

**Exploring the experiences of mothers who live with
and care for an adult son or daughter with
schizophrenia**

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Doctor of Advanced Healthcare Practice**

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Abstract

Background:

The impact of schizophrenia on service-users, their carers, family members, healthcare services and on society in general is significant and the financial cost is high due to the range of health and social care needs associated with the illness.

Families can find it frightening to witness and live with the day-to-day fluctuations of mental state and the symptoms and behaviours associated with schizophrenia. Most are ill-prepared to cope, have little knowledge about the condition, and are frustrated by their attempts at trying to access help and navigate a complex health system.

Existing research on the experience of mothers who have adult children with schizophrenia is largely dated and does not adequately address the UK perspective.

Aim:

The aim of this qualitative study is to explore the experiences of mothers who live with and care for an adult son or daughter with schizophrenia.

Method:

To meet the aims of the study, the Biographical Narrative Interpretive Method was adopted. Six mothers of adult sons or daughters with schizophrenia were purposively recruited from a third sector organisation in Wales. Participants were interviewed using an in-depth Biographical Narrative Interpretive Method of data collection. The data were analysed using Wengraf's (2001, 2006) Biographical Narrative Interpretive Method of analysis.

Findings:

Analysis of individual participant accounts and a cross-case analysis found that participants experienced stigma, disruption, and a profound sense of loss in the context of their sons' and daughters' illness. Findings from the study show the impact of having a son or daughter with schizophrenia on mothers is substantial and affects all aspects of their lives. Mothers experienced significant stigma and disruption in the context of their daughter or sons' illness and interactions with

healthcare professionals were unsatisfactory. Furthermore, this study found that mothers experienced multiple losses and ongoing grief.

Conclusion and impact:

The study addresses the gap in the literature that focusses on the experience of UK mothers who live with and care for their adult children with schizophrenia. Exploring these experiences through the lens of chronic sorrow provided an appropriate rationale for their sense of grief and loss which offers therapeutic potential for healthcare professionals. In developing an understanding of the long-term impact of their experience, healthcare professionals will be able to provide more appropriate and timely support. Furthermore, fostering collaborative, supportive relationships with mothers of those with schizophrenia, is of great importance, if their experiences are to improve.

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Abbreviations

BDA – Biographic Data Analysis

BDC – Biographic Data Chronology

BNIM – Biographic Narrative Interpretive Method

CCCT – Cross-case Comparison and Theorisation

CS – Chronic Sorrow

DARNE – Description, Argumentation, Report, Narrative, Evaluation

EE – Expressed Emotion

EIP – Early Intervention Psychosis

FEP – First Episode Psychosis

IP – Interpretive Panel

LL – Lived Life

LLIPA – Lived Life Interpretive Panel Analysis

MH – Mental Health

PE – Photo Elicitation

PIN – Particular Incident Narrative

SHEIOT – Situation, Happening, Event, Incident, Occasion, Time

SQUIN – Single Question Aimed at Inducing Narrative

SS1 – Sub-session one

SS2 – Sub-session two

SS3 – Sub-session three

TFA – Telling Flow Analysis

TS – Told Story

TSIPA – Told Story Interpretive Panel Analysis

TSS – Text Structure Sequentialization

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Chapter One: Introduction and Background

1.1 Introduction

Schizophrenia is a life-changing mental health condition that has a significant impact on the individual and their wider family. This chapter will outline the historical and contemporary context of schizophrenia and the impact this has on close family members. A brief discussion of how the research question for the study emerged, the rationale for the research, the aims and objectives, and study design are also presented. This chapter will also present an overview of the structure of this thesis.

1.2 The study

The research question was:

What are the experiences of mothers who live with and care for an adult son or daughter with schizophrenia?

1.2.1 Aims and objectives

The study aims were to:

1. Develop an understanding of the experience of mothers who live with and care for an adult son or daughter with schizophrenia;
2. Explore the impact of schizophrenia and the caring role on mothers;
3. Highlight the implications for clinical practice when working with those with schizophrenia and their mothers.

The objectives were to:

1. Provide a critique of existing literature pertaining to mothers' experience of caring for an adult child with schizophrenia;
2. Facilitate mothers' story telling through unstructured interviews, to explore their experience of living with and caring for an adult son or daughter with schizophrenia and the impact of this;
3. Analyse and synthesise findings from the literature and the biographical narrative interpretive method;
4. Disseminate the knowledge and learning from this research to clinical partners, clinicians, academics, and policy makers to inform change.

1.2.2 Approach

To meet the study aims and objectives, a biographical narrative interpretive approach was used, utilising the Biographical Narrative Interpretive Method (BNIM). Key study findings include:

- Participants experienced significant stigma, shame and embarrassment, associated with their daughter or sons' illness, which impacted on their help-seeking behaviour and compounded feelings of social isolation;
- Participants experienced disruption to their own life trajectory, which resulted in loss of professional identity;
- Participants experienced multiple losses, including loss related to their daughter or sons' life, their own life and their underpinning sense of loss for the future.

1.3 Motivations for undertaking the study

I have been a qualified mental health nurse for over 25 years, spending much of my time working in a range of clinical teams that supported people with schizophrenia, including both inpatient and community settings. My clinical work illuminated three key issues that were a significant concern to me. First, that a significant number of adult service users with schizophrenia were cared for by their mothers regardless of their own age, or their mothers' age. Secondly, that the carer burden of many mothers I encountered impacted their own physical, psychological, and social well-being, and thirdly, that the burden experienced by them was not adequately addressed by healthcare professionals regardless of the service setting supporting their son or daughter.

In addition to my extensive experience of working clinically with people with schizophrenia, I also have two close family members with the illness. In order to maintain their confidentiality and anonymity, the full impact of this on myself and other family members will not be disclosed in this thesis, however the impact has been significant and life changing. For a short time, before diagnosis and treatment, both family members lived with me, it was a chaotic, stressful, and traumatic period which gave me a small but very personal insight into living with and caring for close family members with schizophrenia. Coming to terms with the 'loss' of two young people as I knew them, witnessing first-hand the change in their personalities, goals

and aspirations, as well as observing the physical changes to their appearance as a result of medication side effects, has been difficult. The impact has spanned over 20 years and remains ongoing.

I therefore came to realise that gaining a greater understanding of the impact of schizophrenia on mothers was an area worthy of further investigation.

1.4 Schizophrenia

Schizophrenia is a severe and debilitating mental disorder, characterised by profound disruptions in thinking, affecting language, perception, and the sense of self (American Psychiatric Association 2013). The disorder typically begins in late adolescence or early adulthood, and it is more common in males (Jongsma et al. 2019,) with a worldwide prevalence, according to the World Health Organisation (WHO) (2022), of 24 million. Globally, the disorder affects approximately one in every hundred people (McGrath et al. 2008) therefore, it is estimated that over 670,000 people in the UK have the condition, 30,00 of whom reside in Wales. Why people develop schizophrenia remains poorly understood although there is consensus that it is caused by a combination of genetic, personal and environmental factors, which will be different for each person (WHO 2022, Barch et al. 2022).

The impact of schizophrenia on service-users, their carers, family members, healthcare services and on society in general is significant and due to the range of health and social needs associated with the illness, the financial cost is high. According to the Schizophrenia Commission (2012), the annual cost of schizophrenia in the UK was £11.8 billion a year. This equates to £60,000 per individual with schizophrenia, and to the public sector, £7.2 billion - £36,000 per individual with schizophrenia with more than half of this cost incurred as a result of lost productivity such as unemployment and premature death (Schizophrenia Commission 2012). Furthermore, it is estimated that families who provide care to those affected by schizophrenia reduce annual public spending by £1.24 billion (Schizophrenia Commission 2012).

1.5 Symptoms and recovery

The Diagnostic and Statistical Manual of Mental Disorders (DSM 5) (American Psychiatric Association 2013) state that symptoms of schizophrenia include hallucinations, delusions, and disorganised speech. Thought disorder is common,

such as loosening of association where there is a lack of connection between ideas; word approximations, where words are used in unconventional or inappropriate ways; thought blocking, where thoughts are suddenly interrupted and there is poverty of speech (APA 2013). A range of negative symptoms, which describe a reduced level or absence of normal behaviour that impact on social functioning, may also develop (Correll and Schooler 2020). These include alogia (lack of speech), anhedonia (the inability to experience pleasure), lack of volition and flattened affect. Schizophrenia can only be diagnosed by a psychiatrist following a full and detailed mental health assessment and this process can be lengthy as the onset of clinical psychotic symptoms is often preceded by a prodromal period, characterised by changes or a deterioration in behavioural symptoms that can last from several weeks to several years (Larson et al. 2010).

Recovery rates for schizophrenia were identified in the work by Barbato (1998) for the WHO, who identified that 45% of people who receive a diagnosis of schizophrenia will recover after one or more episodes, 20% show unremitting symptoms and long-term disability and the remaining 35% show a mixed pattern with varying periods of remission and relapse. Several studies, systematic reviews and meta-analysis over more recent years suggest that these figures have remained largely static with no significant improvement over time despite advancements in pharmaceutical and psycho-social interventions (Jobe and Harrow 2002, Menezes et al. 2006, Gureje and Cohen 2011, Jaaskelainen et al 2013). Furthermore, people with schizophrenia are at risk of increased morbidity and mortality due to suicide, accidents, and traumatic injuries as well as a range of metabolic disorders associated with the use of anti-psychotic medication, such as diabetes, cardiovascular disease, and respiratory problems (NICE 2014, APA 2021).

1.6 Developments in service provision

Over the past fifteen years, there has been an acknowledgment of the importance of early recognition of the signs and symptoms of schizophrenia with a shift from a traditional medical model that focussed on symptom reduction and medication, to a bio-psychosocial model that focusses on prevention, early detection, and intervention (Birchwood et al. 2013, Morrison et al.2012, Addington 2011). A review

of treatments and services for those with the illness by the Schizophrenia Commission (2012) concluded that early intervention for those with psychotic symptoms was crucial to improving outcomes and was one of the most significant developments in mental health care since the beginning of community care (Birchwood 2014). In England, The Five Year Forward View for Mental Health (NHS England, 2015) included specific recommendations on early intervention, targeting 50% of people experiencing a first episode of psychosis to access an evidenced-based care package within two weeks of referral, rising to a 60% target by 2021. In Wales, the Together for Mental Health strategy (Welsh Government 2012) identified the development of services for people with first-episode psychosis (FEP) as a priority but stopped short of stipulating a national target. However, a recent audit report by the Royal College of Psychiatrists (RCP) (RCP 2022) was commissioned by the Healthcare Quality Improvement Partnership and presented key findings that reflect the current situation of early intervention provision for those with psychosis and their families. Findings were presented across three documents, each relating to a specific area of the UK- England, Wales and Ireland. Within the Welsh context, the report presents an improving picture on timely access to early intervention services but a disappointing one relating to family and carer support (RCP 2022). Nevertheless, despite advancements in service configuration and delivery, there remains a significant population of service-users with an established illness who are cared for by generic mental health services, often finding themselves on the fringes of society and care services, who are cared for and supported primarily by family members. Consequently, families and carers continue to report a lack of best practice interventions and a lack of involvement in care (Schizophrenia Commission 2017).

1.7 The involvement of families: a one-hundred-year issue

Historically there have been many theories that hypothesised an association between the family environment and the development of schizophrenia. As far back as the 1920's, a family role in the cause of mental illness was suggested (Bebbington and Kuipers, 1994) and later, research focussed on interactions within the family with the identification of concepts such as the *schizophrenogenic mother*, who were viewed as cold, rejecting, domineering and lacking sensitivity (Fromm-Reichman 1948). Further concepts related to the interactions within the family

environment were introduced, including *dysfunctional parenting*, *family scapegoats*, *over-dominant parenting* and *double-bind interactions* in which a dichotomous dilemma is posed whereby a successful response to one message results in an unsuccessful response to the other (Bateson et al. 1956).

In the early 1950's a series of studies conducted by Brown et al. (1962, 1972) investigated the outcome of patients discharged from psychiatric hospitals. The initial findings, that those with a diagnosis of schizophrenia who returned to live with their parents and close family did not progress as well as those who lived alone or in hostel accommodation, informed further research to investigate the nature of the home environment. The investigation resulted in the development of the measure of expressed emotion (EE) which generally refers to key aspects of interpersonal relationships including, hostility, warmth, positive comments, and emotional over-involvement (Brown et al. 1972). The correlation between EE and relapse soon became widely accepted as a robust predictor of outcome in schizophrenia (Vaughn et al. 1976, Kavanagh 1992, Bebbington and Kuipers 1994, Scazufca and Kuipers 1996, Kuipers 2006). Expressed emotion has been the subject of much debate over more recent years and it could be argued that the concept may naturally result from caring for a family member with any long-term illness and caution has been necessary as parents can feel unfairly blamed by practitioners for causing mental illness (Callard et al. 2012, Harrington 2012).

Families can find witnessing and living with the day-to-day fluctuations of mental state and symptoms and behaviours associated with schizophrenia frightening (Treanor et al. 2011, Marder and Freedman 2014). Most are ill-prepared to cope, have little knowledge about the condition, are frustrated by their attempts at trying to access help and navigate a complex health system (Tuck et al. 1997, Pitschel-Walz et al. 2001, Coker et al. 2015). They may also find that they are subject to unhelpful and stigmatising stereotypes (Connor et al. 2016, Muralidharan et al. 2017). This suggests that the burden associated with caring for a loved one with schizophrenia and efforts to access support continue to be problematic for family members. This is explored in more depth in the literature review in chapter two.

1.7.1 The role of the mother

It is now generally agreed that there is little evidence to support the previously held hypothesis that parents, especially mothers, were responsible in some way for the development of schizophrenia in their sons and/or daughters (Tuck et al. 1997, Klages et al. 2016). However, few studies have examined the experience of caring for an adult son or daughter with schizophrenia despite many service-users relying on their parents and family members for support. The mother has been identified throughout the literature as a significant care giver who provides practical, emotional, social and care support to those with schizophrenia (Milliken 2001, Hanzawa et al. 2008, Wancata et al. 2008, Klages 2016, Wiens and Daniluk 2017). Further evidence in support of this has been demonstrated in studies of family burden sampling predominantly women who are often the mothers of those with schizophrenia (Roick et al. 2006, Roick et al. 2007, Chan 2011).

Mothers are often a great source of support in times of crisis and are often peacemakers, problem solvers and pragmatic facilitators within families (Ryan 1993, Wancata et al. 2008, McAuliffe et al. 2014). Some authors suggest that mothers are also more likely to express their emotions more strongly than other family members (Hanzawa et al. 2008). Having a son or daughter with schizophrenia however can add a new dimension to family dynamics and, more specifically the mothering role, often resulting in the mother facing a myriad of challenges and difficulties, encountering these alongside an often unpredictable and disruptive disease trajectory within their lives. Due to the age of onset of schizophrenia, individuals have usually reached adulthood when they receive a diagnosis. Typically, then, because mothers often assume the responsibility for caregiving in most families, it could be argued that mothers disproportionately suffer the consequences of having an adult son or daughter with schizophrenia (Ryan 1993, Wancata et al. 2008, McAuliffe et al. 2014). The caregiving role adopted by the mother for her son or daughter therefore can be viewed as extended, pervasive, and sometimes life-long.

1.8 Organisation of the thesis

This thesis is organised into seven chapters. This introductory chapter has presented a rationale for the study, the background and historical perspective of schizophrenia, the impact of this on families and the role of the mother in providing

care. Chapter two presents a critical review of relevant literature exploring mothers' experiences of having a son or daughter with schizophrenia. Chapter three provides an insight into the philosophical underpinnings of the study, the methodology chosen and details the methods utilised in the study including the relevant permissions sought. Chapter four presents the findings from the three 'gold star' cases in the form of individual case presentations. Chapter five presents the findings of the cross-case comparison and theorisation, identifying key themes of stigma, disruption, and loss and grief, drawing on high quality literature to support these. Chapter six explores the key findings in the context of the wider literature: the impact of having a son or daughter with schizophrenia on mothers; motherhood and the mothers' role in caring for an adult child with schizophrenia; engagement with health professionals and the mothers' experience of chronic sorrow. This chapter also outlines the strengths and limitations of the study. Chapter seven presents the unique contribution to knowledge and implications for mental health practice and research. It details a dissemination plan and ends with a brief conclusion and epilogue that offers some final personal thoughts on completing this thesis.

1.9 Summary

This chapter has introduced the topic of interest, the personal and professional motivations for the study and the background and historical context of schizophrenia and the impact of this on families. The next chapter will provide a critical review of the literature relating to the mothers' experience of having an adult son or daughter with schizophrenia.

Chapter Two: Literature Review

2.1 Introduction

Following the introduction and rationale for the study presented in the previous chapter, this chapter presents the review of the literature undertaken to inform the subsequent research study. A scoping review of the literature was adopted for this study to establish what was already known about the mothers' experience of having an adult son or daughter with schizophrenia. The question for the literature review was: *What are the experiences of mothers who live with and care for adult children with schizophrenia?* Key themes were developed from the literature and are presented in this chapter: (1) disruption, struggle and chaos; (2) loss, sorrow and sacrifice; (3) constant caring; (4) coping mechanisms and (5) attitudes of healthcare professionals.

2.2 Approach

Various approaches to literature reviews are proposed in the literature (Coughlin et al. 2013, Aveyard et al. 2016, Booth et al. 2021) and decisions about the type of review to be conducted need to be informed by the nature of the question being asked and the intended outcomes of the review. Therefore, having established the review question, it was necessary to consider the type of review that would meet the review objectives. It was decided that a scoping review would be an appropriate approach. Scoping reviews are concerned with the contextualising of knowledge, identifying current understanding and identifying what is known and unknown on the topic of interest (Anderson et al. 2008). Scoping reviews are increasingly utilised within nursing research (Courtenay et al. 2013, Munn et al. 2018) and add value to evidence-based practice by examining a wide range of literature to identify gaps in the research knowledge base, clarify key concepts, and provide information on the types of literature that address and inform clinical practice (Joanna Briggs Institute (JBI) 2015). Grant and Booth (2009) argue that this type of review assesses potential scope and size of available research literature and aims to identify the nature and extent of research evidence on a topic. Furthermore, scoping reviews have the added advantage in that they are versatile and provide the opportunity to be flexible (Aveyard et al. 2016).

A number of scoping review frameworks can be utilised to identify and review relevant literature including those by Arskey and O'Malley (2005), Levac et al. (2010), Khalil et al. (2016) and Peters et al. (2020). The Khalil et al. (2016) framework for scoping reviews was utilised to identify and review literature for inclusion in this study and is outlined in table 1.

Stage		
1	Identify the research question	Clarifying and linking the purpose and research question
2	Identify relevant studies	Using a three-step literature search, balance feasibility with breadth and comprehensiveness
3	Study selection	Careful selection of the studies
4	Presenting the data	Charting the data in a tabular and narrative format where applicable
5	Collating the results	Identifying the implications of the study findings for policy, practice or research

Table 1: Khalil et al. (2016) Framework for scoping reviews

Khalil et al (2016) framework for scoping reviews was chosen as it is an iterative approach to selecting studies and extracting data and considers the implications of study findings to policy, practice and research.

2.3 Identifying the research question

Stage 1 of Khalil *et al.* (2016) framework seeks to clarify and link the purpose of the scoping review and the research question. The aim of the scoping review was to provide an understanding of the body of knowledge relevant to the research question: *What are the experiences of mothers who live with and care for adult children with schizophrenia?*

2.4 Identifying the relevant studies

The approach to searching for studies for a scoping review follows a three-step method as it does for standard Joanna Briggs Institute (JBI) reviews (Aromataris and Riitano 2014, Khalil 2016). According to Coughlan et al. (2013) the search strategy should be as extensive as possible with the purpose of identifying all relevant literature. For this review therefore, as well as including all relevant databases, the

search also included hand-searching and efforts to seek out unpublished literature. Initial search terms and strategies were revisited as familiarity with the literature increased.

2.4.1 Step 1

This was an initial limited search of the literature of two online databases. The databases chosen at this stage were CINAHL and MEDLINE as these were considered the most appropriate for the current review focussing on the mothers' experience of having an adult son or daughter with schizophrenia and they are also advocated by Khalil et al. (2016). Broad search terms were initially applied using keywords and general terms around the topic of interest to ascertain preliminary research themes and literature abstracts relevant for the review. The initial keywords searched for were mother*, maternal, parent*, psycho*, and schizophreni*. Although using these keywords made the search broad and had the disadvantage of yielding large numbers of articles, it helped to reduce the likelihood of missing relevant papers. Furthermore, the broad search facilitated familiarity of the wider literature from which the search could be narrowed down.

2.4.2 Step 2

The broad search terms identified in step 1 produced thousands of citations, consequently, a pragmatic approach was taken to balance the sensitivity and specificity of the search (Dundar and Fleeman 2014, Boland et al. 2017). Assistance was also sought from the subject librarian to help refine the search. Titles and abstracts were reviewed in order to develop specific keywords and subject areas in which to undertake an extensive search of the literature. Consideration at this stage was also given to synonyms, plurals, different spellings, use of hyphens and abbreviations. The use of both key words (natural) and index/subject (controlled) terms was required to ensure the search was comprehensive. The second step of the search strategy therefore involved the identification of the final search terms (see table 2) and a subsequent search using these terms. The databases searched in step 2 were: MEDLINE, CINAHL, British Nursing Index, EMBASE, Google Scholar, Psych INFO and SCOPUS.

Database	Search terms used
MEDLINE	mother* OR maternal OR parent* AND psycho* mother* OR maternal OR parent* AND schizophreni*
CINAHL	mother* OR maternal OR parent AND psycho* mother* OR maternal OR parent* AND schizophreni*
British Nursing Index	mother* AND schizo* AND burden Carer* AND schizo* AND burden Carer* AND burden AND psycho*
EMBASE	mother* OR parent* AND schizohreni*
PsychINFO	famil* OR mother OR parent* AND schizophrenia
SCOPUS	mothers AND schizophreni*
Google Scholar	Experience of mothers of adult children with schizophrenia

Table 2: Search terms

Inclusion and exclusion criteria

As indicated by Khalil et al. (2016) specific inclusion and exclusion criteria should be used to promote consistency in making decisions about studies to be included and these should be informed by participants, concept and context. In addition, criteria for this review were also informed by familiarity with the literature, examination of the review question and clarification of the purpose of the review.

Participants

- Studies focussed on the experiences of mothers who have adult sons or daughters with schizophrenia
- Studies which either wholly, or in part focussed on mothers' experiences of adult children with schizophrenia

Concept

Studies included in the review had to be investigating the following phenomena:

- Mothers' experiences of caring for an adult child with schizophrenia

Context

- Studies from western countries where care and treatment of people with schizophrenia is similar to the UK
- Studies where adults with schizophrenia lived with and were cared for by their mothers. This was to enhance applicability and relevance of findings as these were the contexts the empirical study being informed by the review focussed on.

Exclusion criteria

- Studies conducted in countries with systems and culture fundamentally different from the UK were excluded because the cultural context is relevant as it affects applicability of the findings.
- Studies conducted where the focus was on caring for an adult son or daughter with schizophrenia under specialist services, such as early intervention, first-episode psychosis or forensic services were excluded, as applicability may be compromised and where emphasis is on the care setting and delivery of care within it rather than mothers' experiences more broadly.
- Studies conducted where the focus was on mothers of children under the age of eighteen, as child mental health was not the focus of the review.
- Studies that focussed specifically on the determinants of expressed emotion (EE) in mothers were excluded as the focus was on certain personality traits linked with EE, specifically critical comments, and emotional over-involvement.
- Studies in languages other than in English were excluded due to the cost of translation.

2.4.3 Step 3

During the final step of the literature search, literature was obtained by searching all bibliographies and reference lists of identified literature for any additional studies. This citation chaining is advocated by Khalil et al. (2016) as it complements the database search. For this review however, this process failed to locate any further studies. To ensure an up-to-date and timely retrieval of new literature relevant to the

phenomena of interest, search alerts were established on key databases, namely CINAHL and MEDLINE. Searches were performed at regular intervals to ensure any newly published literature was captured.

2.5 Study selection

This stage involved selecting the studies to be included in the review. In order to identify seminal work regarding the experience of mothers who have an adult son or daughter with schizophrenia there were no date restrictions set during the literature searches. However, determining the inclusion and exclusion criteria was useful in reducing the number of irrelevant studies for the review. It allowed the use of limits for the database searches, namely geographical area and language. Following the application of limits, the titles and abstracts of the remaining papers were screened with the inclusion and exclusion criteria in mind. Studies that appeared relevant were downloaded to a file on the computer and the full text article was read in order to make a final decision regarding inclusion in the literature review. Following this process, 8 papers were identified for inclusion in the review and are presented on a data extraction form, detailed in Appendix 1.

2.6 Presenting the data

The extraction of data for a scoping review is referred to as 'charting the results' (Khalil et al. 2016), and it should provide a logical and descriptive summary of the results that align to the objectives and questions of the review. Therefore, this process involved developing a data extraction form to extract relevant information from each study, with the aim of enhancing knowledge and understanding, of the scope and nature of the studies included. Summarising the studies in this way helped to develop familiarisation of each study and identify relevant themes. The data extraction form that details the studies that were included is presented in Appendix 1. Additionally, A PRISMA flow diagram, adapted from Page et al. (2021) summarising the search strategy process is presented in figure1.

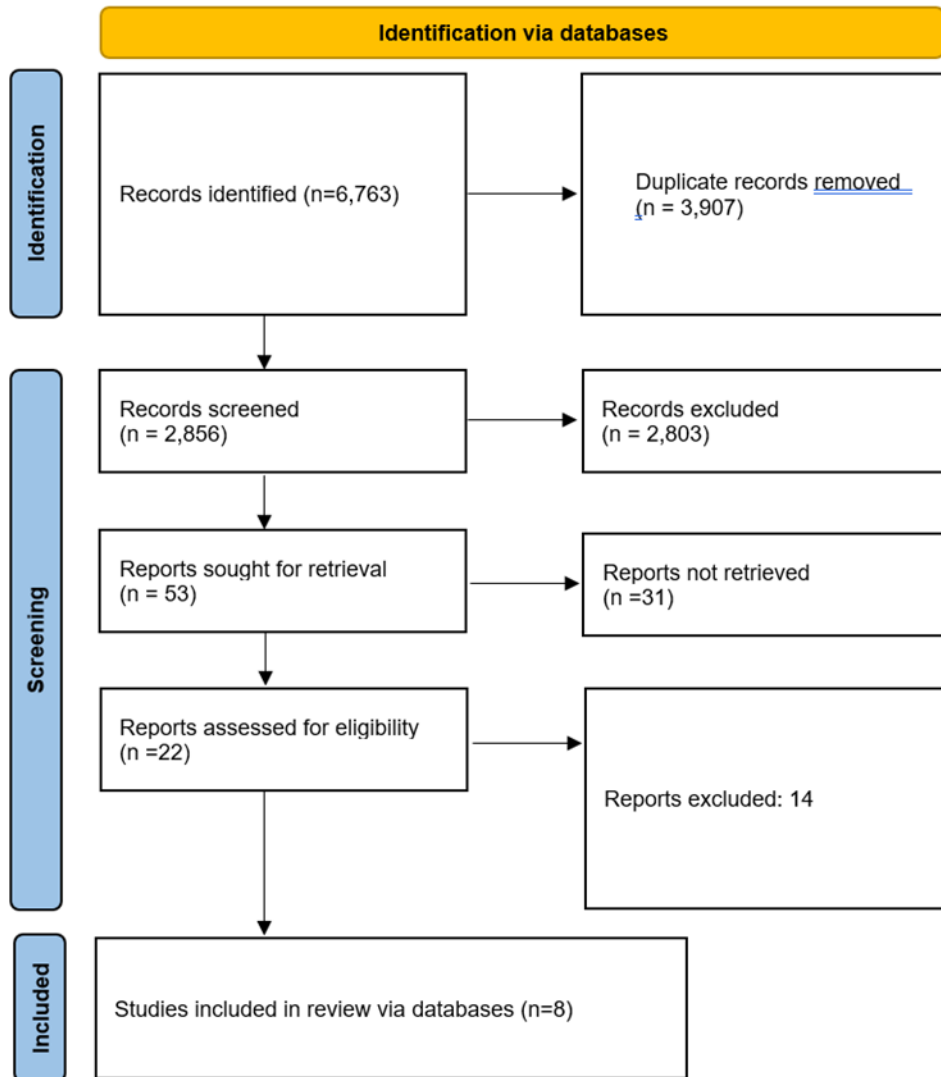


Figure 1: PRISMA (Page et al. 2021) flow diagram

Seven studies were chosen for inclusion in the review: a Canadian ethnographic study by Ryan (1993); a descriptive study by Eakes (1995) conducted in the USA; a phenomenological study by Tuck et al. (1997) also conducted in the USA; two grounded theory studies conducted by Milliken (2001) and Milliken and Northcott (2003) in Canada; a descriptive study by McAuliffe et al. (2014) conducted in Ireland; and a qualitative narrative and cross-narrative research study conducted by Wiens and Daniluk (2017) in Canada. In addition to the seven studies outlined above, an integrative review of the literature by Klages et al. (2017) conducted in Australia was also included, that focussed on parental perspectives of their relationships with mental health professionals in the context of their adult sons' or daughters' illness.

Unlike systematic reviews, scoping reviews do not focus on appraisal and methodological rigour (Khalil et al. 2016), rather, they map and chart key findings of the literature (Arskey and O'Malley 2005). Furthermore, Peters et al. (2020) highlight the way that data are extracted and analysed in scoping reviews is largely dependent on the purpose of the review and subject to the author's judgement and creativity. In this review, a descriptive approach was taken that used identified categories or 'themes' related to mothers' experience of having an adult son or daughter with schizophrenia.

2.7 Collating the results

This was the final stage of Khalil et al's. (2016) five-stage framework. Due to the degree of flexibility in how findings from scoping reviews are presented, there was a need to consider an analytic or thematic construction to guide the narrative presentation of the literature. Weinberg et al. (2019) argue that scoping reviews vary in the extent to which evidence is synthesised across studies, from extensively aggregating and explicating findings to broadly mapping them. In this review, this process was aided by the completion of the data extraction table that summarised the studies and detailed the key findings (presented in Appendix 1). This facilitated the identification of themes which formed the basis of the narrative account of the scoping review findings. Five themes were identified: disruption, struggle and chaos; loss, sorrow and sacrifice; constant caring; coping mechanisms and attitude of healthcare professionals.

Following the completion of the data extraction table, a detailed discussion of the identified themes is presented below. Studies which address the same theme were grouped together, and where studies addressed multiple themes, they will appear under each corresponding theme, as appropriate.

2.8 Literature review themes

In line with the research question, the aim of the scoping review was to provide an understanding of the body of knowledge relevant to the research question. Five themes were developed from the literature that focussed on mothers' experience of having an adult son or daughter with schizophrenia. These themes are:

- Theme one: disruption, struggle and chaos
- Theme two: loss, sorrow and sacrifice;

- Theme three: constant caring;
- Theme four: coping mechanisms
- Theme five: attitude of healthcare professionals.

Each theme is discussed below, followed by a summary of the key findings of the literature.

2.9 Disruption, struggle and chaos

A predominant theme throughout the literature is one of the disruption, struggle, and chaos caused by schizophrenia (Ryan 1993, Eakes 1995, Tuck et al. 1997, Milliken 2001, Milliken and Northcott 2003, McAuliffe et al. 2014 and Wiens and Daniluk 2017).

Ryan (1993) conducted a qualitative descriptive study to gain an understanding of mothers living with adult children with schizophrenia in Canada. This was the only study identified within the search results that focussed specifically on mothers of adult sons or daughters with a diagnosis of schizophrenia only, demonstrating the dearth of available relevant research. Ryan's (1993) study aimed to explore mothers' experiences of living with an adult son or daughter with schizophrenia; how they defined their individual situation, and how the mothers managed on a day-to-day basis. Ryan's (1993) sample consisted of five mothers who were recruited to the study, participants were all Caucasian, employed, married, and aged between 50 and 62 years of age. Ryan's (1993) participant population is a potential limitation of the study however as the involvement of participants who are articulate, accessible, or high-status members of a particular population or group can introduce 'elite bias' (Sandelowski 1986). Ryan's (1993) study is now almost 30 years old, and the findings may not accurately reflect the experiences of mothers over more recent years given the developments in mental health care and treatment, mental health service configuration and service-user and family support. The sample size is small, and whilst appropriate within qualitative research, it can limit the transferability of the findings to other contexts (Silverman 2014).

Within Ryan's (1993) study, all five mothers had other children, but only the adult child with schizophrenia were living at home with them. Living in the same home as the adult son or daughter with schizophrenia is an important consideration within the context of the topic of interest; this criterion is fundamental to the aim of some

studies (Ryan 1993, McAuliffe et al. 2014) but has been less important in others (Eakes 1995, Tuck et al. 1997, Milliken and Northcott 2003, Wiens and Daniluk 2017). The adult children with schizophrenia were aged between 22 and 38 years old with the number of years since onset of illness ranging from 6 to 20 years. Ryan's (1993) sample included one mother of a daughter and four mothers of sons with schizophrenia. To strengthen the trustworthiness of the findings and reduce bias, three out of the five participants completed a second interview, strengthening the trustworthiness of the findings (Noble and Smith 2015).

Ryan (1993) identified that mothers experienced disruption in terms of their relationship with their son or daughter and within their own personal lives. Ryan (1993) suggests that there are three domains to this disruption: constancy – relating to the unremitting nature of the situation: centrality – the mothers' crucial role in providing care for their son or daughter coupled with the perceived lack of understanding and stigma associated with schizophrenia: and uncertainty – in respect of the ambiguous nature of schizophrenia and the unpredictability of day-to-day life. The mothers in Ryan's (1993) study provided repeated descriptions of their involvement and concern that their individual circumstances demanded. Ryan (1993) refers to this in the over-arching theme of a 'lifetime of mothering', whereby engaging in active mothering for an indefinite period of time was common amongst participants and was characterised by ambivalence and dilemmas in care giving. Within the domain of constancy, disruption was a key feature in the mothers' descriptions and related to both the disruption to the parent/adult child relationship, whereby it became difficult for them to engage in a normal adult relationship, and disruption to the mothers' daily lives. All five participants in Ryan's (1993) study focussed almost exclusively on the illness behaviours and their son's or daughter's limitations and how they managed them.

Disruption to the mothers' lives was characterised by the unremitting nature of the situation and the illness and their pivotal role in caring for the ill child. Ryan (1993) referred to this as centrality. Factors influencing the mothers' centrality were a perceived lack of understanding and a lack of support from others, a lack of support from the mental health system and even from their own families. Significantly, the mothers recounted situations in which they received little information about the

illness and its management and reported that comments made by health professionals were sometimes perceived as insensitive.

The uncertainty experienced by the mothers in Ryan's (1993) study was determined by the ambiguous nature of the illness and the fluctuations in mental state on a day-to-day basis. Despite this uncertainty however, there was also a sense of hope that things may improve in time. Ryan (1993) draws on the work of Mishel (1988) and the theory of uncertainty in illness, its appraisal as both a danger and an opportunity, to support her findings. Added to the uncertainty that the illness can bring to family life, the mothers also expressed worry regarding what would happen to their adult son or daughter when they were no longer able to care for them.

Tuck et al. (1997) conducted a phenomenological study to gain an understanding of the lived experience of caring for an adult child with schizophrenia in the USA. A convenience sample of nine participants were recruited to the study. Linked to Ryan's (1993) domain of centrality and the crucial role of providing care, Tuck et al. (1997) found that a constant risk of disappointment made it difficult for parents to provide care and exposed the parent to disappointment and grief. Furthermore, parents describe the blurred identities they experienced, from that of mother or father to caregiver in the context of a severe mental illness (Tuck et al. 1997). Tuck et al. (1997) also found that the beliefs that parents held about themselves as individuals were challenged against a constant background of anxiety about their son or daughter with participants describing a lack of dependability on their sons and daughters and a constant monitoring of activities to protect them from harm. Comparisons can be made with this lack of dependability and monitoring and Ryan's (1993) domain of constancy, where the unremitting nature of the illness impacts on the day-to-day functioning of family members. Furthermore, parents in Tuck et al. (1997) study described their life trajectories being altered and their goals, values and plans affected; also reporting the threat to self-evaluation as a good and successful parent.

