (AOTA 2020) and the participants were aware of the potential benefits of methods such as consultation and parent coaching in engaging the parents in treatment session (Tanner et al. 2023). However, therapists were concerned that a solely consultation-based service fell short of addressing each child's specific needs. Some of their clients, such as children with sensory integration difficulties, who would benefit from Ayres Sensory Integration (ASI; Ayres 2005) services, needed a direct, hands-on service.

Moreover, a consultation-based service made therapists spend more time with the parent or the teacher than with the children themselves, thus treating parents and teachers as the main clients, rather than the child, irrespective of the child's age or cognitive abilities. In Coyne's (2013) study, participants also admitted over-relying on the parents when they faced busy workloads.

Furthermore, the participants reported that they were pressured to provide group intervention for the older age groups, instead of one-to-one sessions, in a bid to decrease the waiting lists. Once again, the participants showed concern that specific goals of the clients cannot be addressed through this mode of service delivery. These findings are consistent with O'Connor et al.'s (2021), who confessed to finding it difficult to individualise goals when running groups. Similarly, participants in O'Connor et al.'s (2021) study were running groups in order to reduce waiting lists.

An essential component of occupational therapists' practice is the environment (AOTA 2014). Participants in this study noted that the clinic's space and the available equipment were unsuitable to provide the sensory-motor affordances the children needed. Participants expressed the greatest concern for the basic need of privacy. Rooms were being shared and curtains were used as separators. While the latter provided visual privacy, the resulting clinic space was not soundproof. Participants lamented a lack of privacy for clients to discuss their concerns and plan goals. They added that the curtains were acting as distractions for children with autism or other children with visual reactivity or attention problems. Similar to Hayes et al.'s (2019) findings, this data indicates that clinic areas were not conducive to the engagement of children in goal setting and shared decision-making. The lack of privacy or inadequate space meant that basic OT areas, such as feeding, toileting, dressing and play, could not be assessed or directly addressed during intervention.

Moreover, due to limited equipment, appropriate tools to address specific issues or specific activities that the child might like were not always available. Research has shown the efficacy of ASI with the client population that was currently receiving the service (Chan et al. 2023). However, such treatment could not be provided to children who required it, because of the lack of equipment and appropriate space. Moreover, child-centred tools were not available. This issue will be further discussed in the section on outcome measures below.

Time is also commonly identified as a significant barrier to the implementation of a client-centred (Wilkins et al. 2001) or family-centred (Edwards et al. 2003) approach. Findings show that there was insufficient time for proper assessment of both the parent and the child and for the therapist to collaboratively set the goals with the child. It is recognised that time constraints and resource limitations may prevent therapists from incorporating structured goal practice into meaningful treatment (Branjerdporn et al. 2018), leading to the therapists' failure to consider the client's specific needs (Phoenix and Vanderkaay 2015). At the time of the study, there was a fixed allocated time for each assessment, which had to include goal setting. The participants noted that this was insufficient for all clients. Additionally, the volume of cases the participants had to handle reduced the frequency of meetings with clients, as reported by Sumsion and Lencucha (2009). The limited time was also affecting the possibility for the therapists to meet as a multidisciplinary team.

The participants felt that working in a rush was affecting the therapeutic relationship with both parents and children. They reported that they did not have enough time to build a rapport with their clients, especially with the child. These perceptions match O'Connor et al.'s (2021) research, where the occupational therapists similarly felt that such service constraints impacted the rapport-building process between them and their clients. Such factors also resulted in children's voices being subsumed. The participants lamented the limited time available to prepare child-friendly activities for the session. Similar to Hayes et al. (2019), participants were having back-to-back sessions, allowing limited time to prepare for sessions and investigate possible varied options with the clients.

There is the perception that the involvement of clients, especially young ones, in shared decision-making takes more time (Boland et al. 2019; Hayes et al. 2019). Sumsion (2006a) argues that client-centred practice may be perceived as requiring more time if one takes a short-term evaluation. However, one must take into account the growing accent on health care quality. Although a client-centred approach may seem time-consuming, it improves the quality of the service. Sumsion (2006a) points out that in the long-term, client-centred practice would take less time as the client then learns to take ownership of the discussed goals and take more responsibility to follow up the OT programme.

In most therapeutic settings, there are high productivity expectations (Chapleau 2015) and this was also the case in this setting. Reported barriers related to large caseloads were also reported in the literature (Sumsion 2006; Sumsion and Lencucha 2009; Boland et al. 2019). It was evident that working under pressure generated increased stress for participants. Similar to Hayes et al.'s (2019) findings, participants described how stress hindered their ability to engage the clients in therapy, preventing them from listening to children and their families and providing the same routine treatment without addressing the values of the child or the family.

The data revealed various barriers to implementing a child- or client-centred service in paediatric OT, and indicated the difficulty of defining the concept of child- or client-centred practice. Moats (2007) regrets that some OT literature on client-centred practice suggests that there are "exceptional" situations in which a client-defined model cannot be applied (p. 97). The findings of this study align with Moats' (2007), demonstrating that problems with the application of client-centredness are not exclusive to any one situation. Instead, they form a large portion of many therapists' daily lives. Moats (2007) argues that to treat them as a trivial side note does not do justice to the OT profession. For the implementation of client-centredness and child-centredness in practice, the profession needs to provide additional support to practitioners.

Similar to Sumsion's (2006a) findings, data from this study show that a client-centred practice is neither straightforward nor easy to implement. While some of the identified challenges may require innovative problem-solving to overcome, none of them are intractable (Sumsion 2006a). It is crucial to anticipate potential obstacles to client-centred practice in order to develop solutions for them (Law et al. 1995). One of the major obstacles to apply client-centred practice is to imagine how to make changes to improve the service (Wilkins et al. 2001).

9.1.2.2 Facilitators for Client-Centred and Child-Centred Practice

Unfortunately, no facilitators were directly identified or discussed by participants during discussions or group reflections. Participants focused mostly on the challenges rather than the enablers, which is consistent with the literature, most of which discusses the barriers to client-centred or child-centred practice. However, on further reflection following the completion of the study, the researcher could identify a number of factors that could enhance client-centred and child-centred practice.

The findings show that the participants valued trust, which they perceived as a crucial factor which their relationship with the client (both parents and the child) was built on. Other researchers identified trust as an ally for client-centredness (Sumsion and Lencucha 2007) and a facilitator for shared decision-making with children (Boland et al. 2019).

Another facilitator is participants' evident desire to be child-centred and client-centred and their dissatisfaction with their current way of practice, as is evidenced by their efforts to adapt their practice to make it more client-centred and child-centred by, for example, using appropriate language when speaking to parents and children, and through their therapeutic use of the self. Boland et al. (2019) identified the will to include children in shared decision as the main enhancer of such practice.

Understanding the obstacles and enablers that influence a health care innovation (in this case a child-centred and client-centred service) is essential for its effective implementation. The identified barriers and facilitators are summarised in Table 10. Professional practice is improved when interventions are tailored to overcome identified challenges (Baker et al. 2010).

Table 10. Barriers and facilitators for a client-centred and child-centred practice

Barriers	***Facilitators***
• Who is the client? • The child being a minor • Obtaining information from a non-verbal child • Children who have cognitive problems or poor insight • Limited research in paediatrics • Conflict in goals • Challenges around engaging the family • Child never asks to be referred to OT or parents who do not feel the need for the service • Power issues • The feeling of disempowerment and resistance to change • Limited understanding of client-centredness and child-centredness • Being in a team, which does not necessarily share the same values • Limited resources ○ Limited human resources ○ Limited time ○ Limited equipment ○ Limited space and facilities	• Therapists' desire to be child- and client centred • Attempts to adapt practice (e.g. use appropriate language etc.,) • Being dissatisfied with the current way of practice • Valuing trust • Valuing the experience and perspective of clients • The fact that therapists could identify the barriers that hamper client-centred or child-centred practice

9.1.3 Current Practice – The Rhetoric versus Reality

The findings of this study reveal a discrepancy between the fundamental concepts of client-centredness/child-centredness and actual practice. This was noted despite participants' conviction that client-centred and child-centred practice is the ideal practice. Hammell (2013) argued that there is scant analysis of client-centred practice in the OT field. Therefore there is still much to discover about the genuineness of the profession's claim to be "client-centred".

There seemed to be consensus among participants that paediatric OT practice should be child-centred. The literature (Pritchard-Wiart et al. 2019; O'Connor et al. 2021) has extensively addressed the importance of children's engagement in child-centred interventions. However, there is a gap between clinical application and rhetoric (Antoniadou 2022). Although the application of client-centred care has been repeatedly recommended across health care settings, evidence indicates that clients, especially children and young people, are seldom involved in goal setting and decision-making (Gondek et al. 2016). Curtis et al. (2022) found little evidence to support the inclusion of children with disabilities in therapy through the use of goal setting tools, particularly those under 5 years old or those with cognitive or communication impairments.

This study has found that the child was not being involved in goal setting or decision-making. Occupational therapists were trying to get to know what the child wanted during intervention and not during the assessment or goal setting stage. This study's findings are consistent with O'Connor et al.'s (2021) study, which showed that children's involvement in decision-making consisted mainly of children being given the option to select an activity during treatment or an instance where the therapist supported the choice of a child to decline to participate in an activity. In light of this, it is evident that the therapist's dedication to child-centredness is compromised.

In this study, the participants acknowledged that the current practice of omitting the child from assessment, goal setting and decision-making did not chime with child-centred or client-centred practice. Indeed, the latter entails the client's involvement in all of the OT process (Missiuna et al. 2006). Client-centred practice is dependent on participation (Maitra and Erway 2006) particularly in decision-making (Law et al. 1995; Rodger and Keen 2017) and goal setting (O'Connor et al. 2021). Albeit challenging, goal setting is regarded as being essential to paediatric rehabilitation (Brewer et al. 2014; Pritchard-Wiart and Phelan 2018). Rodger and Keen (2017) argue that such a partial involvement of the child would constitute merely a 'child-friendly' service not a child/client-centred one. In this study, the participants used the terms "child-friendly" and "child-centred" interchangeably.

The findings demonstrate that children are not being given a chance to voice their concerns. Research confirms this, demonstrating that the voice of the young child is absent in goal setting (O'Connor et al. 2021) and decision-making (Coyne 2006; 2008) and when present, decision-making in health care is frequently limited to involving children in "smaller decisions" (Coyne 2006; Anderson and Dolva 2015; O'Connor et al. 2014).

Research also indicates a discrepancy between the therapists' perspectives and the child's perspective, although this aspect was not examined in the current study. O'Connor et al. (2021) found that while occupational therapists were reporting that they include older children (6 to 18 years) in goal setting, half of the children in their study felt that they were uninvolved in this process.

The findings of this research appear to chime with the outcomes findings in O'Connor et al.'s (2021) study, in which participants reported that assessment data and information from the parents, educators and other professionals were shaping decisions about goal setting. The majority of decision-making appears to be adult-directed, with adult-led services, priorities, and agendas overriding children's voices. Consequently, OT goals for children are typically based on issues identified by the parents or teachers, particularly if the child was non-verbal (Missiuna and Pollock 2000; Pritchard-Wiart and Phelan 2018; Vroland-Nordstrand et al. 2018).

Despite children's right to participate in decision-making, therapists' willingness to support children's decision-making tends to be based on their assessment of the child's competency level and the time constraints that prevent therapists from engaging them in this process.

Research shows that children who have cognitive or communication issues are less likely to be included in decision-making (O'Connor et al. 2021). Notably, although these children are considered to be of a suitable age and maturity, according to Article 12 of the UNCRC (UN 1989), they would need additional efforts to have their opinions heard and their engagement in shared decision-making supported (O'Connor et al. 2021). Consistent with O'Connor et al.'s (2021) findings, participants in this research acknowledged the shortage of time to engage children who needed extra support, but they could also identify some effective strategies to achieve that end.

Research indicates that children encounter significant barriers to actively participate in health care interactions, mostly from health professionals and to some extent from parents (Coyne 2008). The latter can either encourage (Quaye et al. 2019) or prevent children's participation (Coyne 2008). In Coyne's (2006) study some children felt ignored and depersonalised because they were not consulted. O'Connor et al. (2021) laments the insufficient time and space given to children to voice their opinions in an informed manner. Moreover, much less effort is made to listen to and act on their opinions (O'Connor et al. 2021). A paediatric practice based on the adult's goals can prove to be controversial, since research indicates that adults and children tend to have different goals (McGavin 1998; Vroland-Nordstrand and Krumlinde-Sundholm 2012b).

The aforementioned concerns about the relevance of goals are confirmed by research, which shows that implementing a child-centred goal setting increases the child's motivation and returns a positive impact on goal attainment (Costa et al. 2017; Pritchard-Wiart and Phelan 2018; Curtis et al. 2022). Reaching meaningful goals empowers the child, preventing the emergence of learned helplessness (Pritchard-Wiart et al. 2019). Conversely, a lack of child-determined goals leads to a lack of motivation to attain goals (Pollock 1993; Pritchard-Wiart and Phelan 2018) and a diminished engagement that is likely to undermine performance (Pritchard-Wiart et al. 2019).

The findings of this study indicate that this paediatric service seems to be client-centred but not child-centred, since parent's goals are addressed, but not those of the child. In this case, similar to Phoenix and Vanderkaay's (2015), the term "client-centred" would be referring mostly to parents and family. Some participants recommended the practice of setting goals with the adult and implementing the treatment with the child, as a reasonable compromise to move their practice closer to child-centred practice, given the constraints of the service. Although theoretically flawed, participants claimed that this compromise might be the only option when they are working with very young or severely disabled children or children who are unable to communicate, such as children with severe autism. They noted that this might be the only way in which the therapist would be “putting the child first”, as one participant succinctly put it. The participants explained how most of their clients are between 3 and 5 years old, most of whom have autism. Most of these children are non-verbal and their perceived competence has not developed yet.

The literature provides little insight into how such children can be included in goal setting and in shared decision-making. Kjellberg et al. (2012) notes that being client-centred does not always imply that the client should take all the decisions or set the goals of treatment independently. Instead, a client-centred perspective may require the therapist to empower the client and collaborate during treatment or at times to serve as “an advocate for the client’s welfare and desires, however explicit or subtle they may be” (Kjellberg et al. 2012, p. 422). These same principles could possibly apply to child-centredness, when working with very young children or children with severe disabilities. Moreover, Pritchard-Wiart et al. (2019) explains that a ‘child-first’ approach can be applied with young children or children who are unable to express their goals, by taking cues from children by concentrating on tasks that they find motivating and worth accomplishing.

Research shows that children can perform self-evaluation (Missiuna and Pollock 2000; Sturgess et al. 2002; Missiuna et al. 2006; Costa et al. 2017; Vroland-Nordstrand et al. 2016). If appropriate support is provided, they can participate in decision-making (Lundy 2007). Research also demonstrates that children can set goals if they are provided with the opportunity (McGavin 1998; Vroland-Nordstrand and Krumlinde-Sundholm 2012a; Schiariti et al. 2014). There is also data to support the feasibility and benefits of listening to the child's voice (Curtis et al. 2022).

Endorsing clients' views divides opinion. On one hand, the consensus among some therapists was that every client's opinion is valid in line with client-centred principles. On the other hand, other therapists argued that involving clients (including children) in assessment and reassessment might lead to the collection of subjective data, which was perceived as somewhat negative. These participants' concerns are consistent with those reported in Chang and Yeh's (2005) study, in which the inconsistencies between the information reported by children and their parents were identified as a limitation. Such negative views overlook the importance of each client's individual and subjective opinion, which is the heart and soul of truly client-centred practice (Sumsion 1993; Law et al. 1995; Sumsion 2000).

To that end, participants recommended that the administration of an outcome measure might be conducted by the therapist (and not by the client) to avoid subjectivity. Indeed, it is common for therapists to question the client's reporting reliability (McColl et al. 2005). However, a hands-on or observational outcome measure that is administered by the therapist falls short of child- or client-centredness since it overlooks the client's views. These findings indicate that the concept of client-centred / child-centred practice was not being extended and applied to the measurement of outcomes.

Laver-Fawcett and Cox (2021) acknowledge the inconsistency of data collected from self-reports and other observational or direct measures. However, self-reports should not be necessarily seen as inferior but simply different measures reflecting the uniqueness of each client (Barlow et al. 1984). It is hard to envisage how one would deliver a client-centred service without some involvement of the client's perspective in measurement (Carswell et al. 2004).

In order to address this issue, a number of authors have recommended the use of self-reports in addition to observations (Sturgess et al. 2002; Laver-Fawcett and Cox 2021). It has indeed been recommended that the most thorough approach to conducting an assessment is that of gathering information from multiple sources, using a variety of assessment methods, comparing the information and identifying similarities and differences in the data (Laver-Fawcett and Cox 2021). Sturgess et al. (2002) suggest that when working with young children, the therapist can use self-reports, parent reports, and observational methods, such as filming.

A similar issue was encountered when the participants complained that clients tended to change their goals or to create new goals, especially when they are close to discharge. Such a change in goals is common in a client-centred ambience. Clients need to be allowed to "change their goals in line with increased awareness of their circumstances" (Parker 2006, p. 70). On the other hand, having a pre-established number of goals, which are expected to remain uniform, might be incompatible with client-centred practice.

Client-centred practice also offers the specific intervention that the client needs, based on their specific goals (Wressle 2002). The findings indicate that the participants were finding it challenging and frustrating to address the specific goals of the child/family by resorting to the only reasonable choice of treatment regularly available for some of the age groups, namely group-based intervention. Nonetheless, group-based intervention was being regularly provided, enabling the therapist to spend some time with the child and build a rapport with them. The other infrequently provided option for intervention, is a consultation-type service, which therapists felt was hindering the development of a good relationship with the child and the parents. Finlay's (2001) study indicated the more the therapist is engaged in the treatment, vis-à-vis merely performing assessment, the more client-centred they were.

Another instance of the incongruence that transpired in this study between practice and rhetoric is related to holism - a key feature of client/child centredness. Similar to Finlay's (2001) study, participants in this research acknowledged the importance of embracing holism as being a fundamental dimension of their professional identity. Nonetheless, there was an instance when some participants recommended having different therapists addressing different issues for the same child. However, dividing children's situation into school-related issues and health-related issues, rather than considering them as a whole, would defeat the fundamentals of holism.

The findings of this study uncover the lack of congruence between the ideal of client-centred and child-centred practice and the reality of paediatric OT practice, which is consistent with findings from previous studies (Wilkins et al. 2001; Duggan 2005; Gupta and Taff 2015). The latter also highlighted the classic dichotomy between professing and practising; the gap between rhetoric and the actuality of practice. Similar to Duggan's study (2005), the participants in this research could perceive and pinpoint most of these discrepancies. In a study by Maitra and Erway (2006) occupational therapists reported applying client-centred practice principles to their OT services. Nonetheless, their clients had differing opinions about their role as active participants. Their study showed perception gaps and distortions regarding the application of client-centred therapy between the clients and the occupational therapists.

In this distorted scenario, the broader health care context surrounding occupational therapists' work can help explain the challenges posed by heavy work pressures to being client-centred or child-centred in an environment dominated by the medical model. The participants acknowledged that working in a client-centred or child-centred way was an ideal that they admitted that they had not reached yet but which they were aiming for. In this research, when the participants perceived themselves to be non-client-centred and non-child-centred, they felt uncomfortable and disheartened. In order to deliver a coherent child-centred and client-centred service, it is therefore, imperative that paediatric occupational therapists address the anomaly between the rhetoric and practice.

