CARING OVER THE LIFESPAN: EXPERIENCES OF CARING FOR A SIBLING WITH SCHIZOPHRENIA

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ABSTRACT

Siblings can be seen as a huge resource in caring for adults with a diagnosis of schizophrenia: Many expect to take over the caring role of caring when their parents no longer can, and positive sibling relationships are related to better outcomes for adults with a diagnosis of schizophrenia (Smith, Greenberg and Seltzer, 2007). Despite these facts research into family carers has tended to neglect exploring sibling relationships until recently. Previous research has focused on the negative aspects of caring, and the coping strategies of the siblings. Very little has considered the impact of caring on the sibling relationship over the life-cycle, and why some siblings may offer support for their diagnosed siblings, while others do not. This study aimed to explore the sibling relationship over the life-cycle.

Six adults with a sibling diagnosed with schizophrenia were interviewed about their experiences growing up with and caring for their sibling over their life-cycle. Data was analysed using existentialist-informed hermeneutic phenomenology. Following this analysis three superordinate themes were identified, these were: the 'terrible weight' of having a sibling with a diagnosis of schizophrenia, evolution of the caring role over time, and expectations for their life-cycle. The findings from this study support previous findings showing that caring for a sibling with a diagnosis of schizophrenia is a difficult experience. This study also showed that the participants' ability to care for their sibling increased over time, related to access to have some emotional distance, learning to care for themselves, gaining knowledge about schizophrenia and their sibling's idiosyncrasies and being able to negotiate a caring vs a sibling relationship. The findings suggest that the participants felt a sense of obligation to care for their diagnosed siblings and that taking on this role might impact on their life choices, such as to have children. Limitations of the study, the implications for clinical psychology and recommendations for future research are discussed.

CONTENTS

1. INTRODUCTION

Approximately 220,000 People in England and Wales are currently diagnosed with schizophrenia (Royal College of Psychiatrists, 2012), 55% of whom will potentially continue to live at home with their families for at least 15 years after diagnosis (Brown and Birtwistle, 1998). These family members often end up taking on much of the responsibility of caring for their relative and supporting their recovery process, and as such are often described as informal unpaid carers. These informal carers provide an invaluable service by reducing the amount of formal care needed to be provided by the National Health Service (NHS) and other health care systems (Arno, Levine and Memmott, 1999), while also helping to reduce incidence of mental health problems (Willie, Bettge, and Ravens-Sieberer, 2008). However, the care provided by family members, including siblings, comes at some cost.

This introduction and review of related literature will discuss schizophrenia and the theories regarding its development. Firstly by examining what is meant by schizophrenia and the reliability and validity of this construct, before considering theoretical perspectives on the influence of the family environment on the development of schizophrenia. The review will then consider the experience of caring for a relative with schizophrenia and the impact this has on psychological well-being, focusing primarily on the experiences of siblings. The development of the sibling relationship will also be discussed, before considering the research aims of the study.

1.1. Literature search strategy

In order to find the papers mentioned in this study a literature search was completed using the databases psychINFO and psychARTICLES. The search terms 'schizophrenia' and 'siblings' were entered returning 548 papers, and the terms 'psychosis' and 'siblings' returned 88 papers. Several of these papers were not applicable to the research topic and it was necessary to broaden the search in order to find further papers. Google Scholar search was used with the same search terms returning 56,300 and 46,700 papers respectively. In addition

papers referenced in relevant papers were sought, as were the more recent papers in which they were cited. This provided a number of papers from which to begin a detailed literature review.

1.2. Description of schizophrenia

The current Diagnostic and Statistical Manual of Mental Disorders (DSM-5) characterises schizophrenia by symptoms such as delusions, hallucinations, and disorganised speech with negative impact on social and occupational dysfunction (American Psychiatric Association, 2013). Living with the symptoms typically leads to social isolation, withdrawal, and interferes with individual and family development (Brady and McCain, 2004). The life outcomes for schizophrenia are discussed below, as are the critiques of schizophrenia as a concept and varying ways of describing schizophrenia and its associated symptoms.

1.2.1. <u>Outcomes for schizophrenia</u>

The first episode of schizophrenia typically occurs in late adolescence or early adulthood (Kessler et al, 2007). In the UK, people experiencing symptoms will typically be seen in an Early Intervention Service (EIS). This service focuses on recovery by normalising distress and offering medication and psychological interventions if possible, leading to a reduction in hospital admissions, relapses and symptoms (Singh and Fisher, 2007), although these gains are not maintained over time (Bird et al, 2010). Some argue that these services promote the unnecessary use of potentially harmful neuroleptics. These medications may have a negative effect on cognitive function and brain volume (Lieberman et al, 2005), and withdrawal from them is likely to induce relapse (Moncrieff, 2008), potentially locking people into long term use of psychiatric services (Bentall and Morrison, 2002). Some individuals diagnosed with schizophrenia recover well and do not suffer with ongoing symptoms into further adulthood. However 50%-70% of those with a diagnosis will continue to live with schizophrenia for 20-40 years after diagnosis (DeSisto, Harding, McCormick, Ashikaga, and Brooks 1995; Huber, Gross, and Schuttler, 1975).

Treatment services in other countries have greater recovery rates than in the UK, using minimal medication (Seikkula et al, 2006). For example the open dialogue therapeutic practice in Scandinavia embraces systemic ideas, particularly the concepts of multiple perspectives and the idea that difficulties can be reduced through increased communication and dialogue between family members (Seikkula, Alakare and Aaltonen, 2001; Seikkula and Olsen, 2003).

1.2.2. Critique of schizophrenia

The reliability and validity of schizophrenia as a scientific construct has been challenged extensively (Boyle, 2002). There is an assumption that schizophrenia is a medical illness similar to other medical illnesses. However, diagnosis of schizophrenia does not follow the same procedures of investigating and defining as do physical illnesses (Boyle, 1999). Physical illnesses are reliant on both symptoms and signs. Symptoms are described as subjective, i.e. experienced by the person affected, and common, whereas signs are objective, i.e. can be detected by others, and less common. However, with schizophrenia, symptoms alone are indicative of a diagnosis, with the assumption being that a sign that is reliably associated with schizophrenia will eventually be found.

Additionally, in contrast to physical diagnoses, schizophrenia does not describe a discrete or meaningful pattern of behaviour or experience (Bentall, 1990; Boyle, 1999; 2001). In fact, the huge overlap of symptoms with other diagnoses in the DSM-5, and the high level of co-morbidity, implies that the categorisation of the diagnosis is unreliable. Despite these difficulties with diagnosis the use of medical language gives schizophrenia credibility within the scientific world and maintains the power and authority associated with psychiatry (Conrad, 1992).

Despite the debate over whether schizophrenia is an illness in the same way as a physical illness the fact that some people experience hallucinations, delusions and unusual beliefs is not contested. Neither is the fact that these experiences can be distressing.

1.2.3. Pyschosis, schizophrenia or complaints?

Following the critiques discussed above, the term 'psychosis' began to be used by mental health professionals in an attempt to take emphasis away from medical diagnosis. The term has become increasingly popular within mental health literature yet it is not mentioned in the latest DSM-5 (APA, 2013). Despite this the terms 'schizophrenia' and 'psychosis' appear to be used interchangeably and Boyle (2006) has suggested that the assumptions associated with schizophrenia have simply been transferred to psychosis. Boyle (2006) also suggested that psychosis is described in conflicting ways in the literature: as a more generic and broader category than schizophrenia; as something that develops prior to schizophrenia; or as an independent concept, yet one which uses the same medical language and assumptions as schizophrenia (Boyle, 2002). These inconsistent descriptions demonstrate how there is no universal definition for 'psychosis' in the literature. Despite this, 'psychosis' is regularly used by mental health professionals as if it is unproblematic and the meaning is universally understood.

Bentall (2004) agrees that schizophrenia is poorly defined, and suggests that the current classification implies that mental illnesses can be divided into discrete types. In contrast he promotes the 'complain-orientated' approach to understanding mental illness. He suggests abandoning psychiatric diagnoses in favour of describing symptoms or 'complaints' such as hallucinations, delusions, and thought disorders.

The term schizophrenia will be used throughout this study, as it is felt that this term is at least descriptive enough to capture the experience of the person, and has a universal definition that, while flawed, was used and understood by the participants in this study.

1.3. Family involvement in schizophrenia

Over the last century many theories have put families at the centre of understanding schizophrenia. The two most prominent theories are of 'schizophrenogenic mothers' and 'Expressed Emotion'.

1.3.1. 'Schizophrenogenic' mothers

In contrast to modern biological theories of schizophrenia, during the 1940's through to the 1960's theorists took a more environmental and anti-psychiatry approach to understanding the development of schizophrenia. In a series of studies Lidz and colleagues (Lidz and Lidz, 1949; Lidz, Cornelison, Fleck and Terry, 1957) suggested that defective interactions between a child and their parents resulted in the child's inability to develop a sufficiently strong ego identity. In particular he felt that otherwise seemingly harmonious families actually created distorted milieu that were 'skewed' towards the distorted parenting style of one dominant parent, typically the mother, whose ideas went unchallenged by other family members (Lidz et al, 1957). Although he did note that negative paternal influences could be just as harmful as maternal influences (Lidz and Lidz, 1949).

Fromm-Reichmann (1948) suggested that dominating, overprotective and rejecting 'schizophrenogenic mothers' were responsible for causing schizophrenia in their children. Similarly, Arieti (1955) noted that every case of schizophrenia he encountered had an aspect of family disturbance. He believed that negative family environments produced an extreme form of anxiety during childhood which was related to vulnerability for the rest of the individual's life. However, he tentatively disputed Fromm-Reichmann's (1948) suggestions about cold schizophrenogenic mothers, stating that he felt that only 25% of mothers of schizophrenics met this description.

These ideas led the systems theorist Bateson and colleagues (1956) to theorise the 'double bind' hypothesis. This refers to the tendency of parents, particularly those of schizophrenic patients, to communicate ambiguous and conflicting messages to which there could be no successful response by the child. 'Madness' is seen as an expression of the distress the double bind creates, and could be viewed as a cathartic and transformative experience (Bateson et al, 1956).

Throughout the 1960's Laing (1960) questioned the validity of mental 'illness'

but continued to blame families for the development of schizophrenia. He described schizophrenia as an understandable response to family conflict, which placed impossible demands on an individual. While these ideas were less stigmatising for the individual with schizophrenia, this early work has been criticised for focussing mainly on anecdotal and uncontrolled evidence, without investigating alternative influences (Hirsch and Leff, 1975). Furthermore, the focus on dysfunctional family life and particularly on domineering and cold mothers has since been criticised in feminist critiques for blaming mothers, with the post-war western cultural context of the 'castrating woman' and perceived decline of the male possibly influencing the mainly male psychiatrists (Ehrenreich and English, 1987).

As a result these ideas were dismissed by the 1970's, with Milan family therapists instead arguing that interactional patterns of communication within the whole family contributed to the development of schizophrenic type difficulties (Minuchin, Montalvo, Guerney, Rosman, Schumer, 1967).

1.3.2. Expressed Emotion

In response to the blaming nature of the theories of the 1940's to 1960's, alternative less blaming explanations for the development of schizophrenia were sought. The stress-vulnerability model (Zubin and Spring, 1977) brought together the different theories regarding the aetiology of schizophrenia, including genetic, ecological, and developmental models. This model suggests that some individuals have a genetic vulnerability to developing schizophrenia as children that is realised when they experience 'stressful' events, such as family conflict. Therefore this model suggests that family dynamics are not significant in themselves but can precipitate the expression of the 'illness' of schizophrenia. While this is less blaming on families, it suggests that the ordinary 'stresses' that most people can cope with are overwhelming for those with a 'vulnerability' (Boyle, 2002). It is this model that is generally used to explain the onset of first-episode of schizophrenia to parents and families.