Milliken and Northcott (2003) conducted a grounded theory study on parental caregiving and schizophrenia in Canada. The study sample included 16 mothers and 13 fathers of adult children with schizophrenia. In-depth, semi-structured interviews were conducted and in keeping with the constant comparative method of

grounded theory, data collection and analysis were conducted concurrently (Milliken and Northcott 2003). Interview transcripts were coded and collapsed into broad categories. Data collection ended when there were no new categories emerging from the interviews. Disruption to life was also a prominent feature in this study, particularly in relation to the redefining of the parental role as the parental identity shifts throughout the course of parenthood and schizophrenia. Parents described the components of caring being disrupted, high levels of stress, feelings of frustration, powerlessness, and low self-esteem. Furthermore, the parents reported that they lived with the fear that the child may never recover and that they themselves would be a significant cause of relapse and be unable to cope. This further supports Ryan's (1993) domain of centrality and the role conflict highlighted by Tuck et al. (1997) between one of parent and carer.

Similarities are also evident between Ryan's (1993) domain of uncertainty and the work of McAuliffe et al. (2014) in their descriptive qualitative study. McAuliffe et al. (2014) aimed to explore the experience of parents living with and caring for their adult children with schizophrenia at home in Ireland. A convenience sample of five mothers and one father were recruited to the study who had cared for their children for at least two years in their own home. The authors acknowledge the limitation of their sample and reported that it was difficult to identify fathers for their study. Semi-structured interviews were conducted with the use of a topic guide where topics had been identified from the literature review. Interviews were thematically analysed and validated or questioned by the research team until agreement was reached. The study by McAuliffe et al. (2014) found that the uncertainty experienced by parents led to disruption in the day-to-day life of the family with activities that were previously enjoyed being difficult to operationalise, not only as a consequence of the symptoms of schizophrenia but due to the strain that this placed on the relationship between parents (McAuliffe et al. 2014).

Wiens and Daniluk (2017) conducted a study to explore how six mothers of adult children with schizophrenia or schizoaffective disorder experienced personal growth and change in Canada. They utilised a narrative method and a cross-narrative analysis to address the research question. Multiple data collection interviews were conducted over a period of twenty-four months to gain an understanding of mothers' experience within the context of their adult sons' or daughters' fluctuating illness.

Data were thematically analysed, and member checks were undertaken to ensure participants felt there was '*correspondence*' (Wiens and Daniluk 2017) between their experience and the interpreted findings. Wiens and Daniluk (2017) report similar findings to earlier studies, where participants reported a sense of distress and struggle as part of the ongoing uncertainties of their child's illness. Prior to diagnosis, the early years of their child's illness were reported as particularly distressing and chaotic as mothers struggled to make sense of unusual behaviour and the early symptoms of psychosis. During the acute phases of the illness, mothers reported that lives were disrupted by a fear for their child's safety, the day-to-day fluctuations in mental state and by the need for them to change how they responded to their child. This waxing and waning of the mothers' distress is also reported by Milliken (2001), who described that sometimes the only reprieve from this was when the child was hospitalised. Disruption to wider family life was also reported by Wiens and Daniluk (2017), whereby family occasions such as celebrations and holidays would be disrupted due to the fluctuations of the illness. Furthermore, mothers reported that the light-heartedness in the family had been disrupted due to the relationship challenges and tensions experienced by the family as a result of their son or daughter's illness (Wiens and Daniluk 2017).

It is evident that the daily life of the mothers and parents living with and/or caring for an adult son or daughter with schizophrenia is often difficult and that the unremitting nature of the illness can affect their ability to enjoy a stable personal life. The role of mother or parent is often in conflict with the role of carer and threatens the parental identity. This, coupled with the uncertainty that the illness brings in terms of symptoms impacts on their ability to plan, look forward and embrace the future. The research has also identified a perceived lack of support and understanding from other family members and the stigma associated with severe and enduring mental health conditions, which may further exacerbate feelings of disruption, struggle, and chaos.

2.10 Loss, Sorrow, and Sacrifice

One of the common themes across all studies included in this review related to the sense of loss, sorrow and sacrifice by parents of adult sons or daughters with schizophrenia.

Eakes (1995) conducted a descriptive qualitative study in the USA exploring the lived experience of parents of chronically mentally ill individuals and whether parents experienced chronic sorrow. The convenience sample was comprised of four couples and two mothers who were parents of adult sons diagnosed with either bipolar disorder or schizophrenia; the time since onset of the illness was between 4 and 20 years. Eakes (1995) utilised the validated Burke/NCRRCS Chronic Questionnaire (care-giver version) to guide the interviews which were audio-taped, transcribed verbatim and coded so that common themes could be identified. Eakes (1995) found that parents experienced a range of feelings associated with receiving their child's first diagnosis including shock, disbelief, grief, anger, frustration, sadness, and despair and that over time, these feelings were re-experienced with varying levels of intensity.

This sense of loss and sorrow was also identified by Tuck et al. (1997) who found that the shock and grief associated with the chronic nature of the illness and the relatively poor prognosis associated with schizophrenia was significant. Tuck et al. (1997) reported that unlike death, respondents experienced a malevolent transformation of their loved one who remained physically present in their world. Similarly, Milliken and Northcott (2003) reported that parents experienced intense grief but that the grief was somewhat disenfranchised, in that the child was not dead but became a stranger. Parents reported grieving for the child they once had but that this was a very personal, private process as there was often an inability to grieve with wider friends and families, hence they grieved alone.

Milliken (2001) conducted a grounded theory study in Canada that sought to explore the experience of parents caring for an adult child with schizophrenia. A snowball sample of 29 parent caregivers were recruited to the study. *Informal* interviews (Milliken 2001) were conducted, and data were analysed using the constant comparative method of grounded theory. Milliken (2001) supports the findings of loss and sorrow reported by Tuck et al (1997) and suggested there are three dimensions to the loss and grief associated with receiving a diagnosis of schizophrenia and living with and caring for a son or daughter with the illness: grieving for the loss of the child who is gone but not dead; grieving for the life that the child has now, and finally, that the grief is ongoing and unresolved (Milliken 2001). Associated with the concept of chronic sorrow and loss, other authors have reported

that loss is significant amongst parents with an adult son or daughter with schizophrenia. The three domains of grief outlined by Milliken (2001) are evident throughout the literature where the loss of the child's potential to lead a 'normal' life is felt (Ryan 1993, Tuck et al. 1997, McAuliffe et al. 2014, Milliken and Northcott 2003); and the significance of the child changing rather than dying is experienced (Tuck et al 1997, Milliken and Northcott 2003).

A sense of loss was also experienced by parents in relation to their own lives. Ryan (1993) reported that mothers felt a sense of loss of freedom, accepting the situation on a day-to-day basis, where Tuck et al. (1997) and McAuliffe et al. (2014) reported that parents sacrificed their personal goals and made sacrifices personally to promote a good quality of life for their adult child. Supporting Ryan's (1993) findings, McAuliffe et al. (2014) found parents experienced loss of their own life and of the things they enjoyed before their child's illness. Milliken and Northcott (2003) also found that parents of adult sons or daughters with schizophrenia also experienced loss in relation to their authority to direct care as they had when the child was younger.

Loss was also experienced by parents in terms of hopefulness for the future, but despite this, Ryan (1993) reported that the mothers in her study could still see the potential in their children regardless of the illness and continued to maintain hope for the future. Conversely, Tuck et al. (1997) found that parents found it a struggle to remain hopeful for a better future and that any hopefulness they had was always tempered by experience and the knowledge that the illness is marked by exacerbations and remissions. Tuck et al. (1997) found that it was vital for parents to place importance on the need to make meaningful choices, experience feelings and maintain a sense of being separate from the child with schizophrenia to address their feelings of loss and sorrow. Finally, participants in McAuliffe et al.'s (2014) study recognised that life is bittersweet for others also and they were not alone in their circumstances.

Wiens and Daniluk (2017) reported that mothers experienced an enduring sense of sadness and loss, and this was the most prominent theme in their study. The multiple losses experienced by the mothers included losses related to the effects of the illness on their child's life, on their own life and on their family life. Similarly, the

study by Milliken (2001), identified feelings of sadness and loss that fluctuated in intensity and paralleled the fluctuations in their child's mental state, where during more stable episodes, the sense of loss was not as intense as it was during the more acute phases. Drawing parallels with other studies (Ryan 1993, Eakes 1995, Tuck et al. 1997, Milliken 2001, McAuliffe et al. 2014 and Milliken and Northcott 2003), Wiens and Daniluk (2017) found that mothers lamented the loss of relationships previously held with their child, before the illness and shared a profound sense of loss of the hopes and dreams they held for their child which would now not materialise due to the illness.

Unresolved grief, sorrow and loss are widely reported in the literature and due to the un-remitting nature of their son or daughter's illness these feelings are often re-experienced by mothers or parents. Loss of hope for the future is also widely reported in the research, but despite this, some of the mothers and parents could still see their child's future potential. Nonetheless, it is evident that caring for an adult son or daughter with schizophrenia can result in the mothers and fathers making sacrifices in their own day to day lives and, in the decisions they make regarding their own future.

2.11 Constant Caring

A sense of constant caring was also identified as a theme throughout the literature (Ryan 1993, Eakes 1995, Tuck et al. 1997, McAuliffe et al. 2014, Milliken and Northcott 2003). This related to the long-term, unrelenting nature of their sons' or daughters' illness and the extended caring role that participants endure. The mothers in Ryan's (1993) study described living with the peaks and troughs that went along with the child's chronic illness and of their involvement and concern their individual situations demanded. A 'lifetime of mothering' was identified as an overarching theme where the mothers continued to protect their children, nurture their growth, and attempt to shape their behaviour in socially acceptable ways for an indefinite period of time (Ryan 1993). It could be argued that this may also reflect the experience of mothers who care for a child with any other illness or disability, though the age of onset of schizophrenia in early adulthood is somewhat different from other disorders that may have been present from birth or early childhood. The constant caring is supported by Eakes (1995) who report that the parents in their study were caught up in unending caregiving with a lack of respite and this had a

significant impact on family life. Furthermore, Eakes (1995) found that the excessive demands on time, energy, and finances in relation to caring for their adult child resulted in a constant role of looking out for and looking after their child. This is also supported by McAuliffe et al. (2014) who reported parents having initial fears of the unknown and were involved in constant minding in the initial phase of the illness and this was viewed by one participant in this study as the biggest stressor. Despite this constant pressure of looking after their son or daughters, participants willingly cared for their adult child despite the unpredictability of the illness and Tuck et al. (1997) report that no respondents talked about being burdened. This is further supported by Milliken and Northcott (2003) who report that participants felt obliged to safeguard their loved one's health, maintaining vigilance, however this was often motivated by fear, safety, future behaviour, and a constant surveillance waiting for the next relapse. McAuliffe et al. (2014) reported that despite adversity, parents remained steadfast in the love and care they provided, their love was unconditional, and the parents found new meaning in their caring roles.

In their qualitative narrative study, Wiens and Daniluk (2017) explored how mothers (n=6) of adult children with schizophrenia or schizo-affective disorder experienced personal growth and change as they lived with the challenges and uncertainties of the illness. The authors used snowballing as the method of sampling which is viewed as a useful method of sampling when the population is hidden or difficult to reach. Whilst it is an appropriate method of sampling for the population in the studies included in this literature review, a limitation lies within the uncertainty in determining any sampling error and make inferences from the sample to the general population (Polit and Beck 2021).

As part of the inclusion criteria, Wiens and Daniluk (2017) stipulated that each mother had to be the genetic parent of the adult child and actively involved in parenting; they should also have felt that they had experienced personal growth and change as a consequence of the parenting experience, be willing and able to share and reflect on experience and be willing to commit to two or more audiotaped data collection interviews, and one validation interview over the course of several months. This is the only longitudinal study within the literature review and the only study that has stipulated (though not justified) that the mothers had to be the genetic parent

despite the traditional nuclear family of two parents with their birth children becoming less common within the western world.

Wiens and Daniluk (2017) reported that mothers had an on-going concern about their child's future and as the permanence of their illness became clear, they lived with a growing concern about what would happen when they could no longer care for their son or daughter, echoing findings from Ryan (1993). Importantly, Wiens and Daniluk (2017) also found that all the mothers in their study reported a concern that one day their son or daughter may carry out death by suicide. Rather than being defeated by the situation they found themselves in, the mothers demonstrated a commitment to caring to ensure the best possible ongoing support for their son or daughter and the need to live the best life possible despite the circumstances. They recognised the lifelong commitment to their children and the importance of gaining a better understanding of the illness and the management of its symptoms.

The concept of constant caring is evident across all research studies included in this review. It relates to the long-term, unrelenting nature of their sons' or daughters' illness and the extended caring role that participants endure. However, constant caring was not always viewed by the mothers or parents in the studies as wholly negative but there was a concern across studies around who would care for their children when they are no longer able to do so.

2.12 Coping Mechanisms

A range of coping mechanisms are identified in the literature as being helpful to parents of adult children with schizophrenia. These coping mechanisms include: gaining knowledge about their sons' or daughters' illness; engaging with peer support; maintaining hope despite the fluctuating nature of the illness; and in developing an appreciation of the struggle of others which led to some parents leading more meaningful lives.

Tuck et al. (1997) found that parents were often desperately searching for someone to give them an explanation of what was happening and a remedy for this. This desire for information is also reported in the study by Wiens and Daniluk (2017) and McAuliffe et al (2014) who found that the need for knowledge was important. Given that many of the studies included in this review are now over 20 years old and since then there have been significant advances in the accessibility of information with the

growth of the Internet and within mental health services, it is interesting to note that the lack of information provided to parents is still being reported in these more recent studies.

In the largest study in this review, Milliken and Northcott (2003) conducted a grounded theory study in Canada to better understand the challenges of schizophrenia for families. Twenty-nine parents of 19 middle or working-class families were interviewed; these consisted of both parents in 10 families, the mother only in six families and the father only in the remaining three families. In total the interviewed parents had six daughters and 14 sons with schizophrenia, two of whom had died in the five years prior to the study. Milliken and Northcott (2003) conducted in-depth, audiotaped interviews and follow up interviews aimed at theoretical elaboration, saturation of incomplete categories and verification of a theory.

Milliken and Northcott (2003) also found that parents viewed gaining knowledge as helpful and that sharing the experience with others was viewed as beneficial. Milliken and Northcott (2003) and Milliken (2001) refer to this as 'embracing the collective', where parents seek out support groups, connected with others and found empathic people. Milliken (2001) and Milliken and Northcott (2003) found that these support groups became a primary reference group for parents, where they were no longer 'grieving alone but mourning together'. Tuck et al. (1997) reported similar findings with parents reporting value on the empathic understanding from others particularly from those with shared experience. McAuliffe et al (2014) reported that dealing with the public and private perception of schizophrenia was difficult but sharing the experience with others who were in similar positions was found to be helpful.

The support groups accessed by parents allowed them to take on the system collectively, acknowledging realities, identifying personal goals, and leading to a sense of acceptance about the situation (Milliken 2001, Milliken and Northcott 2003), Milliken and Northcott (2003) refer to this transformation as re-enfranchisement. Similarly, in the study by Wiens and Daniluk (2017), several of the mothers became active in the mental health community, serving on parent advisory boards and politically advocating for the rights of the mentally ill. The mothers reported that

taking this action empowered them and helped them cope with the challenges they faced on a day-to-day basis.

The mothers in Wiens and Daniluk (2017) study, reported that hope was highest in the early stages of the illness when they thought their son or daughter would recover fully and return to a 'normal life'. However, as the mothers witnessed and lived through the fluctuations of the illness, from periods of calm to those of acute instability often accompanied by poor hygiene, paranoia and risk to themselves or others, their hope diminished. Similarly, Milliken (2001) and Milliken and Northcott (2003) reported mothers acknowledged their growing recognition that their child's recovery was limited and developed more realistic expectations, but maintained hope for the future. Wiens and Daniluk (2017) reported that mothers experienced fluctuations in their level of hope as they lived with the uncertainties associated with the illness however a number of positive personal and relational changes were reported. Participants gained an increased sense of awareness and sensitivity towards the struggle of others, were less judgemental and more compassionate. The mothers described having an increased patience and tolerance towards others and recognised their own strength and determination (Wiens and Daniluk 2017). These mothers also discussed the importance of being more publicly open about schizophrenia and to tackle the stigma associated with the illness more broadly. Significantly the mothers in Wiens and Daniluk's (2017) study described how their own lives had become more meaningful having gained a greater sense of gratitude and appreciation for their own lives and those of their family including their son or daughter with schizophrenia.

The various studies included in this section identified a range of positive coping mechanisms parents find helpful. These include gaining knowledge about their sons' or daughters' illness; engaging with peer support; maintaining hope despite the fluctuating nature of the illness; and in developing an appreciation of the struggle of others which led to some parents leading more meaningful lives.

2.13 Attitude of healthcare professionals

The attitude of healthcare professionals towards parents of those with schizophrenia was reported as largely negative (Ryan 1993, Eakes 1995, Tuck et al. 1997, Milliken and Northcott 2003, McAuliffe 2014). Participants consistently reported a lack of

communication and a lack of involvement in care (Ryan 1993, Eakes 1995). Furthermore, mothers and parents reported frustration at the inability of healthcare professionals to accurately diagnose (Tuck et al. 1997, McAuliffe et al. 2014, Milliken and Northcott 2003) and a perceived lack of understanding by doctors and healthcare professionals in recognising symptoms as a prodrome to schizophrenia (McAuliffe et al. 2014). Milliken and Northcott (2003) report that once a diagnosis of schizophrenia had been made, their influence on care as parents was severely diminished, with one family being told to prepare for a 'bumpy ride' by healthcare professionals.

In the phenomenological study conducted in the USA, Tuck et al. (1997) set out to explore the phenomenon of caring for an adult child with schizophrenia. Adding to the trustworthiness of the study, representative transcripts and findings were presented to a qualitative research group for review of meaning units, themes, and essences (Tuck et al. 1997). Tuck et al. (1997) found that mothers and parents were often in desperate search for someone who could offer an explanation and a remedy for the signs, symptoms, and behaviours that their children exhibited and when advice was given by health professionals it was often conflicting and confusing. Tuck et al. (1997) also found that initial unhelpful assessments by health professionals were costly and, given that healthcare is not free at the point of contact in the USA, used up their private healthcare insurance benefits significantly. One participant reported that mental health professionals seemed more interested in how much insurance the family had than in the well-being and diagnosis of their son or daughter (Tuck et al. 1997).

Similarly, Eakes (1995) found that the family's faith in healthcare professionals was eroded and a lack of inclusion in care was evident with parents stating that the confidentiality rules associated with care provision denied parents access to relevant information in order to provide care effectively. In this sample, the eight parents interviewed cited a total of 55 examples of mental health care professionals being unhelpful as they struggled to deal with their situations. Most of these examples were around poor communication and the lack of involvement in their son's or daughter's care.

In an integrative review of the literature by Klages et al. (2016), parental perspectives of their relationships with mental health professionals in the context of their son's or daughter's schizophrenia was conducted. The authors utilised Whitemore and Knaf's (2005) integrative review methodology that commences with problem identification. Klages et al. (2016) identified the problem to be addressed as: the impact of professional-family relationships on parents of adult children with schizophrenia. Date parameters were set to retrieve literature published between 2000 and 2015. Fourteen papers were selected for the review, and these were analysed according to Whitemore and Knaf (2005) stages of data analysis. Findings from the review exposed the challenges and complexities of the relationship between parents and healthcare professionals. The themes identified by Klages et al. (2016) indicate the negative experience of parents' relationships with healthcare professionals, namely; trusting your instincts; feeling dismissed and devalued; making connections and making concessions; living with distress and sorrow and becoming your own health-care provider.

The findings of Klages et al. (2016) review indicated that parents in the included studies believed they intuitively knew when their son or daughter was becoming unwell, but when they made attempts to contact health professionals based on this intuition, their concerns were dismissed. Furthermore, the findings also revealed that parents could accurately predict impending problems and proactively prevent relapses and crises but when mental health professionals were involved, the parents were largely ignored. Klages et al (2016) study indicated that the relationship between healthcare professionals and family members in the context of schizophrenia was fragile and it contributed to the parents' distress and grief.

In summary, most of the studies included in this scoping review found that mothers and parents felt let down by the health care system that was supposed to help them and their son and daughter. Assessments often proved futile and costly and there was a significant lack of information and support reported in the studies. This has potential implications for mental health nursing and mental health service provision. Fostering collaborative, supportive relationships with the families of those with schizophrenia is of great importance if the experiences of mothers and parents are to improve.

2.14 Scoping review limitations

The scoping review presented in this chapter has limitations due to the lack of available contemporary studies specifically related to mothers and their experience of having an adult son or daughter with schizophrenia. There are no UK studies and only one study (Ryan 1993) that focusses specifically on mothers of adult sons or daughters with a diagnosis of schizophrenia only. Three papers focussed on parents of people with schizophrenia (Milliken 2001, Milliken and Northcott 2003, McAuliffe et al. 2014) whilst in other studies schizophrenia was often incorporated alongside other disease groups such as schizo-affective disorder (Tuck et al. 1997, Wiens and Daniluk 2017) and bi-polar disorder (Eakes 1995). Where studies relating to schizophrenia specifically were available, they were somewhat dated and did not reflect the disease trajectory in the context of modern-day mental health practice, for example the development of early intervention and first episode psychosis services that may improve long term outcomes for those experiencing psychosis.

Across all studies included in this scoping review, sample sizes were small and not wholly representative of the wider population of mothers and/or parents of adult sons or daughters with schizophrenia. Participants were predominantly Caucasian, highly educated, and employed in high-income professional roles. In studies where the sample included individuals from ethnic minority groups, participant numbers were typically very small, with just one participant who identified as African-American in Tuck et al.'s (1997) study, two participants who identified as African-American in Eakes's (1995) study, and one participant who identified as Asian in Wiens and Daniluk's (2017) study. This is a significant limitation of the literature, as individuals from ethnic minority groups are under-represented and the relevant, available research does not therefore adequately reflect diversity within society.

A further limitation of this scoping review is that, under normal circumstances, a minimum of two reviewers would be involved in the study selection and data extraction process, to reduce the chance of errors and bias (Peters et al. 2020). Due to the requirements of the doctoral programme however this was not possible, but each study was discussed in detail with the doctoral supervisors to try to eliminate these errors and any potential bias as much as possible.

2.15 Key findings

This literature review has illuminated the experience of parents who have an adult son or daughter with schizophrenia. Much of the focus of the studies included has been on the negative impact of this such as disruption, sorrow, the unremitting nature of the illness and the impact of this on family members. The lack of support from health professionals, family members and friends has been a significant finding and the stigma that surrounds severe and enduring mental illness highlighted as a barrier to social inclusion.

Unresolved grief, loss of self and authority to direct care have also been reported and an enduring sadness and the struggle to remain hopeful have been common themes throughout the review. Furthermore, constant caring, and the worry of the provision of care when the parents are no longer able to provide it is well documented. The sense of hope when the son or daughter was first diagnosed is briefly mentioned but how this hope subsides over time is more prominent within the literature.

The search for explanation and remedy is also a recurrent aspect of the experience of the parents within the studies, however sharing the experience with others in similar situations appears to be beneficial and helps develop a sense of acceptance. One study reported that mothers found a renewed sense of purpose, becoming active in the mental health community, advocating for the rights of those with mental illness and tackling stigma.

All studies reported the difficulties experienced by the parents of those with schizophrenia engaging with mental health professionals. Poor communication, a lack of sensitivity, ambivalence toward diagnosis by healthcare professionals, the cost of seeking help for those paying for healthcare and the lack of involvement with their loved one's care are all prominent themes within the studies.

2.16 Summary and rationale for further study

This chapter has presented a scoping review that explored mothers' experiences of having an adult son or daughter with schizophrenia. Whilst these insights have provided an understanding of mothers' experiences and parental world in relation to

existing knowledge, it also highlights that there is still much more that is not known in relation to being a mother of an adult son or daughter with schizophrenia in the UK.

Much of the research reviewed in this chapter is dated and there is a gap in the literature that focusses on the experience of mothers of an adult son or daughter with schizophrenia in the UK. The current study therefore aimed to address this gap by exploring the contemporary UK experience of mothers who live with and care for an adult son or daughter with schizophrenia.

The next chapter will present the philosophical underpinnings of the study and provide a detailed account of how the study was conducted.

Chapter Three: Methodology and methods

3.1 Introduction

In this chapter, I will outline the philosophical, theoretical, and methodological underpinnings of the study. It will start with an overview of ontological, epistemological, and axiological perspectives and how these align with my research question. Later in the chapter, drawing on relevant literature, the methodological approach and the research methods utilised will be explored.

The biographic narrative interpretive method (BNIM) was selected for use in this study, the theoretical underpinnings of which include linguistic analysis, grounded theory, social constructionism and hermeneutic analysis. The rationale for using BNIM and how the approach enabled me to fulfil the aims of the research is therefore also explored. Recruitment and sampling are addressed, followed by a discussion of the data collection and analysis methods. Finally, quality, reflexivity and ethical and governance issues are considered.

3.2 Research question, aims and objectives

The research question is:

What are the experiences of mothers who live with and care for an adult son or daughter with schizophrenia?

The aims of the study are to:

1. Acquire an understanding of the experience of mothers who live with and care for an adult son or daughter with schizophrenia;
2. Explore the impact of schizophrenia and the caring role on mothers;
3. Highlight the implications for clinical practice when working with those with schizophrenia and their families.

Objectives:

- To provide a critique of current literature and evidence pertaining to mothers' experiences of caring for an adult child with schizophrenia
- To facilitate mothers' story telling through unstructured interviews to explore their experience of living with and caring for an adult son or daughter with schizophrenia and the impact of this.
- To analyse and synthesise findings from the literature and the biographical narrative interpretive method through theoretical framework of chronic sorrow.
- To disseminate the knowledge and learning from this research to clinical partners, clinicians, academics, and policy makers.

3.3 Ontological, epistemological and axiological underpinnings

According to Chuckry (1990) and Durant-Law (2005) three philosophical domains need to be addressed in order to position oneself within the research: What exists? (Ontology, Metaphysics), How do I know? (Logic, Methodology, epistemology) and What is valuable? (Axiology, Ethics, Aesthetics, Praxiology). Chuckry (1990) calls this the 'philosophical trinity', an important consideration when exploring one's personal philosophical alignment, asking: How do I see the world? How have I come to 'know'? and Is it 'worth' knowing? In considering these three questions, it is possible to situate myself within the philosophical realm when exploring the research question, as well as informing the methodological considerations and the methods used within the study.

To inform the development of the research process, ideas about truth and reality and how these exist, develop, and are identified were considered. For some, a positivist ontology is assumed, where an underpinning belief that what exists can be observed and measured, where the world is subject to fundamental and constant rules and there is an insistence on objectivity and neutrality (Maltured 2016). This search for objectivity and the requirement for distance between the researcher and those being researched commonly inform the use of many quantitative research methods. Whilst it is accepted that quantitative research is useful and valuable, a major criticism of it and one that reflects my own personal beliefs, is that its fundamental limitation lies in

its neglect of the participant perspective within the context of their individual lives (Lincoln et al. 2011).

I recognise that my own theory or epistemological standpoint has been influenced by, not only a twenty-five-year career as a mental health nurse, but also by my own personal family experience of schizophrenia and, as such, I believe that individuals experience '*truth*' and '*reality*' uniquely. I believe that multiple realities exist and that despite experiencing similar events, individuals experience and interpret these differently. This view aligns with interpretivism, which centres on the way in which people make sense of their subjective reality and attach meaning to it (Lincoln et al. 2011). According to Lincoln et al. (2011), interpretivists approach people not as distinct individuals in isolation but as individuals within their whole life context. This means that the epistemology of meaning is created in the social realm. Interpretivists reject the notion of objectivity and neutrality that positivists strive for, regarding these as impossible to achieve. My philosophical positioning within this study therefore is situated within the interpretivist paradigm (Bunniss and Kelly 2010). I believe that my own values and those of the participants were an essential part of the research process, where knowledge is not found but constructed by the participants.

Reflecting on my ontological alignment, that truth and reality are unique experiences, it became evident that exploring in-depth human experiences was incompatible with a positivist paradigm where any meaning of those experiences is lost and/or ignored. To increase understanding of the human experience therefore, a qualitative research approach was chosen using BNIM methodology, to explore and answer the research question.

3.4 Selecting a methodology

Reflecting upon my ontological and epistemological position facilitated a greater understanding of the role that my personal values and beliefs have when conducting research (Tashakkori and Teddlie 2010). Examining and developing an awareness of my own philosophical position was fundamental in choosing an overall research approach, but it was also important that the overall approach was considered in the context of the central research question (Sullivan and Forrester 2019). It was necessary to identify a research methodology that enabled knowledge to be gained through listening to and interpreting the experience of mothers who have an adult

son or daughter with schizophrenia, taking the unique experience and context of participants into account as well as my own unique and individual viewpoint.

A number of qualitative research methodologies were initially considered including phenomenology, interpretive phenomenological analysis, grounded theory and narrative inquiry. My ideas around the most appropriate methodology evolved throughout the taught component of the professional doctorate programme and further refined through discussions with academic staff, my supervisors and from ongoing engagement with the wider literature. Given the nature of the research question, it was felt that a narrative methodology would be most suitable to fulfil the aims of the research. The justification for choosing narrative research and specifically the biographical narrative interpretive method (BNIM) is provided below.

3.4.1 Narrative research

Narrative research is an umbrella term that captures personal dimensions of experience over time and considers the relationship between individual experience and cultural context (Clandinin and Connelly 2000). It is a means by which researchers systematically gather, analyse, and represent people's stories as told by them, challenging traditional and modernist views of truth, knowledge and personhood (Etherington 2007). Through their stories, participant perspectives are uncovered as they remember significant experiences. Participants select, judge, and interpret what has happened to them with insight into their significance and meaning, telling their story within a timespan that often links the present, past and future (Holloway and Freshwater 2007, Holloway and Galvin 2017).

Bruner (1986) suggests that narrative knowing, and narrative knowledge are created and constructed through stories of the lived experience and the meanings created; that narrative knowledge helps to make sense of the ambiguity and complexity of human lives. Etherington (2007) supports the view that narrative knowing allows individuals to develop memorable, interesting knowledge that combines the different levels of understanding about a person, their culture and how they have created change. The narrative, according to Etherington (2007) permits the individual to articulate their struggles and to make sense of the past, creating meanings as they tell and/or 'show' us what happened to them. The way the narrative, or story is constructed, helps organise the interpretation of the individual experience. Complex

patterns, descriptions of identity construction and reconstruction, and evidence of social discourses can be examined within narrative research and the knowledge gained in this way is 'situated, transient, partial, and provisional, characterised by multiple voices, perspectives, truths and meanings' (Etherington 2007).

The emphasis within narrative research is on 'co-construction of meaning', between the researcher and participants (Holloway and Freshwater 2007). Whilst being involved in the narrative, the researcher must also take in what is being said and compare it with their personal understandings, without filling in any gaps in understanding with 'grand narratives', but rather inquiring about how pieces of the stories make sense together. It allows understanding of how individuals construct meaning from within a system of belief; their attitudes, values and ideas that shape the sense of 'self' and 'identity', with narrative inquiry moving between the internal and external world of the storyteller, across time and within their environments (Clandinin and Connelly 2000). The aim of narrative research therefore, is not to present a 'true' picture of events but rather to determine how sense of these events has been made. It is about exploring an individual's attitude toward the events, the meanings the events hold for them personally and how these feelings came to be (Greenhalgh 2005).

Critics have argued that there are a number of issues with narrative research. Atkinson and Delamont (2006) argue that there can be a perceived simplicity of some narratives, with researchers underestimating the complexity of the relationship between the narrative and the wider social and theoretical context. This view is supported by Silverman (2014) who also acknowledges that some narratives are based on naive assumptions and poorly applied methodological and theoretical assertions. It is important therefore, that the link between the focus of the research and the wider theoretical perspective is made explicit (Reissman 2008).

Another criticism of narrative research is that participant stories are often recalled from faded memories and the content is therefore selective, depending on who the narrator is presenting their story to (Reissman 2008). Frank (2000) however, suggests that by listening to these stories the listener becomes part of a relationship in which the story is presented and that the act of storytelling has a restorative role, creating distance between the narrator and their experience. This suggests that

stories are not simply data for analysis but a validated reflection on the individual's life experience. Atkinson and Delamont (2006) warn against the overuse and uncritical acceptance of participants' stories within narrative research and so it is necessary in presenting the narrative that the reader is convinced of the plausibility of the claims made in order to accept the research as 'valid' (Polkinghorne 2005, Holloway and Wheeler 2013).

As the focus of this study was on mothers' experiences of caring for an adult son or daughter with schizophrenia, I believed that it aligned well with narrative research. However, there are certain features that distinguish narrative research methods within the broad field of qualitative methodology, and this needed to be examined fully before selecting the most appropriate methodology for the study (Bingley et al. 2008). Whilst narrative research focusses solely on generating or working with stories (in any media), narrative analysis encompasses a number of techniques that offer differing levels of engagement with narrative data.

Falling under the umbrella of narrative research, but a methodology in its own right is the biographical narrative interpretive method (BNIM). I chose this methodology because it aligns with my epistemological position, that considers people as historically and socially formed actors whose experience can only be understood within their historical and cultural context. This is important for healthcare research and specifically within mental health nursing, as patient and carer individual life stories are largely invisible and therefore their care and support needs are poorly understood (Ofri 2015). BNIM provides a case-based method, which has value in generating a broader understanding of reactions to life challenges such as serious illness and disability. The methodology will now be further justified and explored in more detail.

3.4.2 The biographical narrative interpretive method

As discussed in section 3.3, the ontological position taken in this study is interpretivist, whereby individuals construct meaning in their lives through narrative, a social interaction. This means that the epistemology of meaning is created in the social realm, whereby meaning is negotiated by actors in social interaction (Crotty 1998). The act of narrating involves a simultaneous process of engagement with self and society (Reissman 2008).

The biographical narrative interpretive method (BNIM) originated from the narrative biographical method used to explore the lives of holocaust survivors and Nazi soldiers in the 1970's (Fischer-Rosenthal and Rosenthal 1997). The construction of the method was determined by the need for a methodological strategy to uncover, what Schutze (1992) referred to as, faded out memories and delayed recollections of emotionally or morally disturbing war experiences. The methodology is informed by a variety of theoretical orientations such as linguistic analysis, grounded theory, social constructionism, and hermeneutic analysis (Berger and Luckman 1966, Glaser and Strauss 1968, Labov 1997). BNIM facilitates retrospective understanding of the public and private lives of the narrator and their interaction with historically evolving contexts (Wengraf 2006). This retrospective understanding and the interaction with the historical contexts were particularly salient to this study, as the aim was to interpret and increase understanding of the experience of mothers who live with and care for an adult son or daughter with schizophrenia. I therefore believed that this research aligned with the BNIM, as participants' retrospective whole life stories and particular incident experiences are articulated, accessing vanished and mutated times, places, states of feeling and ways of living (Wengraf 2008 p.3).

BNIM uses a lightly structured interview technique in the form of a single, initial narrative-inducing question, to elicit an extensive uninterrupted narration where the interviewer avoids imposing a structure on the narrative. It is based on gestalt principles, where the gestalt of the participants' story is maintained by this method of non-interruption. Gestalt has been defined by Holloway and Jefferson (2001) as a whole that is more than the sum of its parts, an order or hidden agenda informing each person's life, which is not influenced by the researcher or their own systems of relevancy (Schutze 1992, Rosenthal 2004). This method of interviewing also aligned with my professional values as a mental health nurse and novice researcher, as it provides a person-centred and humanistic approach to data collection.

In selecting the BNIM for data collection, it would seem appropriate that the BNIM of data analysis was also selected for this study. The two components do not necessarily have to be used in conjunction with one another however, and it is feasible to use the BNIM interview technique to obtain data and then use a different approach to data analysis. Utilising the BNIM analytic strategy, however, *is* dependent on using the BNIM interview as a data collection tool (Wengraf 2006).

The BNIM method of data analysis was chosen for this study as it provides a clear and rigorous structure that facilitates intensive analysis of stories from a small cohort of participants. It also facilitates an understanding of lived experience through multi-level analysis of biography, lived life and the told story (Wengraf 2001).

Furthermore, I was drawn to the formulaic nine-step process of individual case analysis followed by a tenth step that facilitates analysis across cases, (discussed further in section 3.8) which attempts to promote an in-depth exploration of life stories in context.¹

3.5 Recruitment and sampling

Ensuring an appropriate sample is key to establishing rigour in any study (Silverman 2014). In seeking to understand the experience of mothers, participants were purposively recruited into the study from a large national third sector organisation. Purposive sampling is most often used for narrative studies and involves recruiting a sample from a particular group of people that have shared characteristics, experiences and understanding (Patton 2015). Purposive sampling was therefore chosen to ensure that those who participated had sufficient experience to provide rich, relevant data. The definition of 'mother' was used in its broadest sense and included biological, stepmother, adoptive or any adult that identified as having a mothering role. However, once recruited, it became apparent that all the participants were biological mothers.