9.2 The Use of Child-Centred Outcome Measures: A Critical Perspective on Maltese Paediatric Occupational Therapy Practice

This section will address findings related to the use of outcome measures in Maltese paediatric OT practice. The participants reported that no outcome measurement system was in place at the time of the study. The outcomes of OT intervention were not being measured and the effectiveness of the treatment that was being provided was not being routinely evaluated. No client-centred or child-centred outcome measures were available at these paediatric OT departments. Similar to this study, Bowman (2006) found that therapists tended to focus on assessing and discharging clients but not on the measurement of treatment outcomes.

Participants reported that non-formal methods were occasionally but not consistently used to evaluate some outcomes. These included the use of homegrown tools, clinical observations and documentation. Laver-Fawcett and Cox (2021) note that health care professionals have always tended to prefer the use of non-standardised evaluations, such as casual interviews and unstructured observations. A number of researchers (Bowman 2006; Davis and Rodd 2014; Davenport and Underhill 2023) found that most occupational therapists were not using standardised occupational performance tools to evaluate the results of their interventions. Homegrown measures were instead found to be widely used by occupational therapists (Davenport and Underhill 2023). Therapists also found it simpler and quicker to rely on their clinical observation skills (Bowman 2006).

Laver-Fawcett and Cox (2021) warn about the risk that therapists run when drawing conclusions from observed behaviours, since the latter can be influence by the therapist's biases and emotions. Being open to interpretation and lacking a comprehensive protocol for conducting and scoring such tests, the results obtained from non-standardised evaluations are considerably more subjective than their standardised counterparts. The ability to reliably readminister the test is also significantly affected (Laver-Fawcett and Cox 2021). Another downside of non-standardised measures is that therapists cannot know whether clients are benefiting from their intervention or perhaps more importantly, ensure that their treatment is harmless (Bowman 2006).

In light of these downsides, an objective method to document change can help restore therapists' confidence (McLaren and Rodger 2003). Allied health professionals "should not underestimate the consequences of continuing to use non-standardised assessments where standardised measures of the same construct or area of function exist." (Laver-Fawcett and Cox 2021, p. 24). Scholars suggest that homegrown assessments should be discarded (Radomski and Trombly-Latham 2008) and replaced by standardised tools (Stewart and Harvey 1990; Romli et al. 2019) to support evidence-based practice and the continued development of the OT profession (Romli et al. 2019). Despite such recommendations, non-standardised tools that address performance components are still commonly used in paediatric OT practice.

However, participants in this study reported several questionable issues with the available standardised measures that they were currently using. These tools were mainly focusing on the body structure and functions level of the ICF (WHO 2001) and not on participation Moreover, they were being used for assessment purposes only without being repeated at the end of intervention. Furthermore, these measures could not be completed by clients (child, parent or teachers) as they were not self-reports. Research (Stewart and Harvey 1990; Rodger et al. 2005; Brown et al. 2007; Skuthan and Stav 2023) has consistently shown that similar skill-based measures were the most commonly used assessments in paediatric OT.

The excessive accent on skills, rather than participation, might be contributing to the lack of awareness of what OT entails that the participants were experiencing and reporting. Moreover, such a focus on deficits is not congruent with the holistic and occupation-centred values of the OT profession (Hinkley et al. 2021). Skuthan and Stav (2023) assert that the widespread use of skill-based assessments compounds the confusion among both clients and other professionals about the areas covered by OT. Such an approach concentrates on performance abilities, which are not necessarily specific to the OT profession (Skuthan and Stav 2023), hence adversely impacting OT's professional identity.

While there was a general belief amongst the participants that OT should address function, this was not being reflected in the selected measures. The participants were highly critical of the fact that important OT-related areas of function, such as feeding, toileting, dressing, play, social interaction and participation in sports were not being addressed, at assessment, intervention or evaluation. The participants noted that some of these areas are merely mentioned on assessment in the parental interview; however, they were not directly addressed in practice. Instead priority was being given to school performance, which may not be meaningful for the child.

Occupational therapists need to take the child's participation into consideration (Rodger et al. 2005). The use of occupation-based measures has been recommended for several reasons. Choosing occupation-based assessments would support the fundamental principles of the OT profession (Skuthan and Stav 2023) and highlight the unique contribution that OT provides in health care (Klein et al. 2008; Hinkley et al. 2021). An occupation-based focus would differentiate the OT profession from other health care professionals (Hinkley et al. 2021) and demonstrate the profession's contribution to evidence-based practice (Klein et al. 2008). Doucet and Gutman (2013) emphasise that the ability to measure function in a thorough way is a strength of the OT profession and is critical for its survival.

Additionally, the aforementioned assessments that are currently used are not OT-specific. Davenport and Underhill (2023) also found that the use of OT specific measures was rare. Several researchers (Doucet and Gutman 2013; Romli et al. 2019) have recommended that occupational therapists use profession-specific instruments. Since such tools are based on OT philosophy, they are more applicable to OT practice (Romli et al. 2019).

In paediatrics, occupational therapists frequently employ performance-based assessments, especially in the evaluation of children's proficiency in motor skills (Burton and Miller 1998; Rodger et al. 2005). However, therapists must endorse the child's and caregivers' views in the assessment process, in order to comply with the current trend of child-centred and family-centred care (Brown 2012). A recent scoping review (Antoniadou 2022) found that children's engagement in evaluation was not addressed in any of the studies reviewed. The findings of this study also showed that the concept of child-centredness was not being extended to the measurement of outcomes, since children were not being involved in this process.

Participants in this study were able to perceive most of the aforementioned benefits of the use of an outcome measure, including the improvement and development of OT services offered, justification for additional funding, demonstrating the effectiveness of the service and showcasing the impact of OT intervention. In Davenport and Underhill's (2023) research, participants gave similar reasons for the use of outcome measure data. Additionally, in both studies, the use of outcome measures was deemed crucial in promoting client-centred practice, especially regarding setting goals and the ability of clients to track their progress.

However, once again, outcome measures are still not being practised, once more exposing the dissonance between professing a belief and practising it.

It quickly became evident that the participants were concerned about the fact that outcome measure data could highlight areas that were not currently being addressed. This included the need to target specific goals that are beyond group intervention. At one point this was used as a compelling argument against the use of outcome measures. However, as the discussion progressed, participants realised that a child-centred or client-centred outcome measure could provide an opportunity to highlight such issues as a means of improving practice. The clinicians were aware that an outcome measure can indicate whether a particular treatment was being effective or not. Having child-centred and client-centred principles at heart, participants honestly acknowledged that the client's specific goals were not being met, feeling deep down that they were not doing the right thing, as they knew that the requisite tools were not being used.

The findings of this study correspond with the findings from Bowman's (2006) study, which found that most participants agreed that occupational therapists were accountable for the services they offer, and expressed readiness to adapt their practice to become more accountable and evidence-based. However, despite these good intentions, no concrete action was taken because it was simpler to continue their current practice than to make a change.

9.2.1 Factors that Affect the Application of a Child-Centred/Client-Centred Outcome Measure

9.2.1.1 Challenges that Limit the Use of Child-Centred/Client-Centred Outcome Measures

Literature (Bowman 2006; Davenport and Underhill 2023) has reported various restrictions to the use of outcome measures, which were also echoed by this study's participants. The most obvious challenge is the lack of availability of any child-centred or client-centred outcome measure. A similar lack of tools was reported in Davenport and Underhill's (2023) study.

A more subtle challenge that could be elicited from the findings is that there seemed to be a lack of understanding of what outcome measures are and how they should be applied. Despite the fact that participants could provide a description of outcomes and outcome measures, there were occasions when some participants mentioned that the outcome measure can be administered once “for assessment purposes only”. This serious misrepresentation of the notion of outcome measures shows confusion between the key terminology of outcome measure and assessment. Another similar instance was when some participants suggested that it might not be possible to use the outcome measure with every client, since not all clients will improve.

Lack of knowledge was similarly found by Bowman (2006) to be a barrier to the implementation of outcome measures. Outcome measures require the recording of at least two scores to establish any functional change (Davenport and Underhill 2023). The initial assessment offers the baseline, but a later measurement is then required for comparison (Laver-Fawcett and Cox 2021). The inconsistent use of important terms in the literature on assessment, evaluation and outcome measures (Laver-Fawcett 2014) may have contributed to this challenge. Laver-Fawcett (2014) recommends that occupational therapists be familiar with the definition of these terms.

The participants identified a limitation in various resources as an additional challenge. This included the lack of a suitable, private place where to administer such measures. The lack of human resources to cater for the ever increasing caseload was also perceived as a challenge. These findings are supported by Davenport and Underhill (2023), who found that most participants highlighted the demands of caseloads as a challenge.

Participants in this study lamented the insufficient time available to administer such measures. Time constraints feature prominently in many facets of health care (Brewer et al. 2014). Participants believed that the use of an outcome measure would require more time than what is available. Similarly, therapists surveyed by Stapleton and McBrearty (2009) believed that standardised measures take a considerable time in hectic environments where therapists have large caseloads and lengthy waiting lists. This time-consuming nature of outcome measures corresponds with Bowman's (2006) findings too. Moreover, Brown (2012) notes that the adoption of a child-report-focused approach, which is being recommended for this setting, can actually take more time.

In sharp contrast, Davis and Rodd (2014) found that the use of an outcome measure, in this case the COPM (Law et al. 2014), was not found to be time-consuming as the therapists did not encounter major difficulties to successfully integrate it into their existing paperwork. Similarly, Law et al. (2014) insisted that the use of self-reports actually saves time in the long run as therapists match intervention with what is meaningful for the client, thus eliminating unnecessary evaluations.

A number of challenges specifically associated with self-reports were also mentioned. Participants noted that filling in a self-report was beyond the capability of some parents., either because of a low educational background or low proficiency in English since outcome measures such as the PEGS (Pollock and Missiuna 2015) were generally written in English. Moreover, participants reported that they occasionally have international clients who do not communicate in either Maltese or English.

There was a pervasive concern that if the outcome measure was in the form of a self-report questionnaire sent to the parents or teachers, the questionnaire would not be returned to the therapist. Moreover, participants added that some clients might leave parts of the questionnaire unanswered, forcing therapists to chase clients to fill in the missing sections, expending more time, which was currently unavailable.

The same applies for children. Although some outcome measures have child-centred (or child-friendly) versions, some children will not be able to complete these tools. Children need to have some basic cognitive abilities to answer questions (Brown 2012). Another element that may impede outcome measurement is the individual's level of insight. Accuracy of the information obtained through a self-report as well as the setting of goals can be affected by a lack of insight (Laver-Fawcett and Cox 2021).

The consensus was that since teachers were identified as potential clients, they should also be asked to fill in self-reports. However, contacting educators during holidays is not practicable. The participants noted how they might not be able to contact the teacher to set goals or to re-assess goals, if the school were closed for holidays. A change in teacher (following progress to the following school year) might also make it difficult to reassess the goals that were set with the previous teacher.

Participants' feeling of powerlessness in relation to change can be considered as another significant obstacle. Therapists fatalistically felt that any change was beyond their control and this included the introduction of an outcome measure in their setting. Some resistance to change could also be felt although one of the participant was adamant in denying this opposition to change.

Participants were concerned that the use of an outcome measure would make it difficult for them to distinguish between OT-intervention-induced results and those resulting from other interventions. They cast doubt on their ability to discover whether circumstances other than their actions contributed to the client's outcome. This finding is consistent with Bowman's (2006), whose participants expressed the same concerns.

9.2.1.2 Factors Facilitating Child-Centred/Client-Centred Outcome Measure Use in Paediatric Occupational Therapy Practice

Participants could clearly perceive the significance of outcome measurement, identifying and acknowledging the benefits of such measures. This can enhance their use in practice. Similar findings were reported in Davenport and Underhill's (2023) study, where the occupational therapists highlighted the benefits of outcome measures, which could help demonstrate accountability and improve the quality of the service. The participants believed that through the use of a suitable child-centred and client-centred outcome measure they would be able to showcase the values and foundations of OT. They also noted that outcome measures can assist with auditing and could eventually provide a justification for the need of additional services or resources. These positive features of outcome measures are supported by a vast range of literature (Davenport and Underhill 2023; Laver-Fawcett and Cox 2021).

Consistent with Bowman’s (2006) findings, some participants acknowledged that they needed to take on the challenge of demonstrating the efficacy and efficiency of their practice, admitting that they would have to adopt a different mindset regarding the measurement of clinical outcomes. Participants were aware that the change of mindsets and culture was a gradual process that frequently encountered resistance. A change in behaviours and attitudes would enable the therapists to find strategies to manage the barriers that they themselves identified and encountered (Bowman 2006). Table 11 summarises the factors that can affect the application of child-centred or client-centred outcome measures.

Table 11. Factors that affect the implementation of child-centred or client-centred outcome measures

Barriers	***Facilitators***
• Lack of understanding of what outcome measures are and confusion of outcome measures with assessments • Limited resources: ○ Lack of availability of child-centred and client-centred tools ○ Limited human resources ○ Limited time ○ Environmental limitations ▪ Lack of adequate space ▪ Lack of privacy • Problems with contacting educators during holidays • Incomplete questionnaires (self-reports) • Language issues – clients who do not understand Malta's two official languages - English or Maltese • Illiterate clients cannot fill self-reports • Children, who have severe disabilities or significant cognitive difficulties • Therapists feeling powerless to change practice • Resistance to the use of outcome measures	• Awareness of the benefits of child-centred and client-centred outcome measures • Awareness of the need to change practice • Potentially suitable outcome measures have been identified

9.3 Action: A Child-Centred Outcome Measure for Paediatric Occupational Therapy Practice in Malta

Throughout this research, the participants identified some child-centred and/or client-centred outcome measures that could be used in this paediatric service. This identification followed several discussions about the ideal characteristics required for an outcome measure to suit this service. Various forms of outcome measures were recommended, including self-reports, questionnaires and interviews. The recommended properties will be discussed first, followed by the actual outcome measures.

9.3.1 Ideal Properties

“The engagement in client-centred practice requires instrumentation that allows the participation of the child and family in the definition of treatment goals.” (Ruggio et al. 2018, p. 828). Following several discussions and reflections, participants agreed that self-reports would be ideal enabling tools. Self-reports provide a means to involve children in decision-making. Such tools can be used by paediatric occupational therapists to learn about the child’s viewpoint and values, which would then inform their intervention decisions (Kramer et al. 2012b). Self-reports enable children to express themselves by posing meaningful questions and providing the opportunity for children to communicate in developmentally appropriate ways (Kramer et al. 2012b). This also facilitates therapists’ understanding of children’s view, problems and participation (Carswell et al. 2004).

Suitable resources that provide a voice to children and their family should be available (Ruggio et al. 2018). Laver-Fawcett and Cox (2021) highlight that therapists have recently realised the advantages of gathering children’s self-report data. Engaging the client in self-report assessment is recommended, even if the client is thought to have low insight (Carswell et al. 2004), as is the case with children. Kramer et al. (2012a) note that if such self-reports are administered through the use of accommodation techniques, apart from the therapeutic use of the self, therapists would be practising in accordance with OT values and along the standards outlined in the UNCRC (UN 1989) and UNCRPD (UN 2006).

The findings highlight that as a client, the child has to be included in outcome measurement for the service to be a truly child-centred or client-centred one. Given the aforementioned benefits, a self-report would be ideal. The findings also demonstrate that when working with paediatrics, the parents and teachers should also be involved, so outcome measures that allow this should be used. The input of children, as well as parents and teachers can be helpful in setting therapeutic goals (Costa et al. 2017).

Participants noted difficulties that some clients (both parents and children) might have to identify goals for intervention. This might be related to the unavailability of appropriate tools. Therefore, outcome measures that can assist both the child and the parents with goal setting should ideally be selected. A child-centred or client-centred outcome measure can assist parents and the child in identifying their occupational concerns and set mutually agreed desired outcomes. Such a measure would thus enable child-centred and client-centred practice.

"If an outcome measurement system is to be widely used, it must pose minimal burden on the therapist for data collection." (Missiuna and Pollock 2000, p. 132). Given the pressures at work, mostly the limited time available, participants noted that time to administer outcome measures might be excessive. Therefore, ease of administration and scoring, as well as easy interpretation were considered to be important. Moreover, for the tool to be client-centred and child-centred, the outcome measure that is used should be clear, easy to understand and easy to be filled in. It should also use lay terms, so that both children and parents with a limited educational background would be able to use it. The participants remarked that the cost and training of the measure should also be considered.

The literature indicates similar features for outcome measures, insisting that the tool used should satisfy the therapist's requirements, including reasonable and effective administration time and high-quality information for practice (Unsworth 2000; Law 2003). The tool should be sensitive to the client status and facilitate the sharing of results (Unsworth 2000). A measure's availability, affordability, required training, convenience of administration, and effectiveness in scoring and interpretation are additional desirable qualities of an ideal outcome measure (Law 2003).

Being aware of the varied needs of children who require their services, participants added that the outcome measure selected should be suitable for children with disabilities and those with cognitive challenges. It should enable even children with such difficulties to identify and set their goals. They noted that the outcome measure should ideally include visuals.

Participants identified psychometric properties, namely validity and reliability, as being essential features. This chimes with what is recommended by the literature (Romli et al. 2019; Laver-Fawcett and Cox 2021). Participants noted that the tool should allow scoring so that the initial and final score can be compared, thus determining the outcome of intervention. The latter is a basic feature of an outcome measure (Laver-Fawcett and Cox 2021). Some participants expressed the possibility of having normative data. However, this is not compatible with a child-centred or client-centred service, since a client's goals cannot be compared to a norm. Participants added how the cultural relevance of the tool to the Maltese context, the activities included and the language of administration should be taken into consideration. To assess the cultural relevance of some child-centred outcome measures, some researchers have evaluated their use in other countries (e.g., Vroland-Nordstrand 2008; Vroland-Nordstrand and Krumlinde-Sundholm 2012a; Vroland-Nordstrand and Krumlinde-Sundholm 2012b; Costa 2014; Costa and Lindenthal 2015).

Another attribute that was indicated by the participants was that the outcome measure should ideally be applicable to different contexts. All OT domains, such as self-care, productivity and leisure, both at home and at school, should ideally be covered. The area of play and social interaction should also be included. Participants highlighted the importance of focusing not only on school performance, as was the current tendency, but on different occupations, that are relevant for a range of ages. The participants added that an outcome measure that addresses several functional areas would also hopefully allow the therapist to find a compromise between different goals identified by the different clients.

Finally, the participants highlighted that the outcome measure should be congruent with the overarching model of practice, in this case, the CMOP-E (Polatajko et al. 2013). Addressing function and participation is particularly important to maintain OT's professional identity (Hinkley et al. 2021; Skuthan and Stav 2023). By addressing participation, the outcome measure would help therapists focus on what is important for the profession.

9.3.2 Ideal Outcome Measurement

Although the original quest of this study was to identify *the ideal outcome measure*, the findings of this participatory research have highlighted the necessity of having multiple outcome measures in order to meet the fluid nature of a child or varied client requirements. Similarly, no single outcome measure that can address the varied needs of children aged 0 to

16 years has been identified in the literature. In that respect, participants were open to the idea of having more than one outcome measure for various options matching the individual child, client or situation. The child's age, clients' goals, clients' cognitive and communication abilities and the type of intervention play a central role in choosing the right outcome measure (Calder et al. 2017).