Within this model 'Expressed Emotion' (EE) is considered a 'stressful event'.

Thus EE proposes that the emotional climate of the home influences the development of first-episodes of schizophrenia (McNab, Haslam and Burnett, 2007) and relapse (Ivanoic, Vuletic and Bebbington, 1994). The emotional climate relates to unclear, confusing, conflicting and derogatory communication between family members.

EE is measured by the Camberwell Family Interview (CFI; Vaughn and Leff, 1976), and is categorised as either high or low. In the 1970's individuals with schizophrenia who returned to the care of parents who were seen as hostile, critical or over-involved, were shown to have relapse rates four times higher than those with parents who did not act and communicate in this way (Brown, Birley and Wing, 1972; Vaughn and Leff, 1976). Later research confirmed these findings and shown that high EE is one of the most robust predictors of relapse, with individuals returning to high EE environments twice as likely to relapse as those returning to low EE environments (Butzlaff and Hooley, 1998). While families with less conflict and more acceptance of EE were associated with decreased relapse rates (Spiegal and Wissler, 1986). However there is lack of research that has investigated this more recently. In addition there is little literature investigating diverse populations. Given the high proportion of ethnic minorities with a diagnosis of schizophrenia in the UK (Kirkbridge et al, 2012) this is perhaps surprising, and suggests that this older research is not representative of a culturally diverse London in 2016.

However, the debate to whether the relationship between EE and schizophrenia is causal or maintaining is still unresolved. While strong evidence suggests that high EE plays a role in relapse, very little evidence supports a link between first episode of schizophrenia and EE (Raune, Kuipers and Bebbington, 2004). This appears to refute the claim by the stress-vulnerability model that 'stressors' such as family dynamics and expressed emotion trigger the development of schizophrenia. The assumption that high EE attitudes in parents create a toxic environment for the family member diagnosed with schizophrenia ignores the reciprocal nature of these interactions.

Indeed, high EE has been associated with aggression and hostility from the

diagnosed family member (Hall and Docherty, 2000), suggesting that there might be an interaction between difficult behaviour of the relative with schizophrenia and the behaviour of their family. It has been suggested that high EE reflects the family's attempt to control the difficult behaviour of their relative (Greenley, 1986; Hooley and Campbell, 2002) whom they believe can control their symptoms (Harrison, Dadds and Smith, 1998). However, this belief has been found to be unhelpful and is related to feelings of burden (Raune et al, 2004; Kuipers and Raune, 2000). Stirling and colleagues (1993) suggest that these feelings of burden affect EE which in turn impacts on the developmental path of schizophrenia. They found no association between relapse rates and high EE within 12 months of first hospitalisation (Stirling et al, 1991), but a follow up study 18 months later found that all but one patient had relapsed, compared to only 7 of 19 patients from low EE families. This suggests that the burden of caring for a relative with schizophrenia might contribute to some of the rigidity and difficulty seen in high EE families. Therefore relapse might be related to complex family dynamics, to which the attitudes and characteristics of all family members contribute.

Despite the links to the stress-vulnerability model, EE could be considered a continuation of family blaming theories from the 1940's to 1960's. Some have also questioned the validity of EE and suggested that the concepts of criticism, and over-involvement are culturally defined (Jenkins and Karno, 1992). Studies into EE also predominately focus on the interactions of parents. They do not explore the impact of an EE environment on the siblings who do not develop schizophrenia. However, these findings do suggest that the maintenance of schizophrenia is at least associated to family support and dynamics, and therefore highlights the importance of supporting family members to communicate effectively with each other, and gain a better understanding of schizophrenia, in order that they can promote a positive and nurturing environment for their loved ones.

1.4. Experiences of caring for relatives with schizophrenia

As touched on above, schizophrenia does not just affect the person with the

diagnosis, but it also affects their family. Many adults with a diagnosis of schizophrenia continue to live in their family home, cared for by their parents and other relatives, for at least 15 years after diagnosis (Brown and Birtwhistle, 2008). Families offering support for their relative with a diagnosis of schizophrenia have previously been taken for granted, and only in the last 20 years have they been conceptualised as carers, and seen as a resource (Twigg and Atkin, 1994). Yet, while many carers report having a caring role, not all identify themselves as a 'carer' (Henderson, 2001). To reflect this throughout this study family members involved in caring for a relative with mental health difficulties will be referred to as 'family carers'.

1.4.1. Differing family reactions to schizophrenia

Most research in this area focuses on the experiences of parents, spouses and children, very little considers the experiences of siblings. However some studies have explored the different attitudes and experiences of family members towards caring for a relative diagnosed with schizophrenia. Ewertzon, Cronqvist, Luzen, and Andershed (2012) described how siblings reported several 'generational' differences between their attitudes and those of their parents. Many of these differences are related to siblings demonstrating more willingness to accept their sibling's difficulties and feeling less stigmatised by others. For example, siblings reported that their parents did not want to discuss the illness either within the family or with friends, and wished to keep it a secret. However the siblings felt that this was unrealistic and wished to tell people about the difficulties they were facing. In addition, siblings reported that their parents had a negative view of mental health services and wanted to care for their child at home, whereas the siblings had a more positive view of services, at least initially. Finally, parents were not keen for their diagnosed child to become too independent, whereas siblings saw this as an important part of their recovery.

These different attitudes might refer to cohort effects and reflect a changing societal attitude towards mental health with attitudes prevalent when their parents were young being less prevalent today. Siblings may feel fewer stigmas

around discussing their struggles and receiving support. However, the range of ages within the participants, from 28 to 66, represents different generations within the group. These results suggest that these attitudinal changes have been developing for some time, or demonstrate how different relationships with the relative diagnosed with schizophrenia can impact on the family carer's attitudes towards them. Further research to elucidate these possibilities is needed.

Perhaps it is understandable that different family members will have different roles and therefore different experiences and attitudes towards caring for a family member with schizophrenia. In Western cultures parents are expected to care for their children, but only up to a certain age. Parents with a child with mental health difficulties usually have to care for their children far longer than expected. The expected life cycle of a child is interrupted and the parents are unable to successfully 'launch' the young adult into the world (Carter and McGoldrick, 1980).

An interesting study into the different roles adopted by family members by Johnson (2000), found that most families have a primary caregiver, with other members being more peripheral. Johnson suggested that fear of becoming the primary caregiver prevented other family members from taking on care-giving roles. This could reflect the cultural influence of the western small nuclear family and the western preference for individualism in comparison to collectivism (Triandis, 1995), suggesting that these findings would be different in other cultures. Johnson (2000) also found that primary caregivers were rarely siblings, except in the absence of a parent. However, siblings were more involved than spouses, possibly as they shared a family history with their sibling that the spouses lacked. This is yet another reason to consider the views and needs of siblings as not only do they offer a different relationship than spouses, they may also offer more care. However Johnson (2000) reported that siblings do feel less duty bound than parents, with most expressing reluctance to take on caring responsibilities.

1.4.2. <u>Carer burden</u>

Caring for a relative diagnosed with schizophrenia is related to high levels of stress. Most studies investigating the impact of caring for a relative with schizophrenia describe caring for a relative as a 'burden'. The meaning of burden for family carers is discussed below, as are the different reactions of family members to having a diagnosed relative. Most of this research has focused on the experiences of parents, spouses and children, but have neglected to consider the perspectives of siblings in their own right. Therefore the following research is not specific to the experiences of siblings.

Carer burden has been broken down into 'subjective burden' and 'objective burden' (Hoenig and Hamilton, 1966). Subjective burden refers to the family carer's perceived burden, such as psychological strain, explanations and descriptions of which can only be gathered through self-report from the family carers. Objective burden, however, relates to tangible losses such as financial burdens, or loss of employment. Burden, regardless of whether it is objective or subjective, has consequences for the family carer, the person they care for, and also for society: if the family carer feels overwhelmed and overburdened, this is likely to impact on their physical and psychological heath (Pinquart and S'orensen, 2003). With diminished health, they are unlikely to be able to provide the level of care and stability needed by their diagnosed relative, which could result in increased symptoms of schizophrenia and distress for their relative. As a result some family carers place increasing reliance on paid carers (Hoenig and Hamilton, 1966) leading to increased costs for the health service.

Subjective and objective burden are discussed in more detail below.

1.4.2.1. *Subjective burden*

Participants in Gater et al's (2014) study reported that caring was unpredictable, leaving them feeling stressed, anxious and worried; 74% reported feeling overwhelmed and felt that they could not help.

Family carers also report that the stigma related to their family member's

inability to conform to a social role is the greatest factor contributing to carer burden (Birchwood and Cochrane, 1990). Symptoms and behaviours such as lack of initiative, motivation, and the disruption that schizophrenia brings to the ability to hold a job and care for oneself are particularly distressing (Bibou-Nakou, Dikaiou, & Bairactaris, 1997; Weisman, Nuechterlein, Goldstein, & Snyder, 1998) and can be misunderstood as laziness, particularly in Western societies that values independence and hard work.

Not meeting the standards expected by families and neighbours can create strong feelings of stigma in middle and upper-middle class families, and contribute to family carers feeling distanced from family and friends. People from low Socio-economic status (SES) backgrounds report also report feeling embarrassment but report that their family member's difficulties in dealing with professionals such as welfare, mental health services, and the police, is more stigmatising for them than their functional level (Johnson, 2000)

Family members taking on a caring role for relatives with physical difficulties also report that in caring for their relative their personal identity has been subsumed by their identity as a carer (Hughes, Locock and Ziebland, 2013), although this area appears to be less explored within carers of those diagnosed with schizophrenia.

1.4.2.2. Objective burden

Several studies have noted that the pressures associated with caring for a relative diagnosed with schizophrenia can lead to absences from work and even termination of employment (Gater et al, 2014). In the UK in 2007, 15.5% of carers of people diagnosed with schizophrenia took an average of 12.5 days off work per year to care, while 4.8% had terminated employment (Andrews, Knapp, McCrone, Parsonage, and Trachtenberg, 2012). This reflects family carers' reports that their caring had affected their ability to work, with them either having to cease employment, adjust the way they worked or seek out new professions (Gater et al, 2014).

This contributes to the financial burden that many family carers report. Some state that they do not have enough money to care for their relative in addition to their other expenses (Gater et al, 2014), and were having to sacrifice their own savings as a result. Family carers also report feeling that they have no time for themselves, and have noticed the strain put on other relationships, such as marriages or relationships with children or friends (Gater et al, 2014).

Burden is also frequently manifested as distress and depression which might be followed by impaired health habits that can lead to illness (Schultz and Sherwood, 2008) such as fatigue and sickness (Gater et al, 2014).

Despite the considerable evidence for carer burden, family carers offer support for their loved ones. Since the above evidence suggests that this is at great cost to their own mental and physical health and can cause serious financial difficulties, it begs the question: why do they do it? Why do family carers continue to offer support for their loved ones, and why do some family members offer support while others do not? These questions have been somewhat neglected in the research, with most research questions focusing on the negative aspects of caring and very few exploring the positive aspects of the role, even fewer considering the position of siblings that offer caring support. Some studies however have explored which factors affect the burden felt by family carers.