The third sector organisation where participants were recruited, is the principal third sector mental health organisation in Wales, working with individuals (and their families) recovering from severe mental illness. It is member-led and provides help to over 1,500 people affected by severe mental illness, including schizophrenia, bipolar disorder and other diagnoses, which typically involve

¹ I completed a five-day BNIM training programme facilitated by Tom Wengraf. Following this I felt equipped with the necessary knowledge and skills to undertake the study and was reassured by having the support of a small network of researchers who were also making tentative steps using BNIM. Tom Wengraf was available as a critical friend at every stage of the study to offer advice and support.¹

psychosis or high levels of care, that may require hospital treatment. A senior health professional within the organisation acted as a recruitment gatekeeper, having access to relevant carer groups from which prospective participants were recruited, using agreed inclusion/exclusion criteria (see table 3). Gatekeepers are essential mediators for accessing study settings and participants (Andoh-Arthur 2019) and within this study, played an active role in promoting the study. The gatekeeper had a specific interest in working with families of those with schizophrenia and as a senior member of staff had significant influence within the organisation. Furthermore, the gatekeeper had professional links across Wales with other mental health professionals and key stakeholders, such as local mental health services, carers networks and Welsh Government. From our initial conversations about the study and throughout the recruitment process, the gatekeeper was positive, enthusiastic and motivated in helping to disseminate information to facilitate help with recruitment. The gatekeeper disseminated the information to a network of staff throughout Wales who facilitated carers groups and these staff then advertised it each time the carers group met, usually monthly. The study was also advertised by the gatekeeper through the organisation’s internal email system and staff were asked to promote the study to carers they were involved with. The inclusion and exclusion criteria were as follows in table 3.

Inclusion Criteria	Exclusion Criteria
Mother* of an adult son or daughter with Schizophrenia	Mother with a diagnosis of Schizophrenia
More than five years since diagnosis of Schizophrenia	Those whose son or daughter were under Early Intervention/First Episode Psychosis services
Able to provide informed consent	
Ability to communicate in English	
*Biological or those with parental responsibility	

Table 3: Inclusion and exclusion criteria

The gatekeeper used an inclusion/exclusion demographic checklist as a means of recruiting prospective participants in the first instance and eligible women were sent a Research Ethics Committee approved participant information pack, which included

a covering letter (Appendix 2), a participant information leaflet (Appendix 3), a permission to contact form (Appendix 4) and a self-addressed envelope. The participant information packs were also given to the network of staff who ran the carers groups across Wales, and mothers who were interested in participating were asked to complete the permission to contact form and return it to me in the freepost envelope provided. After receiving the permission to contact form, I then made contact by telephone and verified the inclusion/exclusion demographic checklist. In total, eight mothers returned the permission to contact form, six of whom met the inclusion criteria for the study. The two who were ineligible, were informed that they did not meet the inclusion criteria and thanked for their interest in the study. The final sample therefore consisted of six mothers who lived with and cared for adult children with schizophrenia.

The small sample size is consistent with a study of this nature. The narrative study by Wiens and Daniluk (2017) that focussed on the challenges of mothering an adult child with schizophrenia (or schizo-affective disorder) had a sample size of 6. This is further supported by Polkinghorne (2005) who argues that qualitative researchers most often use a small number of participants. This is particularly relevant within BNIM where there is a 'trade-off' between the number of cases in a study and the intensity of the interviewing method (Wengraf 2006) and, given that BNIM interviews and BNIM analysis are resource heavy in terms of time, small sample sizes are both appropriate and necessary. This is illustrated in figure 2 below.

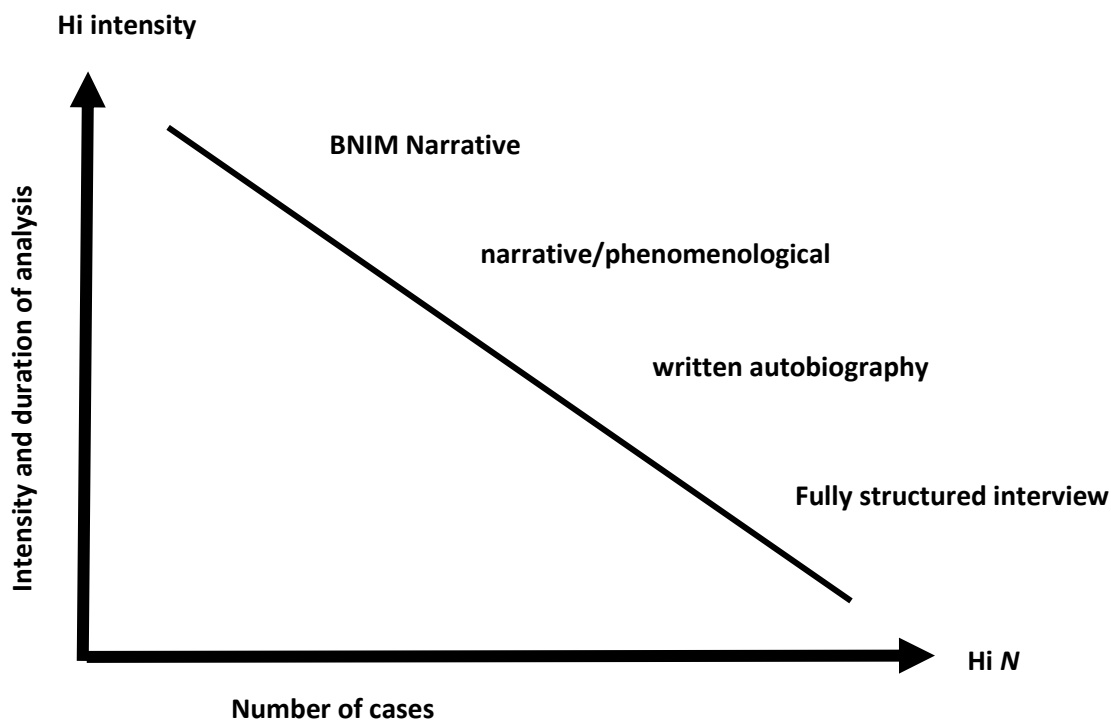


Figure 2: BNIM (Wengraf 2001) Intensity of interview method and cases

Once the purposive sample was chosen, the mothers were contacted to discuss any queries and to arrange a mutually convenient meeting to conduct the interview. The mothers who participated in the study are presented in table 4 below. Pseudonyms have been used to ensure that confidentiality was maintained, and that no personally identifiable data were presented. The mothers in the study were aged between 70 and 79 years. Five of the participants were retired professional women and one participant was working as an administrative clerk. All women were white and were born in the UK. This sample is similar to those included in studies in the literature review in chapter 2, and where the limitations in terms of diversity of participants is discussed in section 2.14. It is acknowledged that this sample also has limitations as it does not include participants from ethnic minority groups. Recruiting from a range of third sector organisations, including those specifically working with ethnic minority communities, may have improved the diversity and representativeness of the sample.

Mother	Age	Marital Status	Adult Child
Carol	Mid 70's	Married	Daughter Rebecca mid 40's Diagnosed 23 years ago
Avril	Early 70's	Divorced	Son Peter Early 40's Diagnosed 20 years ago
Barbara	Late 70's	Divorced	Son Alex Late 40's Diagnosed 30 years ago
Eve	Mid 70's	Divorced	Daughter Paula Late 40's Diagnosed 28 years ago
Daisy	Late 70's	Widowed	Son Philip Late 40's Diagnosed 27 years ago
Frances	Early 70's	Married	Son Gareth early 40's Diagnosed 20 years ago

Table 4: Study participants

Data were collected between January 2019 and October 2019. To fully address the research question, data were collected using the BNIM method of interviewing and through photographic elicitation. Photo-elicitation was included as an optional component of the interview where participants could use photographs to aid their story telling. How photo elicitation was incorporated into the study is discussed later in the chapter.

3.6 Overview of BNIM data collection

The process of data collection using BNIM methodology is complex and defined by a series of steps that are taken before, during and after the interview. The process is further complicated by the use of numerous acronyms that can impede understanding and disrupt the flow of written explanations within BNIM literature. In writing this thesis, I have been mindful of this and have attempted to reduce the use of acronyms throughout, with the aim to enhance the readability of the work.

The process of BNIM data collection was as follows and each stage is discussed in greater detail in the next section of the chapter:

- Development of the Single Question Used to Induce Narrative (SQUIN)
- Facilitating the interview:
 - Sub-session one
 - Using the *coda*
 - Using the break
 - Sub-session two
- Optional sub-session three

3.6.1 Prior to the interview: developing a SQUIN

BNIM utilises a unique interview technique to elicit uninterrupted participant narrations. Wengraf (2001) refers to this as a Single Question Used to Induce Narrative (SQUIN). The interview commences with the researcher reading the SQUIN and then allowing the participant to speak freely, for as long as they wish. The researcher remains silent throughout. The rationale for the development of the SQUIN is similar to Holloway and Jefferson's (2001) free association method and its wording is intentional to promote the *gestalt* of a narration, which would otherwise be disrupted if the interviewer interjected on the narrative flow of the participant (Wengraf 2006, Wengraf and Chamberlayne 2007). The SQUIN enabled participants to say whatever they wanted to say and appealed to me because it aligned with my practice as a mental health nurse and enabled me to be truly participant focussed. It is in contrast to other, more common methods of qualitative interviewing such as semi-structured interviews, where the researcher directs the conversation with pre-defined questions on a specific topic, and consequently, in doing so, probably disrupts the participants' *gestalt*. In using the BNIM method of data collection, and by remaining silent, I was able to limit any influence I may have had on the participants and the way they told their stories.

A SQUIN was developed following a review of the literature and was informed by the aim of the study: to explore the experiences of mothers who have an adult son or daughter with schizophrenia. The SQUIN used in the study was as follows:

'Please tell me the story of your life from when you first noticed your son or daughter becoming unwell, all the events and experiences that have been important to you personally; begin wherever you want to

begin, I won't interrupt, I will take some notes to be used later. You may use the photographs you may have chosen to help tell your story'

I made the decision to pilot the interview design to determine any flaws or limitations and to allow for any further amendments to be made prior to subsequent interviews being conducted. A pilot exercise such as this is particularly useful to novice researchers when they assess and prepare their interview. According to Beebe (2007) the process can aid self-evaluation of one's readiness, capability and commitment to the research process and enhance the credibility of the study (Padgett 2008). For convenience purposes, in this study, the interview was piloted on the first two participants to gauge appropriateness and suitability of eliciting detailed narratives. The interview schedule, or specifically the SQUIN, was found to be appropriate and the pilot data has therefore been included in the main study findings.

3.6.2 BNIM Interviewing

Successful interviewing requires careful planning, and the location of the interviews needed to be considered carefully and sensitively. This was particularly relevant as the participants lived with their sons and daughters and this could influence their ability to take part in the interview and/or to talk freely. Doody and Noonan (2013) argue that interviews should always take place in a location chosen by the participant and in allowing them to choose, affords them a position of comfort and control. With this in mind, participants were offered the opportunity to be interviewed at a location that suited them. Gagnon et al. (2014) suggest that understanding the concepts of *space* and *place* can aid reflexivity within nursing research and that reflecting on interview location can help develop a deeper understanding of the ways in which interactions between researcher and participant are situated in context. Furthermore, Gagnon et al. (2014) suggest that place acts as an active element in its own right during the interview process and influences how the interview is experienced by both the researcher and the participant.

In my study, all participants were interviewed individually, in private, in their own home, at the third sector organisation building or at another mutually agreeable location. The location of the interviews each brought some issues that were not anticipated at the planning stage. Participants were distributed over a large

geographical area and two of the participants lived more than 200 miles away. This necessitated driving to the town in which they resided the night before the interview and staying in a hotel. One of these interviews was the longest interview that took place, at the participant's home address and was interrupted several times by her mobile phone, landline, and a constant stream of deliveries to the door. This did interrupt the flow of the story telling somewhat but she was able to continue her story without any prompting. Another interview took place in a house that one of the participants had purchased for her son, in the hope that he would have moved out from the family home and live more independently. Her son had refused to spend any time there and remained at home with her, however she felt that she would not be able to talk freely at her own home because of his presence, so we met in a sparsely furnished and very cold house where there was the constant beeping of a smoke alarm, due to a low battery. One of the interviews took place in a room at the third sector organisation, due to convenience for the participant, however this room was booked per hour and although I had booked 4 hours, I was conscious of the time throughout. Overall, despite these challenges the interviews ran smoothly, and I was able to facilitate rich narratives from all six participants.

3.6.3 Conducting the BNIM interviews

BNIM Interviews consist of two sub-sessions with a 15-minute break between each session which allows the researcher to review their notes from sub-session one and identify what Wengraf (2001) terms, *particular incident narratives* (PIN's). Sub-session two explores these PINs in more detail to elicit in-depth participant narratives.

In this study, the BNIM interviews took place over two sub-sessions as advocated by Wengraf (2001). Sub-session one and sub-session two took place on the same day with a short 15-minute break between each session. Initially, it was anticipated that these sessions combined would last for approximately two hours, however, two of the interviews took in excess of five hours each, with the longest being seven hours (accounting for numerous interruptions) and the shortest being two and a half hours. It became evident very quickly that flexibility around the time taken was necessary, depending on how long each individual participant required to tell their story.

The BNIM of data collection allows for an optional sub-session three, which can take place by telephone between one and four weeks after the initial interview (Wengraf 2001). The purpose of sub-session three is to seek clarification on the points raised during sub-session one and two – if necessary. In this study, sub-session three was not required as the participants gave full and clear accounts of their experiences and spoke at length during the interview. An outline of the different sub-sessions is presented below:

Sub-session one

Sub-session one commenced with reading the SQUIN:

‘Please tell me the story of your life from when you first noticed your son or daughter becoming unwell, all the events and experiences that have been important to you personally; begin wherever you want to begin, I won’t interrupt, I will take some notes to be used later. You may use the photographs you have chosen to help tell your story’

Following this, participants were free to tell their stories, taking as long as they needed to speak freely and without prompting. Wengraf (2001) argues that the assumption that research interviews involve both the interviewer and the interviewee to participate equally can lead to a strongly structured and strongly controlled ‘interrogation’. He suggests that the BNIM interview reduces interviewer interruptions and interventions to a minimum and so, the power balance ‘tilts’ favourably toward the interviewee (Wengraf 2001). It was important to consider potential problems with this approach however, as Mulcahy et al. (2021) posit that this type of unstructured or ‘lightly’ structured interview can generate large amounts of *shapeless* (e.g. irrelevant) data and it can be an uncomfortable approach when participants are more reserved, distrustful or unwilling to talk at length. Furthermore, Johnson (2002) argues that this type of interview requires a greater level of commitment from participants both in terms of time and the emotional energy required.

By remaining silent throughout the interview, the participants were able to talk much more freely than I had initially anticipated. The participant stories were punctuated across all six interviews by numerous silences. Low (2017) argues that researchers must be aware of the implications of silence as these have meaning within the

context of storytelling and it is therefore important that the researcher does not attempt to speak, resisting any urge to 'rescue the situation' when participants stop speaking. Whilst I am generally comfortable with silence, a skill acquired through many years of mental health clinical practice, in practice, when conducting the BNIM interviews, I was acutely aware of the silences and how important the use of active listening skills were during the interview. Again, this is something I am skilled at but the length of the interviews and the need to remain silent presented a challenge at times. Low (2017) posits that a high level of interpersonal skill is required when conducting unstructured or lightly structured interviews. In the absence of speech, I was more aware of how my body language was used to encourage the participants to tell their story and how important it was to look engaged, interested and comfortable, despite the sometimes-traumatic events they were articulating and the distress this caused whilst they were remembering these events.

The coda and short break between sub-session one and sub-session two

When the participant had stopped speaking freely at the end of sub-session one, I used what Wengraf (2001) refers to as a *coda*. This is essentially a question to determine if the participant had completed their narration as it is important that the participant closes the session rather than the interviewer (Wengraf 2001). An example of the *coda* used at the end of sub-session one was: 'is there anything that you would like to add?'

When the participant had finished their narration in sub-session one, a short 15-minute break was facilitated. This allowed for some light refreshments or comfort break for the participant and an opportunity for me to review the notes taken in sub-session one in readiness for sub-session two. These notes comprised of noted down cue-phrases that identified particular experiences throughout the narrative. Wengraf (2006) proposes the use of a SHEIOT notepad for note taking in sub-session one which is structured around the **S**ituation, **H**appening, **E**vent, **I**ncident, **O**ccasion/Occurrence, **T**ime. The purpose of sub-session two is to facilitate the deeper narration of these *particular incident narratives* (PIN's) (Wengraf 2001).

Sub-session two

The purpose of sub-session two is to ask questions based on the information given in sub-session one. These questions should be asked in the order the information occurred in the participant narratives from sub-session one, using the words that they used (Wengraf 2001). This is facilitated by mirroring the participants' own words within a question. In doing this, the agenda is already formulated by the participants in sub-session one (Peta et al. 2018). The core of narrative according to Labov and Waletzky (1997) is a narration about a succession of events. Consequently, the notes taken in sub-session one were 'event focussed' to make it easier to ask specific questions in sub-session two.

In this sub-session, 'particular incidents' conveyed in sub-session one were pursued. Wengraf (2001) refers to these questions as Particular Incident Narrative questions (PIN). PIN-seeking questions aim to develop deeper insight and a more detailed understanding facilitated by using a slightly more structured approach than that used in sub-session one. In order to maintain the narrative gestalt from sub-session one (Wengraf 2006), the exact words used by participants are used within a question in sub-session two. An example of a question during this sub-session would be: '*you said* [that your daughter was angry that her father had left (participant's own words)]. *Do you remember a particular occasion, how it all happened?*' In practice, particularly during the first two interviews the use of the SHEIOT notepad ensured that the questions I asked were formulated around the topics raised in sub-session one. However, actively listening to the participant stories and ensuring the SHEIOT notepad was completed as fully as possible was difficult and stressful, and it was clear that I was writing too much on the notepad, meaning some of the notes were not used in sub-session two. This tension between active listening and note-taking meant that I had to find a balance as the priority, according to Wengraf (2006) should always be ensuring the participant feels listened to.

As the interviews progressed, I became less focussed on the amount of information recorded on the notepad and this facilitated a more relaxed approach to the interview process, whilst still ensuring I could develop suitable PIN-seeking questions. With the process becoming easier to facilitate over time, it became apparent how this sub-

session allowed for a deeper exploration of the narratives presented in the previous sub-session.

In practice, the interviews were much longer than initially anticipated, and all six participants spoke at length regarding their experience of living with and caring for an adult son or daughter with schizophrenia. Sub-session one lasted between 20 and 180 minutes and sub-session two between 120 and 180 minutes. Following each interview, I made voice recorded notes about my thoughts and feelings immediately following each interview, as well as any pertinent observations that were made. Wengraf (2001) suggests that these activities within BNIM research provides private spaces for free-associative reflection.

The format of sub-session two within BNIM interviewing is not without its criticism. Moran et al. (2022) argue that there are several ethical issues central to biographical interviewing, including the potential for re-traumatising participants and this is heightened when deploying the central BNIM technique of '*pushing for PINs*'. Whilst some authors have argued that participants may experience therapeutic benefits as a bi-product of telling their stories (Wengraf 2001, Vajda 2007), others have suggested that the process of recounting and/or re-living traumatic events and experiences have the potential to cause harm (Moran et al. 2022). Indeed, whilst it is generally acknowledged that research interviews, when managed appropriately, can be cathartic, that is not the purpose of them, and most researchers have neither the training or the time to conduct such an encounter. This therefore, highlighted the importance of ethical responsibility within the study and means to address distress through well-being checks and signposting to professional support, during and, if appropriate, after the interview.

Due to the emotive nature of caring for their sons and daughters with schizophrenia, it was possible that the participants would become distressed as they told their stories. Consideration was therefore made to address this, if necessary, throughout the interview and immediately afterwards recognising my role during the interview as researcher rather than nurse. Whitney and Evered (2022) argue that a formalised, distress protocol can provide a comprehensive and systematic means of safely assessing and responding to participant distress in research interviews. The protocol outlines the procedure to follow and are informed by the principles of

beneficence and non-maleficence, autonomy and justice (Draucker et al. 2009). Consequently, if participants became distressed throughout the interview, I would offer a break and only resume the interview if they were willing and able to. Following the interview, participants who became distressed were signposted to the third-sector organisation they were recruited from, where professional support was available if they became upset or distressed. Two of the participants became very distressed as they told their stories, and it was necessary for me to pause these interviews for a short time. Both participants insisted on continuing with the interview when they were able to do so, and in both cases, this was within fifteen minutes of pausing the interview. Both participants were signposted to the relevant support workers within the third-sector organisation at the end of the interview.

I had not fully anticipated the impact that listening to the mothers' story would have on me personally. As mentioned previously, I have been a qualified mental health nurse for over twenty-five years and during this time I have listened to and witnessed traumatic and stressful events. However, one interview was particularly distressing, as a description of a serious [historical] sexual assault on her daughter was recounted, and I was particularly upset by hearing the details of this. I kept a reflexive diary, which enabled me to make sense of my own thoughts and feelings in relation to the experiences of the participants and I also sought support from my supervisors and was able to debrief with them.

Sub-session three (between 1 and 4 weeks)

Sub-session three is an optional component of the BNIM of data collection (Wengraf 2001). The purpose of this sub-session is to enable the researcher to ask specific direct and pre-prepared questions without the restrictions of sub-session two (Wengraf 2001). It provides an opportunity to seek further clarification of any ambiguous points made by the participant throughout the interview however this was not necessary following the six individual interviews I conducted, so it was not utilised within this study.

3.6.4 Photo elicitation

In conjunction with the BNIM data collection, I decided to include photo-elicitation to aid with participant storytelling. Participants were invited to bring photographs that

were meaningful to them (in whatever way) to the interview, if they so wished, as a way of stimulating reflection, prompting memory and facilitating discourse. Collier (1967) suggests that photographs provide a neutral vehicle for sharing personal accounts, which do not require eye-contact therefore they may be perceived as less threatening than interview questions. This is supported by Schulze (2007) who regards the use of photographs as non-threatening and highly useful in researching sensitive topics. Prior to conducting the interviews, I determined that the inclusion of photographs would perhaps allow the participants to talk more freely about their experience and be prompted by the images, if they found the story telling difficult.

Communicating difficult life events and experiences can be challenging for participants to narrate and the limits of language in communicating the 'unspeakable' is well documented (Rogers 2007, Makaroff et al. 2013). Arts based narrative research therefore extends traditional practices of narrative inquiry, going beyond the limits of language and can be usefully combined with more traditional data collection methods (Leitch 2006) According to Keats (2009) the analysis of multiple texts in narrative research, offers both the researcher and the participants' mutual benefits: for the researcher understanding the participants' experience from what is communicated verbally and non-verbally and for the participant, the opportunity to develop a greater awareness of their situation. Balmer et al. (2015) further supports this, suggesting that the use of photographs in research is 'enabling' for both the researcher and participants. It was anticipated therefore, that using photographs in conjunction with the BNIM of data collection would help mothers describe their experience and further facilitate deep and rich narratives.

Participants were invited to use a selection of self-selected photographs to help construct their individual narratives. This was an optional component of the data collection method, and they were able to choose the photographs they already had or to take photographs after receiving information about the study. It was hoped that using photographs in this way would provide a direct entry to the mothers' point of view.

Given the structure of the BNIM interview, photo elicitation was incorporated into sub-session one with sub-session two allowing for a greater exploration of the

images facilitated by the use of specific PIN-seeking questions as discussed in section 3.6.3.

Participants were asked to provide up to ten photographs that they thought illustrated and represented their experience of having an adult son or daughter with schizophrenia. This was outlined in the participant information leaflet (Appendix 3) and again by telephone, when organising the interview. The photographs could be of anything that was significant to them including people, places, spaces, and objects. The photographs could depict both positive and negative aspects of their experience. Care was taken not to prompt participants with examples of images they may have wished to include. The photographs did not form the basis of data to be collected and analysed as such, but was used to inform the discussion during the interview. Written descriptions of the photographs were, however, documented during the interview.

However, only two of the participants chose to use photographs and one of these also used certificates and a copy of her son's CV, which he had written prior to the onset of schizophrenia. This participant also had psychiatrist letters and various medical reports to hand, in case I found them useful for inclusion in the study. As I had not received ethical approval for the use of such documentation, I politely declined to read them, and they were not included in the study.

Having just two of the mothers utilise photographs to aid their story telling was slightly disappointing, as I had initially anticipated that they would have enhanced the interview process and provide a visual representation of what was important to participants as they told their story. However, participants were given the right to decline the use of photographs as part of the BNIM interview and in this instance, data was collected from the BNIM interview alone. Two participants apologised for the lack of photographs saying that they had not had the time to retrieve any and two stated that they had forgotten to bring them to the interview. Despite having just two participants who chose to use photographs, they did really provide the opportunity for a broader dialogue. One of the participants (Eve) started the interview by laying out ten photographs on the table and took some time to discuss the people in them. They referred to the photographs throughout their narrative and used them to show me who people were if they were mentioned in their story. They

also reflected on the family occasion where the photograph had been taken, and the wider context of it. Another participant (Frances) chose five photographs but also frequently referred to her son's graduation photograph on the wall, as the graduation event had marked a particular turning point in both her son's and her own life, and was seemingly, a constant reminder of it. A description of the photographs used by Frances is presented in Appendix 5.

3.6.5 My performance as a novice researcher in the interview

The use of field notes within qualitative research are widely advocated (Silverman and Patterson 2014, Phillipi and Lauderdale 2017). Their use encourages researcher reflection and identification of bias, which can help to increase rigour and trustworthiness, and provide context to inform data analysis (Emerson et al. 2011). Field notes were recorded following each interview and then written up immediately after each interview. These notes outlined my reflections of the interview, for example the amount of detail given, the flow of the story, my ability to pursue PIN-seeking questions and my non-verbal communication. These notes were helpful when interpreting and analysing the data from each transcript as well as providing a record of my own development and improved confidence, as a researcher, over time. Wengraf (2006) suggests that the use of field notes within BNIM research provides a private space for free-associative reflection.

In choosing the BNIM of data collection, I approached the first interview with a certain degree of scepticism, not in relation to whether the participants would respond to the SQUIN and talk freely but in relation to the amount of depth and detail they would provide. This was a particular concern as I had to ensure any interventions or interjections, I felt compelled to make were kept to a minimum, I had to give up any sense of 'control' and maintain the maximum 'power-asymmetry' against myself, firmly balanced in favour of the participant. Some of the skills I have acquired as a mental health nurse certainly helped with this process and I was able to relate the experience of silence within the interviews with those often experienced as a nurse working with those with schizophrenia.

3.7 Data management

All interviews were digitally recorded and transcribed verbatim. Initially, the plan was to complete transcription myself during the data collection phase of the research.

However, following transcription of the first interview it became apparent that this was going to be too time consuming given the large amounts of data generated from the BNIM interviews. Consequently, I utilised the services of a university approved transcriber to obtain verbatim transcriptions for the five subsequent interviews. Cutler (2004) highlighted benefits to outsourcing transcription, whereby any erroneous assumptions by the researcher are avoided.

Prior to commencement of transcribing, I spoke with the transcriber and explained that some of the participant stories were particularly profound, and in some cases, harrowing. I was reassured when the transcriber told me that they were a professional transcriber for the crown prosecution service and was confronted with traumatic accounts daily. I was also reassured that the transcriber had an appropriate supervision mechanism in place should they be affected by listening to any participant accounts. Once completed, transcriptions were checked for accuracy by listening to the audio recordings and reading the typed transcriptions. Following transcription both the audio and transcribed data were stored on a password protected university computer in accordance with university data security policy. A back-up copy was stored on a password protected external drive that was kept in a locked cabinet, inside a locked office. All identifying participant information was stored in a separate secure location, away from the audio files and transcripts. Pseudonyms were used to label the files in order to maintain confidentiality and anonymity. These pseudonyms are also used throughout this thesis.

3.8 Data analysis

The BNIM of data analysis was chosen as it provided a clear and rigorous structure that facilitated intensive analysis of stories from the small cohort of participants. It also facilitated an understanding of lived experience through multi-level analysis of biography, lived life and the told story (Wengraf 2001). Furthermore, a formulaic nine-step process of individual case analysis, followed by a tenth step that facilitated analysis across cases allowed for an in-depth exploration of mothers' life stories in context. Three days of the five-day BNIM course, facilitated by Tom Wengraf focussed on the development of skills for BNIM data analysis and this gave me the confidence to select this method for this study. Furthermore, numerous studies have utilised BNIM for both data collection and data analysis successfully, including

studies on migration (Meares 2010), social work assessments (O'Reilly and Dolan 2015), wellbeing (Farrier et al. 2019) and prisoners (Bigabo and Jansen 2020).

3.8.1 Selecting 'gold star' cases

Before data analysis can commence, a key component of BNIM is the selection of a small number of 'gold star' cases (Wengraf 2015a). Wengraf (2011, 2015a) stipulates that these 'gold star' cases are determined, by the researcher, to be the 'best cases' for in-depth analysis, in the context of the study's research question. With this in mind, it was necessary to choose a small selection of the six participant narratives to analyse fully using the BNIM analytic process (explained in full below). Initially, the prospect of choosing a small number of cases to take forward to the analysis stage presented a personal moral and ethical dilemma and one that was discussed at length with my supervisors. I struggled with both the justification of this and the process of selecting the gold star cases within my study. Consequently, this tension led to an exploration of other BNIM studies and texts and in doing so, it became apparent that this type of 'data condensation' (Miles et al. 2020 p8) was supported in the wider BNIM literature (Nicholson 2009, Turner 2017, Flynn 2018, Moen 2018).

Interestingly, Turner (2017) presented a similar ethical and moral debate, which paralleled my own position and was linked to the loyalty and gratitude to the research participants and an acknowledgment that this may have been the first time and/or opportunity they had to tell their stories at length and in detail. Furthermore, I came to realise that data reduction, or data condensation is necessary throughout all qualitative research (Miles et al. 2020) irrespective of the methodology and methods utilised. Reissman and Speedy (2007) argue that it is an inevitable task of qualitative researchers where decisions have to be made on what is, and what is not, included within research. It often commences before data collection with the researcher deciding on the conceptual framework, the methodology and methods to be used and throughout the data analysis process, where summaries, coding, categorisation, themes and analytic memos are formulated. Consequently, Miles et al. (2020 p.31) argue that data condensation is not separate from analysis, it is *part* of data analysis that 'sharpens, sorts, focuses, and organises data' so that meaningful conclusions can be drawn and verified.

Consequently, in referring to the wider BNIM and qualitative research literature, I was able to justify the selection of ‘gold star’ cases within the study. However, in order to choose the most appropriate cases to analyse, it was important to determine which ones would be the best, in that, they presented the most rich, detailed narratives in the context of the research question. Wengraf (2015b) suggests that three is an appropriate number of ‘gold star’ cases, as it helps overcome binary or linear thinking (if just two were selected), where participants may be viewed as opposites. Choosing three cases, therefore, is congruent with the BNIM process and is further supported by others who have used the method of data analysis (Nicholson 2009, Turner 2017, Flynn 2018, Mohen 2018). The three cases that were not determined to represent ‘gold star’ cases were not analysed as part of this study. The justification for the inclusion or exclusion of each narrative account as a ‘gold star’ case is presented in table 5 below.

Participant	Interview Sub-session 1	Interview Sub-session 2	Narrative	Gold-star case
Carol	180 minutes	120 minutes	Detailed, rich descriptions of experiences with multiple <i>particular incident narratives</i> PIN seeking questions from SS2 provided more detail.	Yes
Avril	20 minutes	120 minutes	Short SS1 that resulted in a description of son’s life and life-events. Little detail of own experience. Few <i>particular incident narratives</i> to pursue in SS2.	No
Barbara	50 minutes	140 minutes	Detailed account of own experience given, with many <i>particular incident narratives</i> that were pursued in SS2. SS2 very detailed, rich.	Yes
Eve	180 minutes	180 minutes	Difficult to follow narrative, numerous tangents and superfluous detail not related to the	No

			research question or SQUIN Largely descriptive accounts with very few <i>particular incident narratives</i> Numerous interruptions.	
Daisy	20 minutes	120 minutes	Limited amount of detail relating to own experience, focussed mainly on the experience of her son. Few <i>particular incident narratives</i> to pursue in SS2.	No
Frances	60 minutes	120 minutes	Detailed account of own experiences and many <i>particular incident narratives</i> to explore in SS2.	Yes

Table 5: Justification for gold-star cases

Having chosen the three cases, I then commenced data analysis, using the 10-step process outlined below.

3.8.2 The ten steps of BNIM data analysis

Data were analysed following Wengraf's (2006) BNIM of data analysis which consists of ten steps:

- Step 1: Biographical Data Chronology
- Step 2: Lived Life Interpretive Panel Analysis
- Step 3: Biographical Data Analysis
- Step 4: Text Structure Sequentialisation
- Step 5: Told Story Interpretive Panel Analysis
- Step 6: Microanalysis
- Step 7: Telling Flow Analysis
- Step 8: Comparing Lived Life with Told Story
- Step 9: Construction of a Case Account

Step 10: Cross Case Comparison and Theorisation

An overview of each step is provided in Appendix 6, where the aim, objective and actions for each step are outlined in detail.

Stages 1-9 were undertaken and replicated for each individual case, in order to create 'a case account' and, these individual case accounts are presented in chapter four. The tenth stage of BNIM analysis involved a cross-case comparison and theorisation phase, where the cases were then analysed collectively. The cross-case comparison and theorisation is presented in chapter five.

Data analysis within BNIM begins by following a twin-track interpretation procedure (Wengraf 2001, 2006, 2015a, 2015b, 2015c). The first three steps focus on the **lived life pattern**, which refers to the life story events told by each participant. Steps four to seven focus on the **told story** and how and why the narratives were told as they were. Wengraf (2015a, 2015b, 2015c) refers to this as a 'twin-track' procedure. An overview of the BNIM analytic process is presented in figure 3 below:

Step one, biographical data chronology

The first step of data analysis was carried out individually for each of the selected three 'gold star' cases. In this step, a chronology of objective life events was constructed. This involved identifying participant life events throughout the mothers' stories and collating these so that they depicted a unique timeline of events. These events included significant milestones for each mother, such as when their son or daughter was born, when they were diagnosed with schizophrenia and when the mothers retired. This process involved scrutinising the narrative transcripts and removing any subjective experience. For example, in relation to her retirement, one of the participants recalled; 'the day I retired was a really sad day for me'. In this step, this statement was separated into the objective event 'retirement' from the subjective experience 'a sad day' (Wengraf 2006, Flynn 2018). The individual timelines for each participant that were created during this first step of the process are referred to as the Biographical Data Chronology (BDC) within the BNIM analytic process. An example of the BDC for Carol can be found in Appendix 7.

Step two, lived life interpretive panel analysis

In step two of the BNIM analysis the BDC is presented to and analysed with the assistance of a Lived Life Interpretive Panel. Using panels in qualitative research is useful as it prevents what Wengraf (2001) terms the biographic inevitability illusion, where the researcher may have already decided on the interpretation of a story. Furthermore, Holloway and Jefferson (2001) argue that interpretive panels generate broader perspectives and assist with exhausting alternatives; thus, the technique can strengthen the research findings.

The lived life interpretive panel is sometimes referred to as a 'kick start' panel or Biographical Data Analysis (BDA) panel within the BNIM literature (Wengraf 2015). According to Wengraf (2008):

'The function of the panel and the recording of its deliberations is to overcome distorting effects of the blind spots and the hotspots, the defended subjectivity, as you as the individual researcher, and to widen your imagination irreversibly for post-panel work' (Wengraf 2008, p.241).

In this step, panel members were incrementally presented with data 'chunks' (a summary of a data extract) taken from each of the participants' narrative and a series of 'hypotheses' were formulated; Experiential Hypotheses (EH), how the event

may have been experienced; Counter Hypotheses (CH), if the experiential hypothesis were true, what might be expected to occur next or later in the series of life-event chunks; and Tangential Hypotheses (TH), one which is at a complete tangent to the two previous hypotheses that were developed. In essence, these hypotheses were generated from an exploration of how each life event might have been experienced at the time it occurred for that participant (Corbally and O'Neill, Wengraf 2015).

A total of three lived life interpretive panels were facilitated, one for each of the gold star cases. An email was sent out to academic, third sector and healthcare colleagues, to ask for expressions of interest to be involved in each of the interpretive panels. The email also requested they circulate the expression of interest to their network, including asking service-user representatives. A total of eighteen individuals responded. The eighteen volunteers were placed into 6 groups of three to comprise a panel (3 panels for step two and 3 panels for step five). Each panel was unique and comprised of a range of willing volunteers from a variety of backgrounds. These included healthcare academics, service users, mental health nursing students, psychologists, mental health clinicians, mothers, and lay people.