A number of outcome measures were therefore recommended as being potentially suitable for this paediatric service. Very young children and those with severe disabilities, who are non-verbal, comprise the majority of the caseload, so their inclusion necessitates special attention and treatment. Since most child-centred outcome measures are recommended for use with children aged five and onwards, a different protocol needs to be followed for those children, who are under 5 years of age, and who have cognitive and communication difficulties.

This claim that one outcome measure cannot satisfy all the needs of a service is supported by literature in the rehabilitation area (Wade 2009; Ariss et al. 2015; Caldwell et al. 2015). Instead, a range of tools that represent the many facets of the service should be considered (British Society of Rehabilitation Medicine [BSRM] 2005). Although the paediatric literature recommends a range of child-centred outcome measures, only a few studies were found to have done so. Østensjø et al. (2008) have simultaneously used two outcome measures. On the other hand, Galvin et al. (2010) were found to have used two outcome measures, depending on the child participants' abilities. Other studies have simultaneously used two outcome measures, mainly to compare the results (Cusick et al. 2006; Novak et al. 2009). No protocol recommendation that addresses the whole range of clients that this service caters for was found in the literature.

Table 12 summarises the range of potential outcome measures that were identified by the participants and their suitability for this paediatric service. Further information about these child-centred outcome measures can be found in Appendix A. These tools have also been discussed in the literature review (Chapter 3).

Table 12. Potential child-centred and client-centred outcome measures for Maltese paediatric occupational therapy

Outcome Measure	***Suitability***

Perceived Efficacy and Goal Setting System (PEGS; Pollock and Missiuna 2015)	• A suitable child-centred outcome measure that can be used with children, including those with disabilities, who are chronologically or developmentally at a 5- to 9-year-old level.
	• Can be used with children, who can formulate some kind of response.
	• Comprises questionnaires for parents and educators, apart from a protocol for interviewing the child.
	  ○ Parents can be asked to answer the Parent Questionnaire separately from the child, while the Teacher Questionnaire can be emailed to the child's teacher or sent by post.
	  ○ If necessary, parents or teachers can also be interviewed on the phone.

Canadian Occupational Performance Measure (COPM; (Law et al. 2014)	• Identified as being a potential child-centred or client-centred outcome measure for this service. • Can be used when the child is younger than 5 years, or when a child of any age has significant difficulties, thus rendering the PEGS not fit for purpose. ○ In that case, the COPM would be applied only to parents, as proxies, and teachers where applicable. • Can also be administered to children, who are older than 9 years of age, while simultaneously administering this tool to the parent and possibly the teacher as well. • Can also be used to evaluate the effectiveness of programmes that are offered at the OT department, such as consultation treatments, or group intervention.
Goal Attainment Scaling (GAS; Kiresuk et al. 1994)	• An additional potential outcome measure that can measure individualised goals. • Provided that training on how to use the GAS is provided, the GAS could be used to assist with goal setting. • Participants were aware that since this tool is not a self-report; it cannot be considered child-centred unless it is used with another child-centred tool. The GAS could be used with the PEGS or with the COPM. ○ The GAS can be used to set goals, which are based on areas identified by PEGS or the COPM. • Through this measure, the therapist can incorporate the parents' and teachers' goals as well. • The GAS-light version was also mentioned as a possible time-saving option by participants.

9.4 Limitations of the Study

This study has several limitations. Since observational methods were not employed, the study is reliant on the subjective descriptions of the participants, which are subject to interpretation. This study originally aimed to include children; however, this was not possible since otherwise the study would have been too extensive for one PhD. Therefore, the degree to which therapists' shared accounts accurately reflect their work is open to question since this study did not include child interviews or in-person observations of therapists.

My interests, values and life experiences surely impacted this research, both during data collection and during interpretation of the data. Instead of trying to resist this impact, I strove to acknowledge and exploit this insight, together with the extra knowledge that being an occupational therapist entailed.

It is crucial to note that the reflections and learning that resulted from this participatory action research might not apply to other participatory groups. The findings may be skewed towards female occupational therapists (which formed most of the participants) employed by public health services. The discussions could have possibly been broader if a more varied group had been studied. The findings may therefore be restricted to occupational therapists who participated in this study and might not be representative of other occupational therapists working in other areas or in other countries.

Another potential limitation is that some participants might not have felt comfortable reporting their experiences if these ran counter to the views of most of the group; therefore the findings might not reflect the experiences of all the therapists. However, as a facilitator of the action research groups, I supported different viewpoints and reminded the participants that differing views were perfectly acceptable.

Finally, due to the study’s design and time limitations, participants could not discuss emergent themes. However, they were involved in reflection during and after each action group meeting – the preliminary analysis - so they could still collaborate with the researcher in making sense of the data. Future participatory research may allow participants to engage more actively in the final data analysis phases of the study.

9.5 Strengths of the Study

This research study had a number of strengths. One of the strengths is that all the paediatric occupational therapists working in the public health sector were included in this study. This added breath to the data.

Open communication and trust were crucial for this group. The participants agreed on and maintained confidentiality. The participants were already familiar with each other since they worked together, and this made it easier for them to question their own and others’ beliefs. Such a challenging component is an important requirement for change and transformation, when there is reflective learning (Heron 1999).

Furthermore, as a facilitator I used open-ended questions during the action research group discussions. The participants were asked to expand on their responses and were permitted to deviate from my pre-planned questions, thus enabling the collection of richer, more nuanced data.

Finally, all tried hard to ensure that the action research group discussions were mostly focused on thoughtful reflections rather than becoming whining sessions. I facilitated the discussion, steering the discussion away from unnecessary deviations and circumlocutions.

9.6 Conclusion

This chapter discussed the findings in relation to the literature. It addressed issues related to the application of a client-centred and child-centred approach. This included the conceptualisation of the client in paediatrics and an overview of the factors that impact client-centredness and child-centredness. The discrepancy between the rhetoric and the reality of practice was also discussed. The chapter than dealt with the application of outcome measures, starting with a critical analysis of current practice. This was followed by a discussion of the barriers and facilitators to the utilisation of client-centred and child-centred outcome measures. The ideal properties of a child-centred outcome measure for this service followed, together with some identified outcome measures suitable for this paediatric service. The chapter ended with an overview of this research's limitations and strengths.

Chapter 10: Turning Rhetoric into Reality: Conclusion and Implications for Practice and Research

10.1 Conclusion and Contribution to Theory and Practice

This research makes an important contribution to the body of knowledge of OT, because it is the first study that has investigated the factors that lead to a measurable child-centred service for paediatric OT in Malta. This participatory study has shone a light on how Maltese paediatric occupational therapists understand and enact child-centredness and client-centredness. It is also the first study in Malta to scope the use of outcome measures across paediatric OT services.

There is the widespread belief that OT has always been client-centred. However, this research contributes to evidence that indicates that the profession's practice does not always align with its espoused and professed client-centred ideal. Although the theoretical underpinnings of client-centred care in OT has significantly advanced over the past years, there still seems to be a fundamental gap between rhetoric and reality. Moreover, this work has revealed that applying a client-centred approach can pose serious challenges, particularly when one works with children.

Many of the barriers and facilitators to the application of a client-centred or child-centred approach that were identified by the participants overlap with findings from other studies. These factors act on several levels, including those of the clients receiving OT services, the therapist providing the services and the system within which these services are offered. Therefore, to effectively integrate client-centred or child-centred practice, change needs to be implemented at all these various levels.

This study has revealed that determining who the client is poses the most significant challenge that paediatric occupational therapists face, when the term "client" is interpreted broadly to encompass a child's family and significant others. When working with children, the therapist will inevitably have to deal with parents, teachers and significant others, who are deeply involved in the child's lives. Therefore, paediatric occupational therapists must adopt a broad definition of the 'client' that includes all the relevant stakeholders. The findings have shown that given the multiplicity of clients involved, the practice of child-centredness or client-centredness is indeed a complex one. Moreover, the data seem to corroborate various assertions in the literature that children, parents and teachers have different priorities and consequently different goals.

This research emphasises that as clients, children should be regarded as competent individuals who have the ability to be involved in decision-making and who can identify and achieve their own goals if adequate support is provided by the therapist. Involving children in decision-making and goal setting is one means of applying child-centred and client-centred practice. Moreover, there is an increasing recognition that children have a right to participate in matters that affect their lives. Therapists cannot rely on the parents' or teachers' view since the latter may differ quite markedly from the perspective of the child. In addition to being crucial for an occupation-based evaluation process, addressing a child's issues is also a vital component of a therapeutic intervention that promotes health and that may be more efficient and meaningful to the child's life.

Therefore, occupational therapists should recognise the child's right to involvement in shared decision-making, whilst simultaneously acknowledging the need to include the parents' and significant others' views, keeping in mind that these views may be conflicting. This research, even with its limitations, confirms the necessity of shifting to a more authentic child-centred practice, whilst taking into account the views of other key stakeholders such as parents and teachers.

Furthermore, paediatric occupational therapists work with children with a range of unique needs. Some children are very young and some others have cognitive or communication problems. The latter difficulties impact the child's ability to engage in shared decision-making and setting goals. In such cases, the application of child-centredness, which entails the involvement of the child in every step of the OT process, is significantly challenged.

Therefore, occupational therapists should ensure that child-centredness or client-centredness is not viewed as an all-or-nothing approach but as a continuum. It is critical to acknowledge that part of being child-centred or client-centred is indeed acknowledging that children/clients have unique needs. While some clients may be able to communicate their needs, set their goals and participate in shared decision-making, others may only be able to engage in simple choices. As occupational therapists, we should understand the individual needs of our clients and react accordingly. The claim that a child-centred or client-centred approach can only be applied to clients of a certain age and ability contradicts the fundamental principles of child-centred or client-centred care. Therefore, therapists should find a way to apply these concepts to clients of all ages and abilities.

This research has contributed to the use of participatory action research as a methodology in the field of paediatric OT. The discussions and reflections that occurred during the eight action research groups provided a means for occupational therapists to increase their understanding of child-centred and client-centred concepts and to enhance their awareness of issues related to such practice. The therapists also reflected on the measurement of outcome and performance. This is a crucial step in progressing towards a more effective child-centred and client-centred service. New learning took place, as evidenced by the therapists' ability to identify factors that were hindering or enhancing the application of child-centred and client-centred outcome measurement

The therapists acknowledged that this research helped them reflect on their practice and on whether they were giving a voice to the child. Therapists should ensure that their approach is leveraging the child' interests and strengths by reflecting on their beliefs and their practice. Constant reflection on practice is required to ensure that the OT service that is being delivered is child-and client-centred and that outcome measures are used in line with these principles. This is especially crucial when dealing with young children and children who have complex difficulties.

This study supports the idea that ensuring the successful integration of child-and client-centred measurement as a fundamental component of OT practice presents another challenge for therapists. Despite the fact that most therapists are aware of measurement concepts and its benefits, outcome measures are still not integrated into the daily practice.

Another significant contribution of this research is the identification of some child-centred outcome measures that would be applicable for the Maltese paediatric OT service. Rather than a single child-centred outcome measure, the findings have indicated that there is a need for a range of outcome measures, which can be used with the child and the multiple clients that are typically involved, such as the parents and the teachers. The selection of the tool will depend on the age of the child and the child's abilities, including the child's cognitive and communication abilities.

In conclusion, the findings provide evidence of the continued struggle to translate the theory of child-centred and client-centredness into practice. This study has highlighted the complexity around the application of a measurable child-centred and client-centred practice. Despite these challenges, as long as there is commitment, effort and support from all levels of the organisation, OT practice can be improved for the ultimate benefit of the children and clients that we serve. The shift towards the use of child-centred and client-centred outcome measures will reflect occupation-based values, thus strengthening the professional identity of the OT profession.

10.2 Recommendations Arising from the Action Research Groups

This section deals with the recommendations that the participants discussed and reflected upon during the action research groups. It addresses some of the practical realities that therapists face when trying to employ a child-centred and client-centred approach. The following are the suggestions that were provided by the participatory group:

- Occupational therapists should clarify who is the client from the very onset, even before assessing the child. When there are multiple stakeholders, the therapist needs to be prepared for possible conflict and be knowledgeable on how to address such conflict. All potential clients should be involved in all OT stages.

- Occupational therapists should adopt a ‘child-first’ approach, in which discussions about goals are based on child-identified goals. Such practice places a strong emphasis on maximally engaging the child, whilst still allowing the active participation of significant others as well as that of therapists.

- When working with young children or those who may be non-verbal, the therapist should observe the child and concentrate on activities that are motivating for the child or that the child is consistently attempting to accomplish.

- Part of the assessment should involve the children being consulted without their parents, giving children the opportunity to voice their opinions on their own. This should not exclude separate consultation sessions for parents, as some parents might need to disclose information which would be inappropriate to discuss in front of the child. This strategy would enable the therapists to understand each client’s point of view, handle any goal conflicts and work toward a consensus.

- Occupational therapists should spend more time at the assessment and goal setting stage to get to know the clients, including the child. This would enable the therapist to build a rapport with the child and the parents. The child should also be given more time to build trust in the therapist, given that trust is a key foundation of child-centred practice.

- Additional time should ideally be allocated between consequent sessions, so that the therapist would be able to plan each OT session and prepare the activities that are required for that specific child.

- The therapeutic environment should be suitable. The required equipment need to be in place. The issue of privacy should be given particular importance, and should be part of the basic requirements during assessment and intervention.

- The current assessment process should be changed in order to avoid duplication of work. Any new child-centred or client-centred outcome measure should be incorporated in the assessment process. Further discussions need to take place in order to plan how this outcome measure will be implemented.

- Perhaps more importantly is the pressing need to change the approach to practice. Any new outcome measures should be implemented with a different mindset, mainly a more child-centred and client-centred one.

- New child-centred and client-centred outcome measures should be procured and made easily available. Additional research and training should be conducted to ensure that a range of suitable outcome measures is available.

- Child-centred outcome measures should only be applied in situations where the therapists are committed to assisting the child to reach their identified goals. There should be provision for one-to-one sessions, with adequate frequency, depending on the client's needs.

- Service changes should be made, rather than trying to make a fresh approach integrate into the old set-up. Paediatric OT services should be designed to fulfil clients' demands as opposed to having the clients fit into an already existing service model.

- The referral system should be changed. Referees should discuss the intent or need to refer with the parents and the child, before the referral is made. Clients can also be asked to take a pre-referral questionnaire for them to be more involved in the referral. A client-led, self-referral system should be one of the main targets of client-centred practice.

- Further awareness should be raised amongst the public and other professionals on the nature of OT. Referring bodies would hopefully then refer clients who are in need of OT services, thereby saving time for the service, which is currently limited.

- There needs to be a "cultural shift", leading to therapists focusing more on function and participation. Training to reach this aim should be done at a national level.

- There should be more training provision in the various skills related to child-centred and client-centred practice, such as active listening.

- More training should be offered on the use of outcome measures. Continued professional development activities should focus on learning how to implement a standardised outcome measure and how to critically appraise such measures.

- Opportunities should be provided to practise administering, scoring and interpreting these outcome measures in a safe environment, while being supervised by experienced mentors.

- Since some outcome measures are becoming computerised, training sessions should be held on how to use this technology, thus learning to automate certain time-consuming parts of outcome measurement.

- A vision for paediatric OT services in Malta incorporating child-centred and client-centred approaches in all service delivery should be spelt out.

- There should be support from management to reduce barriers and leverage enhancers to a measurable child-centred practice. There should also be full commitment from all organisational levels, including management to deliver a service that is genuinely client-centred or child-centred.

- The relationship between the therapist and the clients should be built on trust and honesty. These are important facilitators for shared decision-making, together with the ability to listen to the client.

- The therapists should be holistic. The therapists’ capacity to be truly holistic is frequently hampered by their heavy workloads.

- There should be good communication between the professionals providing a service to the client, including collaboration with other members of the multidisciplinary team. Moreover, all members of the team should give the same and consistent message to the clients.

- In order for children to participate in shared decision-making in an effective and meaningful way, there should be a high-quality and child-friendly information exchange with them.

- Child and client-centredness should be evident in all stages, including assessment and evaluation of outcomes, and not just during intervention.

- OT service should be flexible.

- OT service should be specific according to the needs of individual client. The clients' values should be respected. The therapists' understanding of their own values is critical as is the need to refrain from imposing these values on their clients.

- OT assessments should be conducted in different environmental contexts.

- OT services should be provided in a timely manner. A welcoming service should be offered while attending to seemingly minor details such as parking and waiting lists.

The recommendations clearly indicate that various changes are required. There are different ways in which an organisation can address change. While some organisations may start with modifications to their mission and guiding principles, others may opt to start with changes at an individual clinical level. Both approaches can be effectively implemented. A participatory management style, where all individuals can share their ideas and come up with solutions (Wilkins et al. 2001) is recommended. This PhD research has served this purpose. It was conducted with all the occupational therapists, who provide paediatric OT services, and all levels of staff in the OT department participated in the study, thus providing each therapist with the opportunity to contribute to the discussions

10.3 Additional Recommendations and Implications for Practice

The following are some additional recommendations and implications in light of the analysis of findings in the literature and the findings in this study. These recommendations address various areas and levels of clinical practice.

- Formal or informal feedback about the clients' perspectives on the level of child- or client-centredness of the service should be collected from the service users.

- Therapists should be encouraged to share ideas between them, about strategies that were or were not affective. The therapists can also discuss innovative ways on how to involve the more difficult-to-engage clients, such as children who have poor communication skills or cognitive difficulties.

- An individual or group should ideally be selected to guide and facilitate the change process and move the organisation towards a child-centred and client-centred model of practice.

- Governments should offer training on children's rights for professionals, who work with children, including occupational therapists, in addition to training for children and their parents.

- A standardised process that is used for goal setting should be put into place, since without such a procedure, a therapist's own preference and knowledge may restrict the opportunity for clients to collaborate.

- Occupational therapists should constantly reflect on their practice at every stage of the OT process, evaluating the extent to which they are following the principles of client-centred practice, and how they are relating to their clients, especially vis-à-vis the partnership between the child, the parent and the therapist.

- Children should be seen as unique individuals and their preference to be involved in decision-making may vary according to the child's age, competency, illness and the kind of decision that needs to be taken. Therefore, children should not always be forced to participate in decisions about their care, regardless of their circumstances, as some children may opt to play the passive role and let their parents or professionals make the decisions for them. Effective communication should be used to determine the extent to which they would like to participate.

- Children should ideally be involved in planning and evaluation of services in health care. Consequently, strategies need to be available to support this partnership.

- There should be a representation of OT in the International Network of Child and Family Centred Care (INCFCC[10]), as well as a representation from Malta.

- Occupational therapists should ensure that the voice and the "expert self-knowledge of the child" are given priority.

- Occupational therapists should understand that setting goals based on what matters to the child and family does not prevent them from sharing the knowledge and expertise they have about expected development, the potential significance of functional abilities, or other insights gained from clinical experience

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[10] The INCFCC is an expanding international network of professionals in child- and family-centred care. The network's members interact and work together in research, practice development, and teaching to find best practices and build the body of knowledge necessary to affect positive change on a local and global scale. The INCFCC includes 54 members from 13 countries. However, there are no members from Malta and the majority of researchers are from the nursing profession with no OT representation.