1.4.2.3. Factors affecting family carer burden

Family carer burden has been consistently found in the research. However many factors appear to affect how the burden is interpreted. Particular clusters of symptoms, such as hostility and aggression, or severity of symptoms, appear to have a significant impact on burden (Mors, Sorensen and Therkildsen, 1992; Magliano et al, 1998). However, family reactions to schizophrenia do not appear to be related just to the cluster of severity of symptoms but in how these symptoms are interpreted (Hinrichsen & Lieberman, 1999; Weisman et al, 1998). For example, family carers that attribute distressing symptoms, such as lack of motivation, to personality flaws, assume that their relative purposefully

act in this way to provoke or antagonise their family, and therefore respond with frustration rather than understanding (Hooley & Campbell, 2002).

The gender of both the person diagnosed with schizophrenia and the family carer also appears to affect carer burden. Males with a diagnosis of schizophrenia are more often associated with high levels of carer burden (Mors et al, 1992) and female family carers often report experiencing higher levels of burden than male carers. This later finding has been seen in a range of family carers including parents (Wancata et al, 2008), spouses, co-habitants and children (Moller, Gudde, Folden, and Linaker, 2009), but again little research has been completed on siblings. Wancata et al (2008) suggested that these gender differences reflected the western societal expectation that women should care for their family members, which resulted in them taking on more responsibilities and therefore feeling more burdened.

Ethnicity also appears to affect family carer burden with White American family carers reporting higher levels of burden than African American family carers (Guarnaccia and Parra, 1996; Rosenfarb, Bellack and Aziz, 2006). This may reflect differing cultural beliefs, for example beliefs that schizophrenia is caused by religious or spiritual factors in African Americans leading to an understanding that schizophrenic symptoms cannot be controlled (Alvidrez, 1999). High EE is linked to the belief that schizophrenic symptoms are controllable (Brady and McCain, 2004), therefore this finding might help to explain why odd or unusual thinking is related to higher EE attitudes within White families (Rosenfarb, Goldstein, Mintz and Nuechterlein, 1995). Rosenfarb et al's (2006) sociocultural stress appraisal and coping model helps to explain these findings by suggesting that patients' symptoms, perceived burden and family cultural attitudes affect the way in which families behave towards their relative with schizophrenia.

While caring for a relative with a diagnosis of schizophrenia is repeatedly reported as stressful and burdensome, very few studies consider the positives of providing care. Those that do, suggest that benefits include the close relationship that is created through caring, the knowledge that their relative is being cared for and the fun they are able to have together (Gater et al, 2014).

However, frustratingly, the studies described in this section often use a mixture of spouses, parents and sometimes siblings in their samples. This makes it impossible to ascertain how the different family relationships with the diagnosed relative affect carer burden or how the relationships themselves are affected by burden. We therefore cannot draw any conclusions about the impact of specific relationships, such as sibling relationships, has on caring and subjective or objective burden.

1.5. Caring for a sibling diagnosed with schizophrenia

Parents, spouses and adult children are often thought to be the most involved family members in the care of adults with schizophrenia and the most commonly consulted or interviewed in research (Ostman, Wallsten and Kjellin, 2005). The impact of caring on siblings has often been overlooked until more recently. This is surprising considering how positive sibling relationships are predictive of greater quality of life for adults with a diagnosis of schizophrenia (Greenberg, Seltzer, Orsmond and Krauss, 1999), and that a large proportion of siblings expect to become primary carers after the death of their parents. The following section discusses the impact of living with and offering caring support to a sibling diagnosed with schizophrenia, the factors affecting their choice to do so, their coping strategies, and their relationships with services.

1.5.1. Sibling experiences of caring

Caring for a sibling has been found to create a mixture of uncomfortable emotions such as guilt, anger, envy, isolation, fear, and helplessness (Barnable, Gaudine. Bennett, and Meadus, 2006). Sin, Moone and Harris (2008) interviewed teenage siblings of individuals diagnosed with first-episode schizophrenia and found that the siblings struggle with conflicting emotions of resentment towards their sibling and guilt over not being sufficiently empathetic and supportive. This dilemma seems to continue into adulthood with Stalberg, Ekerwald and Hultman (2004) finding that adult siblings often struggle with feelings of anger towards their diagnosed sibling, but also feel guilty that they are not as supportive towards their diagnosed sibling as they feel they should be. Other studies have found that siblings have feelings of guilt associated with

being in some way responsible for the illness (Barnable et al., 2006). As a result of these difficult feelings siblings can feel overwhelmed and emotionally exhausted (Sin et al,2008; Barnable et al., 2006) scared of the illness, and sad at losing their sibling (Sin et al 2006; Stalberg et al, 2004; Barnable et al, 2006).

Siblings are sensitive to the embarrassment and stigma associated with having a mental health difficulty. They report feeling concerned that others will lack understanding towards their unwell sibling (Sin et al., 2008; Greenberg, Kim and Greenley, 1997) and fearful about the hereditary nature of the illness (Barnable et al., 2006; Stalberg et al., 2004).

Siblings also report feeling alone in their struggle, feeling forgotten and ignored by their parents as children when their siblings' difficulties took up most of the family's time and resources (Ewertzon et al, 2012). Siblings reflecting on their experiences growing up describe how they wanted to have their emotions recognised by their parents (Kinsella, Anderson and Anderson, 1996) and report feeling envious or lonely as they saw support and attention continuously focused on their diagnosed sibling rather than themselves (Sin et al, 2008; Stalberg et al, 2004). These feelings can contribute to a confusing conflict between feelings of obligation to help care for their sibling and a desire to have their own life and be independent (Ewertzon et al, 2012).

Considering the psychological impact of growing up with a sibling with schizophrenia some have suggested that siblings become 'secondary victims' requiring specialised professional care themselves (Lukens, Thorning, & Lohrer, 2004). Therefore, understanding sibling relationships, the impact of caring for a sibling with mental health difficulties on the relationship, and how siblings cope with this impact will become an increasingly important area to research and understand, in order that we can better support siblings.

1.5.2. Coping strategies

In order to cope with the conflicting and challenging emotions caused by caring for a sibling diagnosed with schizophrenia, siblings appear to either become

actively involved in their diagnosed sibling's care, are crisis-orientated, or become detached and avoidant (Gerace, Camilleri and Ayres, 1993; Friedrich, Lively, and Ruberstein, 2008). Those that are able to develop an involved and caring relationship with their diagnosed sibling seem to manage this by conceptualising their difficulties within the context of an 'illness' (Friedrich et al, 2008). These siblings often support their parents in the role of primary care-giver, such as supporting medication adherence and practical support (Sin et al, 2008). Yet their role might be considered as particularly important during crises when they frequently act as mediators between their unwell sibling and their parents (Bank and Kahn, 1997). They report feeling obligated to help, putting their siblings' and their parents' needs before their own, maturing faster than usual at the expense of their own emotional needs (Bank and Kahn, 1997).

Other siblings report that the mixture of negative feelings caused by growing up with, and caring for a sibling with a diagnosis of schizophrenia is too overwhelming (Sin et al, 2008) and therefore they cope by becoming detaching and having little contact with their sibling and provide little or no support (Friedrich et al, 2008).

However, studies focusing on coping styles of siblings take a very linear and one-dimensional approach, failing to explore why siblings act in these differing ways or ask existential questions such as the siblings' perceived choice about caring, how and why their coping styles may change over time, and is this related to their relationship with their sibling?

1.5.3. <u>Factors affecting caring for a sibling</u>

While less investigated, some studies have explored why some siblings take on the role of caring while others do not. Many siblings expect that they will be needed to provide more support for their sibling in the future (Smith, Greenberg and Mailick Seltzer, 2007) but their future caring is hugely influenced by the quality of their relationship (Smith and Greenberg, 2008; Greenberg et al, 1999; Smith et al, 1997). The quality of the relationship can be negatively affected by a number of factors, but in particular siblings are unlikely to provide care and

support if they are fearful of their diagnosed siblings or feel that they have control over their symptoms (Smith and Greenberg, 2008). Similarly, Hatfield and Lefley (2005) found that hostility, lack of cooperation and unwillingness to use mental health services negatively affected sibling's motivation to care.

These findings suggest that lack of knowledge and understanding about schizophrenia and how it presents can negatively affect the sibling relationship leaving them unwilling or reluctant to offer support. Indeed, Johnson's (2000) study noted that siblings' reluctance to offer support was related to their understanding of schizophrenia. If siblings understood the problem as being part of a mental 'illness' they were usually sympathetic. However if they perceived their sibling had some control over their behaviour they understood the behaviour as laziness, stubbornness or manipulation they responded by rejecting their sibling or distancing themselves (Greenley, 1986).

Other findings suggest that the most difficult aspect of caring for a sibling with schizophrenia is high levels of symptomatology which negatively affects subjective carer burden and psychological well-being (Barnable et al., 2006; Sin et al., 2008). Symptoms such as hallucinations and delusions (Barnable et al, 2006), suicide attempts and physical violence have a marked impact on the well siblings quality of life, again making them more reluctant to become involved.

Gender also appears to influence the amount of care a sibling provides to a sibling with mental health difficulties, with sisters more likely to care for their siblings than brothers (Greenberg et al, 1999; Lohrer, Lukens and Thorning, 2007). The participants in these studies represented an older age range and therefore these results may also reflect cohort effects where societal expectations around female employment and their role within the home might have influenced the expectations of the female participants. However, the younger female siblings in Bowman, Alvarez-Jimenez, Wade, Howie and McGorry's (2014b) study, all aged below 30, also reported lower levels of quality of life. This suggests that these societal discourses in western cultures where women are socialised from a young age to care for others may still be prevalent and might explain why women appear more as carers in research (Johnson,

2000).

Birth order also appears to play a role, with younger siblings more likely to care for their older siblings, and particularly younger sisters more likely to give care than older brothers (Bowman et al, 2014a). This may in part be the result of older siblings having a more established peer group prior to the illness of the sibling, especially if they have already moved out of home, offering them more external support, while younger siblings might spend more time at home with their diagnosed sibling and may not have developed supportive external relationships. However, this finding contradicts older research into families which found that older children usually care for the younger children in the family and take on parental roles and responsibility (Bossard and Boll, 1956). However this study did not focus on children with mental health difficulties and thus does not take the extra pressures of these difficulties into account. This discrepancy could be due to the age of onset of schizophrenia typically occurring in teenage years when older siblings have already moved out of the family home and are letting go of feelings of obligation and dependence and becoming more self-directed, possibly explaining why they feel less responsibility for their sibling (Harvey and Bray, 1991). It could also demonstrate how roles have changed since the 50's when Bossard and Boll's study was conducted, and that adolescents and young adults might feel less responsibility towards their family than might have been felt in the past and have a stronger sense of independence.

Few studies have explored the more existential themes of caring, such as the siblings perceived choice to care. Those that have explored these themes show that some siblings care for their diagnosed siblings in part due to feeling obligated to support their parents who request their help (Jewell and Stein, 2002), possibly feeling that they have little choice. Families caring for a member with mental health difficulties have been found to have rigid expectations regarding the roles family members should provide (Keitner, Miller, Epsteing and Bishop, 1987), emphasising family duty across generations (Horwitz, 1994). However, siblings may also be reluctant to care for their sibling in the future if they feel that it will interfere with the demands of their own life or involve

travelling distances (Hatfield and Lefley, 2005). These reasons suggest an aspect of choice in the sibling's level of involvement as they have a choice over where to live, and perhaps this again reflects the fragmentation of families in western cultures due to individualism.