In addition, to the three types of hypotheses outlined earlier, the lived life interpretive panel were also asked to consider the life events, which might plausibly transpire for each participant with each data chunk presented. These are referred to as Following Hypotheses (FH) (Corbally and O'Neil 2014, Wengraf 2015). Through this process, a Structural Hypotheses (SH) evolved which related to the whole life story of each participant that unfolded before the panel members.

Wengraf (2006) stipulates that panels should be facilitated in a large room where there is space to hang multiple flipcharts on walls so that with each 'chunk' of information presented, panel members become surrounded by the participants' narrative. However, in practice this was not possible, as this step of data analysis was conducted in April 2020, during the COVID-19 pandemic and the period of social distancing when strict rules were in place regarding movement of people. This meant that I had to be creative in the way I facilitated the panels. As a result, two of the lived life interpretive panels were conducted remotely over Zoom, (Barbara and Frances) whereby a shared screen presented each 'chunk' of information to the

panel members. Facilitating the panels over Zoom worked well, all panel members engaged in the activity, and were able to view the data chunks on the shared screen; crucially there were no connection difficulties, and all panel members had used Zoom before, although this was not a requirement of their participation. I explained how the panels would work and what would be required from them following the presentation of each data chunk. As the activity progressed, it was clear that the panel members understood the process and expectations of them to generate the hypotheses and when the panel work concluded, they all stated they had enjoyed the activity. Using Zoom as a method of facilitating the panels worked well although Wengraf's (2006) idea that panel members were surrounded by the participants' narrative was simply not possible.

The third and final lived life interpretive panel (Carol) was facilitated as COVID-19 restrictions started to lift in July 2020. Consequently, this panel was facilitated outdoors, in a private garden and flipchart paper presenting each 'chunk' was held down on the grassed lawn using rocks. This appeared to work well as an alternative to a large room and was enhanced by the provision of non-alcoholic drinks and some light refreshments which added to the enjoyment of the task. In my experience, the facilitation of the lived life panels both over Zoom and in a private, outside space allowed the panels to explore the individual data chunks appropriately and the method of delivery did not seem to affect the panel outcomes. Whilst the face-to-face panel may have been a more enjoyable social experience overall, the remote facilitation did not appear to hinder the execution of the process.

Each panel ran, on average, for two and a half hours and on completion of each panel, each panel member was asked to write a brief report of their own understanding of the participants' life story. These were collected and used to generate a broader perspective of each case and an appreciation of the multiple interpretations of meaning. As mentioned previously, use of interpretive panels is supported in the wider research literature (Holloway and Jefferson 2001, Miles et al. 2020) and is based on the need to resist the single interpretation of the researcher. Following the collection of the panel members brief reports, specific analysis was undertaken that considered the turning points and phases of the participants' lives and an examination of the socio-political and historical context for each case. In practice, this involved gaining a deeper understanding of the participant lives through

an exploration of the way in which mental illness was viewed, determined, and treated over the past twenty years.

Step three, biographical data analysis

Step three of the BNIM analytic process is the creation of a Biographical Data Analysis (BDA) for each participant. This step combined the panel analysis and my own analysis of the participant's story to provide a framework for the creation of the interpretation of events within the lived life. In practice, this process involved examining and combining the participant transcripts, notes, turning points and phases as well as the panel members and my own analysis of the lived life events. This interpretation and analysis was written up for each of the three gold star cases as advocated by (Wengraf 2001, Corbally and O'Neill 2014).

3.8.4 Steps four to seven: the told story

Steps four to seven focus on the **told story** and how and why the narratives were told as they were. Again, in addition to the description below, an example of how these steps were executed using raw data is presented in the Appendices.

Step four, text structure sequentialisation

Step four of the BNIM analytic process is the Text Structure Sequentialisation (TSS). This process consisted of examining the structure of each participant narrative and identifying alterations in speaker, tone and topic. The purpose of this step is to facilitate thinking beyond the topic content and for the researcher to pay attention to the manner in which things are said. Wengraf (2001) refers to this step as a 'textsort' and the process is informed by Labov and Waletzky's (1997) theory of structure within written narratives. Undertaking the BNIM textsort involved examining each participant transcript and identifying distinct changes using the DARNE acronym (Description, Argumentation, Report, Narrative and Evaluation) (Wengraf 2006). A sample of the TSS document generated for Frances is presented in Appendix 8. The TSS was undertaken for all three gold star cases with the process becoming easier with each one completed. Throughout the process, I was struck by how the TSS reduced the participant narratives to a series of fragmented accounts which impacted on the meaning and ultimately what Wengraf (2006) terms the narrative gestalt (i.e. wholeness). Despite this, the process of examining the

participant verbatim accounts, in this way allowed for the identification of topics and sub-topic summaries or ‘gists’ (Wengraf 2015). This became a type of thematic analysis, whereby ‘themes’ were generated that provided greater clarity and understanding of each participant life story.

Step five, told story interpretive panel analysis

Step five of the BNIM analytic process is the Told Story Interpretive Panel Analysis. Three panels were facilitated to generate numerous hypotheses about the participant stories and why the story was told in the way it was. Due to the COVID-19 restrictions outlined in the previous section, one of the told story interpretive panels was facilitated over Zoom (Barbara) and two (Carol and Frances) were facilitated outside in a private garden. As previous, panel members were comprised of a range of willing volunteers including academics, service users, nursing students, psychologists, mental health clinicians, mothers, and lay people with each panel being different. A table outlining the details of both the lived life and told story interpretive panels is presented in table 6.

	Barbara	Carol	Frances
Lived Life Interpretive Panel			
Date of panel	April 2020	August 2020	May 2020
Location of panel	via Zoom	Outside in Private Garden	Via Zoom
Panel members	Female student mental health nurse Male service-user Female Academic and mother	Male Psychotherapist Female lay person Male lay person	Female mental health nurse and mother Male Academic Female lay person and mother
Told Story Interpretive Panel			
Date of Panel	August 2020	September 2020	August 2020
Location of panel	via Zoom	Outside in private garden	Outside in private garden
Panel members	Female Researcher Male PhD student Female mental health nurse and mother	Male lay person Female Psychotherapist Female service-user and mother	Male Academic Female lay person and mother Female lay person and mother

Table 6: Panel members for interpretive panels

The purpose of the told story interpretive panels was to elicit a broader understanding about each participant narrative. Similar in structure to the lived life interpretive panels discussed in section 3.8.3, these panels provided an opportunity for panel members to be presented with data chunks of the participant narratives and to hypothesise on past and current data without the knowledge of what came next. Wengraf and Chamberlayne (2007) refer to these as ‘future blind chunks’. As with the lived life interpretive panels, panel members were encouraged to generate different hypotheses (experiencing, counter, and tangential) what they may not be experiencing (Counter hypotheses), and the main themes that permeated participant stories (Structural hypothesis). Appendix 9 presents a photograph of an example from the told story interpretive panel, and how these hypotheses worked in practice for Carol.

When facilitating these panels, I was struck once again by the profound nature of the participant narratives and witnessing the reaction of panel members when reading some small quotes on the flipchart, reminded me of how powerful the participant narratives were. At the end of the told story interpretive panel analysis, panel members were asked to write a report of their personal analysis of the case. These were collected and used to inform further stages of the data analysis.

Initially I was daunted by the prospect of facilitating the six interpretive panels as part of the data analysis process. However, the value of these soon became apparent as a useful way to unearth meanings that challenged my own perception of the participant accounts and unearthed alternative meanings. The interpretive panels added a valuable layer to my analysis that, in their absence, would have been shaped solely on my own interpretation and biases, potentially misrepresenting participant narratives and impacting on the overall quality of the study.

Step six, microanalysis

Step six of the BNIM analytic process is an optional step that involves conducting a microanalysis interpretive panel which considers any oddities, unique features or puzzling elements of each participant story (Wengraf 2001, Corbally and O’Neil 2014). The use of a microanalysis interpretive panel was not utilised in this study as the told story interpretive panels provided detailed and thorough analysis of the participant accounts.

Step seven, telling flow analysis

Step seven of the BNIM analytic process requires consideration of the structural analysis of the text and the '*thematic*' analysis of the data which is presented as an overall 'telling flow analysis' (Wengraf 2010, Corbally and O'Neill 2014)². In practice, this was a summary document that was formulated following the lived life and told story interpretive panels which sought to understand the participant's gestalt (Wengraf 2006 p272.), that is the pattern or structure that flows through each narrative and detects the topics and their interrelation. The telling flow analysis helps the researcher move toward understanding the flow of the narrative and the topics that emerge (Gurswitsch 1964, Wengraf 2006). For example, the topics of homemaker, motherhood, professional identity, sadness and loneliness, arose multiple times throughout all three participant stories and were therefore, all identified as '*teller flow*' that arose from the data. A sample of the teller flow for Barbara can be found in column three in Appendix 10.

3.8.5 Steps eight to nine

Conducting the previous seven steps of the BNIM analytic process facilitated consideration of each participant account in two separate, twin-track stages (Wengraf 2006) as presented in figure 3. Step eight and nine bring these two tracks together. In addition to the description below, specific examples of these two stages can be found in the Appendices to further illustrate the analytic process.

Step eight, comparing lived life with told story

Step eight brought the two components of the twin-track analysis together and involved a comparison between the lived life and the told story, and the evolving relationship between the two. In this step, a BNIM, 3 column chart was completed for each participant. An example of the chart formulated for Barbara can be found in Appendix 10. Fundamental to this comparison was the realisation that the participant stories were told from a perspective that they held at the point of their narration which was different to the perspective they had when the events and incidents

² Prior to 2010, this stage of BNIM data analysis was termed the *thematic field analysis*. Wengraf (2010) renamed this stage of data analysis as the *teller or telling flow analysis*, but the process of analysis remained the same.

occurred, consequently the participants were telling their past stories in a way that was reconstructed.

Step nine, construction of a case account

Step nine involved collating the various reports from the panel members with my own interpretive account to construct a 'history of the case evolution' for each case (Wengraf 2001, 2006, 2015). These interpretive accounts represented the outcome of the nine stages of the BNIM analytic process and culminated in the presentation of cases as standalone entities. These are presented in the next chapter as individual case presentations and although it is my voice presenting these cases, they were informed by the voice of each participant and co-constructed with the views of the panel members who participated in analysing particular aspects of each case.

Step ten, cross-case comparison and theorisation

Step ten is the final step in the BNIM analytic process and involved a cross-case comparison and theorisation across all three 'gold star' cases. In BNIM, Wengraf (2001, 2006, 2015a) argues that there is a degree of flexibility in this stage of analysis but it's central tenets are in the inter-relatedness of 'themes' from each of the individual case presentations. Consequently, I had to develop a robust system for the cross-case comparison that ensured a thorough, detailed and transparent process. I needed to ensure that this was not just a list of findings but a systematic and comprehensive exploration of key issues across all cases. I completed a matrix, that listed all the 'themes' for each case and then considered the connections and interrelatedness between each theme. Themes that were similar were grouped together and reworded to create a new theme heading. This process continued until all case 'themes' had been generated and no new 'themes' emerged. On completion of the process, the three final 'themes' were: stigma, disruption and despair, loss and grief. An outline of this process is presented in Appendix 11 and discussed further in chapter five.

3.9 Quality in research

Quality issues are important in both qualitative and quantitative research, and it is imperative within BNIM methodology that trustworthiness and methodological rigour are maintained. Quality in qualitative research has been the subject of much debate, particularly in relation to narrative research (Bailey 1996, Reissman 2008).

Reissman (2008) discusses quality issues within narrative research and highlights the importance of the participant narratives, alongside the researcher's interpretation being consistent with the theoretical approach. Furthermore Reissman (2008) posits that the persuasiveness and the consistency and reflection of the participant experiences within narrative research are what makes the findings trustworthy. Lincoln and Guba (2000) argue that ensuring credibility is one of the most important factors in establishing trustworthiness. In their seminal work they proposed a criteria for enhancing trustworthiness in qualitative research: credibility, transferability, dependability and confirmability (Lincoln and Guba 1985). These headings will be used to structure this section of the thesis.

3.10 Credibility

Promoting the trustworthiness of any research project is essential to ensure that research findings are credible (Holloway and Galvin 2017). Credibility refers to the appropriate use of the research methods and the recognition that the researcher's interpretation of the participants' stories are recorded accurately. Detailed descriptions of the research methodology, methods and analysis were presented in this chapter and demonstrated their suitability to meet the aims of the research. Accuracy in recording the interviews, transcription and data management are all further important considerations for demonstrating credibility and these have also been detailed in this chapter.

Reducing bias enhances the credibility of the research (Silverman 2014) and steps were taken to address this by systematically analysing the data, transcribing verbatim and remaining close to the intended meaning in the participants' stories whilst acknowledging my own thoughts and feelings, my role as a mother and nurse and how this could potentially influence how the data was presented. The use of the interpretive panels throughout the data analysis process also mitigated against potential bias as it allowed for multiple perspectives of the data generated. Analysis of the data was also reviewed throughout, with academic supervisors to discuss emerging ideas. This helped guard against lone researcher bias. The purpose of these sessions however was not to seek agreement of opinions regarding themes but to constructively extend interpretation of the data (Wengraf 2006).

3.11 Transferability

Transferability refers to the degree to which the findings from one setting can be transferred and provide insight to other contexts or settings (Korstjens and Moser 2018). Due to the nature of the study design, thick descriptions and detailed data extracts were generated. I also provided a description of the interview participants and presented findings with supporting evidence using narrative quotes. Whilst it is acknowledged that these extracts are specific to the individual participant, they are necessary within the methodology to understand their individual experiences. Undertaking a narrative study at a different time, with different mothers would result in further unique narratives although specific elements of their stories may be similar.

3.12 Dependability

Dependability relates to the operational detail of gathering data and a reflective appraisal of the project (Shenton 2004). Dependability was checked as part of the interpretive panels during data analysis as well as during supervision. The individual presentation of the cases supported by relevant data extracts were also discussed in detail with my supervisors and pertinent information from the reflexive diary was also acknowledged.

3.13 Confirmability

The operational processes of BNIM illustrate a commitment to the process of data collection and data analysis which is methodical, rigorous and potentially confirmable through its detailed audit trail (Atkinson and Delamont 2006). Nonetheless, meticulous planning was important in ensuring confirmability and objectivity of the study findings. It was important that I considered my own preconceptions and values to mitigate against researcher bias and potentially influence objectivity. These were acknowledged and reflected on in supervision and in the reflexive diary discussed in section 3.6.2.

3.14 Reflexivity

A reflexive stance was important in order to enhance the trustworthiness of the study and to fully assess and understand how the interest, position and assumptions I made throughout the research influenced the work. This reflexive stance according to Charmaz (2006) demonstrates how the researcher relates to the research participants and represents them within written reports. Furthermore, the process of

reflexivity was an important consideration within the methodology chosen for the study, not only in providing transparency about the analytic process and reporting the narrative but by carefully considering my own personal responses to it (Holloway and Freshwater 2007). Within this thesis, I have outlined my positional narrative and it was important that through the process of reflexivity I explored my beliefs and values of what it is to be a mother, as well as a mental health nurse, with an extensive background in caring for those with schizophrenia and their families. These needed to be identified, questioned, and challenged throughout the research process. I was aware of my pre-understanding of the research topic due to my previous clinical experience as a nurse. Therefore, I attempted not to take anything for granted, (for example, how mental health care is arranged and delivered), and maintained thorough field notes of all aspects of data generation. I explained to each participant that I was a qualified mental health nurse, but that I was meeting with them in a research capacity and no longer worked in clinical practice. Participants accepted this and saw me as a researcher. Nevertheless, I had responsibilities as a registered nurse under my professional code (Nursing and Midwifery Council 2018) and in my ethical application I had agreed that if I had any concerns about a participant I would signpost them to support from the third-sector organisation they were recruited from. The inclusion of the three 'lived life' and three 'told story' Interpretive panels helped to consider what Wengraf (2001) terms hot spots and blind spots and prevents the biographic inevitability illusion, where the researcher has already decided on the interpretation of the story based on the data collected (Wengraf 2001). These panels within qualitative research aim to generate broader perspectives and assist with exhausting alternatives, thus, according to Holloway and Jefferson (2001), the research findings are strengthened.

3.15 Ethical issues

Cardiff University Research Governance framework (2015, 2019) ensures research integrity. This study was formulated in accordance with these guidelines along with consideration of the professional, legal, and ethical responsibilities of being a registered nurse (NMC 2018, DH 2017).

Cardiff University School of Healthcare Sciences Research Ethics Committee approval was obtained in November 2018 (see Appendix 12). Governance approval from the third sector organisation was also sought and gained in December 2018.

The approved proposal was adhered to throughout. To ensure the ethical principles that underpin research were adhered to, some of the ethical considerations made in this study will now be presented.

3.15.1 Beneficence and non-maleficence

The principles of beneficence and non-maleficence were considered as part of the research planning stage and the application for ethical approval. Beneficence relates to doing good and non-maleficence relates to avoiding or minimising harm (Costley and Fulton 2019). It was recognised that the interviews had the potential to cause distress for some participants as they recalled difficult and painful memories. I therefore managed all interviews in a considered manner and allowed time to pause or stop the interviews if participants became upset. I also provided the opportunity to debrief at the end of the interview schedule.

3.15.2 Informed consent

All participants were made aware of the aims and purpose of the study and that their participation was voluntary. The participant information sheet (Appendix 3) outlined relevant information relating to the study and relevant contact numbers were provided if further information was required. Consent forms were sent by post with a stamped addressed envelope marked *strictly private and confidential* enclosed for their return. Key ethical issues were reiterated before each interview commenced when I met the participants. This included information about informed consent, the right to decline or withdraw their participation at any stage, confidentiality, and an outline of potential harm and benefits.

3.15.3 Confidentiality and anonymity

Confidentiality was maintained throughout all aspects of the research in accordance with Cardiff University Research Integrity and Governance Code of Practice (2019) and the Nursing and Midwifery Council (NMC) Code (2018). All participant data were anonymised, and all participants and their children (if they were referred to by name in the interviews) were given pseudonyms. Care was taken to remove and/or mask any identifying information relating to the participant, their family members and the location of family events. It was explained to each participant that if any information came to light during the interview that raised concern in regard to their

safety or the safety of others, confidentiality would probably need to be broken in line with my responsibility as a registered nurse (NMC 2018). The Data Protection Act (2018) was adhered to throughout.

3.16 Summary

This chapter has presented a detailed account of the philosophical underpinnings of the study and how my ontological, epistemological, and axiological stance is situated within the interpretivist paradigm. Narrative research, specifically the biographical narrative interpretive method as a methodology aligns with the study aims and is well suited for exploring the lived experience through biographic narrative interviews.

This chapter has outlined the study design and the experience of this in practice. The development of the research and consideration of how this enabled me to meet the aims of the research is detailed. A comprehensive overview of BNIM data analysis has been presented and ethical issues have been discussed along with a discussion of the steps taken to ensure methodological rigour.

The next chapter will present the findings following stages one to nine of the BNIM analytic process. It will present the three 'gold star' case presentations, for Carol, Barbara and Frances.

Chapter Four: Findings

4.1 Introduction

This chapter will present findings from the three 'gold star' cases that were fully analysed using the nine stages of BNIM data analysis. The nine steps of analysis are shown in figure 3 in chapter three. The findings are presented as three individual case presentations that demonstrate participants' experiences over many decades, and are still ongoing. These narratives are unique to the storyteller and demonstrate the way in which mothers have rationalised and made sense of their experiences. The mothers who each represented a 'gold star' case are detailed in table 5 in chapter three. Pseudonyms have been used to ensure confidentiality and anonymity and all identifying information has been removed or masked. Where identifying information has been masked within the participant quotes, parentheses are used to highlight any modified data. The participants were aged between 71 and 78 years old and were all retired, professional white British women. Although it is my voice presenting these cases, they were informed by the voice of each participant and co-constructed with the views of the panel members who participated in analysing particular aspects of each case. Carol's case is presented first, followed by Barbara and Frances.

4.2 Presenting Carol

Carol was a mother of two in her mid-70's. Her daughter, Rebecca received a diagnosis of schizophrenia over 23 years ago aged 20. Carol divorced from Rebecca's biological father when she was in her 40's but had re-married. Rebecca lived with Carol and Carol's husband, while Carol's son lived in another part of the country with his wife and children. When I met her, Carol presented as a very well-spoken articulate woman who was very happy to share her story. Carol had a background in education and was genuinely interested in the research and recognised the importance of the topic area. She admitted that this was her very first opportunity to fully tell her story and explained that she had a lot to tell me. She was concerned that she would be unable to accurately present the correct timeline of events but had given this some thought prior to us meeting;

'I was trying to think about this before you arrived and I thought I will try and adopt a chronology, simply because that helps me sort my thoughts out'.

Carol's forethought in how she may have structured her story highlighted a level of preparedness that I had not anticipated and with this she demonstrated a positive, engaging, and at times, mesmerising approach to the telling of her story.

Understanding the cause of Rebecca's schizophrenia was important to Carol, who discussed her feelings of guilt that a childhood trauma could have led to her daughter's illness;

'If you read about it, they always talk about trauma being a possible trigger, and I suppose the reason I'm thinking about it now is that in common with almost anybody I know whose child becomes mentally ill, they tend to feel guilty about it or in some way responsible'.

Carol discussed the possible cause of Rebecca's schizophrenia as her first husband's infidelity and the subsequent disruption on family life when the family moved across the UK.

Throughout her story, Carol repeatedly referred to her husband's infidelity and the effect this had on her and their two children. Carol viewed herself during the time as *'very emotional'* and feared her upset may have been traumatic for her children. This appears to imply an unresolved situation, lack of acceptance and a constant searching for answers and possible reasons why her daughter developed the illness;

'In some ways the damage had been done to me, and yeah, I don't know if I damaged the children as a result. I might have done. I didn't do awful things, I just cried a lot, and that wasn't very adult, and it wasn't very, you know, I didn't neglect the children at all, in fact rather the opposite I think, but it does, you know, if I was looking for trauma - and she was very young - that would be it'.

Following the break-up of her marriage, Carol noticed changes in Rebecca's behaviour and a deterioration in both her physical and mental health as she started university, aged 18 years, and subsequently returned home. Rebecca developed glandular fever, chronic fatigue syndrome (ME) and associated depression;

'She went off to university, although in truth she was in no fit state to go, mentally, and I think then she was increasingly having problems about organising herself and planning, and she came home from university with glandular fever and never went back because that then turned into ME and kind of depression, which is often, as I understand it, a constituent part of ME. So there she is at home, very, very ill'.

After her daughter returned home from university, Carol observed Rebecca's behaviour started to become more unpredictable, volatile, and uncharacteristic. Carol perceived her daughter's anger was directed at her and again linked this to the breakdown of her own marriage;

'I just thought she was being very impetuous, quite aggressive. I think she was very, very angry with me, though [my husband] left me. I think she was much more angry with me. When she wasn't angry, she was utterly exhausted and would spend hours in her room writing, writing, writing and then turning the paper around and writing, writing, writing'.

As Rebecca spent more time alone in her bedroom, Carol described being concerned about her daughter's social isolation, the lack of contact with her friends and, in the absence of these friends, the new acquaintances her daughter had made. Throughout her story Carol referred to these acquaintances often, and there was a sense of concern regarding Rebecca's increasing vulnerability and the relationships she developed;

'All of her friends are now at university, so nobody came around. The only people she was friends with during that time was a guy who had schizophrenia who she'd known from school, and another guy who was an alcoholic, so you know, he was quite a damaged guy but actually very nice to her. At least he came around, nobody else did'.

Following the break-up of her first marriage, Carol began a relationship with another man. They bought a house large enough to accommodate them and their extended families, as they both had children from their previous relationships. Rebecca refused to accept Carol's new partner and refused to live with them. Rebecca started to voice delusional ideation about him and about the police and believed that Carol and her new husband were listening in on conversations and that Carol's new

partner was a paedophile. This had a significant impact on Carol and her relationship with her partner;

'her behaviour was getting more and more difficult to cope with, and then she was saying she didn't want to live with us, that [my partner] was a paedophile, how could I have got involved with a paedophile? He is around the house, he is on his computer all the time, he runs a paedophile ring. I had no idea what to do'.

Her daughter's behaviour and delusional ideas relating to Carol's new partner were difficult for Carol to understand and she found this period particularly upsetting and stressful. Carol found it increasingly difficult to cope and, in light of the allegations her daughter was making, she realised that living together was no longer feasible. Therefore, Carol decided to try and obtain independent housing for her daughter.

'According to her I was keeping her prisoner, she was drinking very heavily, and her behaviour was more and more erratic and aggressive. It soon became apparent that the three of us living together wasn't going to work so I suggested that Rebecca moved out, which she agreed to'.

Carol struggled to find Rebecca an alternative place to live but the impact her daughter's behaviour and delusional ideation was having on her, her partner, and her new relationship, was profound. Despite Carol's daughter becoming increasingly unwell, Carol encouraged and supported her to visit her father who was living overseas, and Carol looked forward to having some respite from the deteriorating situation at home. Now aged 19 years old, Carol felt that Rebecca would be able to travel abroad alone to be with her father.

Whilst staying with her father, Rebecca's mental health continued to significantly deteriorate, with her behaviour becoming increasingly challenging, which Carol described as 'very, very aggressive'. This culminated in Carol's daughter running away from her father's home and being sexually assaulted – a defining moment in Carol's experience as Rebecca's mother. Carol described graphically the harrowing event that occurred when her daughter was away;

'she ran away, got very, very drunk, hitchhiked with two men who took her away and sexually attacked her and beat her up so badly before she escaped'

that everybody was surprised that she didn't die as a result. She was very badly torn on her breast and her private parts, but she threw herself into the water and they didn't know, well no, they did know that the place that they took her out to, and it is full of quicksand, so the horses drown, and people drown there all the time. And she didn't know that, but they did, so they didn't follow her'.

As Carol recalled the painful and distressing incident, she described the impact of this on Rebecca as a '*defining moment*' in her daughter's mental illness. Despite her daughter being unwell prior to the attack, Carol explained that the incident is more acceptable to her and to others who question why Rebecca is unwell;

'I date it to that time, but that's partly to give her an excuse in a way, because she sometimes feels so guilty about the things that she has done when she has been mentally unwell that I think she needs an excuse. Very often I think I use that as shorthand for why she is so mentally unwell, but I think that's also more acceptable to people, there is so much prejudice that people seem to blame her for her behaviour. It is almost that that is an excuse. It is an excuse, but she was ill before'.

Following the attack, Carol's daughter's mental health deteriorated further, and she had begun to experience hallucinations and flashbacks, which Carol found particularly distressing;

'She saw Jesus when she was on the station platform...she would have like very vivid images that she shared with me, and I have to say I found it traumatic, completely traumatic. I mean, you know, what worse thing can happen to your daughter really?'.

As Carol recalled this period of time, the sense of helplessness and hopelessness that she experienced was tangible. Furthermore, Carol experienced desperation as she began to navigate the complex system of mental health services to get her daughter the help she so urgently required;

'she was desperately in need of professional help but I didn't know what to do'.

Carol was eager to find professional help for Rebecca and to find out what was causing her deteriorating mental health. She initially contacted her GP regarding her daughter's deteriorating mental health but was told there was a two-year waiting list for counselling. The GP told Carol they lived in a '*mental health blackspot*' and that she would '*need to look elsewhere*'. As Carol became more desperate in trying to access support for her daughter, she contacted people she knew who worked in mental health services and wrote to her MP, but Carol was told as Rebecca was not '*a danger to herself or others*', nothing could be done. Carol then decided to pay for a private consultation with a psychiatrist who agreed her daughter was very unwell but again Carol was told;

“Yeah, she is very, very mentally ill, but she is not a danger to herself or anybody else. So I can't section her, which means she won't get any support”.

Carol was left to manage her daughter's mental illness alone at home but as she deteriorated further her symptoms became more profound and her behaviour more disturbed, Carol recalled reaching a crisis point and Rebecca was detained under the Mental Health Act (1983) for the first time but this admission to hospital led to further crisis;

‘She was sectioned and taken to the local hospital, a Victorian building with male and female patients in the same area. There weren't any separate cubicles, just a cotton curtain around each bed. And there were a lot of men sexually interested in her who used to approach her, and she was terrified. I think that was more traumatic than the attack actually’.

It was during this admission to hospital that Carol was first told of her daughter's diagnosis although she recalls a difference of opinion initially between two psychiatrists, with one diagnosing '*schizoaffective disorder*' and another diagnosing '*disorganised schizophrenia*'. She recalled the upset she felt at hearing the word '*schizophrenia*' and that although she experienced some relief that Rebecca finally received a diagnosis, the label of schizophrenia and the meaning associated with it has been difficult for both Carol and her daughter ever since;

'It is no wonder that she mostly hates me. When she doesn't love me, she mostly hates me. I delivered her into the mental health services clutches. I labelled her for life'.

As Carol told her story, there was a sense of frustration and, at times desperation, around accessing mental health support and treatment for her daughter whilst in the community. Carol had navigated the complex mental health system on behalf of her daughter for over 20 years but, during this time, her requests for help were often ignored by community mental health services or she was told Rebecca was not ill enough to warrant any input. Carol reflected that there were many times when mental health services were inadequate;

'there's never a mental health worker available. Nobody is ever there. I am prepared to go out and try and stop her doing what she's doing that gets her arrested but nobody else is. You leave a message, and they say they will get back to you, and they do get back to you, but it is sometimes like four hours later'.

Carol's frustration, at what she viewed as an inadequate mental health service, was palpable, as she described Rebecca's mental health deteriorating frequently, and the times when she was detained under the Mental Health Act (1983). Carol recalled visiting her daughter in hospital and how these visits were traumatic and upsetting, not only in relation to her daughter's mental health and presentation at the time, but also in relation to the other patients on the ward, and the chaotic scenes she witnessed;

'I can't actually go back there. If I go back there, if I go back to the images of people in there and her, that's Armageddon all around her. There were people shouting and banging the furniture, some were half naked and some were intimidating, asking for money and cigarettes. There was a real edge to the place, and it just didn't feel safe'.

As Carol described how traumatic she found visiting her daughter when she was detained under the Mental Health Act (1983) it was evident that these visits significantly impacted on Carol's own well-being and her concern for her daughter as she witnessed the '*chaotic*' and '*frightening*' experience of an acute psychiatric ward.

Much of Carol's story focussed on the trauma that her daughter had suffered throughout her life, but Carol's own story mirrored some of this trauma and highlighted her own vulnerability, as she experienced a world that was often dangerous and volatile. Carol described being called by her daughter to collect her from various locations around the city where they lived, often late at night and Carol would often find herself waiting for Rebecca in unsafe areas or buildings. Carol's description of both the hospital ward and locations within her local community that her daughter frequented highlighted how concerned she was for Rebecca's safety and her increasing vulnerability to predatory men;

'Some of my images from that time are just, they are ingrained. You know, both walking into places to find her, you know, with a group of seedy, seedy men, and when she'd been bottled at the hospital'.

Carol again referred to some of the relationships Rebecca developed and how these appeared to foster risk taking behaviour and increase her daughter's vulnerability. Each time Rebecca found herself in high-risk situations, she would telephone Carol in tears, often in the early hours of the morning and ask for immediate help. When this happened, Carol would not hesitate to 'rescue' her daughter but each time she did this Carol did not feel able to tell her husband as; *'He would try to persuade me otherwise'*. Therefore, Carol would *'go off into the night'* to find her daughter despite the risks to herself;

'she will go roaming around in the middle of the night getting stone drunk and wake up somewhere and ring me in the early hours saying, 'I'm with this man, I don't know who he is, I don't know where I am. Please come and help me because he is going to wake up soon and I am frightened of him''.

Carol recalled driving throughout the night to collect her daughter from a *'crack den'* putting herself at great risk and again not telling anyone where she was going. On many occasions Carol visited places where drug dealing was evident despite the obvious risks to her own safety;

'I would drive out and go into these crack dens and pick her up and bring her home to keep her safe. I would go around there, I would take photographs of these people stripped to the waist, you know, things around their arms'.

As Carol recalled the numerous times when she put herself in danger to protect her daughter, she explained that she did not feel able to show any sign of weakness in front of Rebecca;

'She needs me to be strong, and if I ever get ill, she gets angry with me because she needs me to be well. It may be fear, or may be, I mean there are lots of reasons to be angry with me. I make all kinds of mistakes'.

The '*mistakes*' that Carol referred to were centred around times when her own vulnerability was visible to Rebecca; times when Carol was ill or having investigations for her own health issues or when she needed to rest and have her own space. Carol described a time when she was having investigations for cancer and had attempted to discuss this with Rebecca;

'She didn't take the news very well at all and it was as if me being unwell was a catalyst to her becoming more demanding of my time. Her behaviour seemed to become more challenging. I realise that this was her reaction to me being potentially diagnosed with cancer, but it was as if I couldn't have time to get my own head around things. Rebecca always had to take priority and I always had to be there for her'.

The perception of always having to be strong and available for her daughter led Carol to adapt her own behaviour when interacting with or supporting her daughter. Carol described an awareness that her own worries and actions had to be adapted when she was with Rebecca;

'I also have to be on time, I have to always do what I say I am going to do. I can't have a heavy cold or whatever. Maybe it is that, I don't know, maybe it is that. Yeah, I tend to always be kind of as upbeat as I can'.

The constant hyper-vigilance Carol had to her own health, feelings, and behaviour, which was observable to her daughter, added to Carol's feelings of stress and burden. Carol succeeded in maintaining this persona most of the time, but she reported that the situation occasionally reached breaking point. Subsequently, Carol felt guilty as she compared her own feelings with those of Rebecca;

'and then just very occasionally, I don't know, once a year, twice a year, I will express a sense of exhaustion or frustration or something. And then I feel really, really awful, because she's got enough to cope with without me'.

Carol's resilience was evident throughout her story as she recalled the difficulties finding suitable support networks for herself as a family member, carer and advocate for her daughter. Carol remained steadfast in her support for her daughter and had a good degree of insight into her own needs, but she was both surprised and frustrated at the lack of support available to them. Carol's experience in caring for Rebecca motivated her to become an active supporter and campaigner for people with serious mental health conditions. At times however, this required careful consideration of her involvement with different organisations, due to her daughter's delusional and paranoid thinking and also because Carol did not want to disempower her;

'I was going to be a director of a charity for mental health trust fund, but my daughter thought that that meant that I was taking all her money, so I stopped doing that, and I felt that I was kind of getting in her light almost like I was so busy on her behalf that it could become disempowering'.

Carol constantly weighed up her role as carer and advocate with the views and opinions of Rebecca. She tried to be open and transparent with Rebecca, but this was often met with her daughter's wish for her to stay away from any involvement or as she saw it, over-involvement with services. Despite this, Carol's story is one of growth and empathy;

'I suppose if there is any positive to be gleaned from this, it is my compassion towards people with mental health problems, alcohol problems, drug problems, which I don't think was there before, to this extent, and it is also my attempts at getting parity of care and justice for people, not just for my daughter, which has given me a sort of purpose I suppose, and uses the skills that I have. Because I'm quite a good researcher, I'm quite a good communicator, I'm quite a good advocate'.

Carol sought support for herself from a local carers group facilitated by a third sector organisation. Although not a specific mental health focussed charity, the group was a

great source of support to Carol, and she learnt and developed coping skills and also some practical problem-solving ways that she used to deal with different situations. This included adapting her communication style with Rebecca to one that was less 'reactive' and more 'proactive' and this also enabled Carol to turn her phone off at night. The carers group also helped Carol reflect on her personal strengths as she continued to support her daughter;

'I suppose I've also learnt that I'm actually quite resilient, because God knows I've exhausted myself both physically and mentally on my daughter's behalf for year after year after year, and I've neglected my friends and family'

Carol's story was punctuated by the stigma she experienced, as a result of her daughter's mental illness. How Carol was viewed by others was important to her, and this resulted in her experiencing feelings of guilt, blame and shame about her daughter's illness for many years. Carol reported that she lost many of her friends, wider family and social network since the onset of Rebecca's illness and with the exception of her husband, had very few people in her life she could now confide in;

'it has affected a lot of my relationships and I regret that'.

Throughout her story, Carol implied that she was, in some way to blame for the situation both she and her two children found themselves in following her separation from her first husband. This reinforced Carol's feelings of shame and guilt. There was a sense within Carol's story that she protected her ex-husband from any ill feeling towards him; and she presented herself as someone shouldering the blame for her marriage break-up and described wanting the 'pain to stop' so that she could 'get on with my life and kind of be there for the children'.

This sense of blame and guilt was exacerbated further when Carol reflected back on her decision to encourage her daughter to go abroad. At the time, Carol was desperate for respite from the deteriorating situation at home, but she recalled this time in her life with a sense of sadness and it appears that she is regretful for her actions;

'I felt immensely guilty, in effect throwing her out, and she brings it up constantly that I threw her out. If I had not have done that, she wouldn't have been sexually assaulted'.