10.4 Future Research Recommendations

This study sheds light on various issues that need to be further researched:

- This study explored the factors that influence the application of a child-centred and client-centred approach and the use of relevant outcome measures from the perspective of occupational therapists. Similar research is needed that investigates these factors from the perspective of clients, including children.

- Further research needs to be conducted to investigate children's engagement in the various stages of the OT process, possibly through the use of mixed methods. Such research could also address the engagement of children in the evaluation of outcomes and the children's perceptions of their experiences following such participation.

- More research needs to be conducted on the exploration of various therapeutic strategies and tools that give children a voice, and assist with goal setting, and the effect of their use on child engagement and effectiveness of intervention. Such studies need to involve preschool-aged children and children who have cognitive and communication difficulties. More robust studies are required to specifically ascertain the degree to which hearing children's voices influences treatment results.

- Future research about best ways to implement a child centred and client-centred approach that addresses the needs of the child as well as other relevant clients, specifically in paediatric OT intervention, is crucial. Future research could involve child and parent interviews and observation with a view to gaining a deeper understanding of the nature of collaborative intervention planning in a tridactic partnership. Addressing the dilemma of working with more than one client, each of whom may have different goals, can help shine a light on the most effective ways of addressing this conundrum.

- The UNCRC (UN 1989) and its relevance to OT practice, was mostly unknown to participants in this study. Research is needed on how the principles of this convention can be applied and translated into a child- and client-centred OT service.

- Occupational therapist should evaluate international measures and conduct research to investigate ecological validity and cultural concerns. Therefore, research about cross-cultural adaptation for the use of the identified outcome measures in Malta needs to be conducted.

- There is dire need for research to determine whether the proposed outcome measures are indeed a good fit for the paediatric service in Malta. Such feasibility studies should incorporate therapists' views.

10.5 The Way Forward

The way forward is probably that of following a "da Vinci Einstein" (Novak 2017, p. xv) route. The provision of an effective OT service for children can be considered both an art and a science. The art of working with children can be observed in the therapist's ability to listen to the child, design a tailored intervention plan based on the child's goals and priorities, and simultaneously take into account the family's and school's concerns. Moreover, the ability to resolve the thorny question of who the client is, when working with multiple clients with different goals, whilst ensuring that the intervention remains child-centred, definitely bears the hallmarks of an art. On the other hand, the rigours and consistency of science are required to ensure that the intervention that is provided is an effective and evidence-based one. The use of outcome measures helps to provide evidence about the effectiveness of the intervention.

In conclusion, this research has linked the art and the science of paediatric OT practice by linking the art of using a child-centred and client-centred approach with the science of outcome measurement to support evidence-based practice.

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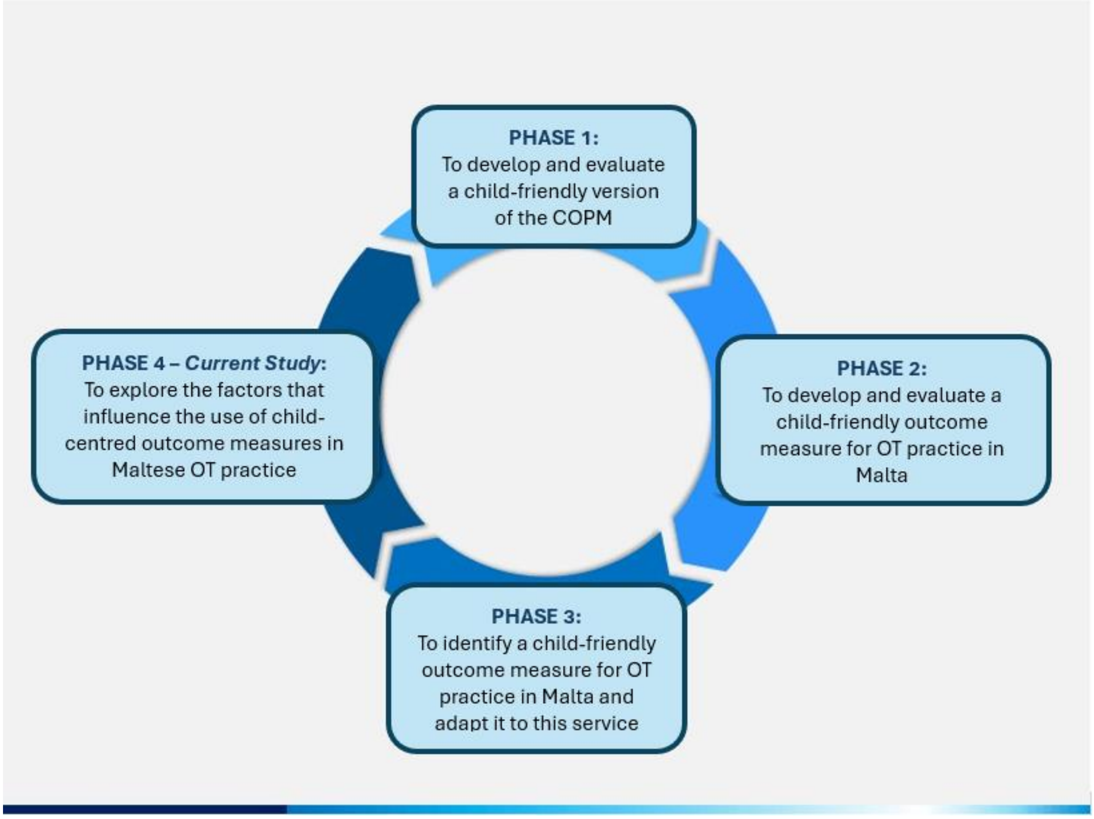
Appendices

Appendix A The Evolution of this Study

The evolution of this participatory action research study.

Although I initially had a clearly delineated plan for the study, the study's objectives and research questions have evolved in response to the literature and the findings. Winter and Munn-Giddings (2001) explain that in action research, the research proposal is open-ended as each phase of the study is shaped by the previous one. Being aware of this dynamic, I actively allowed the research process to evolve.

The following section gives a brief account of how this study has evolved from the initial plans (Phase 1) to the final phase (Phase 4), which this thesis is ultimately about. Figure 7 depicts these four phases characterising the evolution of this study.



PHASE 1:
To develop and evaluate a child-friendly version of the COPM

PHASE 2:
To develop and evaluate a child-friendly outcome measure for OT practice in Malta

PHASE 3:
To identify a child-friendly outcome measure for OT practice in Malta and adapt it to this service

PHASE 4 – *Current Study*:
To explore the factors that influence the use of child-centred outcome measures in Maltese OT practice

Figure 7. The evolution of this participatory action research study

PHASE 1 – Literature review

In this first phase, the aim was to develop and evaluate a child-friendly version of the COPM (Law et al. 2014). In Malta, the CMOP-E was chosen by the OT management as the overarching model deemed capable of guiding OT services. This model is based on concepts of client-centredness, and occupational performance and engagement (Polatajko et al. 2013). Client-centredness requires the client's involvement in the assessment and intervention process (Hong et al. 2000; Dedding et al. 2004).

I started this study by conducting a literature search about the following topics: outcome measures, client-centred practice, child-centred practice and occupational performance. The COPM was identified in the literature as a related client-centred assessment tool (Pollock 1993; Dedding et al. 2004; Cusick et al. 2006), which is based on concepts taken from the CMOP, a predecessor of the CMOP-E. Therefore, my initial aim was to create a child-friendly version of this tool, the COPM, since the latter was not locally or internationally available.

My initial plan was to 'develop' the tool and later involve the therapists in evaluating the feasibility of this tool. Being an OT practitioner myself, as well as a Head of service, I was fully aware of how challenging it would be to have therapists on board and 'make them' use this outcome measure. Therefore, I thought fit to conduct some research on different research designs and research methodologies, while constantly liaising with my supervisors. Consequently, I decided that the tool would be developed together with therapists through action research. The involvement of the participants, as is required in action research, increases the likelihood that the results will be implemented (Greenwood et al. 1993).

I had a one-to-one meeting with Prof. Sue Baptiste, one of the co-authors of the COPM, who happened to be in Malta to provide some training to occupational therapists on the CMOP-E. She recommended that I liaise with the late Dr Nancy Pollock, another co-author of the CMOP-E, who was more into paediatric practice, so I contacted her by email. I was informed that copyright reasons prevented me from developing a child-friendly version of the COPM.

PHASE 2 – A new child-friendly outcome measure for OT practice in Malta.

In view of the aforementioned copyright issues, I decided to develop a new child-friendly outcome measure for OT in Malta and to investigate the utility of this tool. At this point I sought to develop and evaluate a child-friendly outcome measure for Maltese OT practice.

Meanwhile, I continued with a systematic literature search on paediatric OT outcome measures. I discovered a number of already existing child-friendly outcome measures, which were not available in Malta yet. Some of these self-reports, such as the PEGS (Pollock and Missiuna 2015) and the COSA (Kramer et al. 2014), were specifically designed to be used with children. However, these assessments originated in English-speaking countries, so their cultural relevance to Malta was highly questionable. Indeed, the authors of the COSA explain that since the value of some activities depends on the client's culture, the meaning of some of the items may vary across cultures (Kramer et al. 2014). Due to cultural differences, some adaptations were also recommended when using the PEGS in other countries (Vroland-Nordstrand and Krumlinde-Sudholm 2012).

PHASE 3 – Adapting a child-friendly outcome measure for Maltese OT practice.

Rather than re-inventing the wheel, I decided to investigate whether any of the already existing outcome measures would be culturally relevant and would suit our paediatric OT practice in Malta. Being more knowledgeable about action research, I was convinced to let the participants themselves guide the flow and direction of the study. The study's aim in this phase was to identify a child-friendly outcome measure for OT in Malta and adapt it to this service.

I went through the literature again. One particular literature source that influenced my thinking was Rodger and Kennedy-Behr (2017)'s book, Occupation Centred Practice with Children – A practical Guide for Occupational Therapists.

PHASE 4 - Exploring the factors that influence the use of child-centred outcome measures

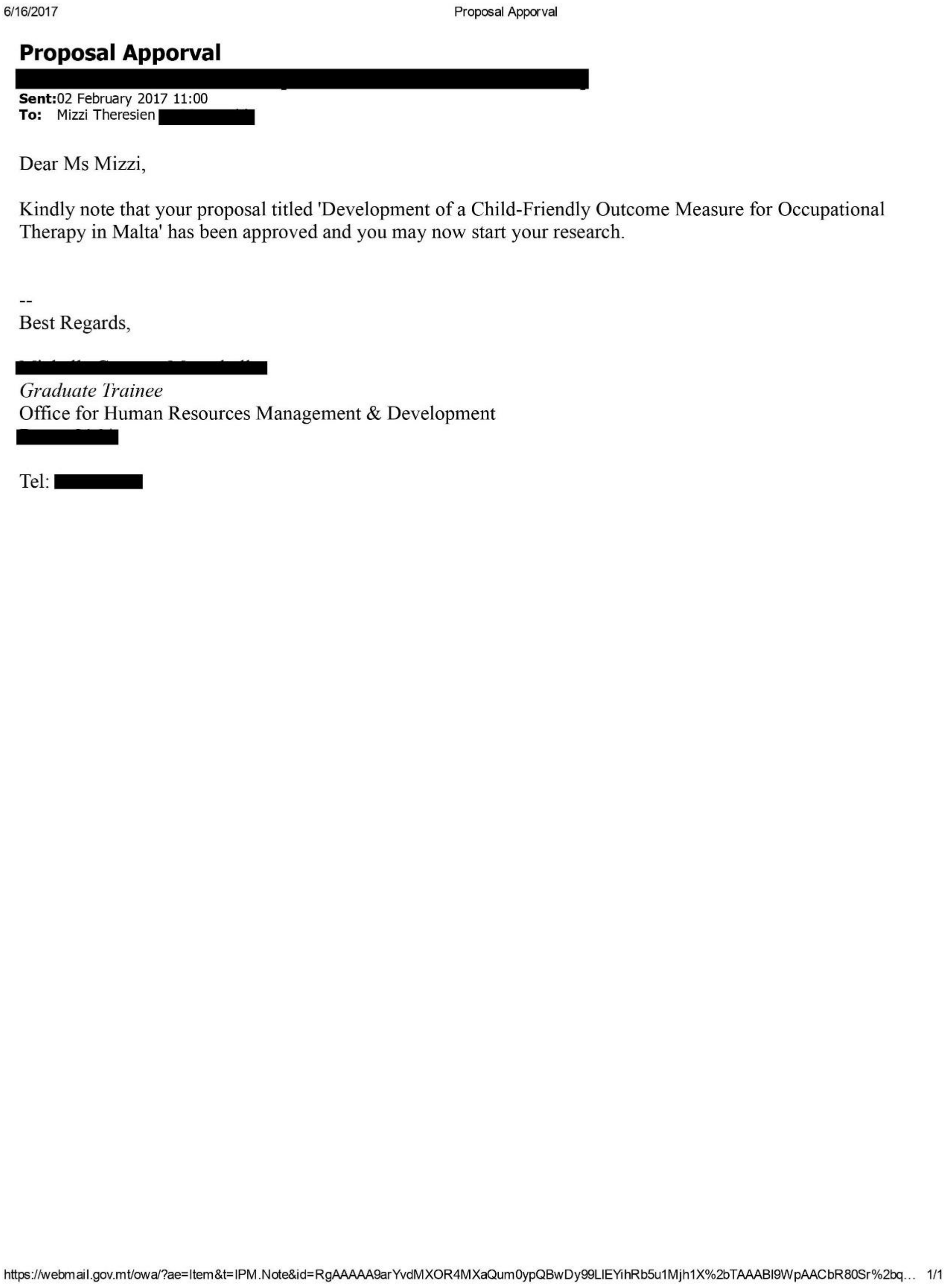
After reflection on both the literature and the emerging findings, I identified challenges that paediatric occupational therapists were encountering in the application of a measurable child-centred service. These challenges had to be addressed before proceeding to the implementation of an outcome measure. Following these reflections and several discussions with my supervisors I could see that several concerns related to child-centredness and outcome measures had made themselves felt. These issues were more serious than I had imagined. This led to the next phase of my research.

Indeed, the aforementioned issues changed the focus of my study. Finding a suitable outcome measure and adapting this measure would have been prohibitively time-consuming and was, therefore, beyond the scope of my PhD. Therefore, my new focus turned on the following:

- Identifying the issues underlying occupational therapists' practice;
- Investigating what needs to be changed;
- Preparing the groundwork for an outcome measure to be used;
- Assessing recommendations for practice

This final phase sought to explore the factors that influence the use of child-centred outcome measures in OT. I opted to use the term 'child-centred' instead of 'child-friendly' (Rodger and Keen 2017) to emphasise the child's participation in all the stages of the OT process, from assessment to evaluation. The write-up of this thesis is based on this final phase.

Appendix B Approval from University of Malta's Research Ethics Committee



6/16/2017 Proposal Apporval

Proposal Apporval

[redacted]

Sent:02 February 2017 11:00
To: Mizzi Theresien [redacted]

Dear Ms Mizzi,

Kindly note that your proposal titled 'Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta' has been approved and you may now start your research.

--
Best Regards,

[redacted]
Graduate Trainee
Office for Human Resources Management & Development
[redacted]

Tel: [redacted]

https://webmail.gov.mt/owa/?ae=Item&t=IPM.Note&id=RgAAAAA9arYvdMXOR4MXaQum0ypQBwDy99LIEYihRb5u1Mjh1X%2bTAAABI9WpAACbR80Sr%2bq… 1/1

Re: Minor changes to PhD study: Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta

Research Ethics HEALTHSCI <research-ethics.healthsci@um.edu.mt> 21 October 2020 at 10:32
To: Theresien Mizzi <[redacted]>

Dear Theresien,

Thank you for your email. Please note that your updated documents have been approved by FREC as per Dr [redacted] [redacted]'s email, dated 8th October 2020.

Sincere Regards,
[redacted]

[redacted]
FREC Secretary

University of Malta
Faculty of Health Sciences
[redacted]
Mater Dei Hospital

https://www.um.edu.mt/healthsciences/students/researchethics

On Wed, 21 Oct 2020 at 10:18, Theresien Mizzi <[redacted]> wrote:

> Dear Ms [redacted],
>
> Following previous correspondence, may I kindly ask whether the changes to my PhD study have been formally approved by FREC/UREC please?
>
> Thanks,
> Theresien
>
> On Fri, 9 Oct 2020 at 22:11, Theresien Mizzi <[redacted]> wrote:
>
>> Dear Ms [redacted],
>>
>> Just to let you know that I have submitted my REDP/UREC form. My supervisors were copied. Could you kindly let me know whether you require a confirmation reply from my supervisors, so I will inform them accordingly please?
>>
>> Thanks,
>> Theresien
>>
>> On Fri, 9 Oct 2020 at 09:25, Research Ethics HEALTHSCI <research-ethics.healthsci@um.edu.mt> wrote:
>>
>>> Dear Theresien,
>>>
>>> This is a kind reminder to forward your updated UREC Form by Monday so that I can update FREC records accordingly.
>>>
>>> Thanks and Regards,
>>> [redacted]
>>>
>>> [redacted]

FREC Secretary

University of Malta
Faculty of Health Sciences
[redacted]
Mater Dei Hospital

https://www.um.edu.mt/healthsciences/students/researchethics

---------- Forwarded message ---------
From: [redacted]>
Date: Thu, 8 Oct 2020 at 00:25
Subject: Re: Minor changes to PhD study: Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta
To: Theresien Mizzi <[redacted]>
Cc: Research Ethics HEALTHSCI <research-ethics.healthsci@um.edu.mt>, [redacted]>

Dear Theresien
I confirm that your changes are approved on behalf of FREC. Kindly submit an updated REDP/UREC form for FREC records.
Thank you and best regards
[redacted]

[redacted]
Senior lecturer
Head, Department of Communication Therapy
Faculty of Health Sciences
University of Malta
Tel.: [redacted]

On Fri, 2 Oct 2020 at 10:56, Theresien Mizzi <theresien.mizzi@um.edu.mt> wrote:

> Dear Ms [redacted],
>
> Hope this email finds you well. May I kindly ask whether you have any feedback about the subjoined email please?
>
> Thank you in advance.
>
> Kind regards,
>
> Theresien
>
> On Tue, 22 Sep 2020 at 10:21, Theresien Mizzi <[redacted]> wrote:
>
>> Dear Ms [redacted],
>>
>> I am writing to inform you about changes made to my PhD study approved by the University of Malta Research Ethics Committee on the 2nd February 2017 (please find copy of approval attached). The changes concern the aims and title of the study. I have contacted UREC about these changes and they suggested that I inform FREC.
>>
>> I am undertaking a participatory action research study and, as is common with this methodology, the research has evolved throughout its development. Being an action research study, the participants were

actively involved in the research process and such collaboration was essential to increase the likelihood that any outcome would be relevant to the Maltese healthcare context. What I had planned to do in terms of this PhD research and what I ended up doing were somewhat different due to issues that specifically emerged during the action research phases of data collection.