As helpful as these studies are, as quantitative studies they fail to give us a true insight into the expectations, perceived choice, and reasons behind why siblings become involved in their siblings care or feel a sense of obligation. Quantitative data can only receive data on pre-determined topics, therefore we cannot gain a clearer understanding as to the reasoning behind their choices. A qualitative approach would allow for further exploration into these more existential factors. In addition these studies do not focus on those diagnosed with schizrenia but those with mental health difficulties in general, therefore the findings might not be representative of those with experiences such as delusions or hallucinations, such as in schizophrenia.

1.5.4. Relationship with services

Having a sibling with a diagnosis of schizophrenia and being involved in their care brings many siblings into contact with health services. In a systematic review of literature Amaresha, Venkatasubramanian and Muralidhar (2014) found six major themes that emerged regarding siblings of people with schizophrenia, including illness management or rehabilitation related needs, need for support groups, need for information about treatment, need for their own psychological support, and a desire to be included in the treatment process. Yet despite their need and desire for support (Hatfield and Lefley, 2005; Sin et al, 2008) siblings receive the least support of all family members (Ostman, Wallsten, Kjellin, 2005).

One of the frustrations noted by siblings, and relatives in general, is that they do not feel listened to by mental health professionals (Lukens et al, 2004), and that they are not given enough information about the illness (Barnable et al, 2006). This seems surprising, as involving families in the conversations and care about their relative from an early stage helps to facilitate their understanding of their

relative's difficulties, of the different treatment options and how to care for their relative. This ensures that their needs are being met which helps the individual with schizophrenia and promotes recovery (Addington, Collins and McCleery, 2005).

Family therapy models such as Multiple Family Group therapy (MFG) aim to support the family through diagnosis, and have been found to be very helpful for families (Jewell, Dowling and McFarlane, 2009; McDonell et al, 2003). Family interventions have been found to reduce relapse, symptoms, feelings of burden in relatives, admission rates, and improve compliance and outcomes (Bebbington and Kuipers, 1994), and are therefore, unsurprisingly, emphasised in guidelines (International Early Psychosis Association writing group, 2005). Open Dialogue, a successful therapeutic practice in Scandinavia, encourages open conversations and embraces multiple perspectives within families, in the expectation that difficulties can be reduced through increasing communication and dialogue, and has had very successful outcomes in reducing admission and improving outcomes (Seikkula et al, 2001; Seikkula and Olsen, 2003). In the UK the availability of these interventions is very low, with only 12% of service users in England and Wales stating they had received family interventions (Royal college of Psychiatrists, 2014). However, while family therapy may improve outcomes it is not always successful in reducing carer burden (McDonell, Short, Berry and Dyck, 2003).

The stress and burden of caring for a sibling also often mean that siblings need support managing their own psychological needs (Hatfield and Lefley, 2005; Sin, Moone, Harris, Scully, and Wellman, 2012). Siblings often report that they would like to be involved in support groups (Kinsella et al, 1996; Main, Gerace and Camilleri, 1993), some asking for groups that include only siblings (Hatfield and Lefley, 2005; Sin et al, 2012). Specific support groups for siblings have been found to be helpful. Siblings report that they had gained knowledge, and that they felt less stressed and that they wanted the meetings to continue (Ewertzon et al, 2012). In particular having the opportunity to talk to others and discuss experiences helps siblings to realise that they are not alone and many express relief when they realise that others are in similar situations (Ewertzon et

al, 2012).

These findings demonstrate the pressure that siblings are under and how having support to manage their own well-being and being involved in family interventions helps them to support their diagnosed siblings. It is therefore surprising that only limited research has been carried out into the benefits of the support services for siblings such as support groups.

1.6. Sibling relationships

Sibling relationships are unique in that they offer companionship, as well as emotional and practical support in a way not provided in other relationships (Goetting, 1986). While sibling relationships may not be central to most adult's lives at any given time, they are unique for their durability (White, 2001).

While the sibling relationship has arguably always been an important relationship, Bank and Kahn (1982) highlighted a number of cultural transformations that may have strengthened the prominence of the sibling relationship in modern times. For example, the average family size has decreased over the last hundred years, placing more importance and intensity on the one sibling relationship that children are likely to have. The higher levels of geographical movement, divorce, and the increase of absent parents due to stress, employment, and marital tension might encourage siblings to provide each other mutual support.

Sibling relationships are related to better coping and adjustment after a stressful life event (Gass, Jenkins and Dunn, 2007), and good mental health in adolescence and early adulthood (Oliva and Arranz 2005). Positive sibling relationships have been found to reduce the risk of developing schizophrenia and of relapse as a result of social exclusion by reducing feelings of feeling like an 'outsider' (Selten and Canton-Graae, 2005). In this way sibling relationships can be seen as protective, demonstrating the importance of investigating the value of sibling relationships over time, and considering their views when

working with people with schizophrenia

This section will review theories of the sibling relationship across the life-cycle, how the relationship changes and when siblings may be closer or more distant.

1.6.1. <u>Sibling relationships across the life-cycle</u>

Family life is a changing and evolving process. The concept of the 'life-cycle' is an attempt to capture this process and chart the developmental stages that families tend to go through. Carter and McGoldrick (1988) suggested that the life cycle can be broken into six stages with accompanying key principles of the transition.

The first of these is 'leaving home'. This stage is focused on young single adults accepting and establishing their own emotional and financial responsibility and independence and developing intimate peer relationships.

In the second stage these single young adults then become a 'new couple', joining their different families through marriage. The young adults show commitment to a new system and extend their relationships to include their spouse's friends and family.

The third stage includes accepting new members into the system, namely children. The new parents must adjust to having children and sharing the childrearing, financial and household tasks.

As these children grow into adolescents, in the fourth stage, the family needs to become increasingly flexible to allow for the children's independence, allowing them to come in and out of the system. This stage is also linked with increasing caring responsibilities for the older generation.

In the fifth stage the children are 'launched' into the world and the parents must accept a number of entries and exits into the system, develop adult relationships with their now adult children, and expand their relationships to

include in-laws and grandchildren. At this stage families are also likely to deal with the disabilities or death of grandparents.

The final stage concerns families in later life and involves accepting the shift in the generational roles within the families, including the parents dealing with the loss of siblings, peers or spouses while preparing for their own death. Stress within family relationships is believed to be highest during transitions between stages, particularly when the life cycle is interrupted or fails to adapt (Hayley, 1973). Although the traditional concept of the nuclear family has evolved to also include single-parent families such as unmarried mother or father, and divorced or widowed parents, this model still influences our expectations and behaviours of family life (Dallos and Draper, 2010).

Goetting (1986) considered the sibling relationship from a life-cycle perspective. She suggests that as siblings move through these life stages of 'childhood and adolescence', 'early and middle adulthood', and 'old age' their relationship changes and a number of different 'developmental tasks' are accomplished. The term 'developmental task' refers to the prosocial behaviours that have been observed in the literature and therefore that might be expected and anticipated through the progression of sibling relationships.

The stages suggested by Carter and McGoldrick (1988) fit loosely in these time frames, with their 'leaving home' stage perhaps fitting into adolescence as described by Goetting (1986). Most of their stages fitting into Goetting's second life stage 'early and middle adulthood' and 'launching children and moving on', with 'families in later life' possibly fitting into Goetting's final life stage 'old age'.

Both these models conform to the idea of a stage model, and the idea that certain tasks must be completed in order to progress through the stages. This concept is problematic as it does not provide explanations for alternative pathways and choices made through life, such as not having children, thereby implying that these alternatives are abnormal. Nevertheless, both these models provide helpful structures for organising our understanding of family relationships. Goetting's (1986) model provides an understanding of how an

individual's family life-cycle might impact and influence the life-cycle of their sibling relationship. The following literature review draws on these two models and other psychological theory in order to gain a life-cycle perspective of sibling relationships. The literature is described within the stages suggested by Goetting (1986); childhood and adolescence, adulthood, and old age.

1.6.1.1. Childhood and adolescence

Sibling relationships are often the primary source of emotional support in pre-adolescence (Lamb and Sutton-Smith, 1982). Goetting (1986) suggested that it is at this point, when the siblings are likely to be in daily contact, that the sibling relationship is the closest and most intense, with siblings offering each other the companionship, emotional support and care-taking roles that are characteristic of normal attachment between siblings (Bank and Kahn, 1982). Indeed, the companionship within sibling relationships has been found to compensate for a lack of other peer relationships (Furman and Buhrmester, 1985), with adolescents reportedly finding companionships with their siblings more important than with peers (Feinberg, Neiderhiser, Simmens, Reiss, and Hetherington, 2000; Whiteman and Buchanan, 2002). Siblings also act as role models (Furman and Buhrmester, 1985) and can influence the development of attitudes and behaviour in each other (Whiteman, McHale and Crouter, 2007). This could possibly be through the processes of social learning theory, such as mirroring and observational learning (Bandura, 1969), suggesting that sibling relationships can have a powerful influence in the development of identity, particularly in families where one sibling develops schizophrenia.

1.6.1.2. Adulthood

As siblings transition into young adults they encourage each other to become confident and independent both socially and psychologically (Cicirelli, 1989) and support each other through the developmental tasks of becoming autonomous individuals (Bowen, 1976). However, once siblings move out of the family home and focus on their own relationships, during the second and third stages of Cartner and McGoldrick's model (1988), the competing demands of family and work contribute to reduced sibling contact and affection (White and Riedman,

1992; Miner and Uhlenberg, 1997). Goetting (1986) described this period as middle adulthood.

Cantor's (1979) hierarchical-compensatory model of kin relationships depicts relationships as residing within a series of concentric rings with those with whom one has the strongest relationships in the inner ring. During the transitions of middle adulthood the occupants of these rings are reorganised and siblings who have until this point been in the inner ring often fall into the second or outer rings, and positions in the inner rings are replaced by spouses and children (Parsons, 1943). The support system of the relationship persists but with decreased intensity (Goetting, 1986).

1.6.1.3. Late adulthood

Once each sibling's own children have been 'launched' into the world and moved out of the family home, in Carter and McGoldrick's (1988) fifth stage, the companionship and emotional support of sibling relationships become important once more (Falloon et al, 1982; Goetting, 1986). Sibling rivalries tend to be resolved and siblings face the problems and difficulties of ageing with greater closeness (Cicirelli (1980). This may suggest positive outcomes for adults with schizophrenia as their siblings might be better able to support them when their own children are less demanding. These findings, that the sibling exchange is high in childhood, decreases in early – middle adulthood but becomes important again in old age are found to be very robust (White, 2001).

This life-cycle approach provides an easy structure for understanding and describing sibling relationships but allows for the stage transitions and development tasks to take place at different ages and periods of 'adulthood'. Cantor's hierarchical-compensatory model (1979) neatly explains the changing intensity of sibling relationships, suggesting that siblings are pushed out of the inner circle in exchange for spouses and children but can be pulled back in if difficulties arise in these other relationships. This perspective suggests that in the absence of life-cycle transitions, such as children, the sibling's relationship remains important, and when these transitions are reversed, through divorce or

being widowed, sibling relationships regain their important status. However, a mental illness, such as schizophrenia, being present in one sibling may well disrupt the expected development of the sibling relationship.