This remorsefulness and sense of guilt continued to the present time often causing many arguments and confrontations with Rebecca as Carol was continually blamed by her daughter for the situation that led to the sexual assault.

These feelings of guilt and blame continued to be evident as Carol implied throughout her story that she was in some way responsible for her daughter's illness. It was apparent by the language Carol used that when she related her daughter's behaviour to mental ill-health and the schizophrenia diagnosis, that she later received, Carol is someone who is still searching for answers as to why Rebecca developed the illness.

Throughout Carol's narrative, her sense of personal despair, loss and grief was profound. Carol recognised that she shouldered much of the burden of her daughter's illness. She had an awareness that if she had not been so supportive, her daughter would not have survived many of the situations she found herself in, and the consequences of this could have been catastrophic. At times, Carol's perception of the support she offered her daughter led her to question her own actions as if, in some way, these have maintained her daughter's suffering. This demonstrated an ongoing moral dilemma for Carol;

'If I had not kept my daughter's head above water she would have died long ago and she would be much happier. I should so have let her die. I wish she were dead. No, I don't wish she was dead. I wish she had died, not by my hand, or in any horrible circumstances, but I just wish she had died, because what she has is an unutterably prolonged degrading existence where she limps from one horrible situation to the next with very little hope of even reaching recovery.'

Carol expressed the conflict she felt between keeping Rebecca alive and alleviating the suffering her daughter experienced. The sense of desperation was palpable as Carol made a comparison of the pain her daughter suffered, and the pain experienced by one of her animals;

'And I had our horse shot when it was in that amount of pain, but I haven't shot my daughter, and if I were brave enough I would, because seeing an animal who is as sentient as she is in that amount of pain and despair, I feel it is wicked for me to allow it to continue.'

Carol had been consumed by her daughter's mental ill-health for over 20 years and there was a sense that she was growing tired of the '*relentlessness*' of the situation. Carol was desperate for the situation to resolve acknowledging the devastating impact it had on her personally;

'So I wish she were happily dead for her sake, and also for my sake, because her illness has been totally detrimental to my own physical and mental health'.

Carol faced the future with uncertainty characterised by risk and vulnerability for both herself and her daughter. Once again, Carol referenced the men Rebecca associated with and the relationships she had that increased her vulnerability. There was a sense of foreboding and being constantly on edge waiting for the next crisis;

'So she is in Indian territory out there, constantly walking this tightrope of either being murdered or killing herself or being buggered to death or any of the things that these horrible men do to her'.

The '*Indian territory*' that Carol referred to implied her lack of control and the unpredictability of an unknown future that is fraught with concern and one where her daughter's vulnerability at any given time may determine the outcome.

Carol's sense of loss and grief permeated throughout her story but at times she acknowledged this more specifically. Carol realised that her daughter's schizophrenia would not resolve, and the future therefore offered little hope;

'I think as illnesses go, schizophrenia is utterly cruel, because you are witnessing a slow destruction and the grief is continuous'.

Carol recognised that life would continue to be problematic for Rebecca and explained the feelings of helplessness she experienced. This led to Carol describing a future full of trepidation and apprehension and a realisation that as long as Rebecca suffers, that she would suffer too;

'Her life has been taken away, but she can't die somehow, and because she can't die, I can't die either, because I am the only person between her and utter degradation and vileness actually. Part of my problem is that she is involved in utter degradation and vileness all the time, so I am obviously. I can only take the edge of it, I can't prevent it, so I don't know'.

4.3 Presenting Barbara

Barbara was a divorced mother of two in her late 70's, whose 49-year-old son, Alex, received a diagnosis of schizophrenia 30 years ago. Before retirement, Barbara had worked for 30 years, completing a diploma and later a master's degree in the social sciences. She described her life prior to her son becoming unwell as *'busy and career focussed'*.

I met Barbara in the offices of a local third sector organisation, as she was reluctant for me to visit her home, due to Alex being very unwell and *'suspicious and unpredictable'* at that time. Nevertheless, Barbara stated she was determined to tell her story and it was important that she did so, as she recognised the experience of carers and, specifically, mothers of people with schizophrenia were often *'unheard'*. Barbara also explained that she felt unable to discuss her own experience with her family due to the stigma and shame she felt in having a son with a severe mental illness, despite living with it for the past 30 years. Barbara also felt unable to properly discuss her experiences with the mental health professionals involved in her son's care, as she believed that their focus was solely on her son rather than her, as his mother and main carer.

Throughout her story Barbara drew on her knowledge and expertise of her professional practice and highlighted how this both helped and hindered her experience of her son's illness.

Barbara explained that Alex had a mild learning disability, was *'not very street wise'* and had always been *'vulnerable to exploitation'* during his childhood and teenage years. He had attended mainstream school, but Barbara recalled he had been bullied and had few close friends, often returning home from school having been followed by other children who *'ridiculed him'*. Barbara recalled an incident that happened when Alex was 19 years old that she viewed as a possible *'trigger'* to him becoming unwell. Alex had commenced a college course and made new friends who he smoked cannabis with, and Barbara had become increasingly concerned about his wellbeing at this time;

'he'd gone with some friends to a nightclub, and I remember being called to the hospital and he'd been assaulted very, very badly. He had a broken nose,

he had a cheekbone that was cracked, lost his sense of smell. And from that stage onwards his behaviour began to change’.

Barbara considered this assault to have been the trigger to the observed changes in Alex’s behaviour that followed. She did not consider her son’s cannabis use to be a possible contributing factor to the changes witnessed in his behaviour, viewing his cannabis use as ‘*dabbling*’ as it was not ‘*serious class A drugs.*’

Following the assault on her son, Barbara observed concerning changes in his behaviour. Alex appeared to be withdrawing and distancing himself from family members and loved ones, often not returning home, or telling others of his whereabouts, and Barbara recalled this being a particularly stressful time for her as she struggled to make sense of what was happening. Barbara explained that these behavioural changes were out of character for Alex, and she described him as a ‘*quiet and unassuming young man*’ up until 19 years of age;

‘his behaviour began to deteriorate to a point where he’d go missing for days and I wasn’t able to find him or contact him. He wasn’t contactable on his phone or anything and it was so, so worrying for me. Even though he was an adult it was worrying because I didn’t know where he was and because he was so vulnerable it made it even worse for me.’

Barbara explained that during this time, Alex would go missing and the police would often be called and would bring him back home, or she would receive calls from the police stating that he had been found in a dangerous situation and to collect him from the police station;

‘one time, I had a call from the police to say that he’d been found on a motorway in the layby asleep.’

During the months that followed, Alex’s increasing risk-taking behaviour left Barbara feeling terrified and consumed by constant concern for him. She also recalled times when he was home with her, and he would go out and stand by his car and start acting ‘*bizarrely*’ in the street;

‘I would look through the window and I would see him, and he would actually be behaving in a very strange way in his car, or sometimes he would be

standing next to his car and be throwing things at it, and shouting at it for hours on end.'

As Barbara reflected on this time in her life and the constant concern she had for her son, she explained that she would often try to minimise the seriousness of what was happening, to both herself and to others. However, more prominent feelings of hope and optimism conflicted against a backdrop of worry and denial as she found her role as a mother often conflicted with her professional role. Consequently, this was a time when Barbara struggled to make sense of the escalating situation at home as Alex's behaviour became more unpredictable. As a way of coping and '*pac*ing' the situation, Barbara began withdrawing from wider social situations and avoiding conversations with significant others about Alex, but despite this, she remained hopeful that the situation would pass, and with her support, his behaviour would improve. In choosing to avoid situations that may have involved discussing the unfolding situation at home, Barbara's own behaviour changed as she started to avoid wider conversations about her son and/or having family members visit the house, mirroring Alex's social withdrawal and non-engagement with others;

'I found myself making excuses when friends wanted to meet up, I stopped inviting the family over. I purposely avoided the neighbours in case they mentioned my son's behaviour. Within a year, I wasn't really going out or seeing anyone much at all'.

Despite Barbara's initial optimism that her son's behaviour would improve, she grew more concerned about it and recalled that he started to spend more time isolated in his room, refusing to leave the house. Barbara recalled a particular time when she heard banging coming from his bedroom;

'then he started to refuse to go out and he would keep himself in his bedroom for days on end. He was dismantling his furniture in his bedroom, taking the draws apart, wardrobe apart, everything he was taking it all apart'.

Barbara acknowledged that almost 12 months from first noticing her son's '*bizarre*' behaviour, she had started to find the situation at home difficult to cope with and despite her avoidance in facing the seriousness of the situation, she recalled reluctantly making the decision to confide in her daughter. Following this conversation, Barbara recalled feeling under increasing pressure from her daughter,

who told her to *'do something about Alex'*, and to contact the GP, but Barbara was still reluctant at this stage and therefore refused to seek help.

As the situation at home became more unpredictable, Alex's behaviour deteriorated further. Barbara recalled her son starting to become *'more and more bizarre'*, and that he would spend much of the day talking to himself;

'my son would talk to himself a lot, there's nobody there but he'll be talking to himself. He would be talking to the television and that type of thing, you know, and I'd say to him, it's not the television, those people are not there, you know, there's nobody there on the television, why are you talking to the television?'

At this stage in Barbara's story, she recalled the expectations she had of herself as a mother, and that she held the view that she *'should be able to deal with Alex's behaviour'* effectively and be able to manage the situation on her own at home. The values Barbara held as a mother, and her view that she should be able to *'manage'* her son despite the deterioration in his mental health, fuelled her avoidance and denial about the situation. This was a coping mechanism that helped Barbara to manage her own feelings at this time and to facilitate a sense of control over her son's escalating psychotic symptoms;

'I knew there was something I had to do then. I was very reluctant to do it even though I, myself, it's ironic really, I should have known that that's what I should have done sooner, because he needed medication, obviously I know that now. But I thought I was Wonder Woman, and I could do this, but I didn't manage to do it because he was ill. Right. So that's how it really happened, that's how I began to realise my son is not well.'

As Barbara reflected, she spoke with a greater understanding of what she could have done and what her son needed at this time. Barbara acknowledged that her reluctance to accept the seriousness of the situation and to confide in others probably delayed her seeking the professional help he needed at that time.

Barbara acknowledged that the personal values she held as a mother initially prevented her seeking professional support for her son, as well as personal support for herself. This was further compounded by her own professional status and values

and the shame and associated stigma she experienced as her son's mental health deteriorated;

'it was quite a lot to do with my pride, you know, here I am a [professional woman] and I can't manage my own son. I don't know. Can I even say that? I felt ashamed that I wasn't able to manage him'.

Shame and stigma feature prominently throughout Barbara's story and as she recalled these feelings, Barbara appeared embarrassed and uneasy describing them. Following her conversation with her daughter, Barbara recalled the strain that this had put on their relationship, and described how they would often argue about Alex's behaviour and the way Barbara had chosen to manage the situation. For example, Barbara's daughter would tell her Alex was '*mad*' and needed to '*get professional help*'. Barbara described this time as being '*like a pressure cooker*' where she tried to find a balance between managing the unpredictability of her son's behaviour and trying to be a mother to both of her children;

'but the pressure mainly was to do with my reluctance to have him diagnosed, I just didn't want to accept it. I didn't want it to be that he was that unwell, I didn't want it to be right, you know? Because he was just my boy'

As Barbara's story unfolded, her reluctance to seek professional help for her son was fuelled by her concern about him being formally diagnosed with a severe mental illness, and what she perceived would be a stigmatising life-long label for her son.

As Barbara described this particularly stressful time in her life and her ongoing reluctance to seek professional help for her son, she explained that part of this reluctance was around her fear of her son being labelled with a severe mental illness;

'it was the issue of labels, labelling people. I now realise that a label is very useful, obviously, in mental health because it can get you, unfortunately you need a label to get the services that you need'.

Barbara's reflection highlights that despite her concerns during the earlier stages of her son's illness, her reluctance to seek professional help, and her own feelings of shame and stigma, receiving a formal diagnosis was crucial to her son's mental health. Barbara now views her son's diagnosis of schizophrenia as important and

helpful, and which facilitated access to professional support, medication and intervention that was appropriate to his needs.

Barbara's son was diagnosed with schizophrenia aged 21 years, two years after Barbara had noticed changes in his behaviour. Barbara had reluctantly contacted Alex's GP, and he had been referred to secondary care mental health services. Barbara recalled her devastation as she learned of her son's diagnosis in a meeting with Alex's psychiatrist;

'And I remember sitting there thinking he is being very gentle with me, and he was very considerate, He was asking me questions which I answered honestly, obviously. And then I was asked by the psychiatrist, what did I think the issue was with my son, you know, what did I think it was? Did I recognise that it was a mental health issue? And I said, yes, I think it is, obviously, but I, I didn't know what it was. And then he told me about schizophrenia, and that that's what it was, and I became very upset, uncontrollably obviously, because it was such a huge thing to learn.'

When Alex received a diagnosis of schizophrenia, Barbara explained that she felt worried and uncertain about his future and recalled how she had difficulty discussing this with the rest of the family. The issues of shame and stigma continued to permeate Barbara's story as she worried about what other people would think of her son, and perhaps of her also, as his mother and qualified professional. Consequently, Barbara found it difficult to share her son's diagnosis with even her closest relatives and struggled to tell her daughter in particular;

'I had the difficulty of deciding what to tell my family, my daughter, about what the diagnosis was because there was so much stigma against schizophrenia and I was worried about their wellbeing then, you see. How would they react to the news?'

Once again, the values and beliefs that Barbara held as a mother and a professional influenced her ability to discuss her son's illness. This was compounded by a personal need to protect others from experiencing the same feelings of stigma and shame. Although Barbara knew a diagnosis of schizophrenia was serious, and she therefore worried about her son being labelled, on reflection, she acknowledged that she had not fully considered the wider implications of this for her son or her family.

Barbara had not anticipated how catastrophic and chronic Alex's illness would become, or of the impact this would have on her own life and her own emotional well-being.

'I knew it would be a lifelong thing, but I never dreamt at that stage that it would be so difficult for my son. I never dreamt at that stage that it would be difficult for my son to ever go out and live on his own, but he was so poorly we needed him to be stabilised, really. So, there we are. He was diagnosed with schizophrenia'.

Barbara recalled 30 years of trying to manage her son's unrelenting difficult behaviour; and even with anti-psychotic medication, this fluctuated considerably. The symptoms of Alex's illness in the years following diagnosis were disruptive to both of their lives, and this 'forced' Barbara to make some significant personal and professional sacrifices. When Alex was 25 years old, the unpredictable nature of his psychotic symptoms meant that Barbara could no longer work in the role she had held and enjoyed for many years. She described always being 'on edge' at work at this time, waiting for the next phone call about the next crisis and so she resigned from her role and obtained employment in a different area, which she could do largely from home;

'it wasn't something I would have done, had the situation with Alex not happened. I was very happy in my job and I did it well, but sometimes you have to prioritise other things, he needed me at home and I felt better being able to be around, even though I gave up my job and all the things that went with it; friends and colleagues, you know?'

As Barbara described her change of career at this stage in her story, she appeared to be more accepting of her son's diagnosis and recalled being driven to find appropriate support for him with a willingness to engage with mental health services. Despite Barbara's growing acceptance of the situation however, she explained the difficulties she experienced in trying to access appropriate services for her son. She explained that trying to navigate services on her son's behalf was often 'frustrating' and 'time consuming' and that there appeared to be a reluctance by some services to provide support to those with a severe mental illness. Barbara reflected on her knowledge gained from her professional role and how this helped accessing the

correct services and support her son required. Despite her professional knowledge however, it was challenging for Barbara to do so;

'but at that stage he was so poorly. We needed him to stop dismantling his furniture in his room, we needed him to socialise again. It was so difficult to get him the help he needed, proper help. It was probably easier for me to access services for my son than it would [be for someone else because of my professional role]. I know where to go, I know who to talk to, I know how to talk, I know what to do to access services for him. But it... it was difficult. It was difficult'.

Barbara's son subsequently started to receive more support from relevant mental health services, primarily involving a psychiatrist and a nurse from the local community mental health team, but this support was described by Barbara as being mainly focussed on medication rather than any type of psycho-social support. Barbara reflected on times when the psychiatrist wanted to increase her son's anti-psychotic medication against her wishes as she believed there was an over-reliance on increasing the dose, and an absence of any non-pharmacological intervention;

'So, there'd be a lot of pressure from the mental health team with regard to medication, shall we just increase it to 7.5, maybe, you know, another increase? And I'd be, no I don't want that'.

Barbara's professional role was important throughout her story and underpinned much of her resistance against, what she viewed as, a medically driven model of care for her son. Barbara reflected on this when telling her story and explained how it was incongruent with her view of the social model of care that she found more acceptable and important for her son. Her dissatisfaction with her son's care and support being primarily medication focussed contrasted with her view that her son should be more enabled to live his life within the context of his illness, where the focus was on building upon his strengths and supporting him to engage in more social activities;

'You know. I just wanted him to be there and to enjoy his life. To get up in the morning and, you know, go out and do things'

As Barbara recalled her own reluctance to seek help from mental health services, and then, when she did, her opposition to what she saw as a medically driven model of care, she explained that her son was also reluctant to engage with services;

'And it was a battle to begin with to get my son to accept the services as well. And the reason, is pride, my son's pride'

Despite Barbara presenting a more accepting view of her son's illness, at this point in her story, there remained a sense of avoidance and denial that permeated through the stages of her narrative. Barbara's reluctance to initially seek professional support was also mirrored by her son, as she attempted to encourage him to engage with the support offered. While Barbara viewed this reluctance as being connected to her son's pride, there was a sense that this was perhaps more to do with her own feelings about her son's diagnosis and the healthcare that was offered.

Throughout Barbara's story, she referred to a perceived lack of support from her extended family and described the personal shame and stigma she experienced. This led to Barbara consciously keeping information about the situation at home from others. This concealment featured extensively throughout Barbara's story and was influenced by her ongoing reluctance to discuss her son's illness, which was further compounded by the associative stigma she experienced. In concealing information and avoiding circumstances where Barbara had to discuss her son, she subsequently alienated herself from significant others, who may have been able to support her.

Barbara was hyper-vigilant to her family's concern and requests for information about Alex. Barbara explained that she viewed any concern raised by her family about her son as *'interference'* and *'constant questioning'* and stated that she would always defend her son;

'So I would get that from them. 'Why is he doing that? Why is he doing this?' And I would always defend him, and I'd say, well, you know, he's not very well, you know, today he's having a bad day. Because he still has good and bad days'.

By viewing family concerns as critical and interfering, Barbara adopted a defensive stance towards others who may have been genuinely concerned about her son's

well-being. This further isolated her and her son from accessing support from family members. Barbara recalled feeling constantly criticised by family members and she felt that her role as a mother was sometimes brought into question. Barbara explained that she struggled when other family members gave their opinion regarding her input into her son's care and although there were times when she realised they were trying to be supportive, most of the time she found their comments upsetting and felt that they were suggesting that she was in some way to blame;

'and people would say, 'you're spoiling him, you've always spoiled him, you've done too much for him. What are we going to do when you're no longer here? What is he going to do when you're no longer here? Who's going to look after him? How is he going to feel?''.

As Barbara recalled this part of her story, feelings of blame and guilt surfaced. She reflected that she faced a dilemma regarding her son's ongoing care, where she was his main carer and also a gatekeeper to support both from professionals and from other family members. There was some slight recognition that she perhaps did too much for her son but in Barbara's view, she was the only person that could advocate for her son, and he was her responsibility. It is at this point in her story that Barbara became visibly upset and reflected on her feelings when family members asked about what would happen to her son when she was no longer around;

'you know, he's gentle, he's a gentle person. And that makes me upset when I think about me not being here for him, you know?'

The stigma associated with severe mental illness and the diagnosis of schizophrenia permeated Barbara's story. Barbara recalled her initial lack of acceptance of the significance of her son's behaviour early on in her story and then a reluctance to seek support from mental health services. Barbara explained that since her son received the diagnosis of schizophrenia over 30 years ago, they had not openly discussed it, either amongst family members, or with Alex himself;

'he sort of knows that he's got mental health issues, but do you know, we don't, we don't ever say that word in our family. We don't even say, you know, you suffer from schizophrenia, we don't do that, we wouldn't do that'

Barbara reflected on this concealment, and she was keen to offer a possible explanation regarding the lack of discussion within her family regarding her son's diagnosis and the omission of key information;

'It's to protect him, really, if you like. We don't discuss it, there doesn't seem a point in discussing it as he will get upset, we will all get upset.'

Throughout her story, Barbara's role as a mother is underpinned by her need to protect both her children in the context of her son's illness and to conceal this from others. Barbara explained that the conversation of her son's illness never arose with others outside of the family, but that it was part of her life that was '*kept a secret*' and as Barbara explained this, there was a sense of sadness and remorse;

'you feel as though you're ashamed to tell someone that that's what it is'

The issue of concealment was very important to Barbara's story and was fuelled by both the feelings of shame and stigma experienced as well as the innate sense of responsibility to protect her son. The concealment of information significantly affected Barbara's life, it perpetuated her stress and anxiety, delayed her son's diagnosis, and continued to affect communication and relationships with her close and wider family.

Barbara became visibly upset at times, as she recalled her experiences since Alex's behaviour changed following his assault. She described how remembering some of the events that occurred since her son became unwell was difficult and there was a sense of loss as she reflected. At times, this was acknowledged more specifically by Barbara, particularly in relation to the loss of an imagined future for both her son and herself;

'I do sometimes wonder what his life would have been like, you know, had his illness not taken a hold of him. Would he have had a job and a family of his own? It wasn't meant to be for him though, was it? He doesn't know any different, but I do, I do. I wonder about my own life, what would I be doing now had my son's illness not occurred. Would I be enjoying my retirement, travelling the world, having hobbies, friends, grandchildren?'

Barbara also reflected on her own vulnerability in the context of her son's illness as she recalled both her own and her daughter's concerns about her age and her ability to care for her son;

'she [daughter] reminds me I won't be around forever, and that upsets me, but all the time I am getting older, I am 78 now and he is still with me, and he is still alive. He has got to cope when I am not around, I am not superwoman, and I worry myself sick as to what will happen when I'm not here'

As Barbara discussed a time when she would no longer be able to care for her son, she became visibly upset and there was once again a sense of avoidance or denial regarding any plan of what may happen to Alex. Barbara alluded to her daughter's attempts to discuss this, but Barbara had been reluctant to engage in the conversation and develop a potential plan. Instead, Barbara changed the focus of her story and recalled attending a meeting with her son and his psychiatrist where she tried to explain to her son there would be a time when she would be unable to care for him, and a time when she would die;

'but he told the Psychiatrist, 'everything is alright, I've got my mother, it is always my mother. I have got my mother', so we have got to get him to realise about the future'

The loss and grief experienced by Barbara was palpable. The sense of avoidance or unwillingness to discuss pertinent issues with her close family and significant others, compounded this, leaving Barbara feeling isolated, alone, and unable to accept any offers of support from significant others. The superhero analogy that she referred to twice throughout her story may have significance in how Barbara portrayed herself to others as a mother and main carer to her son.

4.4 Presenting Frances

Frances was a married mother of two in her early 70's who had worked in education prior to retirement. Frances's son, Gareth, now aged 43, received a diagnosis of schizophrenia over twenty years ago. Usually, Gareth lived with Frances but at the time of the interview, he was an inpatient, detained under section 3 of the Mental Health Act (1983). When I met Frances, she had pre-prepared notes and had

chosen some photographs to show me to help inform our discussion. She stated that being able to share her story was '*long overdue*' and she hoped that by taking part in the study, her experience would help other families and enhance mental health service provision for families and carers. Frances was one of just two participants who chose to use photographs to tell their story and the only participant who included photographs within the three 'gold star' cases presented. Frances chose five photographs to help inform her story telling but also made reference to a framed photograph on the wall of her living room throughout the interview. A description of the photographs Frances chose can be found in Appendix 5.

Prior to Gareth becoming unwell, Frances had been a very proud mother. Both her son and daughter had excelled at school and she and her husband had spent most weekends travelling around the UK as their children competed in extra-curricular activities. Gareth had competed in sport at a national level until he left school at 18 years of age, and up until this point in Frances's life, all her free time was taken up supporting her children to be the '*very best they could be*', academically and within sport. Frances's son received a diagnosis of schizophrenia aged 22, shortly after completing a bachelor's degree in science at university.

Understanding the reason why her son developed schizophrenia was important to Frances. Much of her story focussed on this as she described her initial confusion when, aged 20 years, Gareth started to become unwell. Frances related this time to the break-up of her son's relationship with his first serious girlfriend while he was at university. She viewed this relationship breakdown as the '*trigger*' to him becoming unwell;

'In his second year of university he had planned to live in a flat with his girlfriend, but the relationship had come to an end, so he ended up in a stressful situation where he'd finished a relationship but he was actually living in a flat with a girl that, you know, that he was very serious about. I think that's where his stress started. I think that's where all this started.'

Frances recalled that following his relationship breakdown, Gareth's university work started to deteriorate, and he did not appear to be motivated about his studies. Frances blamed this on the break-up of his relationship and recalled thinking that the situation would improve within a few months, as her son moved on with his life.

Frances however, noticed continued changes in her son's behaviour; he stopped visiting home as often, ignored her phone-calls and became 'distant' and 'withdrawn'. Frances reflected on this time with a sense of sadness and concern as she described becoming increasingly worried for her son's wellbeing and the significant changes she was observing;

'we thought perhaps drugs were involved, we were seriously beginning to think that there was a major drugs problem. Because we couldn't put our finger on anything and he wasn't coming home so often, we were seeing less of him, and it was just this complete change of personality from the person that we knew'.

As Frances witnessed Gareth becoming more withdrawn and 'disinterested' she recalled feeling confused and consumed by worry as she searched for possible answers regarding the change in her son's behaviour.

Over the next 12 months, Frances recalled her son, now aged 21 years, becoming more withdrawn and isolated, refusing to engage in any communication with her. Frances remembered a particular time when she drove over 50 miles to visit her son in his flat at university, but he did not invite her in, and kept her on the doorstep with the door 'only open an inch or so'. Frances remarked how out of character this was and how offended and hurt she had felt at the time, when he did not invite her into his flat;

'not inviting me in was the most unsociable thing to do - and so unlike Gareth. He was a highly sociable person, you know? And for him to do something like that was shocking. I had driven all that way just to see him and then didn't even get invited in. It's not even as if anyone else was in the house. I was so upset driving home; I was concerned about him, but I was also hurt and very, very sad. We didn't bring him up to be like that and I really couldn't understand why he would treat me like that. It was as if I were a stranger'.

In the weeks following her visit to Gareth, Frances had grown increasingly worried about him and had noticed how disengaged he had become in all aspects of his life. Frances recalled how she felt it would be best for Gareth to be home and she persuaded him to return from his university accommodation. Once Gareth returned

home however, Frances became more concerned about the changes in his behaviour;

'we tried to convince him to come home, have some time out, a rest. He finally agreed and came back home but we just became more worried as he spent all his time in his room, he didn't initiate any conversation, he stopped looking after himself, he stopped bothering with friends, with his sister'.

At this stage in Frances's story there was a sense of desperation, as she continued to look for possible reasons for the change in her son's behaviour. She described how difficult she found Gareth at home, and that he was beginning to be a '*total burden*' who consumed her thoughts. Frances acknowledged the importance of Gareth being able to talk to someone and described how she would attempt to facilitate a conversation where Gareth felt able to tell her what was wrong. She also encouraged him to speak to someone other than her as she recognised that Gareth may have found this to be more acceptable;

'he just became a total worry and a total burden to us because we didn't know what on earth was going on. And then, I kept saying 'you need to talk to somebody, you know, is there a problem? are you on drugs? are you gay and you don't want to say something?' You know, giving him every opportunity to tell us what the problem was, and he couldn't do it'.

The burden Frances felt as she reflected back on this time was exacerbated by her desperate attempts to find out what was happening to her son so that she could '*fix*' him. This was further compounded by her son's '*passive*' behaviour which presented a unique challenge to her relationship with him and the stress that she experienced in response to the unfolding situation. She asked her son repeatedly what was going on, what was happening to him. Eventually, Gareth told her what he was experiencing;

'I sat with him on the sofa, and he was so distressed, he'd lost a lot of weight, he was obviously distressed, he was crying, and I said 'what is the matter? We need to know what's wrong' - he said 'I'm hearing voices'.

Frances recalled the shock she felt at learning that her son was hearing voices, and that out of the possible reasons she had considered for her son's change in

behaviour over the preceding months, mental illness had never crossed her mind. At this point in Frances's story, she explained that she had held negative beliefs about mental illness and the people affected by it. These negative beliefs were underpinned by stigmatising views and opinions that Frances held, informed by stereotypes and societal assumptions that framed how she viewed people with severe mental illness. Frances's views of mental illness had remained unchallenged until this point in her life and were particularly difficult for her to confront as her son's mental health deteriorated;

'I thought mental illness affected other people, not anyone I knew and certainly not anyone in my family. I couldn't quite get my head around it, that my son, my very successful, bright, sporty son had this thing, this thing that was so abhorrent to me that I would now have to deal with'

The shock that Frances experienced as she recalled this part of her life was palpable and this was further compounded by a profound sense of loss as she struggled with the dissonance between how things were and how she felt things ought to be. As someone who had been incredibly proud of her son's academic and sporting achievements, Frances reiterated her son's success but now, in a different context, that conveyed her recognition of lost opportunities and lost potential;

'the bottom just fell out of my world at that point because the potential that that lad had got, was immense. I mean, he went to university with excellent A-levels, he was on an excellent course, doing really well in his first year, he'd been in a band, he'd been [very sporty, at an international level], you know, the potential he had...'

Frances's stigmatising views associated with mental illness featured throughout her story. She described her own thoughts about mental illness at this time, particularly in relation to people with schizophrenia and the negative opinion she held of them. Frances apologised for this as she told her story and, as she reflected back, recognised that her own lack of knowledge and awareness fuelled her negative opinions;

'the minute he said I'm hearing voices I, not knowing anything about it, assumed it's a mental illness and he's got schizophrenia and to me anybody

who had schizophrenia were like, I'm sorry to say this, I thought they were the lowest of the low'.

Frances recalled struggling to make sense of the situation and how the feelings of hope that she had for her son's future had now turned to feelings of uncertainty and worry. Frances immediately recognised the severity of the situation, and that life would be difficult for her son from this point on;

'I just felt like I'd been hit with something, you know, because I'd spent, up until that minute when he told me he was hearing voices, I'd spent thinking about his future and developing his future and the minute he told me, I thought, oh, this is the end, he's going to have a difficult life from now on'.

This was a defining moment in Frances's life. The overarching sense of loss that Frances experienced continued to permeate her story, as she began to acknowledge the implications of her son's condition on him and the rest of the family;

'You know, in that instance it was a realisation really that our lives were never going to be the same again'

Despite the worry and uncertainty that Frances felt, she recalled that this was also a time when she tried to start making sense of what had been happening. Knowing that her son was hearing voices allowed Frances to slowly start to process what had been happening over the past 12 months and provided a reason for Gareth's behaviour;

'And perhaps I shouldn't have been so pessimistic because I didn't know enough about it really or perhaps I should, I don't know. But it sort of all fell into place, it sort of explained a lot of the things that had been going on'.

Gareth did not return to his university town following the revelation that he was hearing voices but continued his studies from home. Frances felt more reassured having her son back in the family home, where she could keep 'a closer eye on him'. Despite her initial shock, the knowledge that Gareth was hearing voices provided a catalyst to Frances developing a greater understanding of the unfolding situation, and also facilitated her taking a more pragmatic and problem-solving approach in supporting Gareth at home. Frances explained that her renewed sense of purpose at this time, reinforced her role as Gareth's 'mother and chief supporter' and she

recalled with a sense of hopefulness how she attempted to access support for her son;

'After the initial shock, I thought, well at least now we can do something about it, we can get him the help he needs, some medication and then the voices will go away. So, it was very much, right, let's get this sorted, lets contact the GP, get him on medication and cured and then he can go back to university'.

Despite her initial optimism however, Frances explained that the GP dismissed her concerns and '*played down*' the situation at home, leaving her angry and frustrated, and she therefore requested a second opinion from a private GP. This consultation resulted in a referral to the local community mental health team where her son was assessed by a psychiatrist and commenced on anti-psychotic medication. The psychiatrist explained to Frances that her son was experiencing a psychotic episode, but Gareth was not given a formal diagnosis of schizophrenia at the appointment. Once again, a sense of hopeful optimism was evident at this point in Frances's story as she believed the situation would be short-lived;

'the psychiatrist said that he was experiencing a psychotic episode which led me to believe that it was a one-off. I really believed that the anti-psychotic medication would get rid of the voices and then Gareth would revert back to his normal self. I thought he would be on the road to recovery, fully. The word schizophrenia had not been mentioned at that point'.

Frances's hopeful optimism at this point in her story contrasted with her initial negative thoughts and feelings around severe mental illness and how she viewed Gareth's future when he told her he was hearing voices. As Frances's story unfolded this dialectical dilemma became more pronounced as she moved back and forth between the two opposing viewpoints. Frances recalled how this affected her ability to support her son as she moved from a position of motivation to despair, and back again. This was further compounded by the realisation that the anti-psychotic medication Gareth had been prescribed had little impact on his mental wellbeing and behaviour;

'I swung from feeling quite upbeat at times when I really thought things would improve and he would get better, and I was up for the challenge. But at other times, I was consumed with feelings of dread and thoughts that it would only

get worse. At times I was energised but there were days when I wanted to take to my bed and hide away from everything. He had been taking the medication but there was little change at all, that was pretty soul destroying actually'.

A few months after his initial consultation with the psychiatrist and the commencement of anti-psychotic medication, Gareth, aged 22, completed his university degree. The graduation day was a defining moment for both Gareth and Frances as his psychotic symptoms began to unravel. Frances recalled looking forward to the graduation ceremony, although Gareth was initially hesitant to attend, as he had lost contact with his peers some months previously. Despite this reluctance, Frances persuaded Gareth to attend, as she was concerned he would regret not doing so;

'Because he'd ordered the gown and everything and I was all geared up for going, like you are, so we sort of not pushed him into going but cajoled him into going'.

Frances explained that she was determined for Gareth to mark the end of his degree, but with hindsight recalled this being driven by her own wishes at the time, as she had been looking forward to celebrating his success. Educational success was important to Frances, not just as a mother but as a (retired) professional, and her story is punctuated with moments of pride relating to both her children's educational attainment, as well as their sporting success. Whilst she looked forward to the graduation ceremony, once there, Frances recalled that it soon became apparent that Gareth found the situation extremely stressful;

'he was in with a load of people that he didn't seem to know or recognise or anything so he was terribly stressed and, as the day went on, he became more distracted and it was clear he was finding things really difficult'.

As the graduation day progressed, Frances noticed Gareth's behaviour deteriorating further and that he was *'becoming confused with his words'*. Frances recalled being very concerned, as maintaining a coherent conversation with her son was becoming more difficult;

'after the service we went to see my daughter, who at the time was living away, and I remember making a comment on the way there, something about which

way did the man go, and he was talking about a mango fruit and he was totally, you know, off the wall'.

Frances recalled feeling *'out of her depth'* at her son's graduation as her son's speech became affected and that she felt she was *'going through the motions'* on the day despite recognising that her son's mental health was deteriorating. As Frances reached this part in her story she became visibly upset, she looked at the photograph on the wall of her son in his graduation gown and explained how guilty she had felt encouraging him to attend the ceremony and how guilty she still feels when she looks at his graduation photograph;

'I mean really, I pushed him over the edge, encouraging him to go to the graduation. I know now the mistakes I've made; I know what they were, but at the time I really thought I was doing it in his best interests, that in the future he would regret it if he didn't go'.

Frances looked back on the graduation day that she was desperately looking forward to as *'a day of torture'*. It signified a turning point in her story and one that marked the end of one phase of her life and the beginning of another;

'our lives were never going to be the same again'.