Through action research my participants helped to inform the direction of this PhD study. Data were collected through eight action research meetings with the occupational therapists, as was originally planned. The initial aim of the study was for me to develop a child-friendly outcome measure for occupational therapy in Malta. However, throughout these research meetings a number of issues emerged, which led to a change in the aims and focus of the study. Therefore, based on the current Maltese Occupational Therapy services' needs, the aim and objectives of my PhD were updated as follows:

"The aim of this study is to identify and explore factors that facilitate or inhibit a measureable, child-centred occupational therapy practice in Malta. The objectives are:

- To explore the way in which paediatric occupational therapy practice is currently being carried out in Malta and whether the therapists are evaluating a child's participation in occupational performance
- To identify ideal properties of a suitable child-friendly outcome measure which would meet the needs of the occupational therapy service in Malta
- To identify and instigate a child-friendly outcome measure that could be used to evaluate a child's participation in occupational performance for occupational therapy practice in Malta"

As a result in change in aims, the title of the thesis also needed to change. The new proposed title is therefore:

"An exploration of the factors that influence the use of child-friendly outcome measures in occupational therapy: An action based research study in Malta"

Being collaborators or co-researchers, the participants (occupational therapists) were instrumental in shaping the study. Following the change in aims, there was no need for a trial of a new outcome measure and service users were not involved, as originally planned. However, I would like to assure you that the action research group meetings were undertaken, as outlined in my original proposal.

Please do not hesitate to contact me should you require any additional information. Kindly note that my supervisors, Dr Paul Gill, Dr Carly Reagon and Dr Steve Whitcombe are being copied in this email.

Thank you in advance.

Kind regards,

Theresien Mizzi

Appendix C Approval from Cardiff University’s Research Governance and Ethics Committee

School of Healthcare Sciences
Head of School and Dean Professor Heather Waterman

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes Heather Waterman

15 December 2016

Cardiff University
Eastgate House
13th Floor
35 – 43 Newport Road
Cardiff CF24 0AB

Tel Ffon: +44 (0)29 20 688559
Email E-bost HCAREEthics@cardiff.ac.uk

Prifysgol Caerdydd
13ed Llawr
Ty Eastgate
35 – 43 Heol Casnewydd
Caerdydd CF24 0AB

Theresien Mizzi
[redacted]

Dear Theresien Mizzi

Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta

At its meeting of ***13 December 2016***, the School’s Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

Pass –and that you proceed with your Research after discussing the reviewers’ comments with your supervisor

The Committee has asked that the lead reviewers’ comments be passed onto you and your supervisor, please see below.

A risk assessment is needed
Please refer to Cardiff University guidelines with reference to retention of data
Please add Dr Kate Button as the person to contact in case of complaint
Consent form needs version numbers (and retention of data information)

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months’ time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

[redacted]
Research Administration Manager

Cc Dr Gail Boniface

Cardiff University
Prifysgol Caerdydd
School of Healthcare Sciences
Ysgol y Gwyddorau Gofal Iechyd

Cardiff University
Eastgate House
35-43 Newport Road
Cardiff
www.cardiff.ac.uk

Prifysgol Caerdydd
Ty Eastgate
35 – 43 Heol Casnewydd
Caerdydd
www.caerdydd.ac.uk

Interim Head of School and Dean /Pennaeth yr Ysgol Dros Dro a Deon Professor David Whitaker

13 October 2020

Theresien Mizzi
Cardiff University
School of Healthcare Sciences

Dear Theresien Mizzi

Research project title: An exploration of the factors that influence the use of child-friendly outcome measures in occupational therapy: An action based research study in Malta

SREC reference: REC436

The School Of Healthcare Sciences Research Ethics Committee has reviewed the above application amendments via its proportionate review process.

Ethical Opinion

The Committee gave:

> a favourable ethical opinion of the above application on the basis described in the application form, protocol and supporting documentation.

Additional approvals

This letter provides an ethical opinion only. You must not start your research project until all appropriate approvals are in place.

Amendments

Any substantial amendments to documents previously reviewed by the Committee must be submitted to the Committee via HCAREethics@cardiff.ac.uk for consideration and cannot be implemented until the Committee has confirmed it is satisfied with the proposed amendments. You are permitted to implement non-substantial amendments to the documents previously reviewed by the Committee but you must provide a copy of any updated documents to the Committee via HCAREethics@cardiff.ac.uk for its records.

Monitoring requirements

The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.

The Committee must be informed when your research project has ended. This notification should be made to HCAREethics@cardiff.ac.uk within three months of research project completion.

Complaints/Appeals

If you are dissatisfied with the decision made by the Committee, please contact the School's Research Ethics Officer, Kate Button on HCAREethics@cardiff.ac.uk in the first instance to discuss your complaint. If this discussion does not resolve the issue, you are entitled to refer the matter to the Head of School for further consideration. The Head of School may refer the matter to the Open Research Integrity and Ethics Committee (ORIEC), where this is appropriate. Please be advised that ORIEC will not normally interfere with a decision of the Committee and is concerned only with the general principles of natural justice, reasonableness and fairness of the decision.

Please use the Committee reference number on all future correspondence.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

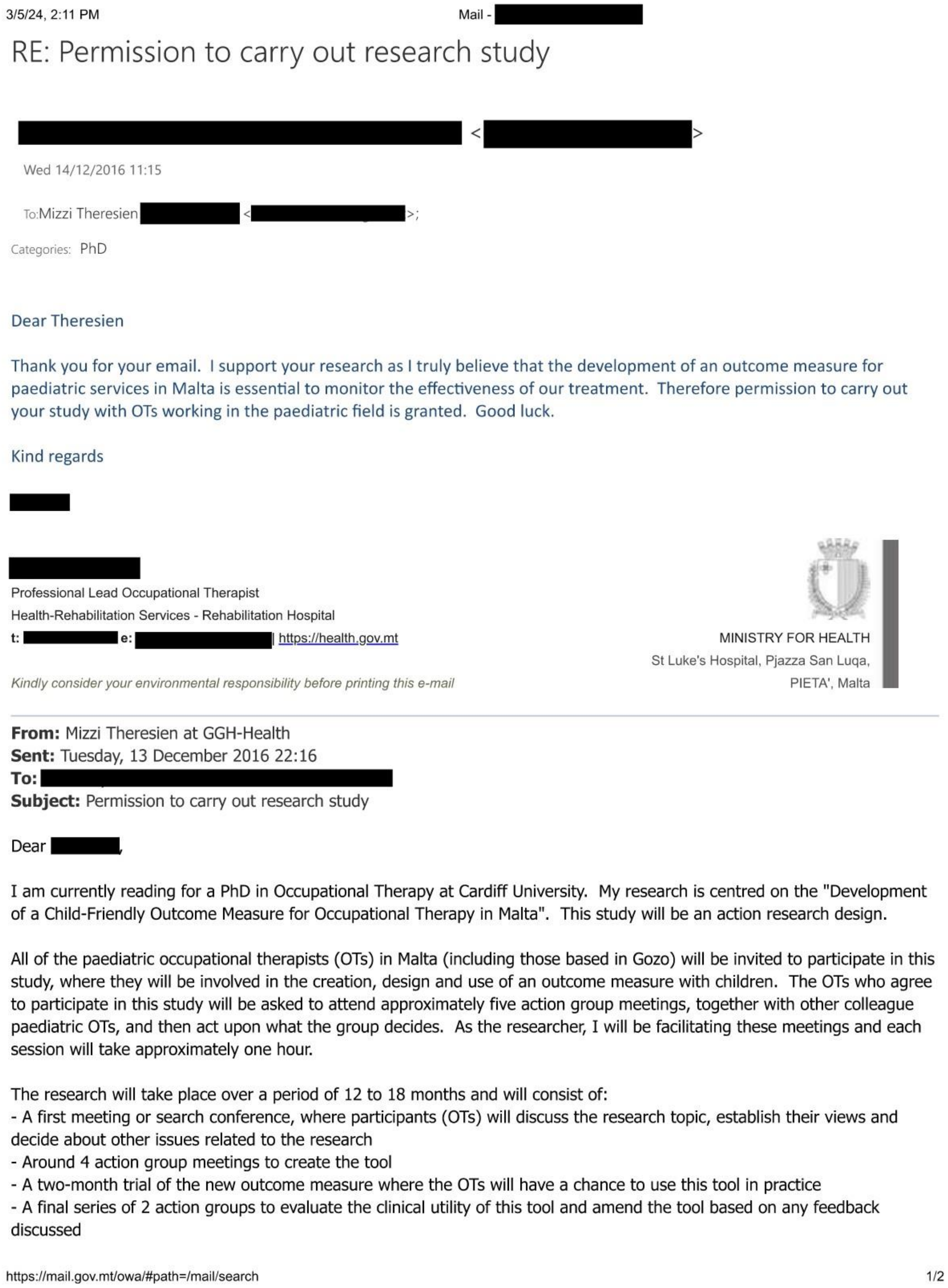
Yours sincerely,

Dr Kate Button

Cc Paul Gill

Appendix D Permission Letters

Sample of permission letter by the Professional Lead for OT services in Malta



3/5/24, 2:11 PM Mail - [redacted]

RE: Permission to carry out research study

[redacted] < [redacted] >

Wed 14/12/2016 11:15

To: Mizzi Theresien [redacted] <[redacted]>;

Categories: PhD

Dear Theresien

Thank you for your email. I support your research as I truly believe that the development of an outcome measure for paediatric services in Malta is essential to monitor the effectiveness of our treatment. Therefore permission to carry out your study with OTs working in the paediatric field is granted. Good luck.

Kind regards

[redacted]

[redacted]

Professional Lead Occupational Therapist
Health-Rehabilitation Services - Rehabilitation Hospital
t: [redacted] e: [redacted] | https://health.gov.mt

MINISTRY FOR HEALTH
St Luke's Hospital, Pjazza San Luqa,
PIETA', Malta

Kindly consider your environmental responsibility before printing this e-mail

---

From: Mizzi Theresien at GGH-Health
Sent: Tuesday, 13 December 2016 22:16
To: [redacted]
Subject: Permission to carry out research study

Dear [redacted],

I am currently reading for a PhD in Occupational Therapy at Cardiff University. My research is centred on the "Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta". This study will be an action research design.

All of the paediatric occupational therapists (OTs) in Malta (including those based in Gozo) will be invited to participate in this study, where they will be involved in the creation, design and use of an outcome measure with children. The OTs who agree to participate in this study will be asked to attend approximately five action group meetings, together with other colleague paediatric OTs, and then act upon what the group decides. As the researcher, I will be facilitating these meetings and each session will take approximately one hour.

The research will take place over a period of 12 to 18 months and will consist of:
- A first meeting or search conference, where participants (OTs) will discuss the research topic, establish their views and decide about other issues related to the research
- Around 4 action group meetings to create the tool
- A two-month trial of the new outcome measure where the OTs will have a chance to use this tool in practice
- A final series of 2 action groups to evaluate the clinical utility of this tool and amend the tool based on any feedback discussed

https://mail.gov.mt/owa/#path=/mail/search 1/2

Following the development of the child-friendly outcome measure, feedback about the utility of this new tool will be gathered from service users (5 children aged 5 to 12 years, and 5 parents) via another action group meeting. Service users will be selected from the occupational therapy caseload through purposive sampling.

Participation is entirely voluntary. The groups will be held at the Occupational Therapy Department, [redacted]. These meetings will be digitally recorded and transcribed verbatim by myself, as the researcher. All data will be anonymised and treated as confidential. Ethical approval will be obtained from the University of Malta's Research Ethics Committee and Cardiff University's Research Governance and Ethics Committee.

I would like to ask for permission to carry out this study. This research will provide a client-centred, culturally-relevant outcome measure for paediatric occupational therapy in Malta and will therefore contribute to the development of our occupational therapy service. Moreover, this measure will be developed in line with the CMOP-E principles. Hence, its use will further assist in the implementation of this model.

If you require any further information, please do not hesitate to contact me on [redacted] or [redacted].

Your permission to conduct this study will be greatly appreciated.

Thank you in advance.

Regards,

Theresien Mizzi

Theresien Mizzi
Allied Health Practitioner
Occupational Therapist
i/c Occupational Therapy Department [redacted]
[redacted]

Appendix E Letter of Invitation

Dear

I am currently reading for a PhD in Occupational Therapy at Cardiff University. My research is centred on the "Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta". You are being invited to take part in this research study.

This study will undertake an action research design, where if you decide to take part you will be actively involved in the research process. The process means that you would take part in some action group meetings, together with other colleague paediatric occupational therapists and then act upon what the group decides. Therefore, by participating in this study you will be involved in the creation, design, and use of an outcome measure with the children.

As the researcher, I will be facilitating these meetings, which will be held at the Occupational Therapy Department, and each session will take approximately one hour. Further information about this research, including your role in this study can be found in the Information Sheet attached. You are kindly advised to read this Information Sheet carefully.

This study has been reviewed and received ethics clearance through Cardiff University Research Governance and Ethics Committee and University of Malta Research Ethics Committee. If you have any queries or if you require any further information, please do not hesitate to contact me (Phone number: [redacted]; email: [redacted]).

If you are interested in taking part in this study, please fill in the enclosed Consent Form and send it back to me either in the pre-paid envelope provided or by sending a scanned copy on [redacted]. Your participation will be highly valued and will contribute to the development of our occupational therapy service in the future.

I thank you for your support and consideration.

Yours sincerely,

Theresien Mizzi

Appendix F Participant Information Sheet

INFORMATION SHEET

Title of Study: *Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta*

Researcher:

Theresien Mizzi

Allied Health Practitioner

Occupational Therapist

Email: [redacted]

Supervisors:	Dr Gail Boniface	Dr Carly Reagon
	Email: [redacted]	*Email:* [redacted]

You are invited to take part in a research study. You are advised to read this information sheet carefully. If you have any queries please contact the researcher using the contact details at the end of this information sheet.

The aim of this study is to develop a child-friendly outcome measure for Occupational Therapy in Malta. This study will undertake an action research design, where if you decide to take part you will be actively involved in the research process. The process means that you would take part in several group meetings and then act upon what the group decides. Therefore, by participating in this study you will be involved in the creation, design, and use of an outcome measure with the children.

If you agree to take part in this study, you will be asked to participate in a number of action group meetings, together with other colleague paediatric occupational therapists. As the researcher, I will be facilitating these meetings and each session will take about one hour. We will agree on the ground rules for behaviour during the meetings.

The research will take place over a period of 12 to 18 months and will consist of:

- A first meeting or search conference, where participants will discuss the research topic, establish their views and decide about other issues related to the research
- Around 4 action group meetings to create the tool
- A two-month trial of the new outcome measure where you will have a chance to use this tool in practice
- A final series of 2 action groups to evaluate the clinical utility of this tool and amend the tool based on any feedback discussed

All participants will be co-researchers and will be involved in decisions concerning the focus of the work and the methods to be used. The groups will be held at the Occupational Therapy Department, CDAU during working hours. These meetings will be digitally recorded and transcribed verbatim by the researcher.

All material concerning the project will be treated as confidential by all participants throughout the period of the project, and all written material will be kept securely locked, and will be accessible only to the researcher. All the recorded data will be stored on a password protected computer.

When the study's results are reported it will not be possible to identify individuals. All the information recorded would be used solely for this research study and would be destroyed upon completion of the study.

It is not anticipated that you will experience any discomforts in any session. The group meetings will be carefully conducted in a way as to ensure that any tensions or anxieties are resolved harmoniously, and I would endeavour to provide whatever support I can, should this become necessary.

You are encouraged to discuss any concerns regarding the study with me as the researcher at any time, and to ask any questions you may have (Phone number: [redacted]; email: [redacted]). In case of any complaints about the research you can contact Dr Kate Button (Phone number: [redacted]; email: [redacted]; Address: [redacted]).

Participation is entirely voluntary. You may decide not to take part in the study. Should you do so, it will not influence your situation, employment or organizational relationships in any way. If you decide to participate in the study, you will be asked to sign a consent form and you will be given a copy of this form. You can still withdraw from the study without fear or prejudice at any time if you change your mind.

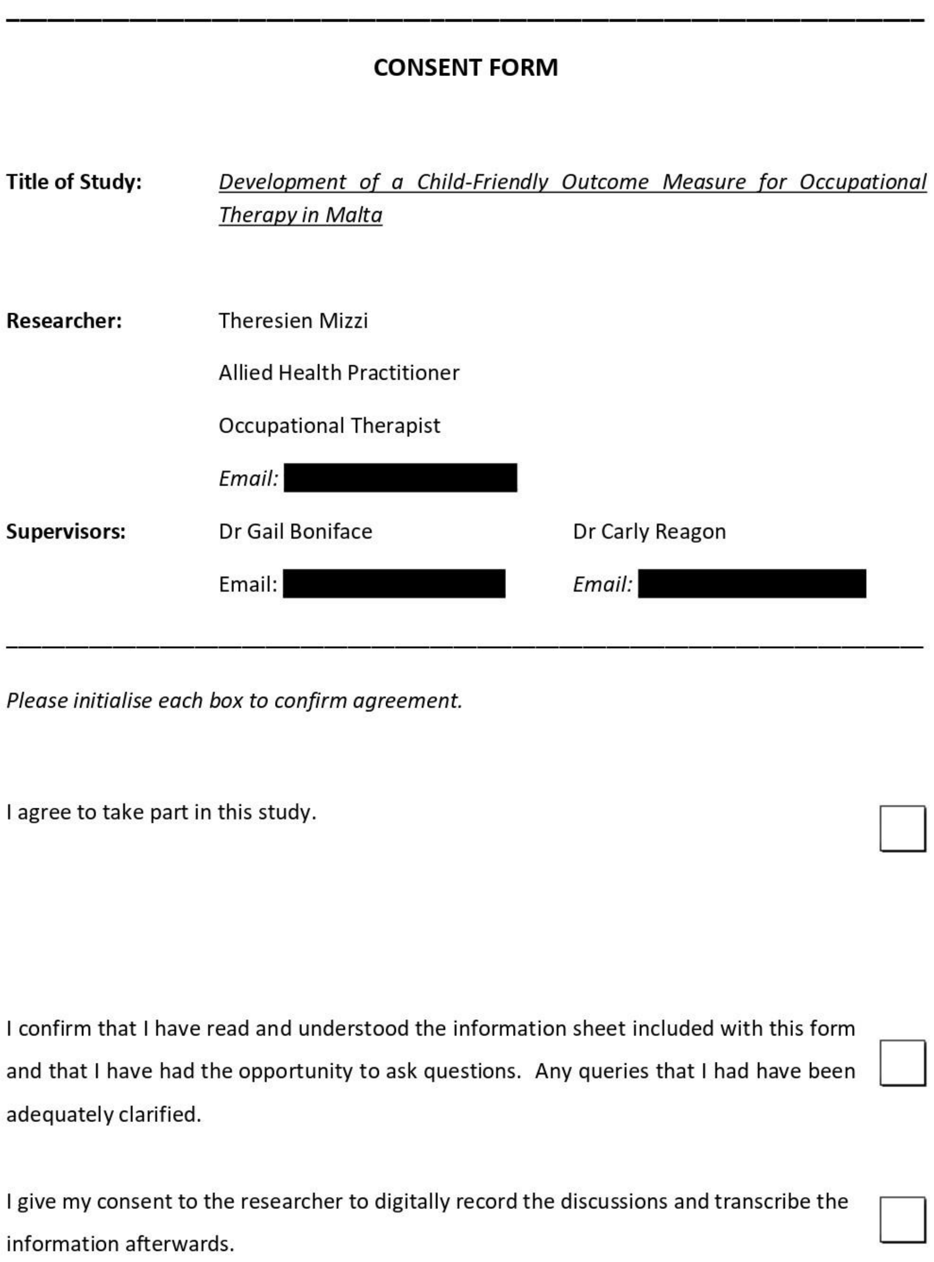
The above points indicate how the project will be conducted overall, and your comments and suggestions about all aspects of this research are most welcome. Your participation will be highly valued and will contribute to the development of our occupational therapy service in the future.