Considering that the stress felt at transitions in the life-cycle is likely to affect how much care and support family members might be able to provide to mentally unwell siblings it is interesting that few studies have investigated the impact of life-cycle stages on the relationships between adults with mental health difficulties, such as schizophrenia, and their siblings. Or indeed the impact caring for a sibling with mental health difficulties, such as schizophrenia, may have on individual life-cycles. Stress combined with the different coping strategies mentioned above could drastically impact how much care or support a sibling provides. One of the few studies investigating the impact of life cycle stages on siblings caring indeed found that those with multiple role commitments, such as marriage, parenthood and a career, felt more strain and were less involved in their sibling's life (Greenberg et al, 1999). However, this study used a quantitative approach and therefore, as discussed previously, is unable to effectively capture the full complexity of the sibling relationship. It therefore begs the question how is this relationship experienced by the undiagnosed siblings? How does their ability to care change over their life-cycle, and what impact does this have on them?

1.7. Rationale for research into sibling relationships over the lifespan

The experience of having a relative with mental health difficulties has been found to have a big impact on family carers, including feelings of burden, grief, guilt, and frustration. However, most of the research thus far has focused on the parents, spouses and children of diagnosed individuals, and siblings have been neglected until recently. This is surprising considering the unique relationship siblings have (Goetting, 1986) and the protective nature of sibling relationships against mental health difficulties (Oliva and Arranz, 2005). Since individuals being involved in the care of their diagnosed sibling is related to better outcomes, and how siblings expect to take over the main caring role from their parents (Smith, Greenberg and Seltzer, 2007), siblings could be seen as

resources. Therefore exploring the impact of caring on siblings' well-being, their ability to care and their life expectations and choices appears to be vital.

An individual with a diagnosis of schizophrenia may need stable support throughout their life, yet this may be difficult for siblings to provide at times, particularly around transitions in the life cycle, such as having a family, or their desire to help may wax and wane, or their caring role may prevent them from having the life they expected or wanted. As a profession we therefore need to gain an understanding of how the sibling relationship between a sibling diagnosed with schizophrenia and an undiagnosed sibling evolves over time. If we are aware when there might be periods of stress which might reduce a siblings caring capacity, we can provide support when they need it most, or be able to provide extra support for individuals with schizophrenia.

The research thus far into the reasons why siblings offer support and care has been predominately quantitative and thus are unable to capture the full complexity of the siblings' experiences. They therefore offer a linear and one-dimensional understanding related to familial obligation and geographical location (Jewell and Stein, 2002) but do not consider the many other possibilities for sibling involvement. The more existential questions such as siblings' perceived choice about caring, their desires and expectations for their life, and how these factors might change over time and as the sibling's progress through their life-cycle have rarely been explored in the recent literature. Yet answers to these questions would give us a richer understanding of the sibling's subjective experience, and therefore how we might be better able to support them.

This study therefore aims to investigate how siblings of adults diagnosed with schizophrenia retrospectively perceive their relationship with their sibling across their family life cycle.

1.7.1. Research questions

1. How do siblings of adults with a diagnosis of schizophrenia describe and perceive their caring role, currently and retrospectively?

2. How do siblings of adults with a diagnosis of schizophrenia retrospectively describe their subjective experience of how life cycle transitions affected their relationship?

2. METHODOLOGY

This chapter reviews the methodology and research design used in this study, informed by the epistemological position.

2.1. Existentialist-informed hermeneutic phenomenology

2.1.1. Rationale for using qualitative methodology

Research into the caring role of siblings of adults with a diagnosis of schizophrenia is currently quite limited. As such research into this area needs to be explorative, in order that possible avenues for research are not prematurely dismissed. Quantitative methodologies are only able to study pre-determined factors and therefore fail to provide a thorough and rich understanding of all the aspects of an individual's experience. They aim to record the objective regularities of behaviour in order to make predictions (Gunzenhauser and Gerstl-Pepin, 2006). In contrast, qualitative methodologies allow for exploration of an individual's experience and can offer a richer, more in-depth understanding. As such qualitative research methods are better placed for exploration developing topics such as this.

2.1.2. Rationale for using existentialist-informed hermeneutic phenomenology

The aim of this research is to understand how adults experience their relationship with their siblings with a diagnosis of schizophrenia. After considering the possible qualitative methodologies, existentialist-informed hermeneutic phenomenology felt the most applicable to this study.

This approach is distinct from other descriptive methodologies as it seeks to not merely describe the participant's experiences of phenomena but tries to offer interpretations of the meanings they ascribe to them. In contrast to other interpretive phenomenological approaches such as Interpretive Phenomenological Analysis (IPA) it takes an existential approach to the analysis of the data and is therefore interested in fundamental life concerns such as the focus of the participants life and their perception of their choice in that focus and

their expectations for the future, their sense of sacrifice on the participants experiences and how their experience is characterised over time (Willig, 2012). Thus it lends itself to research questions about how it feels to undergo life events, and transitions between life stages (Willig and Billin, 2011). It also allows researchers to be flexible in the way the data is obtained, including creative approaches such as including pictures, music or timelines.

The three aspects of existentialist-informed hermeneutic phenomenology are discussed in more detail below.

2.1.3. Phenomenology

Phenomenology attempts to understand a person's experience in the way in which the person perceives the world they inhabit. It can be described as a focus on people's subjective, lived experience of the world (Langdridge, 2007) or as the study of how people experience phenomena (Von Eckartsberg, 1998). This is not an approach that can assign causality but instead considers what is experienced and the way it is experienced. Phenomenology was established as a philosophy by Husserl (1962), who noted that we try to find meaning in our experiences and developed phenomenology in order that these experiences and meanings could be studied. As a research methodology it is concerned with investigating first person accounts of life experiences to arrive at an understanding of the essences of the experience and the meaning the person gives to it. The premise of this approach is that the world of human beings is subjective (Patton, 2002), and phenomena may be experienced differently depending on who is perceiving them and the context in which they are perceived. Therefore the focus is on individual's perceptions of 'things in their appearing' and how they focus their attention on them.

According to phenomenology, the object being perceived cannot be separated from our experience of it. In this way phenomenology avoids the subject-object dualism central to positivism, which understands reality as being an objective 'other' separate from the individual (Laverty, 2003). Instead phenomenology argues that objects in the world cannot be viewed or thought about separately

from the subjectivity of our perception of them (Langdrige, 2007).

Phenomenology can be descriptive or interpretive. Descriptive phenomenology aims to investigate and describe how objects manifest in our consciousness and create reality within our 'life-world'. The phrase 'life-world' was coined by Husserl (1962) and describes the world as we perceive it. However, as Glense (1999) noted, our perception of the world is influenced by the ever changing social construction of our reality. While, descriptive phenomenologists recognise that interpretation influences how people experience and perceive the world, they prefer to focus on phenomenological purity. In contrast, interpretive phenomenology aims to understand and interpret the meanings that people associate with their experiences, within the individual's personal context. Interpretive phenomenology is associated with existentialist-informed hermeneutic phenomenology.

In order to be able to truly describe and interpret another's experience, Gadamer (1975) suggested we must first understand our own position which is dependent on our culture and personal history. Giorgi (1981) spoke about the importance of researchers 'bracketing off' and suspending their presuppositions and assumptions in order that they can focus on the analysis of experiences without bias. The aim of this is that a researcher is able to describe phenomena as they appear to the consciousness free from any preconceptions.

Phenomenology covers a range of different philosophies and research approaches, with different emphases and therefore implications for how we might study people's experiences, of which hermeneutic phenomenology is one.

2.1.4. Hermeneutics

Hermeneutic phenomenology is concerned with interpretation, with a focus on language. Gadamer (1975) argues we gain understanding of our life-world through language. Ricoeur (1979) specifies that it is discourse more than language that enables understanding, particularly discourse that occurs in dialogue, when an individual is speaking to another person. In this way

language, understanding and interpretation are inextricably linked (Langdridge, 2007). Von Eckartsberg (1998) argued that, although we are unable to fully describe our experiences through language, if we make an effort our ability to 'observe, remember, report and reflect' (1998, p5) allows us to build a rich picture of our own and other's experiences.

The semi-structured interviews used in phenomenology allow for analysis of this dialogical language. Van Manen (1997) describes how researchers can elucidate the participant's meaning when analysing the transcripts by moving in a 'hermeneutic circle'. This involves focusing on sections of the text and considering how this corresponds with the text as a whole, and also considering how the whole text corresponds with each individual section. Via this circle the researcher gains a fuller understanding of the meanings within the text.

2.1.5. Existentialism

Existentialism is a philosophy that developed and became culturally significant in the 1940's after the brutality of the Second World War prompted people to question the meaning of life. In contrast to other philosophies existentialism posits that there is no purpose to existence, but emphasises that individuals are free and responsible for determining their own purpose and development (Satre, 1946). Heidegger (1971) suggested that the world comes into existence for us through our participation in it, that we are the creator of our world. Merleau-Ponty (1968) goes further, suggesting that our world is an extension of our body.

Using phenomenological methods, existentialism can be used to expand on Husserl's work in phenomenology (Spinelli, 2005) and explore concepts such as the nature of existence for individuals (Smith, Larkin and Flowers, 2009). In order to do this the existential-phenomenological approach relies on the supposition that people with a shared language and cultural heritage name and identify experiences in a similar and consistent manner and therefore assumes that experience and associated phenomena are fundamentally the same for different individuals. This is what gives us access to and helps us understand

others experiences (Van Kaam, 1966).

Similarly to phenomenology 'bracketing off' presuppositions and assumptions about the phenomenon being investigated in order to be open to a participant's experience is also considered important in existentialist phenomenology. However, in contrast to pure phenomenology, existentialist phenomenologists believe that it is not truly possible to do so. Heidegger (1971) felt a researcher's biases are likely to impact on how a researcher interprets a person's meaning-making and therefore needs to be reflected upon. Merleau-Ponty (1968) similarly suggested that we can never gain total clarity over our reflective and critical orientation. However he saw this as a positive and felt it could enhance our understanding of the phenomena being considered.

2.1.6. Summary

Existentialist-informed hermeneutic phenomenology is a combination of these philosophies. Hermeneutic phenomenology explores an individual's unique life world, with the understanding that there are wide range of life worlds reflecting the many human realities and existences. Willig (2012) suggests that as humans we engage with the existential concerns, such as our relationship with time, and our relationship with our environment, our bodies, and others, which structure of these life worlds, even if our engagement is demonstrated by our avoidance of it. Willig goes on to note that 'existentialist-informed hermeneutic phenomenology research involves both participant and researcher in a process of trying to make sense of what it means to 'be (human)', that is to say, what it means to live as an embodied being in a (particular) physical and social world' (2012,p10).

As in other phenomenological approaches the researcher is reflexive about their own position and attempts to 'bracket off' some of their pre-suppositions, while understanding that this might not be totally possible. This type of research is usually undertaken through semi-structured interviews and the language and discourse used is interpreted, in order to reach a shared understanding of the experience of a phenomena. It may not be possible to totally express the

experience of a phenomena but the aim is that through reflection, discussion and interpretation we can get close.

2.2. Epistemological position

The aim of this study is to gain knowledge about people's inner thoughts which influence their experiences of the world. It therefore does not engage with the epistemologies of the external world, but instead focuses on the subjective world (Willig, 2013). It therefore holds a position in relation to existentialism, hermeneutics, and phenomenology. This study is interested in the internal thoughts and beliefs in relation to the phenomenon under investigation, in this case caring for a sibling diagnosed with schizophrenia, which influence their experiences. It is therefore phenomenological in approach. It also acknowledges that the researcher's understanding of participants' experiences is influenced by their own assumptions. However, rather than being biases to be eliminated these presuppositions are necessary in making sense of the participants experiences. Therefore this methodology is influenced by hermeneutic versions of phenomenology. This study is also interested in existentialism and the way the fundamental concerns such as our relationship with time, death and the meaning of life influence our understanding and experience of the world.