The day after his graduation, Frances was confronted with what she described as her *'worst nightmare'*. Gareth would not get out of bed and was *'mumbling'* to himself incoherently. He did not respond to Frances when she spoke to him and *'he could not string a sentence together'*. Frances described how, when he did attempt to speak, Gareth's words were all *'jumbled'* and how, at first, she feared he may have suffered a stroke. Frances eventually managed to take her son to the GP who arranged for an urgent, same-day, mental health assessment at a local psychiatric hospital. At the hospital, Frances described sitting alone in a small waiting area as her son was assessed by a psychiatrist and mental health nurse in one of the consulting rooms. Frances was affected deeply by the experience and recalled how she felt as she waited for her son;

'it totally floored me because I didn't know anything about these places and I sat and I waited while he went in. I was there on my own and I remember feeling cold and shivery and thinking there was nobody walking in and out, the

place was dead. He was in there for ages, and I remember thinking what a lonely place to be. It was awful'

As Frances recalled her experience of sitting in the hospital waiting room, she reflected on her thoughts at that time and how her son had reached this crisis point. Frances explained that she had been convinced that the medication initially prescribed by the psychiatrist would have resolved the symptoms her son was experiencing, and he would quickly return to his former self and be able to continue with his studies or employment and that his life would return to 'normal'. However, this sense of hopeful optimism dissipated as Frances sat waiting for her son's assessment to finish and she recalled her frustration and disappointment at the lack of information she had been given at her son's first consultation with the psychiatrist months earlier. This was further compounded by Frances's own response to her son's symptoms and how she had remained optimistic, despite the severity of the unfolding situation;

'I felt that they should have warned me more that there was a possibility that that might not happen. But nobody warned me, nobody said if he stops taking his meds it's going to go this way, and I assumed he was taking his meds you see. I thought he was going to go from strength to strength to strength and I was lulled into a false sense of security at that point'.

Frances explained how Gareth was assessed by a 'very cold and matter of fact' psychiatrist who informed her that her son was experiencing a mental health crisis and needed to be admitted to hospital under the Mental Health Act (1983) due to his psychotic symptoms;

'He ended up being admitted. It all happened quite quickly in the end, I couldn't quite get my head around what was going on. Looking back, I knew things were bad but I don't know if I was in denial or I truly believed things would improve but there he was, being admitted to a psychiatric hospital'.

As she reflected back on Gareth's admission to hospital where he received a formal diagnosis of schizophrenia, Frances's experience of the past 20 years became more apparent. Frances described significant feelings of guilt and a personal sense of responsibility, viewing herself as culpable for not only Gareth's first admission to hospital and subsequent diagnosis, but the cycle of admissions he has had since. Her

feelings were compounded by Gareth receiving the 'label' of schizophrenia and her view of the significant impact and suffering his illness had on the wider family;

'If I had not convinced him to go to his graduation, perhaps none of this would have happened. Perhaps he wouldn't have become so stressed that he couldn't speak, perhaps he wouldn't have been admitted to hospital. Perhaps they wouldn't have labelled him with schizophrenia. I pushed him too far and we have all suffered because of that. It started a cycle of admissions where he spends more time in hospital than he does at home'

The negative opinion Frances held towards those with mental illness and the stigma surrounding schizophrenia contributed greatly to the feelings of shame and embarrassment she experienced. The shame experienced by Frances was also fuelled by her own self-criticism and her previously held view that those with severe mental illness were the 'lowest of the low';

'I was thinking what other people would think about my son. That my opinion of people with serious mental health problems were that they were like the down-and-outs in society and, you know, they'd had a bad time and that they were just mad, really'.

This view of severe mental illness was incongruent with Frances's personal values as a mother and professional and the impact of this internal conflict on Frances was profound. It facilitated concealment of information where she deliberately altered her own behaviour and avoided social situations where she may have felt obliged to discuss her son, resulting in Frances experiencing social withdrawal, loneliness and low self-esteem;

'I kept it hidden. I didn't talk about it to anybody. [I mean I was a professional working in education]. I never mentioned the word schizophrenia, would never have said that. It wasn't until after I retired, and I left the situation of being in work that I was able to start talking about it. Up until then, I avoided any gatherings or social events where someone may have asked after him and I would have felt pressure to discuss him. It was a lonely time really and I could feel my confidence and my own mental health dipping'.

The shame Frances experienced was multi-faceted, affecting her behaviour, her work life, her own mental well-being and how she communicated and interacted with others. By avoiding social situations and concealing information about her son, Frances excluded herself from the informal support mechanisms that were around her, further exacerbating her sense of loneliness and isolation. Consequently, over time, people stopped asking her about Gareth, as if he was invisible or forgotten about;

'I don't discuss my son's illness with anyone, in fact, I don't discuss him at all. And people don't ask after him anymore, sometimes it is as if he doesn't exist. My husband has very different views about the situation than I do, so we have stopped discussing it. It's a lonely place to be really.'

Throughout her story Frances recalled times when the situation at home would cause feelings of despair, particularly in relation to when her son would be detained under the Mental Health Act (1983). With each admission to hospital, Frances described her son deteriorating further;

'the long and the short of it is he's had quite a lot of re-admissions really and he's never ever got back to being as good as he was, there doesn't seem to be a space in between where he gets better. He just seems to get worse and worse and worse'

The impact on Frances of Gareth's multiple admissions to hospital over the past 20 years was profound. As Gareth's illness became more established, he continued to hear voices, neglected his personal hygiene, and developed delusional thinking that Frances found particularly difficult to deal with. The unrelenting nature of his illness compounded Frances's sense of despair and hopelessness;

'The voices have never gone away despite the amount of medication being pumped into him. He has some strange thoughts about some sort of conspiracy that is going on and that often leads to arguments at home when we disagree with him. He doesn't look after himself, he has become the great unwashed. It has been incredibly difficult to have him at home when he is supposedly well. Most of the time I dread him going back into hospital, but I also dread him coming back home again, so I don't know.'

Frances described a sense of worry about the future and her advancing years. Although at times she reported difficulty in accepting her son's illness, it was apparent that Frances recognised the severity of the situation and the lack of support her son receives from other family members;

'I worry about the future a lot. Mainly, I worry about not the immediate future, but I worry about what happens to him when I'm not here anymore.'

Frances's concern about her son's future after her death punctuated her story at times and there was a sense of her being alone in her caring role. Frances did not make any meaningful reference to her husband or daughter during her interview and their part in supporting her and her son. This impacted on the sense of loneliness and isolation in caring for her son and the feeling of despair that was evident throughout her story.

Frances experienced multiple losses throughout her life as a result of Gareth's illness. In a reflective moment as she told her story, Frances described not only grieving for the son she once had but also, the son she could have had, as well as her daughter's loss of an extended family and the loss of her own hopes for her family as they grew older;

'you wonder what your life would have been like if it hadn't of happened, you know, if he'd got married and had kids, and my daughter would have had her brother and... her kids would have had cousins. You wonder about what job he would have had; he was bright, he was going places with a degree in [science], but it wasn't meant to be was it?'

Frances recalled that she imagined what may happen if Gareth developed more insight into his condition, something that he never fully had despite the fluctuating nature of his illness. She described her concern that her son may one day realise the severity of his illness and reflect on a lost life, and as Frances discussed this, there was a sense that she was still trying to reconcile the situation herself, despite the passing of time;

'if they do take him to rehabilitation and his senses come back and he's more with it is he going to get a point where he thinks, oh God, my life's gone and I've got nothing, you know?'

The sense of loss that Frances experienced as she reflected on the past 20 years was palpable. Feelings of sadness and grief were compounded by her experience of the wider repercussions of Gareth's schizophrenia and how this impacted on his civil liberty and freedom. Frances articulated this in a way that was at the same time, both monumental and inconsequential;

'I am sad for him that he has been sectioned because once you're sectioned it like stays with you, doesn't it, even when they release the section. It's like, you know, you've been sectioned in the past, you can't go to America and things like that'

4.5 Summary of findings

This chapter presented the three 'gold-star' cases of Carol, Barbara and Frances, that were fully analysed using the nine stages of BNIM. The narratives drew on the mothers' experience of the initial stages of their daughter or sons' illness, receiving a diagnosis and the impact on their lives since. All participants reflected on the difficulties in accepting the changes in their daughter or sons' behaviour and an initial reluctance to seek help. The stigma associated with mental illness and schizophrenia specifically, was a prominent feature of the participants' stories. The disruption to their own lives in the context of their daughter or sons' illness was also significant and the associated despair, loss, and grief, was profound.

The next chapter will present the findings of the tenth step of BNIM data analysis, the cross-case comparison and theorisation.

Chapter Five – Cross-case comparison and theorisation

5.1 Introduction

This chapter presents the final stage of the BNIM 10-stage intensive analytic process, the cross-case comparison and theorisation detailed in section 3.8.5 in chapter three. This stage builds on the previous nine-steps of data analysis, as well as the findings presented in the individual case presentations in the previous chapter.

5.2 Cross-case comparison considerations

A greater understanding of the impact of schizophrenia as a long-term condition, was facilitated with each maternal narrative, and the challenges of caring for a son or daughter with the illness, further illuminated. In this final stage of analysis, the individual biographies were collectively analysed, enhanced by utilising existing relevant, high-quality literature where appropriate and the voices and subjectivity of Carol, Barbara, Frances and the eighteen panel members who took part in the *lived life interpretive panel analysis* and the *told story interpretive panel analysis* discussed in chapter 3.

The cross-case comparison necessitated a return to the literature presented in chapter two, which includes relevant literature that is now somewhat dated. However, this literature offers seminal work on the experience of mothers of adult children with schizophrenia and are therefore included within this cross-case comparison and theorisation chapter.

Numerous tensions were negotiated in conducting and presenting this cross-case comparison and theorisation chapter. Firstly, it was important to retain the link between the socio (society or sociologically defined contexts) and the biographical (individual) as this is a defining principle of a socio-biographical study (Chamberlayne et al. 2002). Secondly, care was taken to avoid over abstraction and generalisation of case data that would risk reducing the ‘particularities’ and coherence of the mothers’ individual lives as mere ‘aggregates’ and ‘averages’ (Chamberlayne et al. 2002, Wengraf 2006). Finally, there was a recognition that the participants’ accounts were not whole life stories, but partial and selected accounts

told on a single-story telling occasion (Frank 2000). Wengraf (2006) argues that stories may be truthful, partly deceptive, and often self-deceptive and, as such, anything expressed in participant interviews should be viewed as 'fallible evidence of extra-interview realities' (Wengraf 2006, p59). The stories are told by social actors exercising discretion in the construction of their life trajectory (Wengraf 2006).

5.3 Developing 'themes'

BNIM offers a rich understanding of participant narratives and enables the researcher to establish a sense of how the apparently straight-forward is much more complicated, and how 'surface appearances' may be misleading about 'depth realities' (Wengraf 2006). One of the characteristics of BNIM, and of the findings in this chapter is the movement between the particular, the general, and back again, that is, from the differences between the mothers' narratives, to the similarities, and back again. This illustrates the relationship between mothers' narratives and the broader social discourse in their life stories.

The process of developing 'themes' was discussed in chapter three and an example of how this worked in practice can be found in Appendix 11. Three key themes were developed from the cross-case comparison and theorisation process. Firstly, how the experience of **stigma** was central to the mother's stories; secondly, how the mother's lives were **disrupted** due to their son or daughter's illness, finally, the means by which mothers expressed their personal experiences were framed by **despair, loss and grief**.

5.4 The experience of stigma

Goffman's (1963) seminal work on the concept of stigma identified three distinct categories of stigmatisation; tribal stigmas (such as race and religion), physical deformities (such as amputation and blindness) and blemishes of character (such as addiction and mental illness). Goffman (1963) defined stigma as an attribute that is deeply discrediting and considered how its impact on every-day interactions influences how the stigmatised avoid engaging with those who do not share their stigma. Underpinned by Goffman's (1963) work, two types of stigma specifically relating to mental illness have been identified: anticipated stigma, the extent to which a person expects to be the target of stereotypes, prejudice, or discrimination in the future and, internalised stigma, the extent to which people endorse the negative

beliefs and feelings associated with the stigmatised identity for the self (Quinn and Chaudoir 2009, Quinn and Earnshaw 2011). Carol, Barbara and Frances all experienced the 'blemished character' highlighted by Goffman (1963), which was further compounded by their own internalised stigma and the prejudiced opinions they held about those with schizophrenia. In light of this, all three used the following strategies to negotiate the stigma they experienced: concealment and secrets, and setting selves apart from others.

5.4.1 Concealment and secrets

The strategy most readily available to the mothers was to actively avoid situations or conversations where they thought they might be stigmatised. Across all three narratives, the mothers' public and private lives were separated, nevertheless their individual experience of stigma permeated the two aspects of their lives, and, as such, there was an avoidance of interactions on a personal level in immediate relationships and also, on a professional level, with their employers and colleagues. Frances felt unable to verbalise the word *schizophrenia* out loud and avoided conversations where the subject of her son's illness may have arisen;

*'I didn't say the word schizophrenia for fifteen years, because to be honest, I hoped they had made a mistake. I didn't say schizophrenia ever, it never got mentioned and I couldn't even discuss it or say the word to my own Mum'.
(Frances)*

Barbara and Frances were both aware of their stigmatised identities and kept as much information as possible to themselves, refusing to discuss their sons' illness even with their spouses or closest relatives. Both Barbara and Carol described how they deliberately avoided encounters with others where the subject of their child's schizophrenia may have been discussed and all three mothers described the concealment of information, even within the very inner circle of close family members, and what they did communicate, was always highly censored. Barbara recalled a particular time where she actively avoided a family gathering;

'I couldn't bring myself to go, you know. I knew they would all be asking after my son, and I couldn't think of anything worse than talking about how ill he was and what had been going on. I couldn't lie to them either, so I just said I was ill, so I got myself out of that one'. (Barbara)

Research highlights how a fear of a stigmatising label induces secrecy as a coping response within families and the subsequent impact on individual's self-esteem and self-efficacy (Boydell et al. 2006, Compton et al. 2006, Franz et al. 2010). Carol described how she slowly withdrew from social situations despite being a very 'sociable' and 'outgoing' person prior to her daughter becoming unwell;

'It slowly eats away at your confidence, you avoid social situations for fear of having to explain what has been happening and slowly but surely, before you know it, you haven't seen any of your extended family, you haven't seen any of your friends and the thought of doing so fills you with dread'. (Carol)

Frances reported keeping her son's illness hidden from her employer, refusing to mention the word schizophrenia until she retired. Sometimes, keeping secrets from significant others also led to risk-taking behaviours by the mothers. This was particularly evident in Carol's story where she would go out alone, late at night to 'rescue' her daughter from 'crack dens', never disclosing what she was doing or where she was going to her husband. Secrecy and the concealment of information was used as a coping mechanism by all three mothers, but this led to negative and unanticipated consequences. For example, the stigma they experienced influenced their withdrawal from social support and wider family networks and, at times, increased their own vulnerability, which put them at risk. The constriction of social support as a consequence of being stigmatised is highlighted by Greenberg et al. (1993) who assert that stigma is the most pervasive subjective burden experienced by families of those with severe mental illness.

5.4.2 Setting selves apart from others

At times, Frances used the educational status of herself and her family as a 'prestige symbol' (Goffman 1963 p43) to ameliorate stigma. This was also evident in Barbara's story, who used her own status as a professional to try to minimise the stigma associated with her son's diagnosis. All three mothers highlighted their social statuses, educational attainment, and professional standing, as if being different from other mothers of sons or daughters with schizophrenia, but they all believed they would be treated differently if others knew of their sons' or daughter's schizophrenia. Frances referred to her professional status and the educational attainment of both

herself and close family members repeatedly throughout her story as if this would perhaps mitigate in some way against any form of mental illness:

'I am an educated woman, [a professional], my husband has [a degree], my daughter a first-class honours degree and Masters. I didn't think this happened to people like us'. (Frances)

Barbara also repeatedly mentioned her role as a professional as if, in some way, this could have influenced her son's onset of schizophrenia and how she should care for him:

'And here I was, [a professional woman], with a son who was so desperately ill, who was psychotic and doing all sorts of strange things, and I can't manage him, I can't manage my own son. This sounds really selfish, but my own status was at risk'. (Barbara)

A further strategy utilised by the mothers to help them cope with the stigma they experienced was in making comparisons with others who were stigmatised. Goffman (1963) argues that stigmatised persons tend to display a separation from more profoundly stigmatised people within the same broad category. Barbara made comparisons that drew on her experience as a professional working with children who had been abused and Carol compared herself to those who had children with muscular dystrophy:

'I knew someone who had a child with muscular dystrophy, others treated her differently, and she had no hope of a husband, a family or a career. They had an awful time of things, it broke my heart to witness such a prolonged and degrading existence'. (Carol)

All three mothers experienced stigma because of their daughter or sons' illness. This included both anticipated and internalised stigma that was further compounded by their own personal prejudiced opinions about severe mental illness. The stigma experienced by Carol, Barbara and Frances was far reaching, and despite utilising a number of strategies to negotiate this stigma, it greatly influenced their lives and their relationships with their children, and with others.

5.5 Disruption

A predominant theme from previous studies exploring the experience of mothers caring for a son or daughter with schizophrenia was one of disruption (Ryan 1993, Eakes 1995, Tuck et al. 1997, Milliken 2001, Milliken and Northcott 2003, McAuliffe et al. 2014 and Wiens and Daniluk 2017). This theme was also clear from the individual cases and the cross-case comparison within the current study, where Carol, Barbara and Frances described how they experienced disruption both in terms of their relationship with their son or daughter, their other children and within their own personal and professional lives.

The stress and distress experienced by all three participants was evident as they told their stories of living with and caring for their adult children with schizophrenia. This was further exacerbated by the multi-faceted nature of the illness and the impact this had on their relationships with others which were often fragmented. Family and social relationships are a primary source of care and support for those who care for others with long-term conditions. This support, according to Rolland (1999), is vital to effective coping but in the context of a severe, mental illness, these relationships are threatened, causing distancing and a deterioration in family life. Whilst the stigma experienced by the mothers (discussed in the previous section) meant that they were already distanced from their friends and wider family networks, this was further compounded by disruption and fractured relationships with immediate family members. Ryan (1993) proposed three domains to the disruption experienced by mothers: constancy, the unremitting nature of the situation; centrality, the mothers' crucial role in providing care for their son or daughter coupled with the perceived lack of understanding and stigma associated with schizophrenia, and uncertainty, the ambiguous nature of schizophrenia and the unpredictability of day-to-day life. This mirrors the findings of the current study where the mothers experienced multiple disruptions to lives.

5.5.1 Disruption to the parent-child relationship

Carol, Barbara, and Frances all described a disrupted relationship with their adult son or daughter with schizophrenia. The symptoms of their child's illness, particularly the unusual behaviour they witnessed, made it difficult for the women to establish and maintain what they viewed as an adult relationship with their grown-up

child. This was exacerbated by the negative symptoms associated with schizophrenia where their children exhibited poor personal hygiene, poor social skills, and lack of volition. This type of disruption can be related to Ryan's (1993) domain of constancy, where it becomes difficult for mothers to engage in a 'normal' adult relationship with their son or daughter. The unrelenting nature of their parenting relationship, whereby their adult children were unable to achieve a level of independence and maturity associated with the particular stage of their lives was evident across all three cases, with Frances describing her difficulty in encouraging her son to look after himself;

'He is in his 40's and yet he is unable to organise anything himself. He can't manage bills, he can't manage relationships, he can't manage anything really. I have to ask him to wash and put clean clothes on, to take his tablets, to cook a meal. It's not just once either, I have to keep on and on because he just doesn't do it – it's like those things don't even feature in his world'. (Frances)

Barbara also described the difficulty that the symptoms of her son's illness created and the impact this had on their relationship;

'It is difficult for me to understand why he doesn't want to do anything, even the most simplest of things that we all do every single day. I have to constantly prompt and cajole him, sometimes it feels like I have a petulant child in my home, but I know he can't help it'. (Barbara)

Linked to Ryan's (1993) domain of centrality and the crucial role mothers have of providing care, Tuck et al. (1997) highlighted the blurred identities parents experience, from that of parent to caregiver. Carol echoed Barbara and Frances's frustrations and described the chaotic nature of her daughter's life and how this affected their relationship and the role she has as mother and caregiver;

'What my daughter does not have is capability. She hasn't got the capability to live unsupervised or to have supportive networks or to keep her accommodation clean, or to not impulse buy, or to not get involved with people who harm her. She just seems to go from one chaotic situation to another, taking to her bed for days on end, partying for days on end, excessively spending money or getting involved with people who physically or sexually abuse her. It is a conundrum that I have to live with every day. She

should be able to do these things and to manage them in a better way but she doesn't, so I have to'. (Carol)

5.5.2 Disruption to the relationship with other adult children

All three mothers had one other adult child and described the relationship between their son or daughter with schizophrenia and their siblings having been altered or disrupted because of the illness. Consequently, this also had a significant impact on Carol, Barbara, and Frances, as their own relationships with their other children were also affected. Across all cases there was a desire by the mothers for both children to have a meaningful relationship, but this was tainted by a sense of disappointment, as the mothers reflected on how these relationships had altered in the context of a severe mental illness. Carol described how Rebecca's older brother rejected a relationship with his sister following her diagnosis:

'He will have very little to do with her. He doesn't want her at his home, he doesn't want her around his children. And I have to say, I find that very disappointing. He wants her to go into care, he thinks she is not capable of living alone'. (Carol)

Frances reported that her daughter had taken a similar standpoint in distancing herself from her sibling, resulting in a lack of support for Frances and Gareth:

'My daughter has always kept the situation at arm's-length really, I am not sure if she cannot cope with it, or doesn't understand it but she has distanced herself since my son became poorly, the relationship has not broken down completely, but she doesn't go out of her way in any sense to support him, or me'. (Frances)

These fractured relationships between their two children contributed to Carol, Barbara and Frances's stress, distress, and sense of burden. The ramifications of this were far reaching, as all three mothers described disrupted relationships between themselves, their other children and consequently, their grandchildren. Carol described her regret at the impact of this disruption:

'I mean, I rarely get to see my grandchildren because he won't let me take Rebecca there, and when she is here, like on Christmas day, she can be okay, but sometimes she isn't okay, and he doesn't want his children to be

*frightened or upset. It has affected a lot of my relationships and I regret that'.
(Carol)*

Studies by Hatfield and Lefley (2005) and Seeman (2013) suggest that there is often an expectation that adult siblings assume caregiving responsibilities when parents are no longer able to do so. All three participants stated that although they longed for a more supportive and caring relationship between their children, they did not want or expect their other children to take over the caring role and did not want them to suffer the same disruption to their lives that they had experienced. Frances reflected on what may happen when she could no longer care for her son;

'I worry about us no longer being around and who will care for Gareth then. My daughter has her own life, a husband, a good job, and children of her own. She needs to focus on those things and not have to worry about her brother. It would be impossible for her to care for him, and why should she? He is not her responsibility'. (Frances)

Barbara described similar feelings as she reflected on the issue of responsibility for her son. There was a sense that Barbara's daughter wanted to help her in caring for Alex, for Barbara's sake, if not for Alex's. Despite this, Barbara admitted to concealing information as she attempted to protect her daughter from the disruption to life that she had experienced;

*'I try to keep most things from Alex's sister. She worries about me and will start to take over. I have always been clear that he is not her responsibility, she has enough on her plate with her own family. I wouldn't want her life to be put on hold to look after Alex. It's not even as if he would appreciate it'.
(Barbara)*

The mothers' concern about the impact of their child's illness on their other children mirrors findings by Wiens and Daniluk (2017) where participants lamented the loss of 'normal' family life and family relationships, the impact of the illness and how this may affect the future of their other children. Similarly, this study also found that mothers did not want their other child to feel a sense of responsibility for their sibling or to feel obliged to change their life plans as a consequence of it.

5.5.3 Disruption to the relationship with partner

Barbara was the only participant who did not have a current partner, divorcing the father of her children 30 years ago. Carol was divorced from the father of her children but had re-married. Throughout her story, Carol mentioned her husband on three occasions only, and alluded to the disruption to her relationship with him due to her daughter's illness. As Carol chose to keep much of her involvement with Rebecca to herself, she consequently revealed a level of concealment and secrecy within her relationship with her husband, particularly when this involved her 'rescuing' her daughter in the early hours of the morning from 'crack dens'. This concealment and secrecy was discussed in section 5.4.1, in relation to the stigma experienced by Carol, but this secrecy was also driven from a position of perceived protectivity, where Carol did not view her daughter's illness as her husband's problem;

'I don't ever tell him where I am going. He needs protecting from as much of it as I can. It is unlikely that these people [in the crack-dens] would hit a woman, much more likely that they will hit a big bloke with a beard. And anyway, it's not his daughter, it's not his problem, so most of the time, I don't tell him things. There is no point in telling him the bad things'. (Carol)

France's narrative also highlighted the disruption to her relationship with her husband to whom she had been married for fifty years. Frances alludes to the 'man's view' that her husband has of their son and his illness suggesting that she believed her husband coped differently with the situation:

'We definitely take a different perspective on my son, his illness and the level of support we give, and it has caused, not friction, but it has caused – we just agree to disagree on things. He is more chilled out, or appears to be, and I fret that, you know, he sees things from a different angle to me very often. He takes a man's view and has told me in the past that I need to back off, but how can I, he is my son, and he needs me'. (Frances)

A study by Nystrom and Svensson (2004) focussed on fathers' experiences of having an adult child with schizophrenia and found that most fathers interviewed experienced similar caregiving stressors to those reported in the wider literature that focussed on mothers' experiences. This is further supported by Davis and Schultz

(1997) and Ghosh and Greenberg (2012) who argue that men and women are equally vulnerable to the impact of the caring role. In Nystrom and Svensson's (2004) study however, some fathers viewed their wives as being too involved and too deeply concerned with their son or daughter's illness with some blaming their wives for failing to adapt to the situation (Nystrom and Svensson 2004). Wancata et al. (2008) examined gender aspects of parents' needs in relation to having an adult child with schizophrenia, and demonstrated marked differences between mothers and fathers. In examining the wider literature on the relationship between husband and wife in the context of schizophrenia it is evident that this is an area that warrants further investigation, as both parents do not always have the same experiences and men and women might define problems differently.

5.5.4 Disruption to family and professional life

According to Tuck et al. (1997), schizophrenia is a destructive force that interrupts and transforms the family life trajectory. The disruption experienced by Carol, Barbara and Frances in the current study was an evolving and continuous process that manifested throughout the different stages of their individual biographies. The disruption to family life is encompassed in Ryan's (1993) domain of 'uncertainty' and McAuliffe et al. (2014) domain of an 'uncertain pathway' in respect of the ambiguous nature of schizophrenia and the unpredictability of day-to-day life.

The structures of participants' everyday life and the knowledge which underpinned them were challenged. Carol, Barbara and Frances all described how their child's illness disrupted family life, their future plans, and how they had thought and hoped life would be in the absence of the illness. Carol explained that there '*was no spontaneity*' to family life, which was echoed by Barbara, as she described the level of planning required for any family occasion;

'We don't really have a normal family life. Everything we plan has to be carefully considered and there has to be a plan A, plan B and plan C to try to cover all eventualities. We can't be spontaneous in the way other families can because everything depends on how Alex is, how he is behaving and if he wants to get involved. If he does get involved then it feels as though we are all on pins, waiting for something to happen, or to put a dampener on things.'
(Barbara)

According to Ghosh and Greenberg (2012), employment has a powerful effect on the well-being of mothers who care for an adult son or daughter with schizophrenia. They argue that employment can provide a source of respite from the caring role and the everyday demands associated with caregiving and provide a sense of pride and a place where the mother feels in control of her environment. The participants in the current study were all professional women at the onset of their daughter or sons' illness. Carol and Frances had worked in education and Barbara held a professional role working with vulnerable people. Across all three cases however, the mothers reported that their sons and daughters caused them a great deal of anxiety and anguish, and a high level of involvement by them in their day to day lives. Consequently, all three mothers reported the disruption that their child's illness had on their professional life due to their disrupted homelives. Whilst Barbara was able to secure a job working from home so that she was able to care for her son, Frances remained employed but took early retirement due to the impact of her son's illness on her life. Carol gave up her job altogether, instead taking on a range of temporary part-time jobs. Carol reported that the onset of her daughter's illness marked the end of her professional life:

'So my professional life came to an abrupt stop at that moment. It was impossible for me to continue in [my full-time role]. In fact, for a time, I thought I may never be able to work again but I did find a part-time job as a receptionist for a while'. (Carol)

Despite the benefits of employment outlined by Ghosh and Greenberg (2012), the impact of their son or daughter's illness on their professional lives for all three mothers was significant. They all made sacrifices in their own day-to-day lives and in the decisions they made regarding their own future. Often, these decisions had consequences for the mothers, as Carol reflected on the financial impact giving up work had on the family home;

'I went from being a very independent woman financially, to someone who had to really consider how we spent money. Working part-time suited the situation at home, but it was very difficult to adjust to the drop in pay'. (Carol)

Barbara also reflected on her decision to give up her career and take a role where she could work from home so that she could care for her son;

'It was a huge change for me because I loved the team I worked with and I felt comfortable in my role there. Changing to a situation where I was working from home and essentially on my own was difficult. I missed feeling part of a team and it felt quite lonely and isolating at first'. (Barbara)

5.5.5 Disruption to motherhood

The disruption to motherhood was a prominent feature throughout the mothers' narratives, whereby mothers continued to care for and support their adult son and daughter for an indefinite period of time. Within the literature, Ryan (1992) refers to a lifetime of mothering that facilitated protection and nurturing of the adult child and attempts by the mother to shape their behaviour in socially acceptable ways.

Constant caring was also a theme developed by Eakes (1995) who discussed the unending caregiving, lack of respite and the impact of this on family life and McAuliffe (2014) reported constant minding and constant pressure experienced by parents due to the unrelenting nature of the caring role.

Carol, Barbara, and Frances all reported that they felt under constant pressure to maintain the caring role as, in their view, if they stopped, there would be no-one else who could or would take on this responsibility. This view is shared by all three mothers distancing themselves from close family members and rejecting offers of support and help from others. Barbara explained that as a mother, her son was solely her responsibility, particularly so in the absence of his father;

'I will care for him until the day I die. His father doesn't have anything to do with him and stopped all contact just before he was diagnosed with schizophrenia. I think his odd behaviour and the sense that something wasn't right was the only excuse he needed. I suppose you could say he abandoned him, so I have to be both his mother and his father. If I don't do it, who will?'. (Barbara)

For Barbara, the abandonment she described in relation to her son and his father was far reaching and had a significant impact on her life. Barbara had a sense of

responsibility to fulfil both mother and father roles, whilst experiencing her own sense of abandonment in coping with her son's illness.

5.6 Loss and grief

Carol, Barbara, and Frances's stories were all underpinned by a sense of loss and grief. This sense of loss and grief was also a prominent theme within the literature presented in the literature review in chapter two and is further supported by Wancata et al. (2008) who identified an enduring and pervasive sense of sadness and loss amongst parents of adults with schizophrenia. Multiple losses were evident for all three mothers and included those related to the effects of the illness on their son or daughter's life, their own life and on family life. The chronic nature of schizophrenia and the relatively poor prognosis associated with the illness further exacerbated the mothers' feelings of loss and grief and impacted on their views of the future.

5.6.1 Loss related to their daughter or sons' life

Milliken (2001) posits that there are three dimensions to the loss and grief associated with receiving a diagnosis of schizophrenia and living with and caring for a son or daughter with the illness: grieving for the loss of the child who is gone but not dead; grieving for the life that the child has now and the ongoing and unresolved grief experienced.

Across all three cases there was a range of feelings associated with receiving a diagnosis of schizophrenia and the experiences the mothers had over the years that followed. This included feelings of shock, disbelief, grief, anger, frustration, sadness, and despair. These findings are supported by Eakes (1995) who suggest that these feelings are re-experienced by parents' multiple times, over many years with varying levels of intensity. Carol described her feelings of loss as she reflected on her life in the context of her daughter's illness;

'I feel so sad about it all that it actually overcomes my anger with her. I am not angry; I am in despair. I do find the whole thing of acceptance very, very difficult, constantly falling in and out of denial, the grief is continuous'. (Carol)

Barbara explained how the feelings of loss and sadness she experienced often mirrored the ebb and flow of her son's psychotic symptoms, remaining hyper-vigilant to any fluctuations in his mental state. Barbara recognised that her feelings of

sadness often changed in response to her son's symptoms but even when his symptoms were relatively stable there was a sense that this would soon change;

'this whole thing has had a catastrophic impact on me. Sometimes I am angry but mostly I am sad. Don't get me wrong, there are times when I feel a little more upbeat and positive but that is usually when my son is reasonably stable, and things are going along without any major drama. It is usually short-lived though and something will happen that will trigger him off again. I am always waiting for the next crisis, always on egg-shells'. (Barbara)

Feelings of loss over the adult that would never be were encapsulated by Frances, who remarked on the loss of the life she had hoped for her son and family including marriage, children, and employment:

'All those hopes and dreams I had for my son have gone. He will never be in a position where he can have a relationship, so will never get married and have children of his own. My grandchildren won't have any cousins and my daughter won't have nieces or nephews. You wonder about what job he would have had; he was bright, he was going places with a degree in [science], but it wasn't meant to be was it?'. (Frances)

The loss of the 'adult future', which Frances envisioned for her son, is also mirrored by Carol who described the loss of not being able to witness her daughter's adult goals. Carol compared her daughter's life to those of her daughter's former friends and expressed this in terms of a 'life taken away'. This draws parallels with findings from Milliken (2001), whereby mothers of adult sons or daughters with schizophrenia, grieve for the loss of the child who is gone but not dead:

'She doesn't have any hope of a husband, a home, children, and a career, even though her family and the rest of her former friends have all of those things. They have done really worthy, wonderful things with their lives, and her life has been taken away'. (Carol)

Greenberg et al. (1993) argue that the type of loss experienced by mothers caring for an adult child with schizophrenia is particularly distressing for mothers because unlike the death of a loved one, the person is physically present but psychologically 'no longer the person they knew'. Tuck et al. (1997) take this further and suggest

that unlike death, parents' of an adult child with schizophrenia experience a malevolent transformation of their son or daughter who remains physically present in their world. Carol, Barbara, and Frances all described their loss and grief as a lonely and isolating experience that no-one else truly understood and was, apparently, not shared in the same way with others. Others may not recognise their grief or that they are grieving however because the person remains present and has not died. This is termed disenfranchised grief by Milliken and Northcott (2003), who suggest that the experience of grief is obscured by commonly held assumptions and stereotypes that impact on their ability to share their experiences and access support, leading them to grieve alone (Doka 1989, Milliken 2001).

5.6.2 Loss related to own life

Wiens and Daniluk (2017) found that mothers experienced loss relating to their own lives and their own career aspirations, with some abandoning their professional lives due to the ongoing and unpredictable demands of caring for their child. Carol, Barbara, and Frances all experienced a sense of loss related to their own lives and the activities they enjoyed before the onset of their child's illness. Carol described how she used to enjoy a busy social life prior to the onset of her daughter's illness and Frances recalled how she used to enjoy spending weekends away especially in relation to her son's sporting activities which also provided a social outlet for Frances and her husband. Barbara reflected on her own life and how her son's illness had changed who she was as a person;

'My son's illness has had a profound effect on my life. It has affected my well-being and changed me as a person, I am not the person I was. I used to be positive and confident and enjoy a good social life but all that has changed since my son became unwell. Sometimes I look at photographs of me, taken before Alex became ill, when life was carefree. If only I knew then what was ahead'. (Barbara)

Similar reflections were made by Frances who described having been a career focussed professional who enjoyed working life and her relationship with her colleagues;

'I used to really enjoy my job, it defined who I was I suppose, as well as being a mother, a working mother. I had a great relationship with many of my work

colleagues, many of who were my friends. We all used to go out socially, especially at the end of every term. All that went out of the window I suppose as most of my time was spent caring for or worrying about Gareth'. (Frances)

5.6.3 Loss of hope for the future

Across all three cases, participants described feelings of loss related to their hope for the future which was impacted by the unpredictable nature of their son or daughter's illness. This loss of hopefulness for the future is supported in the wider literature (Ryan 1993, Tuck et al. 1997, McAuliffe et al. 2014). Carol summarised how the loss of hope she experienced impacted on her feelings;

'it makes me angry and frustrated and sometimes desperate and in despair because I can't see a future, either for Rebecca or for me'. (Carol)

Frances also recalled how, prior to her son becoming unwell, she had focussed on his future and how this changed as she faced the reality of the unfolding situation and the diagnosis he received;

'Up until Gareth became unwell, I had been so focussed on his future and developing his future, and then he got the diagnosis of schizophrenia. That is when the reality hit me, and the reality is, there doesn't seem to be much of a future now'. (Frances)

The grieving process for all three women was particularly difficult due to the unrelenting nature of schizophrenia. At times, they discussed when their hopes were raised, in relation to the introduction of a new prescribed medication for example, only to be dashed again when symptoms persisted. Frances explained that the psychiatrist suggested her son was commenced on Clozapine and had spoken very positively about this line of medication, leading her to be more hopeful of a recovery for her son;

'It wasn't long before the psychiatrist put Gareth on clozapine and he said that was the best thing he could possibly be on and, you know, that was going to do the trick. And he did start to improve slowly, but it sort of levelled out and then it didn't seem to work anymore, so we were back to square one'.

5.7 Summary

This chapter focussed on the final step of the BNIM analytic process and presented the findings from the cross-case comparison and theorisation across and between cases. Three key 'themes' were identified that centred around stigma, disruption, and despair, loss, and grief. The findings from the individual case presentations presented in chapter four, and the cross-case comparison and theorisation presented in this chapter, will now be critically discussed.