I thank you for your support and consideration.

Yours sincerely,

Theresien Mizzi

Appendix G Consent Form



CONSENT FORM

Title of Study: *Development of a Child-Friendly Outcome Measure for Occupational Therapy in Malta*

Researcher:
Theresien Mizzi
Allied Health Practitioner
Occupational Therapist
Email: [redacted]

Supervisors:
Dr Gail Boniface
Email: [redacted]

Dr Carly Reagon
Email: [redacted]

Please initialise each box to confirm agreement.

I agree to take part in this study. ☐

I confirm that I have read and understood the information sheet included with this form and that I have had the opportunity to ask questions. Any queries that I had have been adequately clarified. ☐

I give my consent to the researcher to digitally record the discussions and transcribe the information afterwards. ☐

I understand that any comments I may make may be used verbatim in the write up of the study but that they will be anonymous. ☐

I understand that raw data (i.e., the transcripts and recordings of meetings) will be stored for five years and then destroyed. ☐

I understand that I may withdraw from the study at any time without giving any reason. This will not influence my situation, employment or organizational relationships in any way. ☐

Name of Occupational Therapist: ______________________________

Signature of Occupational Therapist: ______________________________

Date: ______________________________

Name of researcher: Theresien Mizzi

Signature of researcher: ______________________________

Date: ______________________________

Name of supervisors: Dr Gail Boniface & Dr Carly Reagon

Signature of supervisors: ______________________________

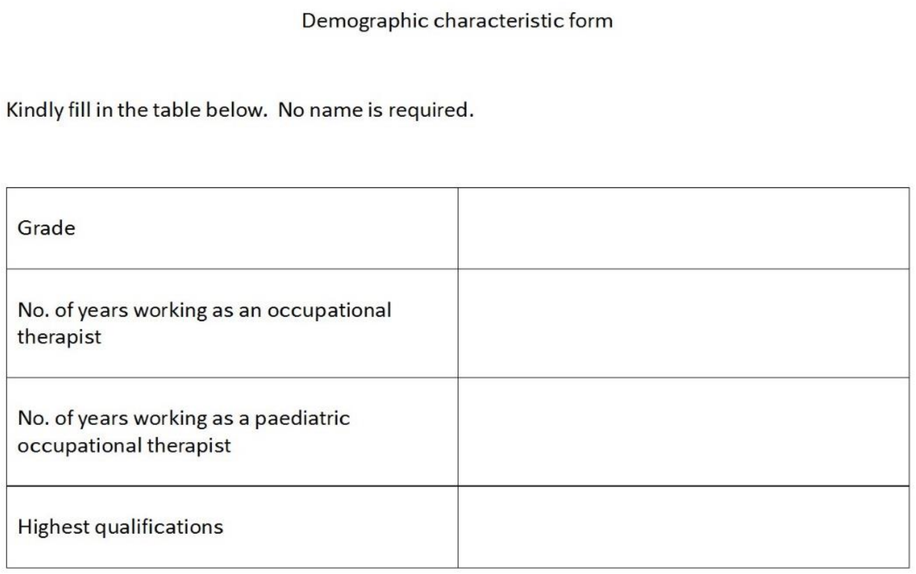
Date: ______________________________

Appendix H Timeline of Data Collection

Writing of initial research proposal & identification of study setting	October 2015
Application to Cardiff University's Research Governance and Ethics Committee	November 2016
Approval from Cardiff University's Research Governance and Ethics Committee	December 2016
Application to University of Malta's Research Ethics Committee	
Approval from University of Malta's Research Ethics Committee	February 2017
Letter of Invitation & participant information sheets sent to occupational therapists	October 2017
Action Group 1: Search Conference	November 2017
Action Group 2	June 2018*
Action Group 3	July 2018
Action Group 4	September 2018
Action Group 5	October 2018
Action Group 6	November 2018
Action Group 7	December 2018
Action Group 8	January 2019

*There was a considerable lapse of time between the Search Conference and Action Group 2. This was due to a number of reasons, including: transcription and translation took longer than planned; time spent attempting to use NVivo; time spent identifying a method to analyse the data and on becoming familiar with "thematic analysis"; personal and family reasons of the researcher; a number of issues going on at the OT department, including a change in management; and unavailability of the therapists due to a high workload and problems with finding a common date.

Appendix I Demographic Characteristics Form



Demographic characteristic form

Kindly fill in the table below. No name is required.

Grade	
No. of years working as an occupational therapist	
No. of years working as a paediatric occupational therapist	
Highest qualifications	

Appendix J Sample of a Transcript

Sample from the transcript of Action Research Group 2 (AG2, pp. 4-7)

Rory: I think it’s important because … sometimes the children’s goals and the parents’ goals differ. If we’re treating … the parents see one type of problem and the children who have insight, maybe, they see a different aspect of the problem. They see that they’re refusing to go to school, maybe, because they don’t like it, they don’t like to write, but the parents are saying that they have attention difficulties, that they’re always moving around, they’re always on the move.

[Pause. No comments.]

Me: Do you want to add anything, about why, why is it important for us to know who is our client?

Rylie: Because the intervention needs to be tailor-made for the client. Not knowing who the client is … it won’t be tailor made for the client, so I believe that’s the most important thing, the first thing we need to be aware of.

Gwen: And to set goals with the client. Goal setting should be done with the client so we need to see who the client is, to set goals and work towards them.

Sarah: To set up a programme as well, a home programme, possibly school recommendations, so everything needs to be based on the client and his needs and what he really sort of wishes out of the treatment or intervention.

Taylor: Even knowing the client's interests, to plan activities according to what the child likes to do or . . .

Maya: And even the concerns might be linked as well. Maybe as we've said the child is seeing a handwriting difficulty, he doesn't like to write and they're seeing attention difficulty and it might be that he has poor attention because he doesn't like handwriting. The difficulties might be linked as well if you discuss with the child, with the parents and the teachers.

Me: You're saying, you're referring to when they do not agree, or to . . .?

Maya: No, I am referring to you have to discuss with all . . .the child is involved . . .all . . .to see if the difficulties are linked and maybe you can work on them in the play.

Me: [addressing Elin] Where you going to add anything?

Elin: No, what I was going to say was that you can use the client's interests or you need to know the client well to see what motivates them for example, so that you can get a better response. And it's important, sort of, to know the client well especially when you're assessing, just to find the actual reason for the difficulty, because something could be . . .'sub' . . .(um) like on the surface it would be one thing, and then when you actually get to know the child, or when you know more about the child then obviously something else will come out which you wouldn't have thought about if you just had that knowledge about that particular interest.

Me: And how would that be different if, like if we thought that our client was the child, or if we thought that our client was the parent, how would that change?

Elin: Well, generally, what I end up seeing, that parents have more of an educational framework in their mind, sort of they're more geared towards education, whereas a child or an older child would go for more things related to self care for example, because it's something that they're experiencing personally and they have a difficulty with. So I think that even in terms of what goals you set, it does make a difference knowing the child and what they're interested in.

Me: [addressing all the group] Do you need to add anything?

Alianna: You have to take everyone's concerns because everyone is seeing a different angle of the issue. The child is seeing, if they're old enough, the child is seeing one angle, the teachers are seeing their angle, the parents or the guardians are seeing another angle and sometimes they're all valid. So you have to see everyone's, even ultimately if one of the difficulties is not real, but you have to then . . .(um) you have to target it and say that it's not the real case, so that, I don’t know, if the parents are perceiving something, and it actually is not the case, than that has to be addressed and they have to realise it and stop expecting an outcome for it. It could be the other way around as well, and a lot of the time i believe that everyone, every stakeholder, has a bit of (um) … right, in their own (um) way, because different people see different aspects of the problem. So probably, the child is seeing one part, the parents are seeing another, and the parents are … whatever … teachers, whatever, see another. So I think it's very important to get that general feel …

Melody: But then, that's the difficulty kind of. What are you going, which goal are you going to start first, the child, the parents, or the children. That is why it's important to know who is the client. [Cross talk] … at least which goals you're going to start tackling first, and do like an overall, a bit of everyone's or one thing at a time.

Alianna: But we're saying that the client is a lot of people, can be a lot of people and also depend on the age as well.

[Cross talk]

Ruby: I think an issue in this setting is because we're dealing with minors, because if you have an older client you would go with the goals or with the priorities highlighted by the older client. But because we have a minor you'd have to listen to the child and the parents as well.

Faith: And I think, ok, initially, it's the child that is primarily the main client. The performance issues that you bring from the assessment are primarily of the child, but then let's say you see that, I don't know, this child has sensory processing issues and you note that, I don't know, the relationship with the parent or (um) the class environment is hindering the child, further oppressing the child, then obviously you have to train the school, you have to train the . . .his mother, to adapt the environment and to adapt her approach, etc, so the school and the parents will end up main clients as well, because you have an active role with them as well.

Elaine: But I think in younger children, because you mentioned that parents, sorry, the child is usually the client initially. With younger children I think we tend to automatically just speak to the parents.

Me: And 'in younger' what age are you referring to?

Elaine: Under 4, sort of. My case load is made up of children under 4 mostly, . . .[another OT jumped in]

Sarah: But automatically you acknowledge the child but you ask the parents for their concerns regarding the child, you don't ask … [another OT jumped in]

Faith: Regarding the child, so it's still . . .

Sarah: . . .Yes regarding the child.

Faith: So the child is the main client.

Sarah: Yes, it's about the child but it's not the child's voice, it's not his concerns. It's the parents' concerns about the child.

Ruby: But then it's about assessing what is called 'the goodness of fit', between, as she was saying, the child and the mother …

Aaron: The father.

Ruby: . . .And the father and the child and the environment and the school environment, how do, for example, if you had the mum had a different sensory profile than that of the child, how both are they going to fit and interact with each other? So I think, that is what . . .what she was trying to explain. In . . .in that way then the mum is also a … a client, is also …

Sarah: It is difficult to have one client in this setting, I mean …

Me: The goodness of fit that you mentioned [addressing Ruby] . . .?

Ruby: … a terminology that is used when you're assessing how, how well a mum can deal, or how well a profile of a parent can fit the profile of the child. If you have an over-responsive parent and an under-responsive child … there are some studies that advice that you ask about the parents' (um), the parents' profile as well, I mean this is only one aspect of intervention

Appendix K Sample of an Action Research Group Plan

Plan for Action Research Group 1 - Search Conference

Thanks for coming. I invited you all to participate in my PhD study where we will be looking at outcome measures for paediatric OT services in Malta.

In Malta, the Canadian Model of Occupational Performance and Engagement (CMOP-E) was chosen by the occupational therapy management as the overarching model to guide occupational therapy services. This model is based on concepts of client-centredness, and occupational performance and engagement. Client-centredness requires the client's involvement in the assessment and intervention process. That is why I decided to do my research about a child-friendly outcome measure.

1. Introduction about the aims of the study by the researcher:

2. Participants will say their name and something about themselves (for voice recognition purposes when it comes to translation).

3. Explain how the study will be carried out and what action research is.

- Action research involves cycles of reflection and action.
- Data will be collected over a period of 12 to 18 months, mainly through a number of group meetings.
- The first meeting we will discuss the research topic and decide about other issues related to the research
- In action research each phase is dependent and shaped by the previous one. It is difficult to determine the exact number of action research groups that will take place as this will depend on how the research flows.

4. Discuss the role of the researcher and the role of the participants.

- Equal contributors

- There is no right or wrong answer; it’s not like a test or anything like that
- It’s all about us all participating equally
- Important for all members to participate
- The researcher will act as a group facilitator.

5. Explain some other issues related to the research.

- All groups will be held at the Occupational Therapy department.
- These meetings will be digitally recorded and transcribed.
- This data will be analysed after each meeting and will be used to begin the discussion at the following group meeting.
- Inform the OTs that I will be sending them the main points/themes that come out of our meeting, following each meeting.
- Participation is voluntary.

6. Discuss the ground rules:

- The researcher will aim to avoid raising any overly sensitive issues and will aim to create a respectful and encouraging atmosphere.
- The group meetings will be carefully conducted in a way as to ensure that any tensions or anxieties are resolved harmoniously, and the researcher accepts responsibility to provide whatever support she can, should this become necessary.
- Discussion of confidentiality. Participants will be asked not to disclose information about individuals outside of the groups. All the data collected would be stored and treated with confidentiality. Pseudonyms will be used when reporting the results of the study. One will not be able to identify individual members
- Participants will be encouraged to discuss any concerns regarding the study, with the researcher, at any time.
- IMP: For recording purpose, it is important not to talk over each other, as this will make it very difficult to transcribe.

7. Probing questions (See ‘Probing Questions for Search Conference’)

8. Ask if there is anything else that they might want to discuss (anything that you think is relevant but that we have not discussed yet)

9. Closure

- Thanks for coming along today. It has been a very useful discussion. I think that the key things that came out of this meeting were . . .
- Sum up what was discussed and what might need to be explored further
- What we have suggested to do for next session is . . .
- Discuss we may continue to meet as one big group or I might need to split the group in two, depending on how it goes.

Conclude by thanking them for participating and informing them that I will be in touch with them for another group, probably around the end of January.

Appendix L Sample of a List of Probing Questions

Probing Questions for Action Research Group 2

- We need to understand who our client is. Why is that? Why is that so important?
- “Being client-centred may be more straight-forward in some other settings” Why is that? When would it not be so straightforward?
- “It is important to hear what the child has to say”. Let’s discuss more about this.
    - How can we implement this in practice?
- We talked about who our client is (mainly the child, but also parents and school). How are we involving these 3 in practice?
- Our client is the child, but also the parent or the school? How can we work around this?
- How can we address the dilemma that the child/parent/school may have different concerns?
    - Dilemma of different concerns between child, parent and school. We need to find a compromise. How will we address this in practice?
- How does this change with age?

Appendix M Samples from my Reflective Journal

An extract from my personal reflection following Action Research Group 1 (Search Conference)

I felt relieved that I had done the readings that I did, which helped me to change my way of thinking with regards to finding "a way to measure outcomes" rather than stating that we will have to "develop a tool". I thought that the latter would have been felt as more invasive and might have been less easily accepted by the participants. Moreover it would not have been in keeping with action research, which is participant led.

On this first group (which was my first ever action research group) I was too directive and I might have led the group too much. I also encountered difficulties with assuming a researcher's or facilitator's role and rather that of an occupational therapist or colleague. I was rather undecided as to the level of participation that I should take and about whether or not I should express my thoughts or opinion to the group. Being a paediatric occupational therapist working in Malta, I had my own views about the issues that were being discussed. This was especially the case when I had differing views to what was being said. A recurring thought that I had was: "Am I allowed to voice my opinion as a co-participant of the group?" On one hand, I felt that if I were to express my views and participate in the discussion, I would not be seen as an outsider and that the therapists would accept me as being part of their group, with the ability of feeling the concerns that they had. On the other hand, I was concerned that that I could bias the group discussing. Koshy et al. (2011) advises that "facilitators should avoid the temptation of disagreeing with the views of other members, which may be different to theirs". (p. 112).

There were times when I felt that I needed to redirect the discussion but I did not always manage to do that. I was unsure as to whether the discussion went out of point or whether the discussion simply took a different angle than what I was expecting. I felt unsure as to whether or not I should have intervened and most of the time I ended up not intervening at all.

Additionally, I failed to enquire further about some of the comments. Being an occupational therapist, I assumed that I knew and understood what the participants were talking about. Being an insider I may have assumed too much, and there were instances where I did not probe as much as I would have done had I been an outsider. There were instance where I thought I knew the answer and I did not challenge the way I was thinking to "alternative reframing" (Coghlan and Brannick 2014, p 134). With some further probing I could have gathered more rich or deep data.

I admitted some of my mistakes with the participants. For example, I brought the wrong type of food (as refreshments), since it was wrapped in plastic and the noise could have affected the recording. I was hoping that by admitting my mistakes this would help to establish trust with the participants.

I found it particularly hard to do prepare a summary, there and then, of what was said at the end of the session. I had taken some points during the discussion and I used those as guidelines. I also found it quite challenging to decide on what the action was going to be. In fact, I failed to discuss what the action following this session would be. When I will write the summary, which will be distributed to the participants, I will include some ideas about what actions the participants might follow. I will encourage the therapists to reflect about some points that they would like to discuss further during the next group session. I might suggest that we discuss what outcome measures we are currently using and any issues that we may be encountering with these.

Sample from my reflexive data analysis

"One of the participants suggested that a research study be conducted with higher management. "Theresien, what do you think about the PhD? You do it with higher people above [and] ask these questions?" (Elin, AG7, p.33). The therapists were expressing serious doubts about the possibility of change for the better unless the top management is convinced of the need to change the system. They were also hoping that I could help them by involving the senior management. Indeed, one participants even said: "[Theresien] will solve our problems" (Rylie, AG8, p.15)."

Appendix N Sample of a Summary of an Action Research Group Discussion

Summary of Action Research Group 3

Dear all,

The following is a summary of what we have discussed in our third action group session (Action Group 3).