2.3. Reflexivity and quality

Van Manen (2007) sees phenomenology and reflexivity as intrinsically linked. It describes the process in which researchers consider and reflect on the ways in which their position, questions, methods and the participants' position might impact on the data or the psychological knowledge produced in a study (Langdridge 2007). Willig (2001) differentiates between two types of reflexivity: she describes 'personal reflexivity' as reflecting on the ways in which our own values, experiences, political beliefs and social identity influence the research; while 'epistemological reflexivity' questions the quality of the research, including how and if the research questions have limited what could be found, and how the analysis and design of the study may have constructed the findings.

This section will discuss the issues surrounding personal reflexivity and consider the position of the researcher to the research in and how this might impact on the research. It will then consider 'epistemological reflexivity' and how quality can be assured.

2.3.1. <u>Personal reflexivity</u>

The personal, prior experiences of the researcher are likely to have an influence on the focus of their research, their choice of interview questions, and how they interpret the answers of the participants. In this way their own background, prior knowledge and experience of the participants might influence all aspects of the research from data gathering to interviewing to analysis.

Finlay (2003) argues that we should reflect on and recognise our assumptions and keep them separate from the phenomena being studied. She argues that reflexivity is the "process of continually reflecting upon our interpretations of both our experience and the phenomenon being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes" (Finlay, 2003, p. 108). She terms this 'hermeneutic reflexivity'

In order to remain personally reflexive Gadamer (1975) recommended that interviewers keep a diary to record and describe their experience and emotional response to the interviews. However, he argued, that these reflections might help inform the researcher's understanding of the topic and aid the analysis of the data and facilitate the interpretation of an experience and the meaning assigned to them.

In this study the researcher kept a diary in order to reflect on the experience of interviewing. It was felt that due to the researcher's experience of similar phenomena, these reflections might help inform the analysis of the data and facilitate the interpretation of meaning-making of particular themes, as suggested by Gadamer (1975). However, the diary also highlighted any presuppositions of the researcher and therefore helped them to remain mindful

that alternative avenues of interpretation were explored and not shut down.

2.3.2. Reflexive note

My interest in this area is related to my own experiences of growing up with an older sibling with mental health difficulties. My experiences give me an insight into the difficulties and emotional pressures faced by siblings in these circumstances. I have therefore always felt a connection and understanding of the sibling's position within any systems and families I have worked with. However, my interest in this area increased and developed as I immersed myself in the research thus far. Although I responded and related to much of the literature, and the experiences of the siblings reported within it, I felt that it failed to truly convey the richness of the experience of having a sibling with mental health difficulties. Neither did I feel that the literature adequately considered the long-term impact of mental health difficulties on siblings. I therefore have a vested interest in investigating and campaigning for siblings contributions in research. This interest needs to be considered in the analysis of the data to ensure that my keenness to support siblings does not encourage interpretations that are not valid. Further discussion about my experiences interviewing and analysing the data will be discussed in chapter 4.

2.3.3. Epistemological reflexivity and quality criteria

Validity and reliability are not applicable to qualitative research in the same way as in quantitative research. Rather, 'trustworthiness' is sought (Yardley, 2000). Yardley's (2000) flexible principles for quality in qualitative research will be followed to evaluate if the current study has reached sufficient levels of quality. These principles include sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. These principles will be reviewed in chapter 4. A reflective note has been included to contextualise the research and consider any presuppositions that might have impacted the analysis. A further reflexive note can be found in chapter 4 to discuss the process of interviewing and analysis. The researcher will also keep a diary in order to reflect on their own presuppositions and in order to be open to alternative meanings and not impose their own interpretations on the data, as

discussed above. An excerpt from this can be found in appendix A.

2.4. Participants

2.4.1. Recruitment

All the participants from this study were recruited from a support group for siblings of adults with mental health difficulties within London. They were recruited after the researcher attended a support meeting and explained the research. Only those with a sibling with a diagnosis of schizophrenia were invited to take part. Attempts to recruit participants from other support groups were unsuccessful.

Giorgi (2009) noted that how participants are recruited in qualitative research is less important than whether they have experienced the phenomena wished to be studied, in other words, whether the participants are representative (Giorgi, 1988).

Representativeness does not necessarily mean a range of individuals from different contexts, ages, genders etc, as in quantitative data, but rather a more closely defined, homogenous group of people that have experience of the phenomena the research is aiming to study, and to whom the research questions apply (Smith and Osborn, 2008). Therefore Englander suggests that the main question that should drive recruitment is 'Do you have the experience I am looking for?' (2012, p19).

As the participants in this study identified as having a specific experience of the phenomena to be studied (having a sibling with schizophrenia) and were seeking support from a support group specifically for siblings of individuals with mental health difficulties, the researcher felt reasonably confident that this group of individuals would have had experiences of caring for a sibling with schizophrenia. Therefore the answer to Englander's question is 'yes'. However, it is only once the analysis has been completed that one can say with confidence that the participants had the experiences the research intended to study, and therefore if they are indeed representative (Englander, 2012). Therefore the question of

representativeness will be discussed further in chapter 4. However, it is worth considering that these participants were recruited from a sibling support group. That they sought support from others may suggest that their experiences reflect more severe presentations of schizophrenia. The experiences of these participants may not represent the voices of siblings whose relatives with a diagnosis of schizophrenia live more independent lives.

Adults with a diagnosis of schizophrenia were not included in the sample as it was felt that this might affect their ability to take on a caring role. Those with a sibling who had recently been diagnosed were also excluded as it was felt that they would not have held the caring role for a sufficient period of their life.

2.4.2. Number of participants

Six siblings of adults who have lived with a diagnosis of schizophrenia for much of their life were interviewed with this study. The focus on an individual's experience within phenomenological research reduces the number of participants that can practically be interviewed. Therefore researchers recognise that this in-depth analysis can only been done on a small scale, with few participants (Smith and Osborn, 2008).

The concept of saturation affects the number of participants considered necessary in qualitative research. Saturation describes the point at which further interviews will uncover no further themes. Guest, Bunce and Johnson (2006) found that in their study saturation occurred at an early stage, with 34 of the 36 themes found in their study developed from the first six interviews. They therefore suggest that "a sample of six interviews may [be] sufficient to enable development of meaningful themes and useful interpretations" (p.78).

Considering these findings it was felt that the six interviews conducted in this study would be sufficient to fully investigate the subject matter and would provide an opportunity to focus on the richness of the individual experiences of the participants.

2.4.3. Description of participants

All participants had lived with their sibling at some point during their life and supported caring for their sibling, either through regular phone-calls, or through providing financial or advocacy support. The participants ranged in ages from 27 to 68, with an average age of 45. Four of the participants were female and two were male. The table below provides limited information concerning the participants age and details of their sibling. All participants have been given pseudonyms. Further information regarding the participants has not been included in Table 1 in order to protect the participant's anonymity, but is given below.

Table 1. Patient demographics

Pseudonym	Sex	Age	Ethnicity	Sibling with diagnosis
Alice	Female	27	White-British	Older brother
Emma	Female	30	White-British	Older brother
Tom	Male	35	White-British	Younger sister
Alan	Male	52	White-British	Younger sister
Susan	Female	56	White-British	Younger brother and sister
Kathy	Female	68	White-British	Younger sister

All participants had at least one sibling with a diagnosis of schizophrenia and one participant had two siblings with a diagnosis of schizophrenia. Two participants were younger than their sibling with a diagnosis of schizophrenia and four were older. All were in some form of employment, except one participant who had retired. One participant was also completing a degree in mental health part-time. All the participants lived within or near greater London, and were White-British. None of the participants had any children of their own, although all bar two were in relationships.

2.5. Interview schedule

Data collection in phenomenological research typically consists of in-depth semi-structured or unstructured interviews (Langdridge, 2007). Therefore a semi-structured interview was completed face-to-face with each the six

participants. An interview schedule (Appendix F) informed the questions asked during the interview. The interview schedule consisted of only a few questions in order that the researcher limited the extent to which they imposed any preconceived ideas on to the participants (Van Manen, 1990). This style of interviewing relies on open-ended questioning so as to allow and encourage the participants to explore the themes they consider pertinent to the phenomenon and questions, resulting in the production of rich data. Follow up questions were also asked in order to facilitate rich descriptions of the participant's experiences. The overarching questions of the interview were around the evolution of the relationship over time, and the impact of life-cycle transitions on the relationship. The interviews lasted between 60-90 minutes with an average of 78 minutes. The interviews were audio-recorded and transcribed for analysis.

As this study asks participants to recall experiences and memories from different times in their lives some participants may have difficulties with retrospective recall. However, the flexible nature of the existentialist-informed hermeneutic phenomenological approach helps facilitate the participants' recall by focusing on creative engagement (Van Manen, 1990). Therefore genograms and timelines, were used in addition to the semi-structured interview questions in order to facilitate memory recall.

2.6. Ethical considerations

2.6.1. <u>Informed consent</u>

Research ethics approval for this study was obtained from the University of East London's Ethics Board (see appendix G). Participants were given an invitation letter for the study when they showed interest in taking part in the research at the initial support group meeting. This outlined the purpose of the study, their right to withdraw, confidentiality, and how their data was to be stored (See appendix D). Those that agreed to take part were then given a consent form (Appendix E) which they were asked to sign. It was considered whether consent should be sought from the individual with the diagnosis, since they would be discussed in the interviews. However, it is not their experience that this study is concerned with, and no questions were asked directly about their individual

history. For these reasons consent was only sought from the participants. They were able to tell their relative about the study, but this was negotiated verbally.

2.6.2. <u>Confidentiality</u>

The interviews were recorded using a digital voice recorder and then transferred to a laptop. The computer and all electronic files were password protected and kept at home. Only the researcher had access to this computer. The recordings were transcribed after each interview and all identifiable details were omitted from the transcripts. The participant details were kept separately from the transcripts.

The personal nature of the interviews made it possible that the participants may have found the interview experience distressing. They were reminded of their right to decline any questions, pause the interview or withdraw at any time. It was also suggested that they continue to use the support group they already used and a therapist if they had access to one. Risk to the researcher was also considered and any difficulties that arose as a result of listening to the participant's accounts were to be discussed with the research supervisor, however this was not necessary.

2.7. Data Analysis

The existential interest of this study in change over time and expectations for the future was explored in the questions focusing on the transitions between the life-cycle stages. Questions about the impact of these transitions aimed to explore the subjective experience of the participants, the phenomenology. While the hermeneutics is reflected in the engagement of the researcher with the participant, asking how it was and is to be in their situation and have that experience.

Hermeneutic phenomenological data is analysed thematically, similarly to other qualitative approaches. However, the themes are generated in a less prescriptive fashion, to other phenomenological approaches, such as IPA, which utilise the 'mechanical application of coding' (Van Manen, 1990, p.79). Analysis

is guided by the relationship or 'dialogue' the researcher has with the text (Grenz, 1996). This is an attempt to avoid prematurely closing down possible ways of understanding and to free the researcher up to see the meaning.