Chapter Six – Discussion

6.1 Introduction

The aim of this study was to develop an understanding of the experiences of mothers who live with and care for an adult son or daughter with schizophrenia; to explore the impact of schizophrenia and the caring role on mothers and to highlight the implications for clinical practice when working with people with schizophrenia and their mothers. In chapter four, the findings of three ‘gold-star’ cases were presented and chapter five presented the final stage of the BNIM 10-stage intensive analytic process, the cross-case comparison and theorisation. The cross-case comparison and theorisation enabled a deeper understanding of participant experiences and, where appropriate, referred back to the pertinent evidence presented in chapter two, as well as wider related literature around stigma, disruption and loss and grief.

Four key themes will be discussed in this chapter:

- The impact of having a son or daughter with schizophrenia on mothers;
- Motherhood and the mothers’ role in caring for an adult child with schizophrenia;
- Engagement with health professionals;
- The mothers’ experience of chronic sorrow.

6.2 The impact of having a son or daughter with schizophrenia

This study identified that the impact of having a son or daughter with schizophrenia on mothers is significant and affects all aspects of their lives. This section will focus on that impact and will specifically address issues around help-seeking behaviour, social withdrawal and isolation, and the disruption to participants’ life trajectory in relation to their professional role and identity.

6.2.1 Help-seeking behaviour

The sociological literature on chronic illness places great significance on diagnosis but first suggests that the period prior to diagnosis, when people experience medically unexplained symptoms, is often characterised by chaos and ambivalence (Nettleton 2006). Furthermore, the uncertainty around the emerging symptoms

disrupt identity and contribute to feelings of isolation (Vann-Ward et al. 2017). Families find this situation increasingly stressful, as they occupy an ambiguous position between health and illness and the demands upon them are exacerbated by the prodrome (Reczek et al. 2020, Halpin 2021). McAuliffe et al. (2014) refers to this period of parental life as a *psychological tsunami*, where parents experience devastation against a backdrop of foreboding that something is seriously wrong. This study found that initially, participants did not recognise their daughter or sons' symptoms as a sign of mental illness and consequently did not seek professional support or help; instead, they misattributed their daughter or sons' symptoms to other possible causes such as drug use or a struggle with coming to terms with their sexuality. This draws parallels with wider research on families and carer experiences of the prodromal phase of psychosis (Corcoran et al. 2007, Bergner et al. 2008, Perkins et al. 2018), the early experience of young-onset dementia (O'Malley et al. 2021) and the prodromal signs of Huntington's disease (Halpin 2021).

Significantly, in this study, participants' help-seeking behaviour was further impacted by stigma as they became more aware of a possible mental illness and, therefore, diagnosis and treatment of their loved one was further delayed. The wider literature around the impact of stigma on help-seeking behaviours in mental health, largely focuses on the experience of the person with the illness themselves (Corrigan 2007, Thornicroft 2008) and two systematic reviews excluded the experience of families and informal carers (Clement 2014, Schnyder et al. 2017). This suggests that further research into the impact of stigma on help-seeking behaviours by primary carers in mental health is warranted.

6.2.2 Social withdrawal and isolation

For some service-users and their families and carers, receiving a diagnosis of a long-term condition following the period of uncertainty, can provide relief. The diagnosis can provide a sense of control and containment, offer hope for recovery and improve relationships with healthcare providers (Perkins et al. 2018). In this study however, participants recalled how the diagnosis of schizophrenia was unwelcome, traumatic and marked a turning point in their lives. Participants spoke of the 'label' that their son or daughter had been given, and the impact of this on their

own lives going forward. Studies have consistently shown that stigma is greater for those with severe mental illness than those with common mental health conditions such as anxiety and depression (Corrigan 2007, Pescosolido et al. 2010) and a recent study by Hazell et al. (2022) concluded that schizophrenia was the most stigmatised of mental health diagnoses, with fear being the most attributed predictor of the stigma associated with the condition. Participants in this study described how the diagnosis of schizophrenia led to shame and embarrassment that contributed to them withdrawing from social contacts, rejecting offers of support, which compounded their feelings of loneliness and isolation in their role as mother and primary carer. Xanthopoulou et al. (2022) supports these findings stating that the avoidance of social situations by carers is compounded by the stigma and embarrassment of a diagnosis of schizophrenia. The loss of social contact is one of the multiple losses participants experienced as a result of their daughter or sons' illness. These multiple losses are outlined in more detail later in this chapter, as they are significant in participants' experience of chronic sorrow.

6.2.3 Disruption to the life trajectory

Bury (1982) referred to the impact of receiving a diagnosis of a chronic illness on the self as *biographical disruption* (p.169) and whilst this concept is largely unexplored within mental health literature, it relates to how individuals make sense of their lives and cope with their conditions. Furthermore, biographical disruption relates to how the illness disrupts normality, and impacts on self-identity (Bury 1982). This study found that participants experienced biographical disruption as a consequence of their daughter or sons' diagnosis where the diagnosis, by association, interrupted their own life story or life trajectory. This biographical disruption was compounded by the ambiguous and unremitting nature of schizophrenia, as the situation the participants found themselves in affected their daily lives and how they lived them. Milliken and Northcott (2003) discuss the redefining of the parental role as parental identity shifts throughout the illness trajectory of schizophrenia. The participants in this study were retired professional women who all made sacrifices in their professional lives, as their daughter and sons' illness unfolded. Studies that focussed on the loss of professional role amongst mothers demonstrate that the disruption of losing their role can have a long-lasting and detrimental impact on women's lives. Caregiving often over-shadows other concerns that shape women's professional pathways (Damaske

2011) and for mothers who worked in professional occupations there can be on-going struggles to redefine who they are. Consequently, it is suggested that women who have a parental role face a conflicting situation in which they have no choice and no real alternative but to give up their professional role (Putnam et al. 2014, Kanji and Cahusac 2015). In this study, the mothers' self-evaluations as good and successful parents were framed by their educational status and professional roles that gave them a sense of identity. However, as their lives became dominated by their daughter or sons' health, their competing obligations became problematic. As a result, they were forced to make changes to their working lives, either by changing professional roles or forsaking roles completely. Consequently, their identity was challenged and/or redefined due to the demands placed upon them. Milliken (2001) refers to the competing obligations that mothers have in the context of caring for a son or daughter with schizophrenia as *fragmentation* and argues that this can further compound feelings of frustration and hopelessness. Furthermore, Batchelor and Duke (2019) posit that social isolation increases when there is loss of a previously held social connection such as work or a career and when parents view themselves as the main carer, a heightened greater sense of isolation is experienced. The loss of professional role and identity is significant and is further compounded by the loss of social contact discussed in the previous section. It adds to the multiple losses participants experience throughout their lives and impacts on the chronic sorrow they endure. The wider literature on women's career interruptions in the context of the caring role is largely focussed on mothers who have children under the age of 18 at home or those with older parents and there is a dearth of literature relating to career interruptions as a result of the extended parental and caring role for those with children in early adulthood. This study therefore adds to the literature around women's career trajectories and the impact on this of the mothering role across the lifespan.

In summary, this study identified that the impact of having a son or daughter with schizophrenia on mothers is significant and affects all aspects of their lives. The study found that during the prodromal phase of the illness, mothers did not recognise their daughter and sons' symptoms as a sign of mental illness and consequently did not seek professional support or help. Whilst this study reinforces findings from earlier studies on the prodromal phase of schizophrenia, and other studies on the

prodromal phases of illness, such as those that focussed on young onset dementia and Huntington's disease, what is significant in this study is that the mothers help-seeking behaviour was severely impacted by stigma which further delayed their daughter or sons' diagnosis and subsequent treatment. The diagnosis of schizophrenia that their daughter or sons received marked a turning point in the participants' own lives with the stigma associated with the label of schizophrenia fuelling a sense of embarrassment and shame. The biographical disruption and interruption to their own life trajectory was a significant finding, particularly in relation to their loss of professional identity and role, which was profound. This study therefore also contributes to the limited literature relating to the disruption on the career trajectory of mothers who have adult children with chronic illness.

6.3 Motherhood and the mothers' role in caring for an adult child with schizophrenia

This study found that participants' gendered views about being a mother, reinforced how they perceived their obligation to provide care and how they approached their caring responsibilities. These gendered views changed over the course of their lives, but a more traditional attitude emerged as they became mothers which was further reinforced following the disruption to their professional roles and identity in the context of their daughter or sons' illness. Sociological literature on motherhood, generally refers to an identified relationship between a woman and her child, and an interaction between women, children and society more broadly (Russo 1976, Hays 1996, Reger 2007,). It encompasses a range of physical, emotional, social and care activities (Reger 2007) and is an historically constructed ideology, that provides a gendered model of behaviour for women, which socialises them to develop sensitivity to the needs of others and the assumption of responsibility for taking care (Russo 1976). Participants in this study reported that they felt under constant pressure to maintain the caring role as, in their view, if they stopped, there would not be anyone else who could or would take on the caring responsibility for their daughter or son. This explains the participants' internalisation of their role as mothers and caregivers, and the need to continue to be the primary source of care for their daughter or son despite their advancing years. This supports findings from other studies on mothers in the context of schizophrenia (Milliken 2001, Hanzawa et al. 2008, Wancata et al. 2008, Klages 2016, Wiens and Daniluk 2017) as well as the

literature on mothers of those with disability more broadly (Kiernan et al. 2019, Aksamit and Wehmeyer 2022). Consequently, participants in this study reported an ongoing concern about the future and what would happen when they were no longer able to look after their son or daughter, and what would happen when they die. Studies on mothers with adult children with autistic spectrum disorders (Baumbusch et al. 2017, Herrema et al. 2017) and intellectual disability (Taggart et al. 2012, Ryan et al. 2012, Kruithof et al. 2022) discuss similar findings where aging parents approach the future with apprehension as the inevitable shift in their child's care becomes more apparent. Despite the apprehension amongst participants of what would happen when they could no longer care for their daughter or son, this study found that there was a reluctance by them to relinquish their caregiving role and to proactively plan for the inevitability of their own mortality. Similar findings were reported in a systematic review of the literature by Walker and Hutchinson (2018) where most aging parents of adult children with intellectual disability did not plan for the future, despite their ongoing concern about it.

A significant finding of this study was the sense of blame and guilt experienced by participants, not only in relation to the overall caring role but in compounding their sense of culpability. That is, the sense that they were in some way responsible for their daughter or sons' first psychotic episode and subsequent diagnosis of schizophrenia. Feelings of guilt are common in caregivers of those with long-term chronic conditions and is widely reported in carer studies such as those who care for people with dementia (Martin et al. 2006, Prunty and Foli 2019, Gallego-Alberto et al. 2022), cancer (Ochoa et al. 2019), and Duchenne muscular dystrophy (Donnelly et al. 2022). In this study, the findings differ somewhat from the broader focus on carers as they are inextricably linked to the participants' role of mother and the *maternal guilt* that they experience. Maternal guilt has been defined as feelings that are incongruent with mothers' expectations and desires in performing their mothering role and their idea of motherhood, which are underpinned by a sense of inadequacy (Constantinou et al. 2021). Literature has consistently demonstrated that guilt is synonymous with motherhood (Aantzen et al. 2019, Collins 2021), whereby women aspire to be the best mothers they can be, but the high, and often unrealistic standards by which they judge themselves mean that their aspirations can never be realised (Constantinou et al. 2021). Furthermore, McDonald et al. (2005) posit that

maternal guilt relates to the complete responsibility of caring for a child and the view held by mothers, that their own care is superior to the care of others. Seagram and Daniluk (2002) argue that the notion of maternal guilt is so pervasive in the western world that it is considered a natural component of motherhood. Studies that have focussed on maternal guilt have largely centred on mothers with children under the age of 18, (Liss et al. 2013, LeBeau 2014, Frankhouser and Defenbaugh 2017) or, in relation to chronic illness, on maternal guilt in relation to the inheritance of genetic conditions (James et al. 2006, King 2014, Turriff et al. 2020). A small number of studies reviewed in chapter two, highlight that guilt is experienced by mothers who care for an adult son or daughter with schizophrenia (Milliken 2001, Wiens and Daniluk 2017), but the findings from these studies are discussed in relation to the caring role more broadly and not specifically related to motherhood and/or maternal guilt. Findings from this study suggest that maternal guilt is an important consideration when attempting to understand the experiences of mothers who have an adult son or daughter with schizophrenia, as it often underpins their feelings of inadequacy, blame and guilt and is further exacerbated in the context of their daughter or sons' mental illness.

In summary, the sociological literature on motherhood refers to an identified relationship between a woman and her child and an interaction between each other and society more broadly. The woman's responsibility for caregiving is promoted through a model of behaviour that underpins women's innate drive to be the primary source of care for their daughters or sons. This study found that participants were reluctant to relinquish their caregiving role, or to proactively plan for the inevitability of their own mortality despite their advancing years. Furthermore, participants also experienced significant feelings of blame and guilt that were inextricably linked to their role as mothers which perpetuated a sense of culpability and inadequacy.

6.4 Engagement with health professionals

Section 6.2.1 discussed how during the prodromal phase of schizophrenia, participants' general lack of awareness of mental illness and the misattribution of initial symptoms were factors in help-seeking delays. Furthermore, when participants ultimately recognised symptoms as being problematic and warranting professional intervention, further delays occurred due to the stigma associated with mental illness and the potential prospect of receiving a mental health diagnosis. This

section will focus on four key aspects relating to participants' experience of their engagement with health professionals: difficulty and delay in accessing formal mental health support; lack of compassionate communication, empathy and inclusion; feeling ignored in the face of crisis; and lack of psychological support.

6.4.1 Difficulty and delay in accessing formal mental health support

This study identified that there were significant difficulties and delays experienced by participants when they attempted to access mental health support for their son or daughter. The difficulties experienced by mothers were three-fold: difficult encounters with their General Practitioner (GP) as gatekeeper and barriers to referral to mental health services by them; difficulties receiving a diagnosis; and ongoing poor communication and engagement by mental health professionals. All participants experienced barriers to accessing support for their daughter and sons. In the United Kingdom (UK), apart from accident, emergency or crisis situations, GPs are the gatekeepers to mental health services. Literature on gatekeeping suggest it is a model of health care in response to a shortage of health care specialists and a requirement to reduce healthcare spending (Loudon 2008, Sripa et al. 2019). Critics argue however, that the model of GP gatekeeping in the UK, particularly around onward referral to specialist services is flawed and is associated with delayed diagnosis and adverse outcomes, as well as negating person-centredness, patient choice and shared-decision making (Kerr et al. 1999, Greenfield et al. 2012, Greenfield and Azeem 2016). Findings from this study align with these criticisms, where GPs appeared dismissive of the mothers' concerns, were ambivalent in their view of local mental health provision and were reluctant to refer on to mental health services. Furthermore, the findings reveal that participants' initial negative encounters with GPs in relation to their daughter or sons' mental illness compounded their own feelings of stigma and challenged their self-efficacy as mothers.

6.4.2 Lack of compassionate communication, empathy and inclusion

This study found that when participants' daughter or sons were eventually referred on to mental health services, their interactions and communication with health care professionals continued to be negative, whereby the mental health staff they encountered appeared unsympathetic, cold and distant. These findings support those found in the related international literature on the mothers' experience

discussed in chapter two of this thesis (Ryan 1993, Eakes 1995, Tuck et al. 1997, Milliken and Northcott 2003, McAuliffe 2014). Furthermore, negative encounters with healthcare staff are common in the wider literature on the experience of families and carers, focussing largely on suboptimal communication and conflicted and/or contradictory information (Lund et al. 2014, Sewell 2018, McManimen et al. 2019). Communication that lacks compassion and empathy is also reported in studies on primary carers across a range of long-term, and sometimes life-threatening conditions such as cancer (Waldrop et al. 2012, Lund et al. 2015) and dementia (Laparidou et al. 2018), and in other studies focussed on mothers of those with neurodegenerative disease (Bettle and Latimer 2009). These findings are disappointing, particularly as the literature on compassionate communication and advanced inter-personal skills is vast, multi-disciplinary and advocated by healthcare regulators, organisations and by mental healthcare professionals themselves (Ennis et al. 2013, Papageorgiou et al. 2018). In this study, the perceived lack of empathy experienced by participants influenced their subsequent interactions with healthcare professionals, and they became less trusting of them. Consequently, this impacted on the participants' motivation and energy for pursuing information.

In addition to their dissatisfaction with healthcare professionals' communication, highlighted above, this study found there were further problems when participants' daughter or sons were initially diagnosed with schizophrenia, both in relation to the length of time it took to receive a diagnosis and in relation to the conflicting opinions of psychiatrists. This supports findings from the literature reviewed in chapter two whereby parents reported frustration at the inability of healthcare professionals to diagnose accurately (Tuck et al. 1997, McAuliffe et al. 2014, Milliken and Northcott 2003) and there was a perceived lack of understanding by healthcare professionals in recognising symptoms as a prodrome to schizophrenia (McAuliffe et al. 2014). This also echoes findings from the wider literature on the diagnosis of severe mental illness where the time taken to diagnose (Perkins et al. 2018) and the accuracy of diagnosis is problematic (Soares-Weiser et al. 2015, Cruz-Matinez 2022). Findings in this study indicate that participants commonly felt excluded from conversations about their daughter or sons' condition by healthcare professionals, which resulted in them being dissatisfied with the information they were given. Research indicates that this is a common concern amongst family members and confidentiality is viewed

as an excuse to avoid engagement with families and carers (Wynaden and Orb 2005, Gray et al. 2008, Casey 2015, Wilson et al. 2015). Nevertheless, healthcare professionals must respect patient confidentiality and navigate the ethical dilemmas posed, especially when patients refuse sharing of relevant information with family members and carers, as they are legally and professionally obliged to do so (Beauchamp and Childress 2013, NMC 2018, GMC 2017, HCPC 2022).

The impact for participants of these negative interactions, the delays and problems with diagnosis, and the lack of involvement and information from healthcare professionals is profound. It suggests an unequal power balance between healthcare professionals and parents underpinned by paternalistic practices and behaviours that are far reaching. This power imbalance within psychiatry is well documented (Foucault 1982, McCubbin and Cohen 1996, Laugharne and Priebe 2006) and widely criticised within service-user and carer movements and policy (Sewell 2018) nevertheless, for the participants in this study there was a disconnect between policy aspirations and their experience in practice.

6.4.3 Feeling ignored in the face of crisis

In this study, participants reported that they intuitively knew when their daughter or sons were becoming unwell. However, when they alerted mental health professionals, they described responses that were dismissive and invalidating, even when the situation escalated, and their daughter or son was experiencing a mental health crisis. This supports findings by Albert and Simpson (2015) and Klages et al. (2016) who highlighted the disparity between what parents and carers view as a crisis and what mental health services do. The issue of intuition as reported by participants in this study is an interesting one and the role of intuition in decision making is widely debated within healthcare, psychology and social psychology literature. The concept has been criticised as irrational and biased (Kahneman et al. 1982) but others argue that intuitive decision making is based on one's past experiences, and therefore, is repeatedly successful in similar situations, and therefore the result of learning (Hogarth 2010). This suggests that when participants in this study refer to intuition, they are drawing on their past experience of caring for their daughter and sons and making decisions, albeit unconsciously, on it. It would seem, that the mothers in this study were often a good barometer of their daughter

or sons' mental health and appropriate and timely care could be expedited, if they were listened to by healthcare professionals and gatekeepers.

6.4.4 Lack of psychological support

In addition to the negative interactions with healthcare professionals, this study found that participants reported a distinct lack of psychological support being offered to them. Psychological support in the form of carer-focussed education and support programmes, which may be part of a family intervention for schizophrenia, is an important recommendation for families of those with the illness (NICE 2014, Bucci et al. 2016, McFarlane 2016, Claxton et al. 2017, Sin et al. 2017) though the implementation and availability of this is inconsistent (Kuipers 2011, Bucci 2016). Family intervention, or behavioural family therapy, is a practical, skills-based intervention that typically involves sharing information with the service-user and their family about the service-user's mental health issues, experience, and treatment. Family intervention for psychosis was not offered to the participants in this study at any stage of their caring experience despite the effectiveness of this intervention being clear (Fadden 1997, Pilling et al. 2002, Kuipers 2006). Since the introduction of early intervention and first episode psychosis teams in Wales in 2010, family intervention may now be more accessible to family carers. However, a recent audit report by the Royal College of Psychiatrists (RCP) (RCP 2022) was commissioned by the Healthcare Quality Improvement Partnership and presented key findings that reflect the current situation of early intervention provision for those with psychosis and their families. Findings were presented across three documents, each relating to a specific area of the UK- England, Wales and Ireland. Within the Welsh context, the report presents a disappointing picture where there is a generally poor, but wide variation in the offer, take-up, waiting and refusal of family intervention across Health Boards in Wales (RCP 2022). Therefore, there is a significant disconnect between the development and recommendations of best-practice guidelines and their implementation in practice, none more so than for those with schizophrenia and their families and carers. This does not bode well for those with a longer diagnosis of schizophrenia and their families and suggests that for the participants in this study they may have been left behind.

In summary, participants in this study reported frequent and ongoing issues related to their engagement and interaction with healthcare professionals. These negative experiences led to a delay in treatment and care for their son or daughter and led to participants feeling ignored and dismissed, even when their daughter or son was experiencing a mental health crisis. Furthermore, this study found that there was a lack of psychological support available to participants despite these being recommended in best practice guidelines.

6.5 The mothers' experience of chronic sorrow

As discussed in chapter five, all participant stories were underpinned by a sense of loss and grief. Related to this, findings from this study indicate that mothers also experienced a constant sense of sorrow in living with and caring for their adult children with schizophrenia. Consequently, participant experiences align with the concept of chronic sorrow (Olshansky 1962) where there is profound sorrow and invalidation, which includes social isolation, feelings of unfairness and a perception of lack of voice. Additionally, where they are physically overwhelmed, exhausted or vulnerable (Kendall 2005). The concept of chronic sorrow was developed in the 1960's to categorise the loss and grief experienced by parents of children with a learning disability (Olshansky 1962). Olshansky (1962) defined chronic sorrow as a natural response of feelings to a tragic event. Unlike grief and mourning, specifically related to death and dying, chronic sorrow is an unresolved phenomenon, which differs from more traditional models of grief, such as that proposed by Kubler-Ross (1969). Chronic sorrow, therefore, provides a useful lens to examine the participant experiences of having a son or daughter with schizophrenia.

The literature on chronic sorrow to date has largely focussed on physical illness such as diabetes (Lowes and Lyne 2000, Monaghan et al. 2011), sickle cell disease (Northington 2000, Olwit et al. 2018), epilepsy (Hobdell et al. 2007), neurodegenerative disease (Bettle and Latimer 2009, Mercer 2015) and cancer (Fletcher 2010, Nikfarid et al. 2015). Over more recent years however it has been identified in broader populations such as long-term spousal carers (Rossheim and McAdams 2010) and older people (de Lissler 2017). Moreover, it has been identified in a limited number of international studies that focus on the caring experience of parents with adult children with psychosis, including bi-polar disorder, in the USA (Eakes 1995) and in caregivers of patients diagnosed with schizophrenia in Uganda

(Olwit 2015). To my knowledge, there are no studies that have identified chronic sorrow specifically in relation to mothers who care for an adult child with schizophrenia either internationally, or, within a UK and/or Welsh context.

This study found that participants experienced multiple loss experiences, including loss related to their daughter or sons' life, their own life and their underpinning sense of loss for the future. These losses occurred multiple times, as participants provided care to their daughter and sons. Further findings revealed participant loss in relation to the support mechanisms available to them, both in terms of formal professional support from healthcare staff (discussed in section 6.4.3) and from informal support mechanisms from family and friends. This supports the findings of previous studies (Eakes 1995, Lowes and Lyne 2000, Bowes et al. 2008) and highlights the relevance of the concept of chronic sorrow in relation to the family and caregiver experience.

In this study, participants struggled with the dissonance between how things were, before their daughter or sons developed schizophrenia, how things are, and how they felt things ought to be. Furthermore, they frequently made comparisons, of life before and since, the development of the illness, particularly when there was an occasion or family event that provided a reminder of their losses. This dissonance between the past, the present and an imagined future, where different events bring this disparity to the fore, is a key feature of chronic sorrow and is evident in the trajectory of a chronic illness or disability (Lindgren et al. 1993, Teel 1991). These findings support the work of Lindgren et al. (1992) who state that the defining principles of chronic sorrow include: a perception of sadness and sorrow over time, in a situation with no predictable end; sadness or sorrow that is cyclic or recurrent; sadness or sorrow that is triggered internally or externally and brings to mind a person's losses, disappointments, or fears and sadness or sorrow that is progressive and can intensify. The defining characteristics of chronic sorrow therefore align with the understanding of schizophrenia as a long-term, pervasive illness and the participants' experience of caring for an adult son or daughter within my study.

The unresolved disparity experienced by the participants is a common attribute of chronic sorrow and is also evident in studies on disenfranchised grief, where participants grieve for losses associated with their previous life and the loss of their imagined future (Milliken 2001, Gill and Lowes 2014). Antecedents, or trigger

events, are closely connected to the disparity. These trigger events are also referred to as milestones within the literature and refer to circumstances or situations that exacerbate the experience of disparity (Eakes et al. 1998). Such milestones were evident in the findings in this study, when participants discussed family celebrations and gatherings for milestones of other family members, such as weddings and the birth of a child, that reminded them of how things might have been for their son or daughter in the absence of the illness.

In this study, the experience of chronic sorrow amongst participants was high as they experienced profound sorrow, social isolation and feelings of unfairness and being ignored and dismissed. This was compounded by the unresolved disparity and the dissonance between the past and the present that they repeatedly encountered as they experienced milestones and events in their lives. For the participants in this study, it was the dissonance between the past and the present and the repeated triggers that were the most significant in their chronic sorrow. Consequently, the participants were constantly reminded of their loss, and their grief was reactivated with each celebration, occasion, and milestone.

Exploring participants' experiences through the lens of chronic sorrow has provided a valuable insight into being a mother of a son or daughter with schizophrenia. It improves our understanding of their experiences and provides an appropriate rationale for their sense of sorrow, grief and loss which offers therapeutic potential for healthcare professionals. Its implication for mental health practice will be discussed in the following section.

In summary, findings from this study indicate that mothers' experience a constant sense of sorrow in living with and caring for an adult son or daughter with schizophrenia. This is compounded by multiple loss experiences and a dissonance between how things were and how they felt things ought to be. Exploring these findings through a lens of chronic sorrow has provided a valuable insight and an improved understanding of their experience and provides a rationale for their sense of sorrow, grief and loss.

6.6 Strengths and limitations

Inevitably, there are limitations of this study and thesis. My inexperience and relative naivety when first considering the study meant that there were certain unanticipated

consequences in my choice of methodology. In choosing a rigorous approach to data collection and data analysis it became apparent that specific training in BNIM would be required in order to execute the interviews and subsequent analysis accurately. Fortunately, I was able to access an intensive 5-day training programme facilitated by Tom Wengraf where I was able to acquire and rehearse the skills necessary, however, my relative inexperience may have meant that I occasionally missed *particular incident narratives* during sub-session one of the interviews which were worthy of further exploration in sub-session two.

Another limitation linked to my inexperience and methodological choice was the lack of appreciation for the amount of data generated from BNIM interviews and the intensity of the BNIM 10-step method of data analysis. Some of the interviews were in excess of four hours, and one lasted over seven hours, resulting in a transcript that was over 40,000 words long. Due to the amount of data generated, analysis took much longer than initially planned and this was further compounded by the Covid-19 pandemic and the UK wide lock-down that impacted on the facilitation of the lived-life and told-story interpretive panels.

The sample size was small, and all participants were white, born in the UK and predominantly professional women. This draws parallels with the research studies presented in the literature review in Chapter 2, where the samples were identified as a limitation across the included studies. A more ethnically diverse sample in this study therefore, would have been more representative of the population and enhanced the transferability of the research findings. Despite this, I believe this study has provided an accurate understanding of the experience of the mothers that took part, the findings can only be related to this sample and should not therefore be assumed to be representative of the wider population. Furthermore, the selection of the three gold-star cases meant that three narratives were excluded from the BNIM analytic process, however this, and the small sample size, is congruent with BNIM methodology.

In addition to the limitations outlined above, the study also has a number of strengths.

The method of data collection using the SQUIN allowed for an uninterrupted account of participants' life experience. The ability of this method to elicit participant stories was truly remarkable and generated a wealth of detailed and profound data.

Participants were keen to participate in the research and tell their story. Indeed, following the interviews, they all reported how cathartic the process was and how it had been the first time they had felt truly listened to.

Another strength of the study was participant recruitment from around Wales. This meant that despite the homogenous sample, participants were recruited from different regions and therefore their experiences do not relate solely to one health board.

Finally, a significant strength of the study was in the decades of experience participants had and willingly shared with me throughout their storytelling.

6.7 Summary

This chapter has presented four key findings of the study: the impact of having a son or daughter with schizophrenia on mothers; motherhood and the mothers' role in caring for an adult child with schizophrenia; engagement with health professionals and the mothers' experience of chronic sorrow. The discussion identified areas where this study supported and disputed findings from the literature and highlighted new knowledge gained from the study. Specific strengths and limitations of the study have also been discussed.

The final chapter will highlight the unique contribution to knowledge that this thesis has made and the implications for mental health practice and further research. A detailed outline of my dissemination plan will be presented, and a brief conclusion will bring the thesis to a close, ending with an epilogue that offers some final personal thoughts on completing this thesis.

Chapter Seven – Conclusion

7.1 Introduction

This final chapter will commence with a discussion of the unique contribution to knowledge that the study has made and the implications for mental health practice and research. A comprehensive dissemination plan will be presented, and a final conclusion will bring the thesis to a close. The conclusion will be followed by an epilogue that offers some final personal thoughts on completing this thesis.

7.2 Contribution to knowledge

This study makes unique contributions in the field of mental health by providing an exploration of the experiences of mothers who live with and care for adult sons or daughters in the UK. Having reviewed the relevant literature and evidence within this field, it is evident that similar experiences have been reported previously, albeit in different countries, with different aims, methodologies and theoretical frameworks. The findings in this thesis are relevant and can inform current mental health practice in the UK. It is evident that despite many years of focus on family and carer support, mothers of those with schizophrenia still experience significant burden and lack of support. Furthermore, the study found that mothers experienced significant stigma and disruption in the context of their daughter or sons' illness and that interactions with healthcare professionals were unsatisfactory.

As a result of this thesis, we can now understand the experience of mothers through the lens of chronic sorrow. This highlights the multiple losses they experience, the dissonance between how things were, how things are, and how things ought to be and the numerous ongoing triggers they experience that reactivate their grief and sense of loss. It therefore provides a meaningful rationale for their profound sense of sadness and has important implications for health and social care professionals.

Finally, this study brings attention to the apparent lack of progress made in supporting those who live with and care for those with schizophrenia despite advances in service configuration and delivery. Best practice interventions are still not being offered to those who need them and supportive interventions for mothers remain wholly insufficient.

7.3 Recommendations

The new knowledge generated by this study has implications for mental health practice and future research:

7.3.1 Mental health practice

- Participants reported that initiating contact with healthcare professionals was initially daunting and compounded by stigma and feelings of shame and embarrassment. Mental health professionals working in both primary and secondary mental health services are well-placed to tackle the stigma associated with mental illness, working closely with third-sector partners, service users and their carers/families.
- This study highlighted that participants were reluctant to relinquish their caring role and proactively plan for the future despite their ongoing concern related to their inevitable mortality. Gaining an appreciation of the profound impact schizophrenia has on mothers is important for healthcare professionals so that conversations can be initiated, that sensitively address and document this, to ensure their sons and daughters are cared for in the future, in the way that is acceptable to them, their son or daughter and their wider family.
- Findings from this study revealed significant negative encounters between participants and health care staff. Therefore, ongoing education for health professionals across the multi-disciplinary team, that focusses on compassionate communication is required. This should involve service-users and their families and carers, in the delivery of such education programmes.
- Participants reported they had not been offered any psychological support despite this being a recommendation by NICE (2014). Mental health staff should make every effort to implement NICE guidelines for schizophrenia and offer a carers assessment to family members and offer and refer them for family intervention. Furthermore, family members should be provided with information relating to their loved one's illness that clearly highlights the types of support available for carers, the role of teams and services and how to get help in a crisis as advocated by NICE (2014).
- Participants experienced high levels of chronic sorrow as a result of multiple losses and the dissonance between how life was and how they felt things

ought to be. Individual counselling should be available to close family members who provide care and support to those with schizophrenia that take into account their experience of chronic sorrow and offer help and support in dealing with their profound feelings.

7.3.2 Research

- This study demonstrated that seeking professional help in the early stages of schizophrenia is an uncertain and daunting experience. Furthermore, help-seeking behaviour is impacted by the realisation that symptoms could indicate a severe mental illness and is further compounded by the stigma associated with it. Consideration of the impact of stigma on help-seeking behaviours in the prodromal phase of schizophrenia is therefore warranted.
- The wider literature on women's career interruptions in the context of the caring role is largely focussed on mothers who have children under the age of 18 at home or those with older parents, and there is a dearth of literature relating to career interruptions as a result of the extended parental and caring role for those with children in early adulthood. Further studies should explore this disruption so that efforts can be made to reduce its impact on life trajectory and identity.
- This study explored the experience of mothers who live with and care for an adult son or daughter with schizophrenia. Two participants were married but their husbands did not feature in their narratives. Therefore, exploring the experience of fathers and/or couples would offer further insight into the impact on parents more fully.
- A limitation of the wider literature, and of this study, has been the under-representation of people from ethnic minority groups and the predominantly white, highly educated, professional participant population. Further studies should therefore explore the experiences of mothers and/or parents from a more diverse background to ensure that findings are representative of the broader population and the voices of those from ethnic minority groups are heard.

7.4 Dissemination Plan

The purpose of this study was to develop an understanding of the experience of mothers who live with and care for an adult son or daughter with schizophrenia; to explore the impact of schizophrenia and the caring role on mothers and to highlight the implications for clinical practice when working with people with schizophrenia and their families. The findings from this study are important for clinical practice and will inform health care professionals' involvement and communication with mothers and facilitate a deeper appreciation of their level of participation in their son or daughter's care and their specific needs within the context of the illness. This will hopefully raise practitioners' willingness to hear the maternal voice and foster true, meaningful partnerships with them as they care for their loved one.

In order to achieve these goals, I plan to add to the limited body of research relating to mothers of those with schizophrenia. I feel there are various components of the research that could be turned in to academic papers; the support needs of mothers who have adult sons or daughters with schizophrenia, how an awareness of the chronic sorrow framework can be useful for mental health professionals to meet the needs of mothers and how the biographical narrative interpretive method of data collection can be used to facilitate story telling. In addition to this, I will incorporate my findings into my teaching across the Bachelor of Nursing (Mental Health) undergraduate programme and postgraduate MSc programmes with post registration health professionals who work with families of those with long-term health conditions more broadly to raise awareness of the key issues that affect carers and family members. I will submit conference abstracts at local, national and international level and present webinars through the International Society for Psychiatric-Mental Health Nurses, of which I am an active member.

The table below outlines the dissemination activity, including some activities that have already taken place throughout this doctoral journey.

Activity	Where	When	Delivery
Presenting the study: Research methodology and method Findings	Undergraduate and postgraduate curriculum	Ongoing	Lectures, workshops and seminars

Working with families and carers			
Presentation of findings	Welsh Assembly of Women Annual Conference, Cardiff	November 2021	Oral presentation as an award winner for Welsh women in research
Presentation of method of data collection and analysis	Qualitative Research on Mental health Conference, Malta (moved online due to covid-19)	September 2021	Oral presentation concurrent session
Presentation of method of data collection	International Society of Psychiatric-Mental Health Nursing conference, California (moved online due to covid-19)	March 2021	Oral presentation concurrent session
Presentation of findings	Horatio: European Psychiatric Nurses Congress	March 2023	Oral presentation, concurrent session or poster
Presentation of findings	Cardiff and Vale UHB Conference Aneurin Bevan UHB Conference	Awaiting dates	Oral presentation, concurrent session or poster
The support needs of mothers caring for adult children with schizophrenia	Journal of Advanced Nursing	By late 2023	Journal Article
Understanding the chronic sorrow model to improve mothers support	Healthcare for Women International	By late 2023	Journal Article
Facilitating story telling using the biographical narrative interpretive method	International Society of Psychiatric-Mental Health Nurses Conference, TBD	By late 2023	Workshop

Partnership working with mothers in the context of schizophrenia	International Society of Psychiatric-Mental Health Nurses (ISPN) Webinar Programme	By late 2023	Webinar
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Table 7: Dissemination plan

7.5 Conclusion

Schizophrenia is a life-changing mental health condition that has a significant impact on the individual and their wider family. Literature shows that mothers often assume the responsibility for caregiving in families, and therefore, they can disproportionately suffer the consequences of having an adult son or daughter with schizophrenia. The caregiving role adopted by mothers for their sons or daughters is extended, pervasive, and often life-long.