- Possible changes that would enable our service to be more child-centred (although not directly under our control):
    - Increasing the OT paediatric services in Malta (e.g., services in schools in addition to [redacted])
    - These services should be well coordinated
    - More awareness about the role of each of the different service available
    - Services need to be context-based
    - Need for more human resources

- Limited time available for assessment
    - Will two sessions be enough to gather data from the child as well as the parents (and maybe school)?
    - Will two sessions be enough to build a rapport with the child for him/her to tell us his/her difficulties?
    - Need more time for assessment

- Parents should somehow be involved as well

- Having an outcome measure that will be used in addition to what we do may not be feasible
    - Ideally any outcome measure used should replace some of the things that we already do

- Benefits of having an outcome measure
    - Be able to measure the quality of our intervention
    - It would help in auditing of our services
    - Can be used to back up the need for more human resources
    - "A plus" to our service

- Solutions / way forward:
    - To give less time to the parents during the interview and more time to the children

- Ideas about properties of a suitable outcome measure:
    - Quick
    - Short
    - Should it be filled in by the parents or teachers, or should it be filled in by the OT?
    - Should not be subjective
    - Related to function (occupation, function, activities of daily living, play, how child functions at home/school, how child interacts with others)
    - Possibly having numbers to score
    - Not based on observation
    - Maybe a questionnaire or interview
    - To be done on assessment and after a block of individual sessions or a block of group sessions
    - Can be done individually for each child or collectively as a group
    - The measure should allow us to test/focus on specific areas of concern, e.g. handwriting or ADLs
    - Has to be suitable to a consultation-based service, where improvement is dependent on parents/teachers
    - Has to capture change given the low frequency that we follow the children with

    - Need to be careful because at times parents' reports are inaccurate (especially about school performance)
    - The tool could possibly show an increase in parents' awareness of the child's problems and satisfaction, even if not necessarily in performance
    - It should ideally help us in identifying what to focus on during our intervention, since different parties (e.g., child, parent, teacher) might want different things
    - GAS (Kiresuk et al. 1994) goals were mentioned as an example – can be done following individual or group sessions

- Currently we are not formally measuring the outcomes of our interventions
    - Observations (structured or non-structured), documentation and looking at HW samples before and after is being done
        - Informal

- Currently we are using the following methods to look at occupational performance issues:
    - Observations, parental interviews, phone calls, email
        - Informal and depending on the time available
    - Attending IEPs and IEP reviews
    - Limitations for these include:
        - Time
        - The environment
        - Space
        - Lack of human resources

- We do not have outcome measures that assess the functional areas that we had identified as being important for paediatric OT, available in our clinics

- Other issues that would need to be considered when looking at outcomes:
    - Children might improve due to development or because of input from other services

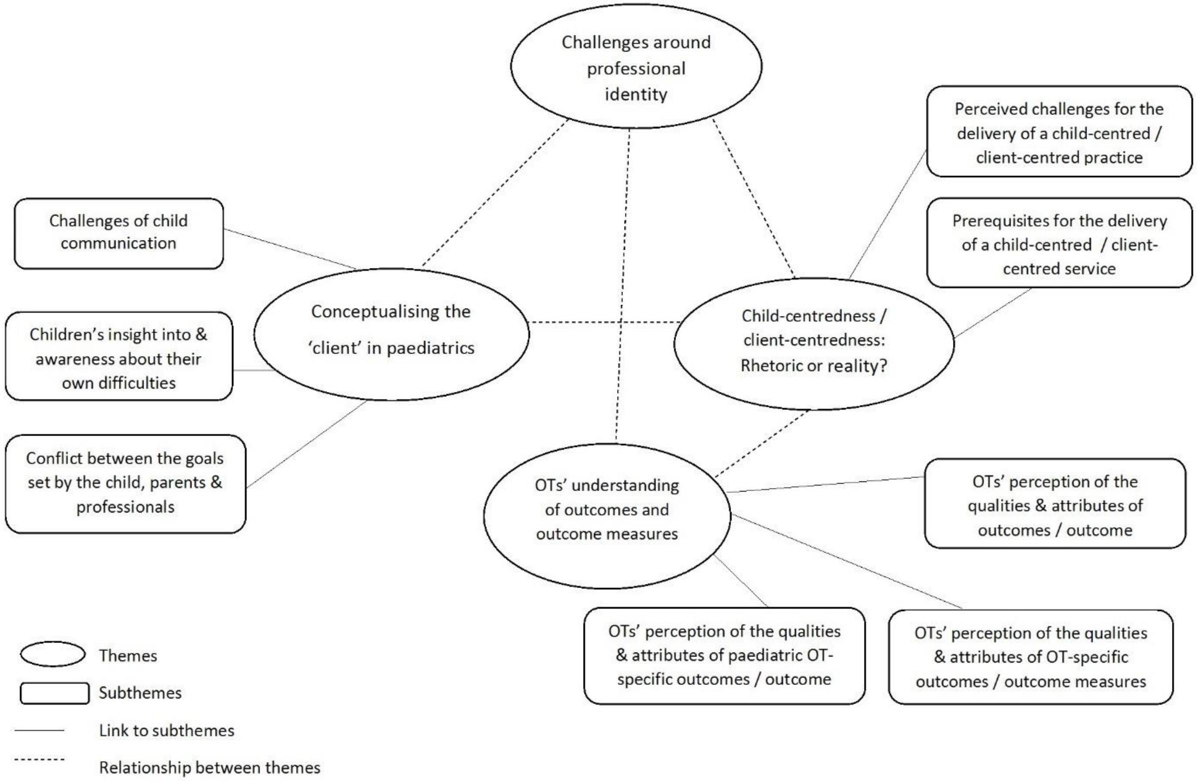
    - Children might be receiving intervention from other services which is not in line with what we’re doing in OT
    - Some children receive group intervention rather than individual sessions

I encourage you to think about some points that you would like to discuss further for the next group session.

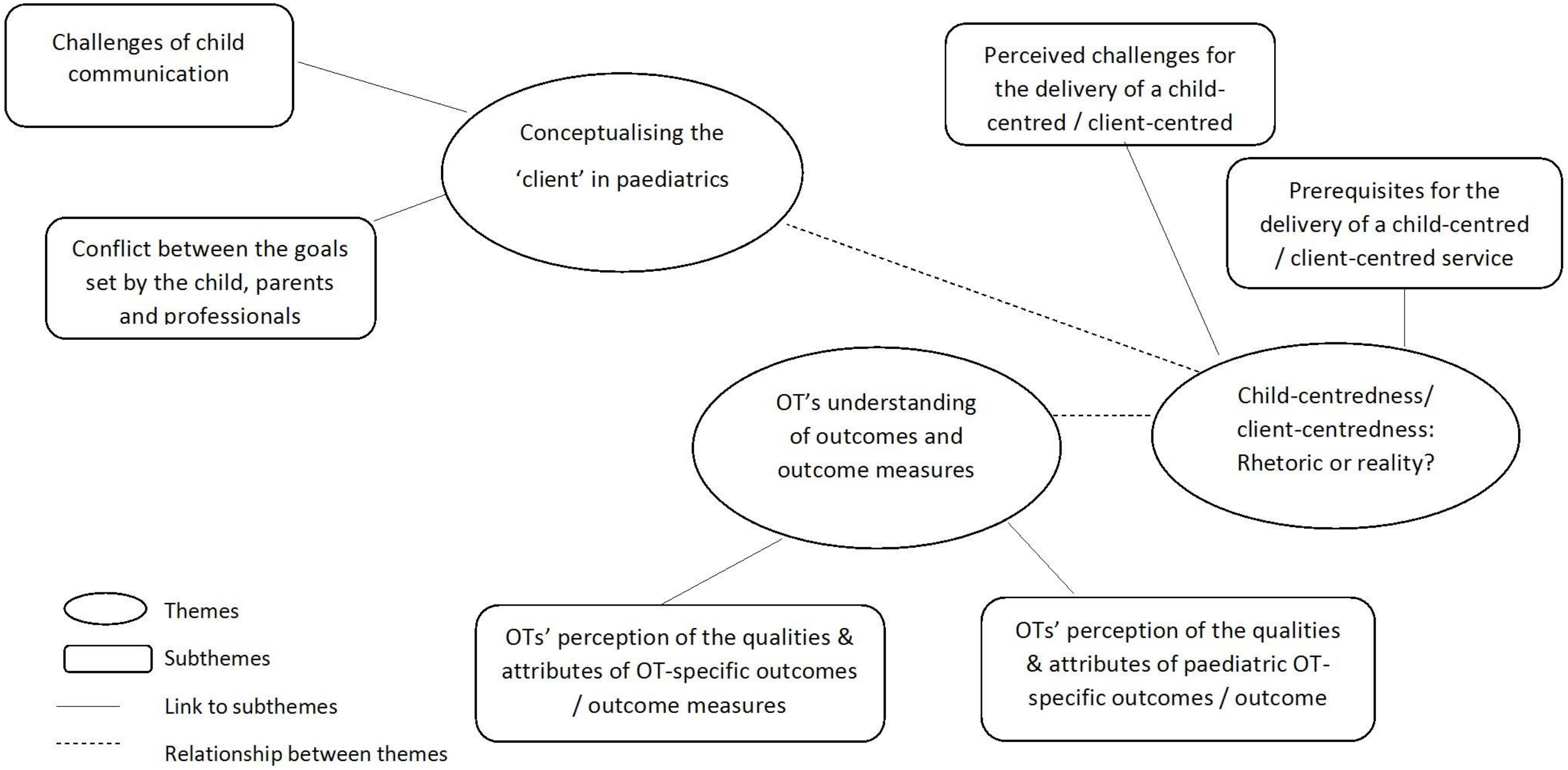
We have also agreed to look at some already existing outcome measure (even if not currently available in our clinics) and discuss their properties as well as their potential suitability to our service. We can look at the actual outcome measures or any other research/information about them and discuss these during our next session. Every one of you is encouraged to bring something related to this for the next session.

Thanks,
Theresien

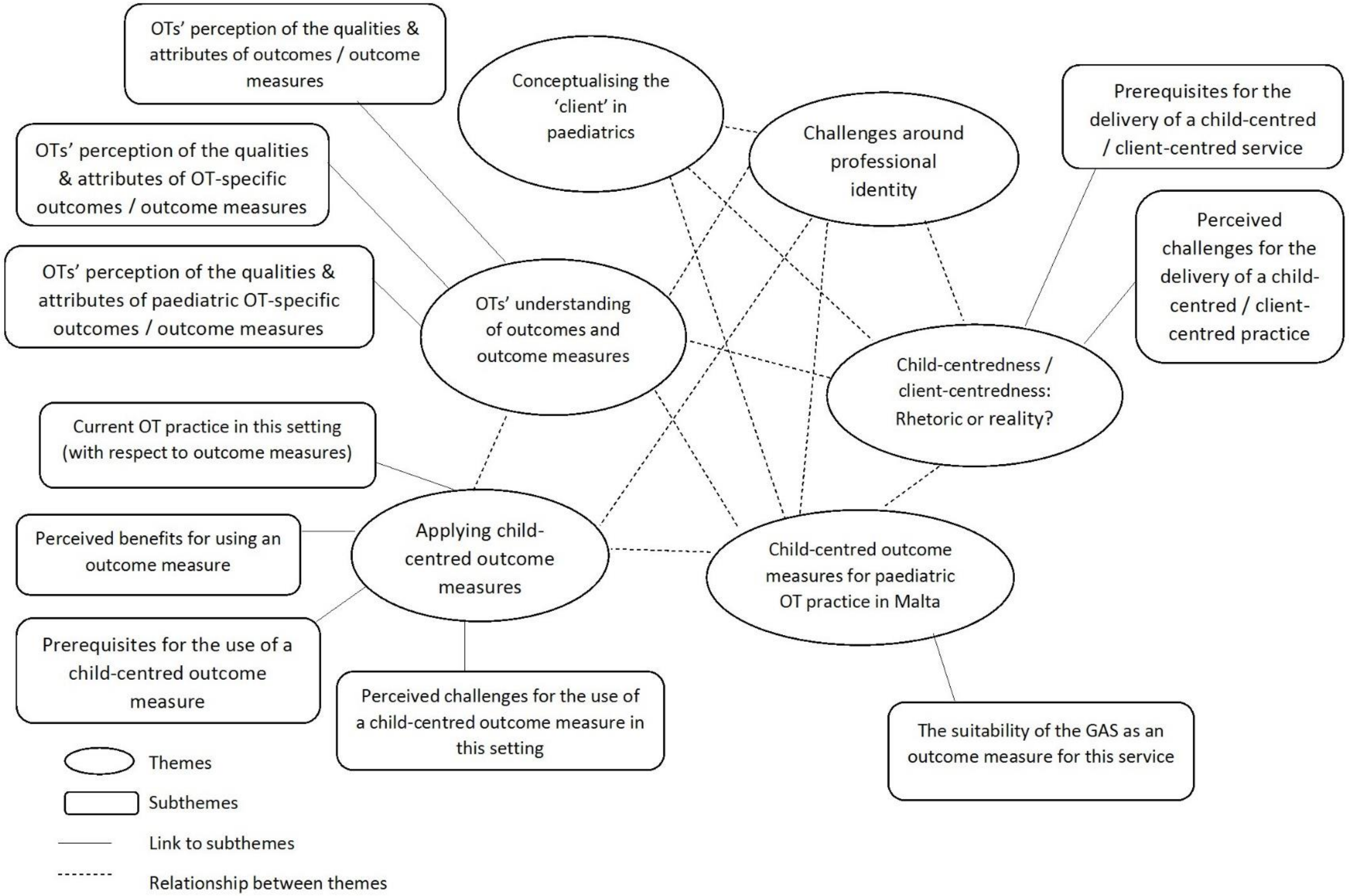
Appendix O Mind Maps for the Action Research Groups



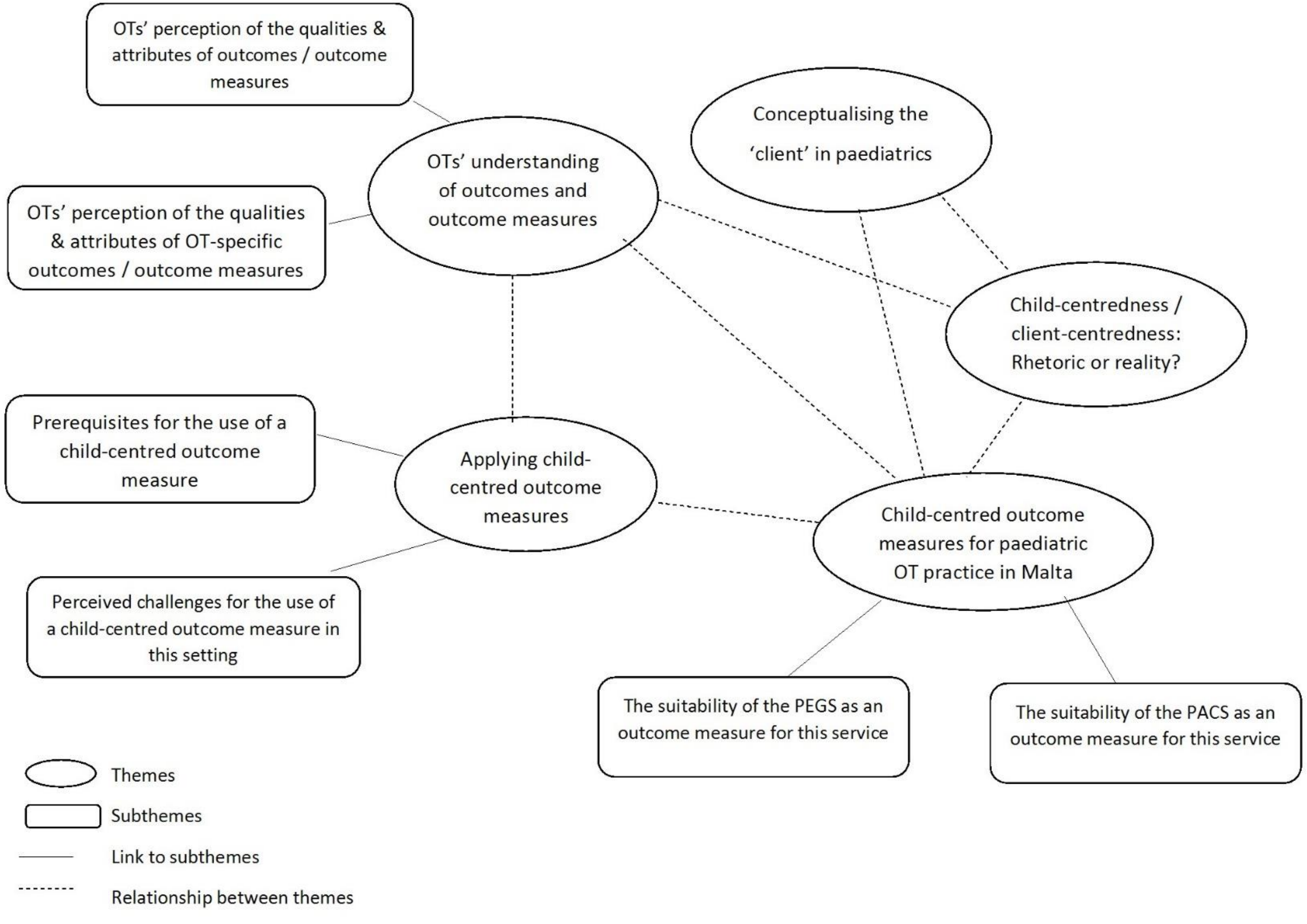
Mapping themes and subthemes of Action Research Group 1 – Version 3



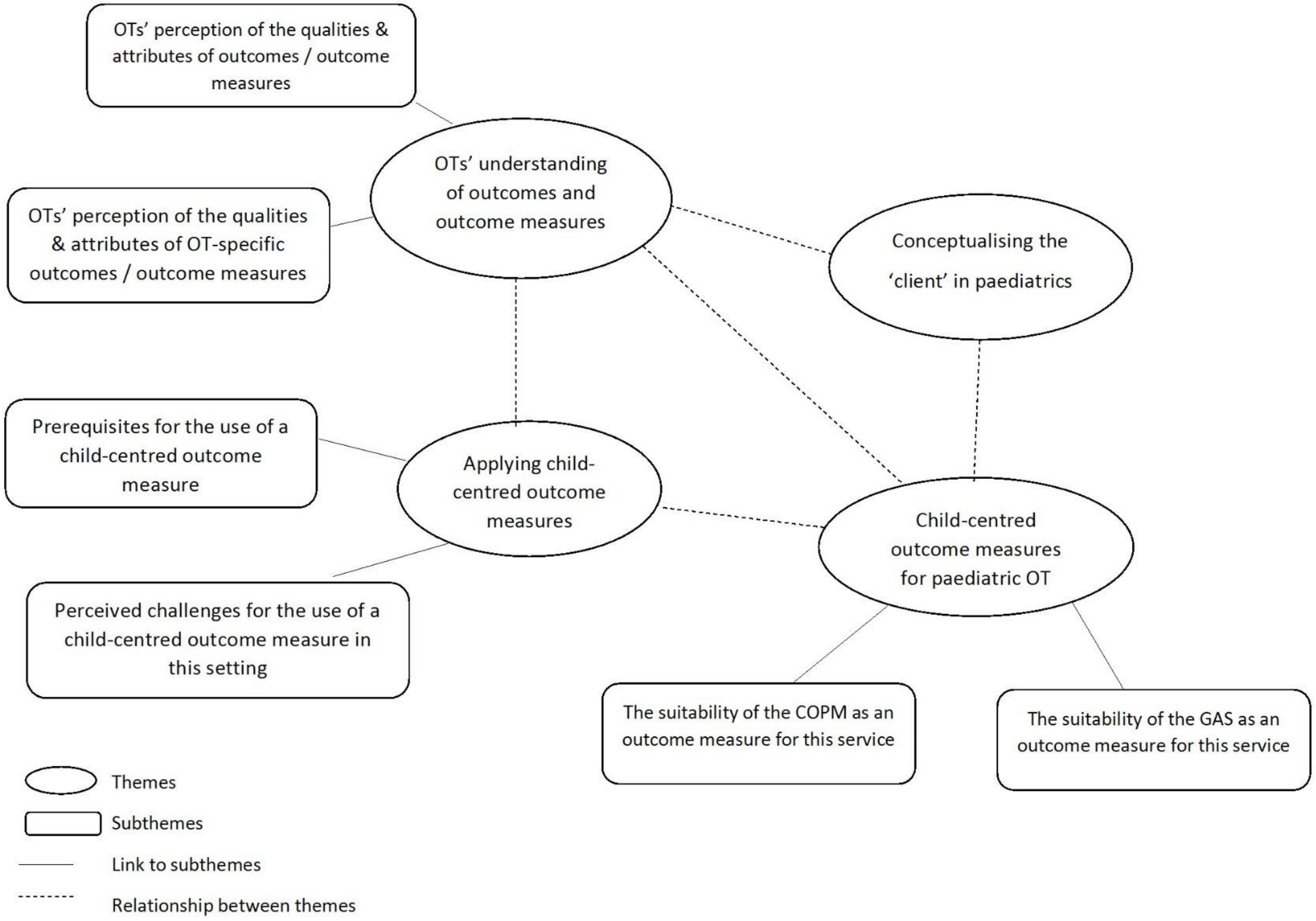
Mapping themes and subthemes of Action Research Group 2 – Version 4