Van Manen (1990) suggests three approaches to analysis: holistic, meaning that the data is attended to as a whole looking for the fundamental meaning of the text; selective, where the text is read several times looking for particular phases which are revealing about the phenomena or experience which are then highlighted; and detailed, where each sentence or phrase is considered in terms of what it reveals about the phenomenon. Van Manen (1997) described working in a 'hermeneutic circle' moving between detailed analysis to holistic analysis and back again in an effort to get a better understanding of the meaning of the experience to the participant. This simultaneously broad and detailed analysis helps to ground the analysis and prevent idiosyncratic interpretations that are beyond the data. In this study this process has been used for each participant's transcript and then for the data from all participants as whole. In this way the analysis will be presented as the meanings and essences of each participants' individual experiences and the experiences that are common to them all. As discussed above the analysis will be supplemented by the reflexive observations captured in the researcher's diary. These reflections will help the researcher to be aware of and attempt to 'bracket off' presuppositions, while being aware and reflective that this may not be possible.

3. RESULTS

This chapter presents three super-ordinate themes that were identified through the analysis of the participant's interviews. These themes are shown in Table 2.

Table 2. Super-ordinate themes and related subordinate themes.

SUPER-ORDINATE THEMES	SUBORDINATE THEMES
The 'terrible weight' of having a sibling diagnosed with schizophrenia	• 'It was just a roller-coaster all the time': The unpredictable and dominating nature of schizophrenia • 'I just felt torn up inside': The emotional impact of having a sibling diagnosed with schizophrenia
The evolution of the caring role over time	• 'I need to have distance': The need for emotional distance • The importance of developing self-care • 'I sort of know what drives him': The value of gaining understanding • Negotiating a caring relationship vs. a sibling relationship

The expectations of the sibling's life-cycle	• 'I had no choice': Siblings' perceived choice about caring
	
	• Choices regarding life-cycle transitions
	  ○ Difficulties having relationships
	  ○ Choices to not have children
	
	• Expectations for the future

Despite the separation of the data into themes, these themes are related with each other therefore there may be some overlap in the presented data. Each super-ordinate theme will be discussed using direct excerpts from the participant interview transcripts to provide evidence for each theme. An example of the analysis demonstrating how the themes were achieved can be found in appendix B and C.

3.1. Details of each participant

3.1.1. Alice

Alice is a 27 year old woman. She was the youngest in her family behind two older brothers, the oldest of which was diagnosed with schizophrenia when she was around 14 years old. She has struggled with her brother's difficulties having intense emotional reactions to it. She also struggled with her own mental health difficulties and physical health difficulties (epilepsy). Alice and her parents initially tried to keep her brother's difficulties from her, and were keen to keep them a secret from their friends and family but over time Alice found this a heavy burden to carry. She recently decided to become more involved in her brother's care, but her other brother has little contact with her diagnosed brother. She was articulate and honest about her experiences. I felt immediately at ease with Alice, perhaps because we were a similar age and I could relate easily to her emotions and experiences. Below is a genogram of the people Alice felt were important in her family.
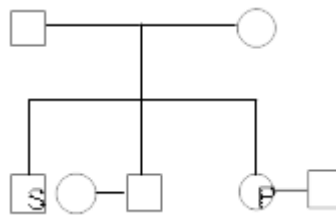
'P' denotes the participant and 'S' denotes the sibling diagnosed with schizophrenia.

3.1.2. Emma

Emma is a 30 year old woman, with herself, her older brother, and their parents in her immediate family. When she was much younger she was close with her brother, Adam. However, when he started to develop difficulties she found his behaviour very difficult to manage. Emma's parents also tried to hide the difficulties from her and she was regularly left with feelings of uncertainty. It was only when she left home to move to London that she was able to face some of the difficult emotions that she had felt had been neglected. She has recently decided that she wants to contribute to her brother's care. Similarly to Alice, I connected with Emma as we were a similar age and I shared a number of her

fears and her experiences. I was aware that Emma was nervous during the interview and often used humour to deflect from difficult moments. At times the interview was difficult for her and therefore I was grateful that she agreed to take part. To me this demonstrated her strength and her conviction in the importance of promoting research for siblings, which I hugely respected.
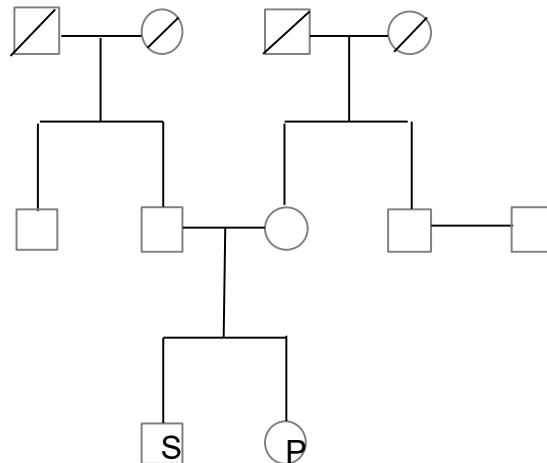

3.1.3. Tom

Tom is a 35 year old man. He is the middle child with an older brother and a younger sister who was diagnosed as a teenager but has now recovered. Tom had been at university when his sister was diagnosed but was keen to support his mother in caring for her. He feels responsible for not being around when his sister first developed difficulties. I was immediately struck by Tom's caring attitude and his clear affection for his sister. I felt that he was keen to care for his sister and to be helpful but doubted how helpful he had been. Tom appeared to struggle with the questions at times, appearing shy and unsure of himself, however as the interview progressed he gained confidence and was increasingly insightful into his relationship with his sister and the rest of his family.
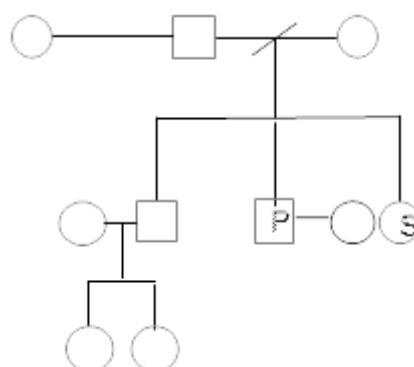
3.1.4. Alan

Alan is a 52 year old man. He is the second eldest of four children, including his older brother who is diagnosed with schizophrenia, a younger sister, and his youngest sister who is also diagnosed with schizophrenia. His mother also has a diagnosis of schizophrenia. Alan decided to care for his diagnosed siblings from the beginning as he was aware that his father was already caring for his mother. He feels his experiences with schizophrenia have made him calmer and more tolerant of people's behaviour. He indeed has a calming personality and I admired his calm and patient persona in the face of the pressures that he faced.
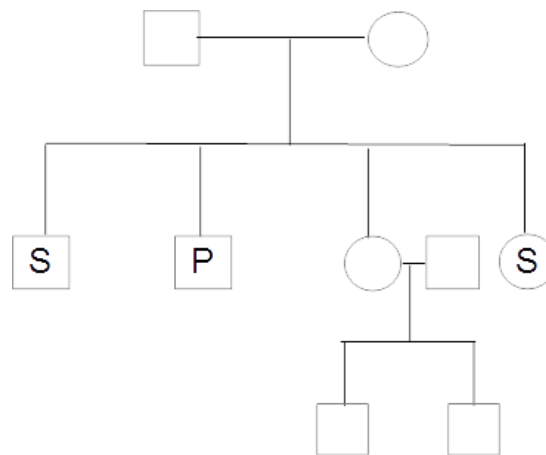
3.1.5. Susan

Susan is a 56 year old woman. She is the eldest in a family of five children including 2 younger brothers, her younger diagnosed sister and another younger sister. Although very close with her sister as children, in contrast to the other participants Susan was able to be more distant from her sister's difficulties as a young adult. Her mother's attitude enabled her to live her own life, although she maintained contact with her sister during numerous hospitalisations. Susan became involved in her sister's care only after their mother died, after feeling that her sister would otherwise be ostracised from the family. While she has found caring difficult at times she has developed a close relationship with her sister. Initially I did not feel I connected with her as her experiences of being distant from her sibling during adolescence and early adulthood were so different from my own. However I came to develop a great respect for her

considerate and attentive care of her sister.
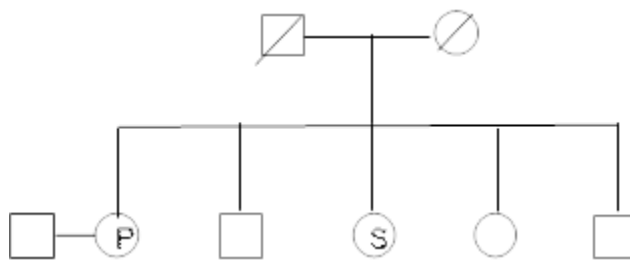
Kathy

Kathy is a 68 year old woman, the eldest of three children including her younger unwell sister and a much younger brother. Kathy was a very assertive woman with a no-nonsense approach who had been involved in her sister's care from the beginning. She had sacrificed much to care for her sister including promotions, working full time, and relationships. Kathy also was the organiser of the sibling groups from which all the participants were recruited. Kathy clearly had a wealth of experience and I admired the assertive way that she dealt with her sister's care.
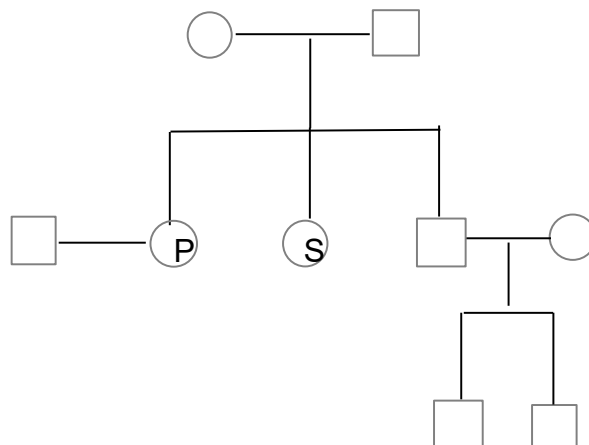
Personal reflections on the experience of interviewing can be found in the discussion section.

3.2. The 'terrible weight' of having a sibling diagnosed with schizophrenia

This theme is concerned with the burden and pressure that the participants felt as a result of having sibling with a diagnosis of schizophrenia. This theme has been found numerous times in previous research and as such will not be discussed here in detail, other than to empathise aspects that are salient for these participants.

All the participants noted how merely having a sibling with schizophrenia had an impact on their lives, even before they consider taking a caring role:

> Interviewer: And how do you feel that, in a general sense that your sister's illness has impacted on your life?
>
> Kathy: Oh massively, I mean... massively, I mean, it's, it's been my life-cycle
>
> (Kathy, p28)

This except suggests that having a sister diagnosed with schizophrenia has been an influence, if not the major influence on Kathy's life, and in all likelihood influenced the choices she made. Alan also describes how his life was impacted from the moment he learnt of his brother's diagnosis. This happened after growing up with his mother's mental health difficulties, and was later followed by his younger sister's diagnosis. He described a vivid memory of his intense reaction on discovering his brother's diagnosis:

> it felt like a big weight dropping on me, I went 'my brother?'.... and I just remember this weight dropping on me, I don't know, God, and I feel like it's never been lifted off, it's just this terrible weight on my shoulders.
>
> (Alan, p8)

Alan's vivid description describes the huge amount of pressure he feels he has been unable to escape from. The use of 'terrible weight' conjures pictures of an overwhelming burden that he struggles to hold and manage, that he finds exhausting and from which there is no escape. This perhaps also hints at Alan's sense of obligation, he seems to assume that his brother's difficulties will impact

on him, as if he has no choice but to be involved. Yet Alan does have a choice, something is driving this sense of obligation. These ideas will be discussed further in the 'siblings' perceived choice about caring' subordinate theme.
Alice felt 'haunted' by her brothers diagnosis:

> it sort of felt like I was haunted by it, I couldn't stop thinking about it but I wanted to stop thinking about it, and it all just felt so sinister, that this thing could happen to a person, that they, that their experience of the world just fragments and it falls apart, and I was so scared.'
>
> (Alice, p6)

Here Alice describes how scared she was by the diagnosis, perhaps as a result of her fear of the unknown and lack of understanding or previous contact with mental health difficulties. It is possible that she worried about how her brother's difficulties would affect his life, how they would affect her life, and for how long. Perhaps it felt so 'sinister' because she was fearful that if this could happen so easily to her brother it could also happen easily to her, as if it were lurking in the background, waiting for her. While this suggests a sense of unpredictability, another interpretation could be that Alice almost feels a sense of inevitability, that there is a lack of control over one's mental health, and that 'this thing' can happen to them without them being able to stop it.
Emma described it as an injury that could never heal:

> it just feels like this never ending scab, a wound that's constantly being ripped open.
>
> (Emma, p23)

The image of a wound powerfully conveys the emotional pain she felt. The idea of the scab being ripped open implies that even when it feels that things are getting better, as a wound starts to heal and forms a scab, it deteriorates again, and her pain once again becomes exposed. Similar to Alan, she describes how this process continues to repeat, as she believes her brother's difficulties will 'never' end. These excerpts demonstrate how the burden of having a sibling with a diagnosis can dominate the participants' lives.