This study sought to explore the experience of mothers who live with and care for an adult son or daughter with schizophrenia. To do this, a narrative approach was used utilising the Biographic Narrative Interpretive Approach (BNIM) for both data collection and data analysis. The introduction and background chapter identified a dearth of contemporary evidence on the mothers' experiences and there were no UK studies that focussed specifically on this. This study has therefore given a voice to women who are rarely examined as part of the research into schizophrenia. The findings provide an understanding of how mothers' whole lives are impacted in the context of their daughter or sons' illness and how the mothers' role in caring is extended, life-long and freely offered. The findings also highlight how the mothers' experience of mental health services is largely poor and they are often dismissed, ignored and neglected despite the role they play in providing care, support and monitoring of their loved one. Finally, the study provides an insight into the mothers' experience of chronic sorrow and how this aligns with the multiple loss experiences and unresolved disparity they endure.

7.6 Epilogue

Returning to the beginning of my doctoral journey, and my motivation for undertaking the study, this thesis grew from my observations in clinical practice and wanting to explore the experience of mothers of adult children with schizophrenia. Both my professional life and personal circumstances influenced this decision and, throughout, I have been mindful of my experience and knowledge and the influence it potentially had. Whilst it has been difficult to separate myself from this work, I have kept a reflexive journal and endeavoured to be true to the participants' voice, constantly examining my analysis, making full use of the interpretive panels, and keeping things in check through frequent and detailed supervision.

My doctoral journey has not been easy an easy one. It has been punctuated by illness, loss, grief and a global pandemic and there have been many times, particularly during the final year when I could have easily walked away, none more so than following my father's failing health and subsequent death in the early part of the year. Despite this, I have moved forward with my participants in mind, determined to see things through so that their voices can be heard.

As a novice researcher I found my journey a lonely and isolating experience I have demonstrated a level of resilience that I was unaware of at its commencement. I have doubted myself, lacked confidence and battled with imposter syndrome. Nevertheless, writing these last few sentences remind me of how far I have come and whilst the thesis draws to an end, it does so with recognition of the ongoing journey of the participants.

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Appendix 1: Papers for inclusion and data extraction

Author, Date and Article title	Aim	Methodology and Methods	Population and Sample	Findings	Conclusions and Recommendations
Ryan (1993) Mothers of adult children with schizophrenia: an ethnographic study	To sensitise health care professionals to the mother's experience by increasing the understanding of those who are attempting to provide family centred care	Ethnography	Canada 5 mothers of adult children with schizophrenia	A lifetime of mothering where mothers were engaged in active mothering for an indefinite amount of time. Consequently, significant disruption was experienced by mothers in terms of relationship with child and to mothers' life Significant loss: Loss of the child's potential to lead a normal life. Loss in own lives: loss of freedom Accepting it, going from day to day, having some time out. Continue to maintain hope for the future. Negative interactions with healthcare professionals, lack of hope, lack of future	Clinical practice with mothers of adult children with schizophrenia may be enhanced by an understanding of the mothers' experience. Further research is necessary with mothers of female adult children, minority ethnic groups and at different stages of the illness trajectory. The domain of loss requires further study to provide more insight into the different dimensions of loss.
Eakes (1995) Chronic sorrow: the lived experience of parents of chronically	To investigate the incidence of chronic sorrow in parents of chronically mentally ill children	Descriptive	USA Parents (6 mothers, 4 fathers) of adult children with either bi-	A range of grief related feelings associated with receiving their child's first diagnosis. Over time these feelings are re-experienced with varying levels of intensity.	Healthcare professionals to provide specific practical tips and situation-specific information that is accurate and timely.

mentally ill individuals			polar disorder or schizophrenia	<p>Feelings include shock, disbelief, grief, anger, frustration, sadness, confusion, and despair. Unending caregiving Grief related feelings reactivated by trigger events, situations, and circumstances:</p> <ul style="list-style-type: none"> Lack of respite Impact on family life Excessive demands on time/energy Financial drain Interpersonal (talking to others) Emotional (crying) Cognitive (thinking positively) Action orientated (keeping busy) <p>Negative attitude of healthcare professionals towards family members.</p> <p>Lack of communication</p> <p>Lack of involvement in care</p>	Healthcare professionals must respect the parents' knowledge and acknowledge and reinforce strengths.
Tuck et al. (1997) The experience of caring for an adult child with schizophrenia	To explore the phenomenon of caring for an adult child with schizophrenia	Phenomenology	USA Parents (7 mothers, 2 fathers) of adult children with either schizophrenia or	<p>Caregivers' identities become blurred. Beliefs about themselves were challenged. Constant background anxiety about the child. The parent cannot depend on their child.</p> <p>Caring for an adult child with schizophrenia/schizoaffective alters the parents life trajectory.</p>	Healthcare professionals should be sensitive to the frustrating aspects of seeking diagnosis, and provide information on it, its prognosis, and the availability of community resources.

			<p>schizoaffective disorder</p> <p>Parents identified as primary family caregiver</p>	<p>Goals, values, and plans are affected. A threat to a parents' self-evaluation as a good and successful parent.</p> <p>The child has not died but has changed. Consequently, there is a need to make meaningful choices, experience feelings and maintain a sense of being separate from the child.</p> <p>Loss of the adult future which they had envisioned</p> <p>Frustration at the inability of professionals to accurately diagnose. Interactions with the health care system were frustrating. Family's faith in health care professionals is eroded. Confidentiality rules deny parents access to information needed to provide care.</p>	<p>Parents need to have their loss and struggle recognised.</p> <p>Family support groups are valuable in offering practical advice and understanding.</p> <p>Issues about confidentiality must be dealt with in a way that recognises the family role in caring for an adult child with schizophrenia. Clear and honest communication is needed.</p> <p>Replication of the study with other populations is recommended to broaden understanding.</p> <p>There is a need to evaluate interventions to decrease the frustration and alienation experienced by parents.</p>
McAuliffe et al. (2014)	To explore the experience of parents living with and caring for their adult children with schizophrenia	Descriptive	Ireland Parents (5 mothers, 1	The relationship between one or both parents with the child with schizophrenia was strained at times. This causes disruption	The period following diagnosis is a key point for parents requiring

<p>Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study</p>			<p>father) of adult children diagnosed with schizophrenia and who had cared for their son or daughter in their own homes for at least 2 years</p>	<p>to activities which were previously enjoyed.</p> <p>An uncertain pathway – the future viewed as a mixture of hope, uncertainty and as 'never-ending'; where uncertainty exacerbated by unpredictable nature of the illness and perceived fear that the child would not manage without the parents' support.</p> <p>Yearning for the return of the lost child is reported. Reporting loss of their own life and of the things they enjoyed before their child's illness. Personal sacrifices were made to promote good quality of life for the child.</p> <p>There was a lack of understanding from Drs and health professionals – who failed to recognise the symptoms as a prodrome.</p> <p>Emotional burden and dissatisfaction when in the care of professional staff and a lack of inclusion in care.</p>	<p>information. Family centred care is needed.</p> <p>Support from mental health services can facilitate parents to discuss their concerns but this should be done by personnel specifically trained in family intervention/family centred approaches.</p> <p>A need for longitudinal perspectives on living with schizophrenia to strengthen studies and capture parental journey at critical stages.</p>
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<p>Milliken (2001)</p> <p>Disenfranchised mothers: caring for an adult child with schizophrenia</p>	<p>To show how a mothers' parental identity may differ from that of a father, following the diagnosis of schizophrenia in an adult child</p>	<p>Grounded Theory</p>	<p>Canada</p> <p>29 parent caregivers,</p>	<p>Redefining of parental identity was evident amongst participants. Mothers felt emotional strain of their disenfranchisement more than fathers. Fathers agreed that mothers were affected the most. Parents felt obliged to safeguard their child's health and to seek professional help to avoid crises. Continually met obstructions in trying to access help. Once diagnosis made, parents influence on care was severely limited.</p> <p>Many parents accessed support groups for practical information and an opportunity to mix with others in similar situations. These connections then became the primary reference group for parents.</p> <p>Parents became advocates for people with schizophrenia, raise public awareness and try to reduce stigma against mental illness.</p>	<p>Professional caregivers must recognise the contribution that families make to the patients' therapy. Case management and assertive community treatment are needed for safe and comprehensive community care. Inpatient treatment should be readily available when needed.</p>
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<p>Milliken and Northcott (2003)</p> <p>Redefining parental identity: caregiving and schizophrenia</p>	<p>To understand the challenges of schizophrenia for families and to inform mental health researchers with interests in grief, caregiver burden and quality of life</p>	<p>Grounded Theory</p>	<p>Canada</p> <p>Parents (16 mothers, 13 fathers) of adult children with schizophrenia</p>	<p>The mental health care system does not support parents or value the care they give for their adult child with schizophrenia.</p>	<p>The parents' contribution to their son or daughters care should be recognised by health professionals. Support and education for parents should be provided along with practical advice in managing their son or daughters' illness at home.</p>
<p>Wiens and Daniluk (2017)</p> <p>Loss and change: the challenges of mothering an adult child with schizophrenia</p>	<p>To explore how mothers of adult children with schizophrenia or schizoaffective disorder experienced personal growth and change</p>	<p>Narrative</p>	<p>Canada</p> <p>6 biological mothers of an adult child with schizophrenia or schizoaffective disorder and actively involved in parenting their child</p>	<p>Mothers experienced an enduring and pervasive sense of sadness and loss which paralleled the fluctuations of their son or daughters' mental state.</p> <p>There was distress and a sense of struggle amongst mothers, as they tried to make sense of what was happening. Powerlessness was also linked to the struggle mothers experienced.</p> <p>Levels of hope fluctuated and there was an ongoing concern about their child's future.</p> <p>A number of personal and relational changes were</p>	<p>Healthcare professionals should develop an understanding of the complexities of caring for an adult son or daughter with schizophrenia.</p> <p>Mothers require timely and appropriate information regarding the illness and how to respond to the challenges associated with the associated fluctuating symptoms.</p> <p>Mothers require support to access assessment and early diagnosis.</p>

				reported and their priorities in life changed over time.	
Klages et al. (2017) 'Canaries in the mine'. Parents of adult children with schizophrenia: an integrative review of the literature	To evaluate the current state of knowledge of parents who have adult children diagnosed with schizophrenia and their relationship with health professionals	Review of the literature using Whittemore and Knaf'l's (2005) integrative review methodology.	14 International studies	Findings from the literature review relating to the relationship between parents of adult children with schizophrenia and their relationship with health professionals: Parents believed they knew their child more than anybody but when they approached healthcare professionals when their child required support, they were excluded from decision making Parents felt devalued and dismissed and identified the need to be comforted but did so by seeking help from their own healthcare provider rather than those of their son or daughters.	Implications for educational programmes for mental health nurses on the promotion of professional-family relations.

Appendix 2: Participant covering letter



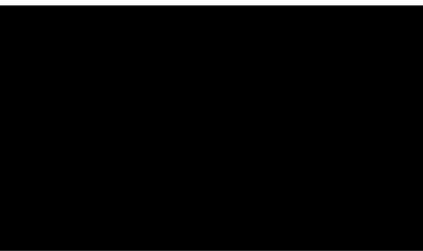
School of Healthcare Sciences, Cardiff University

Chief Investigator: Mrs Alicia Stringfellow

Supervisory Team: [REDACTED]

Study title:

Exploring the impact on mothers who live with and care for an adult son or daughter with schizophrenia.



Dear

I would like to invite you to take part in a study exploring the impact on mothers who live with and care for an adult son or daughter with schizophrenia.

Enclosed is an information sheet which explains more about the study.

It is your choice whether or not you would like to take part in the study. The enclosed information sheet should provide everything you need to know about the study but if you would like to discuss this further please do not hesitate to contact me on [REDACTED] or email me at [REDACTED]

Yours sincerely

Alicia Stringfellow

Appendix 3: Participant information sheet



Study title: Exploring the impact on mothers who live with and care for an adult son or daughter with schizophrenia

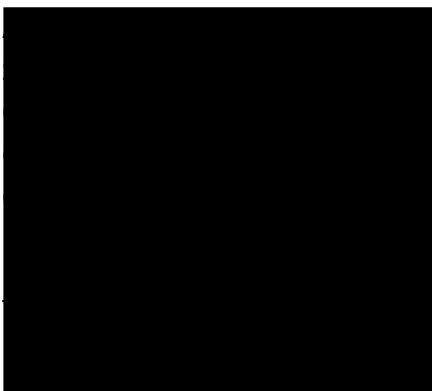
Introduction

Thank you for taking the time to read this information sheet. You are invited to take part in this study to explore the impact on mothers who live with and care for an adult son or daughter with schizophrenia. Joining the study is entirely voluntary. Before you decide whether you want to take part it is important for you to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Content

1. Why this study is being conducted
2. What taking part will involve
3. The possible advantages of taking part
4. The possible risks of taking part
5. What to do if something goes wrong
6. What will happen if you no longer want to take part
7. How your information will be kept confidential
8. What will happen with the results of the study
9. Who has approved the study
10. What to do if you would like to take part

Contact details:



Alternatively, you may contact the study supervisor:



1. Why is this study being conducted?

Schizophrenia is a severe and often debilitating mental disorder characterised by disruption in thinking, affecting language, perception and the sense of self. The impact of schizophrenia on the individuals themselves, their carers, family members, healthcare services and on society in general is significant. However, little is known about the experience of mothers who live with and care for adult sons or daughters with schizophrenia.

It is important to understand the experience of mothers to ensure adequate support and information can be provided.

You have been asked to take part in the study because:

- You are the mother of an adult son or daughter who has had a diagnosis of schizophrenia for more than five years
- You reside at the same address as your son or daughter

2. What would taking part involve?

If you are happy to take part, please complete the permission to contact form and the principal investigator (Alicia Stringfellow) will contact you by telephone to arrange a date to take part in a face to face interview. This interview will take place in your own home, or, if you would prefer, in a room provided by Hafal or a mutually agreeable location and will take up to two hours to complete. You will be asked to sign a consent form before the interview. Some background information will be collected to help the researcher understand different people's experiences. Following the interview, you may be contacted by telephone once more and within four weeks of the interview if the researcher requires clarification of any of the points raised in the interview.

You will also be offered the opportunity to use photographs as part of the interview process. These may be photographs you already have or that you wish to take prior to the interview. The photographs can be used as prompts during the interview and help you to verbalise your experiences. The photographs will not be copied, taken away or reproduced.

3. What are the possible advantages of taking part?

Although there will be no immediate benefit to participating in the study, it is hoped that the process will allow you to reflect on your experience and provide you with an independent safe space to tell your story. Many people often find telling their story in this

way helpful/cathartic. It is also hoped the information you give will help other mothers in Wales who live with and care for an adult son or daughter with schizophrenia.

4. What are the possible risks of taking part?

Thinking and talking about your experience may be upsetting and may cause you distress. If you feel upset or concerned about the information you disclose you will be provided with the details of support agencies who can help you such as Hafal carers support groups. You will be able to withdraw from the study at any time without prejudice. The interviews will be conducted sensitively, and you will be able to pause or stop the interview at any time if you wish.

5. What should I do if something goes wrong?

It is not anticipated that anything will go wrong during this study. However, if you are unhappy with how the research has been conducted you can make a complaint by contacting [REDACTED] Director of Research Governance at Cardiff University School of Healthcare Sciences on [REDACTED]

6. What will happen if I no longer want to take part?

You can withdraw from the study at any time without any impact or consequence. The research team will use the information already collected from you but will not collect any more information.

7. How will the research team keep my information confidential?

All information collected about you will be kept confidential and stored securely for 5 years after the study has ended.

8. What will happen to the results of the study?

Your identity will not be revealed in any publication, conference presentation or the study report (thesis).

A final report will be written that details the findings of the study and sent to participants if they wish. Findings of the study will be submitted for publication in relevant journals and conference presentations.

9. Who has approved this study?

The study has been reviewed by Cardiff University School of Healthcare Sciences Research Ethics Committee who have supported the study.

10. What should I do if I would like to take part?

If you would like to take part, please complete the attached form and return it in the stamped addressed envelope.

Thank you for reading this information leaflet. If you have any questions, please contact the researcher whose contact details are on page 1 of this information sheet.

Appendix 4: Permission to contact form



Exploring the impact on mothers who live with and care for an adult son or daughter with schizophrenia

Permission to Contact Form

If you are happy for the researcher from Cardiff University to contact you about a face-to-face interview, please fill in your name, contact details, the brief information relating to your son and daughter and sign below. Please return the completed form in the stamped addressed envelope provided. This information will only be used to contact you about this research study.

Name:

Signature:

Telephone Number:

Email:

Son/Daughter * delete as appropriate

Son/Daughter's Age:

Geographical Location:

Son/Daughter's Diagnosis:

Years since diagnosis:

Appendix 5: Description of photographs chosen by Frances

Photographs chosen by Frances

Frances was one of just two participants who chose to use photographs to tell their story and the only participant who included photographs within the three 'gold star' cases presented. Frances chose five photographs to help inform her story telling but also made reference to framed photographs that were on the wall of her living room throughout the interview.

As discussed in chapter four, as part of the planning of the study design, I determined that the inclusion of photographs would allow the participants to talk more freely about their experience and be prompted by them if they found the story telling difficult. It was anticipated therefore, that using photographs in conjunction with the BNIM of data collection would help mothers describe their experience and further facilitate deep and rich narratives. Below is a description of the photographs Frances used to facilitate her narrative:

Photograph 1: The national sportsman

This photograph depicted Gareth standing on a winner's podium inside a national sports venue. National flags were visible in the background and Gareth was wearing a sport kit. Around Gareth's neck was a gold medal.

Photograph 2: The birthday party

This photograph depicted a large gathering in the family garden. Frances's husband was at the forefront of the image standing next to a bar-b-que with an apron on. Frances, her daughter, and Gareth were in the background of the photograph surrounded by family and friends. Frances informed me this photograph was taken on Gareth's eighteenth birthday when they held a garden party to celebrate.

Photograph 3: The pebbled beach

This photograph was of a wide pebbled beach. Gareth was sat on the pebbles holding an ice-cream. He is smiling at the camera. There are no other people, buildings or landmarks shown in the photograph. Frances informed me that this was taken when Gareth was 16 years old. She explained that Gareth had not wanted to

go on holiday with Frances and her husband, but they had insisted as they believed he was too young to stay home alone. Frances explained that it was the only time she saw Gareth smile whilst on the holiday.

Photograph 4: The Student

This photograph was taken on the day Gareth left for university. He is smiling at the camera holding a large bag. Frances explained how upsetting this photograph was for her as at the time it was taken, she had been so proud and excited for Gareth as he embarked on his higher education, moving away from home, and marking his success at gaining a place at a highly regarded university.

Photograph 5: The great-unwashed

This photograph was saved on Frances's phone. She was keen for me to see it. The image was of Gareth, taken the day before I met Frances when she had visited him in hospital. Gareth was an inpatient, detained under the Mental Health Act (1983) when the photograph had been taken. He had gained weight and wore a beanie hat and t-shirt. Frances pointed out that there were tomato sauce stains on Gareth's beanie hat and she referred to Gareth as the 'great-unwashed'.

Photograph 6: The pictures on the wall

This was the photograph that Frances mentioned on numerous occasions throughout her interview. It was a framed photograph of Gareth at his graduation wearing his graduation robes. He is holding a scroll. The photograph sits next to the clock on the wall, and on the other side of the clock hangs a framed photograph of Gareth's sister at her graduation, mirroring the image of Gareth

Appendix 6: Overview of the BNIM analytic process

Step	Aim	Objective	Actions	Informed by:
Lived Life				
Step one Biographical Data Chronology	To establish the chronology of 'publicly' verifiable events experienced in the lived life.	To create a Biographical Data Chronology (BDC)	Creation of a BDC which presents an overview of 'objective' biographical information. This is written in chronological order.	Interview transcripts External sources in public domain to cross validate (if appropriate)
Step two Lived life interpretive panel analysis	To pursue multiple perspectives of interpretation and reduce lone-researcher bias	To ascertain multiple perspectives to inform creation of Biographical Data Analysis (BDA)	Facilitation of lived life interpretive panels To identify: experiencing hypotheses, counter hypotheses, tangential hypotheses, and structural hypotheses Based on events in the BDC Events are presented in sequential 'chunks' to panel to elicit hypotheses. Key questions asked during lived life interpretive panel (Wengraf 2001): <ol style="list-style-type: none"> 1. How could this have been experienced in relation to age, personal development, culture, family development? (experiencing, counter, tangential hypotheses) 2. How could the sequence of events so far 	The BDC document

			<p>shape the future lived life? (experiencing, counter, tangential, following hypotheses)</p> <p>3. For each hypothesis generated, what event could be expected later in the biographical data? (following, tangential hypotheses)</p> <p>Each panel member is asked to write a short report or summary statement</p>	
Step three Biographical data analysis	To establish a Biographical Data Analysis based on information gathered from the lived life interpretive panel	To create a Biographical Data Analysis	Information from the panel is analysed by the researcher along with the BDC and the interview transcript to create a full BDA. Phases and turning points of the lived life are noted.	<p>Flip chart notes taken during panel analysis</p> <p>Reports and summary statements from panel members</p> <p>Field notes taken following facilitation of panels</p> <p>Interview transcript</p>
Told Story				
Step four Text structure sequentialisation	To determine the structure of the	To create a Text Structure Sequentialisation (TSS)	Examination of the structural changes in the biographical account. Transcripts	The verbatim interview transcript

	conversation within the text		are analysed line by line and condensed into small segments according to when: <ol style="list-style-type: none"> 1. The speaker changes 2. The topic changes 3. The textsort changes: using DARNE typology <ul style="list-style-type: none"> • Description • Argumentation • Report • Narrative • Evaluation 	
Step five Told story interpretive panel analysis	To pursue multiple perspectives of interpretation and reduce lone-researcher bias	To ascertain multiple perspectives to inform creation of a Teller Flow Analysis (TFA)	Facilitation of told story interpretive panels To identify: experiencing hypotheses, counter hypotheses, tangential hypotheses, and structural hypotheses Based on information from the TSS Events are presented in sequential 'chunks' to panel to elicit hypotheses. Hypotheses are strengthened or refuted by the panel following the presentation of each data 'chunk'. Key questions asked during told story interpretive panel (Wengraf 2001): <ol style="list-style-type: none"> 1. Why is the biographer presenting this experience or topic now? 	TSS Verbatim transcript Field notes

			<ol style="list-style-type: none"> 2. Why is this person using this specific sort of text to present it? 3. What was the speaker experiencing at this point 4. Why might the speaker have changed topic? <p>Each panel member is asked to write a short report or summary statement</p>	
Step six Microanalysis	To increase understanding about puzzling or challenging parts of the text	To inform Teller Flow Analysis	Optional facilitation of microanalysis interpretive panel.	TSS Verbatim transcript Field notes
Step seven Teller flow analysis	To create a teller flow analysis	The creation of a TFA	All information is analysed in relation to the told story and a full and detailed TFA is produced	<p>Flip chart notes taken during panel analysis</p> <p>Reports and summary statements from panel members</p> <p>Field notes taken following facilitation of panels</p> <p>Interview transcript</p> <p>Notes from microanalysis panels (if conducted)</p>
Step eight	To bring the separate lived life and the	Lived life and told story comparison.	A framework is created to document the phases of the lived life	BDA TFA

Comparing lived life with told story	told story patterns together.		with the told story and the biographers 'mutating' subjectivity over the story of their life.	Verbatim interview transcripts
Step nine Construction of a case account	To communicate the biographer's subjectivity in their life story.	To construct a case account	An informed interpretive account is constructed and presented.	Verbatim interview transcripts All documents collated as part of the previous eight stages of analysis.
Step ten Cross case comparison and theorisation	To present a theoretically informed answer to the research question.	Comparison between and across cases	Compare and contrast between and across cases and examine them critically using relevant theory.	Appropriate literature Case accounts

Appendix 7: Biographical Data Chronology for Carol (all identifiable data removed)

Year	Event	Notes
1947	Born, [City in England]	
		Unremarkable school years; some poverty growing up; highly strung child
1965	Attended University	
1968	Travelled to Asia and attended University there	Country declared National Emergency. Contracted dysentery 'I thought I was going to die'.
1969/1970	Attended [name]University, [name] College to study MPhil and PGCE Teaching practice in [a University]	Socialised with [leader]
1970	Got married (aged 23years)	
1976	Son born Working in education Started MA but did not complete Published textbooks	Difficult birth; difficult baby
1978	Daughter born	Easy birth but son ill with whooping cough at the same time
		Husband moving all the time: [City and Towns] (3 times)
1981	Husband had an affair Moved to [City] which was disruptive for the children	
1996	Divorced Husband Father died Investigated for Cancer Son 'walked out of University' Daughters' behaviour started changing	

	<p>Daughter moves to University</p> <p>Change of jobs from education to administration</p>	<p>Daughter becomes more noticeably anxious, aggressive and 'angry at me'</p> <p>Daughter becomes unwell - contracts Glandular Fever, then ME, depression and doesn't return to University</p> <p>Daughter admitted to hospital for surgery and on the same day, received a call from son who had been admitted to hospital</p>
2005	<p>Trip to USA</p> <p>Daughter sexually and physically assaulted</p>	
2007	<p>Met second husband Got married</p> <p>Working part-time in admin role</p>	
2015	Retired	

Appendix 8: Sample from the Text Structure Sequentialisation for Frances

TOPIC: Son's University life

Page/line no. In transcript	Summary of Structure	Brief indication of content, the gist
1/13-21	Description	Breaking up with girlfriend and changes in personality
1/21-23	Argumentation	Husband takes a different perspective
1/27-31	Report	Son drops out of Master's degree, parents continue to pay his rent
2/35-36	Description	Son keeps [husband] on the doorstep
2/36-39	Argumentation	We thought it may have been drugs, seeing him less often
2/39-41	Description	A total worry and a total burden to us

TOPIC: The bottom fell out of my world

2/43-46	Narrative	Son admits to hearing voices
2/46-50	Argumentation	lost potential, the potential he had was immense
2/50-54	Evaluation	I thought anyone with schizophrenia were the lowest of the low
2/55-58	Narrative	Son goes missing just prior to GP appointment
2/63-3/72	Narrative	First contact with the psychiatric hospital, prescribed olanzapine but wouldn't take it due to potential weight gain

TOPIC: The graduation

3/72-74	Argumentation	When he gets on medication, he's going to get better, and he will be ok
3/74-76	Report	We cajoled him in to going
3/78-81	Narrative	'Where did the man go?' Mango fruit
3/85-89	Argumentation	I pushed him over the edge

		I know the mistakes I have made
3/91-92	Argumentation	As a parent, its your life's work – he got pipped at the post

Appendix 9: Example from Told Story Interpretive Panel for Carol

CAROL.

I would go out to crack
dens in the middle of
the night

EH: BRAVERY

FH1. Immune to danger

FH2. Feels free

FH3. Increased risk taking

FH4. Takes drugs,

FH5. Brags about it.

EH: EMPOWERMENT

FH1. Increased visits

FH2. Able to achieve anything

FH3. Feels better than others.

EH: TERRIFIED

FH1. Withdrawal from pleasurable activity

FH2. Takes extreme measures to protect self
(carries weapons)

FH3. Becomes secretive

FH4. Displays aggressive behavior / attitude

EH: STRESSED

FH1. Family find out

FH2. Becomes secretive

FH3. Starts self-medicating

FH4. Seeks help and support.

Appendix 10: Sample of comparing lived life with told story for Barbara, depicting telling flow analysis

Biographical Data Analysis – phases of the lived life	Subjective phases – told story	Telling flow analysis
<p>Phase 1 Young family life Born 1942</p> <p>1966 Met partner</p> <p>1967 Married</p> <p>1968 Daughter born</p> <p>1969 Son born,</p> <p>1971 Son develops physical health problems, hospital admission</p>	<p>I was a quiet teenager, left school early, working in a shop. I wanted to go to university and be a [title] professional. When I met him, my priorities changed, wanted a family more than anything.</p> <p>I wanted to be settled, with a home of my own and children. I wanted my children to have what I had growing up. I wanted to be there for the children no matter what.</p>	<ol style="list-style-type: none"> 1. The early days 2. Left school, first job 3. Marriage, children, family values, traditions 4. Having stability 5. Homemaker 6. Caring for physically ill child 7. Taking things in stride 8. Babies and motherhood 9. Being available 10. Return of ambition and focus on career aspirations
<p>Phase 2 Stability and focus Raising family</p> <p>Completed access to higher education course</p> <p>Trained as a Professional</p> <p>Completes Master’s degree</p> <p>Working as a qualified [title] professional</p>	<p>I realised that staying at home and being a full-time Mum wasn’t everything. I wanted to make something out of my life.</p> <p>I was determined to be a [job title], I became a bit obsessed with that, as a goal in life.</p> <p>I had just completed my master’s degree.</p> <p>I was abandoned</p>	<ol style="list-style-type: none"> 11. Determined to succeed 12. Going to college and succeeding 13. University course and professional training 14. Academic success and wanting more 15. Post-graduate training leading to better prospects 16. Professional identity 17. Success
<p>Phase 3 Deterioration Husband leaves</p> <p>Divorces husband</p> <p>1989 Son’s behaviour starts to change</p> <p>1990 Conflict with daughter</p> <p>Difficulty accessing support</p>	<p>I was so busy with my job and looking after the children</p> <p>I was on my own, trying to do everything</p> <p>I didn’t want to see it at first, but it became much worse than I thought it would</p> <p>I was determined to play the system to get help</p>	<ol style="list-style-type: none"> 18. Difficult years: husband leaves 19. Difficult to look after children and home and work 20. Competing demands 21. Trying to do everything 22. Sadness and loneliness 23. Feeling abandoned 24. Coping without husband 25. Worry for the future 26. Determination

Appendix 11: Developing themes for the cross-case comparison

Initial cross-case comparison matrix

THEME	CAROL	BARBARA	FRANCES
1. Impact on relationships	Between daughter and others and self and others, daughter and self, emotional impact, social withdrawal, impact on relationship with partner, allegations of paedophilia, loss of friends, family and social network	Perceived lack of support from others, own and sons' withdrawal from social situations, avoiding conversations, purposely avoiding, non-engagement, work relationships, strained relationship with daughter	Between son and others and self and others, isolated from others, social withdrawal, keeping self to self, impact on wider family dynamics, perceived lack of support
Concealment and secrets	Withholding information, not discussing situation, dealing with things herself, no-one to confide in	Difficulties discussing son and diagnosis, alienating self from significant others, hyper-vigilant to requests for information from others, refusing to converse	Avoiding conversation with others, social withdrawal, loneliness, low self-esteem, isolation
Concern and Unpredictability	Volatile, uncharacteristic, chaos, challenging behaviour – hallucinations, delusions, allegations, high-risk situations, crack-dens, crisis, impetuous, aggressive, vulnerability, isolation, lack of friends, new acquaintances	Chaos, out of character behaviour, dismantling furniture, disruption to life, risk-taking by son, bizarre behaviour, minimising severity of situation, confusion, concern for the future, difficulty coping, what will happen after death	Chaos, behaviour change, isolation, passivity, hallucinations, crisis, Concern for son's well-being, drugs, gay, confusion, offended, uncertainty and worry, escalating symptoms, consumed by thoughts of son, concern for future and advancing years
2. Mothering and constant mothering	Resilience, Burden, viewed as strong, blame, responsibility, not ill, on time, do what I say I will do, have to be upbeat, own expectations of motherhood, morality	Expectations of self as a mother, values, mother to two, superhero analogy (coping, strength), responsibility, defending son, defensive, gatekeeper, protection, guilt, personal and professional sacrifice, recognition of own	Guilt, blame, responsibility, culpability, self-criticism, burden, wanting to 'fix', proud – academic and sporting success, problem-solver, resilience
Searching for answers			

	Blame, guilt, trauma, sexual abuse	vulnerability and death, resilience Trigger event, being assaulted	Trigger and defining moment – relationship break-up and graduation
3. Stigma	Lack of acceptance, guilt, blame, shame, label, diagnosis, looking for reasons that are more acceptable for behaviour	Lack of acceptance, shame, pride, embarrassment, life-long label, what others think, not discussed, diagnosis and sharing it with others	Own negative beliefs about mental illness, apologetic for views, label, shame, embarrassment, self-criticism, affected behaviour, work-life, impact on freedom and civil liberty
4. Despair, loss, and grief	Keeping alive v alleviating suffering Unresolved, foreboding, on-edge, relentlessness, waiting for next crisis, hopelessness, trepidation, apprehension	Catastrophic impact on son and self, impact on own emotional well-being, waiting for next crisis, loss of imagined future for self and son	How things were v how things ought to be, lost opportunity and lost potential, loss of hope for the future, lives were never going to be the same again, unrelenting, loss of a life, loss of daughters extended family, loss of Frances's hopes
5. MH services	Lack of help, 'palmed off', GP dismissive, contacted MP, Paying for private consultation, sexual vulnerability	Navigating the system, frustration, time-consuming, reluctance to engage and accept, medication focussed, in conflict with social model of care, diagnosis helpful	Attempts to access, dismissed by GP (gatekeeper), angry, frustrated, paid privately, assessment, coldness of place and psychiatrist, lonely, detention under MHA.

Final cross-case comparison matrix

1. Stigma	Lack of acceptance, guilt, blame, shame, label, diagnosis, looking for reasons that are more acceptable for behaviour	Lack of acceptance, shame, pride, embarrassment, life-long label, what others think, not discussed, diagnosis and sharing it with others	Own negative beliefs about mental illness, apologetic for views, label, shame, embarrassment, self-criticism, affected behaviour, work-life, impact on freedom and civil liberty
2. Disruption	Between daughter and others and self	Perceived lack of support from others,	Between son and others and self and

	<p>and others, daughter and self, emotional impact, social withdrawal, impact on relationship with partner, allegations of paedophilia, loss of friends, family and social network</p> <p>Withholding information, not discussing situation, dealing with things herself, no-one to confide in.</p> <p>Changes to career</p> <p>Volatile, uncharacteristic, chaos, challenging behaviour – hallucinations, delusions, allegations, high-risk situations, crack-dens, crisis, impetuous, aggressive, vulnerability, isolation, lack of friends, new acquaintances</p>	<p>own and sons' withdrawal from social situations, avoiding conversations, purposely avoiding, non-engagement, work relationships, strained relationship with daughter.</p> <p>Changes to professional role, adapting this to care for son.</p> <p>Difficulties discussing son and diagnosis, alienating self from significant others, hyper-vigilant to requests for information from others, refusing to converse.</p> <p>Retired early</p> <p>Chaos, out of character behaviour, dismantling furniture, disruption to life, risk-taking by son, bizarre behaviour, minimising severity of situation, confusion, concern for the future, difficulty coping, what will happen after death</p>	<p>others, isolated from others, social withdrawal, keeping self to self, impact on wider family dynamics, perceived lack of support</p> <p>Avoiding conversation with others, social withdrawal, loneliness, low self-esteem, isolation.</p> <p>Retired early</p> <p>Chaos, behaviour change, isolation, passivity, hallucinations, crisis, Concern for son's well-being, drugs, gay, confusion, offended, uncertainty and worry, escalating symptoms, consumed by thoughts of son, concern for future and advancing years</p>
3. Despair, loss, and grief	<p>Keeping alive v alleviating suffering</p> <p>Unresolved, foreboding, on-edge, relentlessness, waiting for next crisis, hopelessness, trepidation, apprehension</p> <p>Lack of help, 'palmed off', GP dismissive, contacted MP,</p>	<p>Catastrophic impact on son and self, impact on own emotional well-being, waiting for next crisis, loss of imagined future for self and son</p> <p>Navigating the system, frustration, time-consuming, reluctance to engage and accept, medication focussed, in conflict with social model of care, diagnosis helpful</p>	<p>How things were v how things ought to be, lost opportunity and lost potential, loss of hope for the future, lives were never going to be the same again, unrelenting, loss of a life, loss of daughters extended family, loss of Frances's hopes.</p> <p>Attempts to access, dismissed by GP (gatekeeper), angry, frustrated, paid</p>

	Paying for private consultation, sexual vulnerability		privately, assessment, coldness of place and psychiatrist, lonely, detention under MHA.
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Appendix 12: Ethics Committee approval

School of Healthcare Sciences
Head of School and Dean Professor David Whittaker

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes David Whittaker



14 November 2018

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Dear Alicia

Exploring the impact on mothers who live with and care for an adult son or daughter with schizophrenia.

At its meeting of **13 November 2018** 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 in collaboration with your supervisor

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