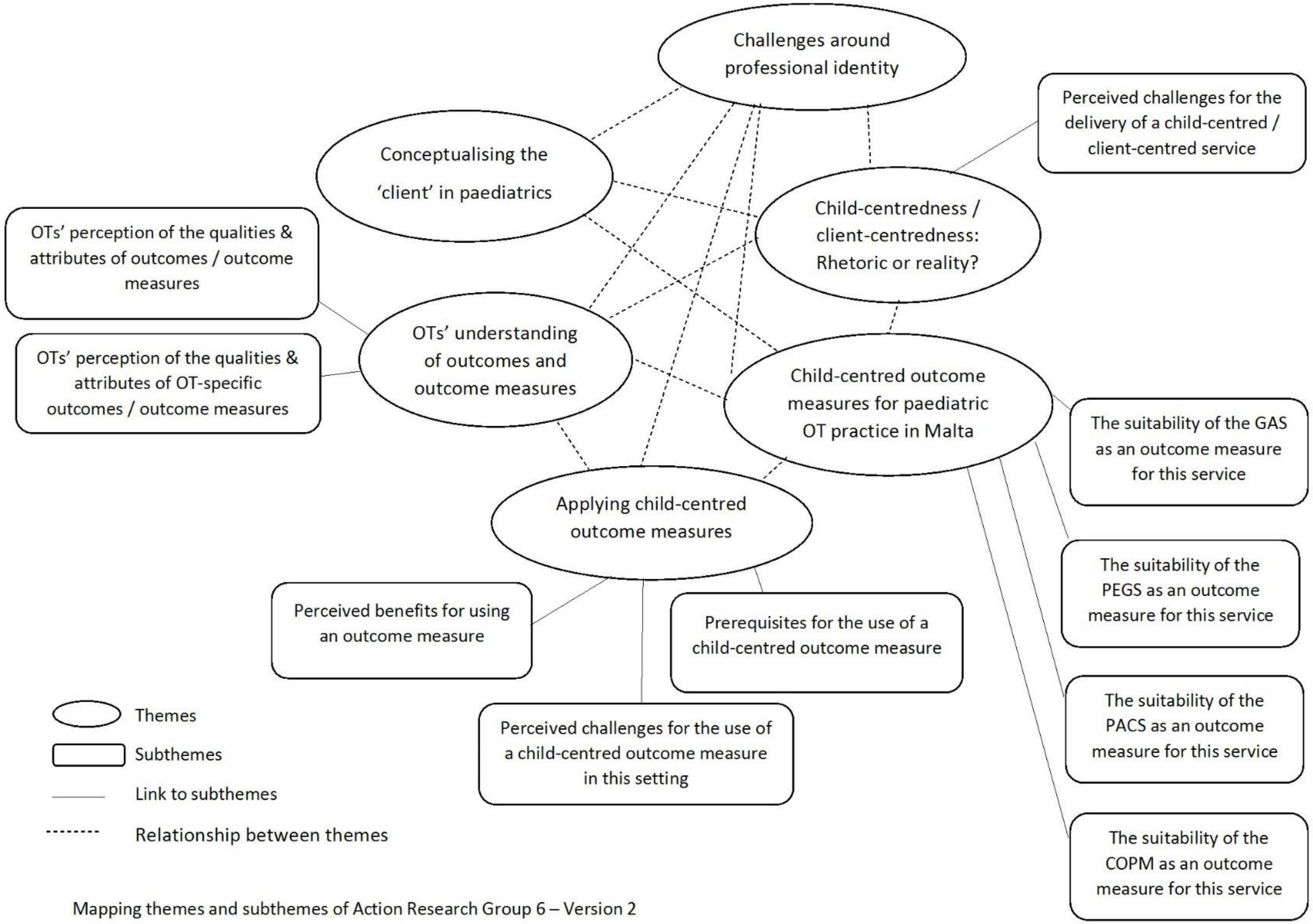
Mapping themes and subthemes of Action Research Group 3 – Version 2



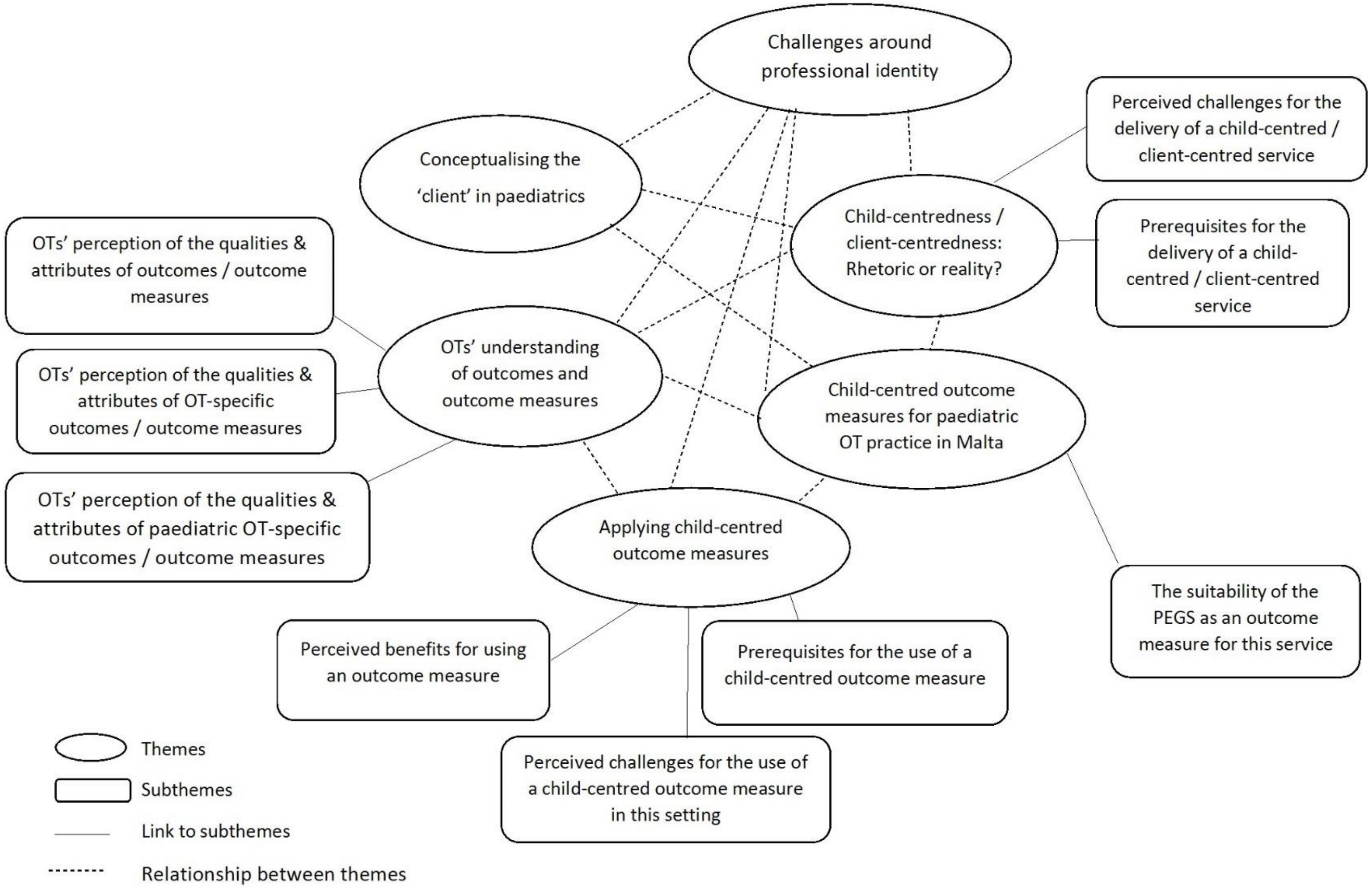
Mapping themes and subthemes of Action Research Group 4 – Version 2



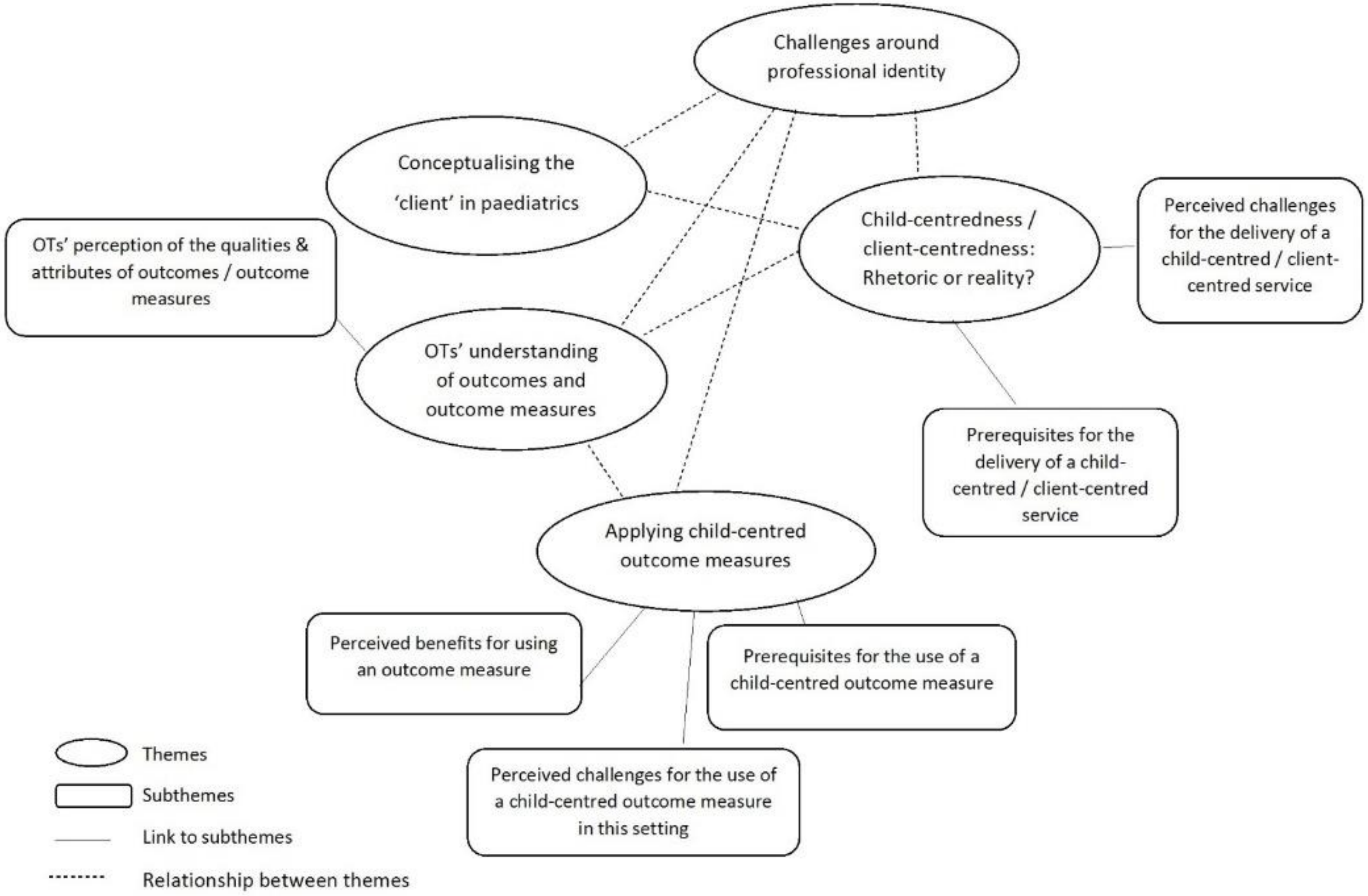
Mapping themes and subthemes of Action Research Group 5 – Version 2



Mapping themes and subthemes of Action Research Group 6 – Version 2

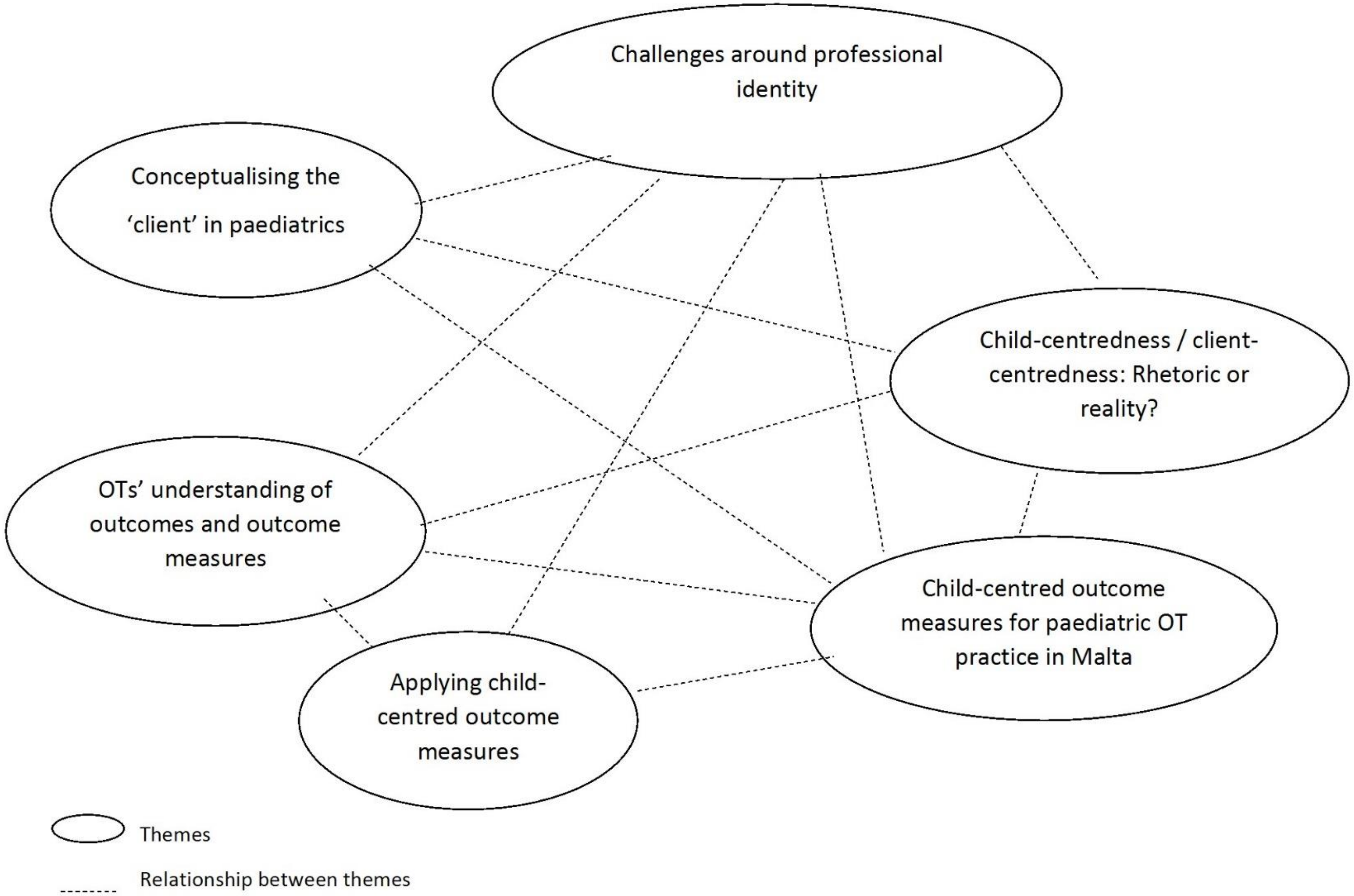


Mapping themes and subthemes of action group 7 - version 2

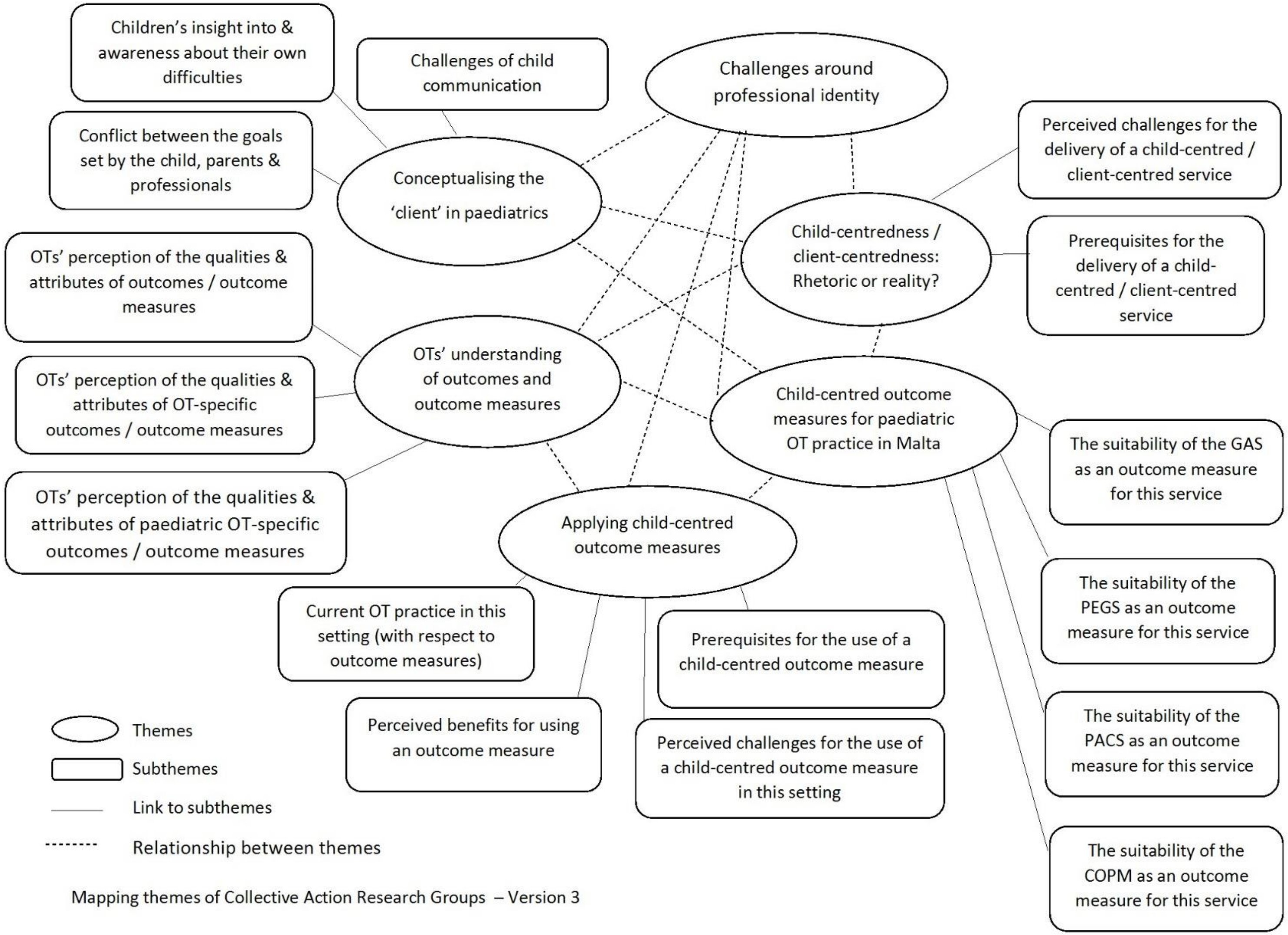


Mapping themes and subthemes of action group 8 – version 3

Appendix P Mind Maps for the Collective Groups



Mapping themes of Collective Action Research Groups – Version 3



Mapping themes of Collective Action Research Groups – Version 3