3.2.1. 'It was just a roller-coaster all the time': The unpredictable and dominating nature of schizophrenia

This theme refers to the unpredictability of schizophrenia and how it seemed to dominate the family lives of the participants. All the participants described a catalogue of difficult behaviours including their sibling's lack of independence and needing support for 'basic' skills such as food shopping, aggression, and a lack of understanding of the participant's own needs. In particular, several participants described how their life had been 'roller-coaster', and how this in particular affected them.

> it was just a roller-coaster all the time
>
> (Susan, p3)

Roller-coasters conjure a picture of unpredictability, of ups and downs and of high adrenaline. Perhaps the idea of high adrenaline reflects the stress and energy needed to deal with Susan's sister's crises. Susan might be suggesting that the unpredictability of crises was repetitive and constant. Her use of the past tense might imply that she feels that life is now more predictable. Perhaps now she has spent more time with her sister she has gained an understanding of her behaviours and what to expect. This will be discussed more in the subordinate theme 'the value of gaining understanding' below. Alan also described the metaphor of a roller-coaster:

> And I just said to him, I'm not willing to go on this, get on that roller-coaster with you and go up and down and up and down you know.....I want my life to be stable and normal
>
> (Alan, p18)

Here Alan indicates that he has seen this up and down cycle of behaviour several times and he seems exhausted and exasperated by it. Alan has been caring for his brother since he was diagnosed when Alan was in college, and it has clearly had a big impact on his life. He notes that he wants his life to be 'normal', suggesting that he believes his life circumstances are 'abnormal'. One interpretation could be that dealing with this unpredictability for a number of years has led him to feel increasingly burnt out and frustrated with his brother.

Perhaps he feels that he has done his part, and he does not want to deal with the stress and unpredictability any more.

This unpredictability seemed to dominate family life for some participants:

> family life was dominated by what mood Adam was in.
>
> (Emma, p10)

This excerpt suggests that Emma did not find family life relaxing but was always concerned about the mood of her brother. Being controlled by someone else's mood means the environment would have been unpredictable and perhaps led Emma to mediate her own behaviour and mood to ensure that she was not negatively impacting on this mood. Alice similarly found that her family was dominated by her brother's difficulties:

> he in many ways was the focus on our family, not for lovely reasons but because it takes, because we're worried and anxious, and it feels not fair, all of these things.
>
> (Alice, p7)

Alice's brother was the focus of concern in her family, causing them worry and anxiety. Anxiety for her brother and his emotional well-being, but perhaps also anxiety about how and when his behaviour might impact on her and her emotional well-being, contributing to feelings of unpredictability and a lack of control. There is also a sense that her brother's situation and her own is not fair. Perhaps she compared her situation to that of her peers and was envious of other's seemingly less stressful environments. Alice could also be referring to the importance of fairness between siblings in families. In families where one sibling is physically ill or has mental health difficulties there may be an inequality of attention. She may be alluding to feeling that her needs were not met.

Emma also described feelings of uncertainty:

> not wanting to go home any more because it didn't feel like home any more, it basically felt like a war-zone where you constantly, even now

> when you go back you're a little bit on tenterhooks to 'Christ what's going to set him off'. Which sometimes is not necessary, he's perfectly fine.

<div align="right">(Emma, p10)</div>

Emma appears to have felt, and at times still feels, unable to relax as she was constantly worried about her brother's reactions. Her description of a war-zone suggests that there was an aggressive and perhaps violent element to his behaviour, which might have added to her anxiety and fear. These strong and uncomfortable feelings towards their siblings were particularly salient for these two youngest participants. Perhaps they have had less time to adjust to their situation and maybe have not yet learnt what their siblings' triggers might be, which makes their situation feel volatile and unpredictable, leading to them feeling on 'tenterhooks'. The use of this word suggests that these participants are not only having these thoughts, but are also having to physically carry themselves in a different way in order to not upset their sibling. Indeed, these participants appear to have spent much of their time considering their siblings' emotional needs before their own which is likely to be tiring as well as breed resentment.

3.2.2. <u>Emotional impact</u>

The unpredictability the participants experienced with their siblings seems to reflect the roller-coaster of their own emotions. In addition to the anxiety and uncertainty described above, participants described the grief and guilt they felt as a result of their sibling's difficulties and they felt this impacted on their emotional well-being and development. Here Emma describes her sense of grief:

> it is almost a sense of grieving at times, you've lost the person that you used to know and instead you've got this other one.

<div align="right">(Emma, p3)</div>

Here when Emma talks about grief she might be describing the loss of a hoped for and anticipated future for her brother. She indicates that she misses her

brother's previous personality and has not yet been able to accept the person he has become instead. She may be mourning the person he might have become and the relationship that she might have had with him.

Tom described the guilt he felt:

> I feel like maybe I should have been around or around at the time they were divorced so Sarah [his sister] could have like, confided in me I think, being away and that. So, so I felt a little bit of guilt really, to be honest with you.'
>
> (Tom, p7)

Here Tom seems to feel guilty and partly blame himself for his sister's difficulties. Perhaps as her older brother he believes his role was to support his sister when she needed it, but he feels he failed in this task.

The combined impact of these emotions appears to be the most difficult aspect for some participants to deal with. Here Emma describes a very vivid and intense response which played out in a dream:

> I'd had a nightmare because my dad was throwing me out because I hated my brother, I during that I'd never hated anyone so much and I really hated him during that period. Erm, I just felt torn up inside with guilt and fear that because I hated him that dad wouldn't accept me
>
> (Emma, p12)

This excerpt demonstrates how confusing and conflicting the emotions felt by the participants could be. Emma felt hate, anger, guilt and fear all at the same time. These different emotions are difficult to reconcile and might have added to the 'heavy weight' that she felt. Indeed, she believes that these difficult emotions had an impact on her on well-being:

> me not emotionally growing up until really quite late and having that [low] self-esteem again meant that I didn't pursue opportunities'.
>
> (Emma, p20)

Perhaps here Emma is describing a loss of hoped for future for herself too. She

indicates that she had expectations about normative emotional development and that she does not have this. Perhaps she felt her own emotional needs were ignored due to the focus on her brother's more challenging needs. She implies that she had to cope more emotional pressure than most adolescents, which she believes resulted in stunted emotional development.

In contrast to these more negative views, there were some positive outcomes from the participant's circumstances:

> I guess you get used to all that weird behaviour so you're not quite so freaked out by, when it's the first time round it's all very strange. And I think it's left me quite calm in a way'
>
> (Alan, p3)

Perhaps here Alan suggests that his experiences changed the way that he interacts with and responds to the world. He became used to the pressures or the unpredictable behaviours from a young age and developed particular strategies for looking after himself, such as remaining calm. He notes the first time around the situation was 'all very strange' suggesting that strategies developed over time.

3.3. Evolution of the caring role over time

This study found that having a sibling with a diagnosis of schizophrenia can be an enormously pressured and stressful experience which continued to have an impact over the course of a lifetime. However, as the participants matured the opportunities for either emotional or physical space, the knowledge they acquire about their siblings difficulties, and their ability to care for themselves all impacted on the way they coped with and supported their sibling.

3.3.1. The need for emotional distance

This subordinate theme relates to how emotional distance was important for the siblings and served different functions at different times; such as being a short-term coping strategy, enabling emotional development, facilitating the

participants to live their own life, and developing autonomy in their sibling. These factors appeared to facilitate the participant's ability to care for their siblings. Here Emma describes how being distanced from her brother helped her:

> I'm able to rationalise it better now that I'm older. But at the time I just, and my only way of seemingly not being frustrated with him was to take a massive step back away from everything.
>
> (Emma, p13)

Here Emma might be referring to taking a physical step back and spending time away from her brother, or she may be referring to emotional distance where she emotionally disengaged from a relationship with him, or both. Perhaps by 'taking a step back' she was able to maintain a relationship with him without being emotionally sensitive to his behaviour, helping to reduce her feelings of anger and frustration towards him. She says she is able to 'rationalise it better' which might suggest that she has a new perspective perhaps as a result of increasing maturity developed through time and distance. She explains further:

> I moved up to London about 7/8 years ago, and I had a complete meltdown. Erm, I got so depressed that even my parents got worried about me and I thought I was doing a good job of hiding it. Erm, cos I think all of those, my emotional development and my self-esteem had just been pushed to the bottom. All I could do was keep pushing all this stuff into a box cos I just couldn't deal with any of it.'
>
> (Emma, p13)

Here Emma suggests that her emotional development was neglected whilst living at home. This suggests that she may have compared her development to that of her peers and had expectations about how she could have developed had it not been for her experiences with her brother. Perhaps this assumption contributed to her negative feelings about her situation. It seems that creating distance between her and her brother's situation allowed her to fully feel and address the emotions she felt she had previously ignored. However, her use of the past tense might imply that she is no longer in a depressed state and she does go on to say that she is 'happier'. Although she may also be referring to

her feelings at that period in time. Perhaps the distance has provided the time and space to focus on her own emotional needs. This idea of taking time to care for oneself will be discussed further in the following subordinate theme, but this excerpt suggests that this cannot be achieved without first having some emotional distance. This sense that distance allowed emotional development was prevalent in many of the participant's narratives. However finding the balance was difficult for Emma:

> I know I'm struggling with my own emotional distance, that still rips something in me. That kind of, that he's that worried that I'm going to reject him, even though I'm possibly creating a situation where he feels like that.'
>
> (Emma, p23)

It appears that finding a medium between having distance yet still maintaining a relationship with her sibling was challenging for Emma. It seems that having a sibling in this situation created dissonance between feelings of obligation and the desire to live her own life. Emma also suggests that while creating some distance made it easier to have a relationship with her brother, it had a detrimental impact on how he viewed their relationship.

Kathy also described her realisation that she needed distance after having agreed to move back home to help her mother care for her sister:

> I had one of these light-bulb moments, I thought my God, that's not what I should be doing, that is a bad mistake. A bad, bad mistake to say I'll go back to Bristol cos I need to have distance, I'm gonna have to have distance, at least for a while to be able to work out what's going on for me, erm, so that I can remain at, sort of maintain some sort of wellness.
>
> (Kathy, p12)

This was a brave decision for Kathy, one which could be seen as selfish, but doing so may have enabled her to care more effectively for her sister in the future. Kathy realised that she would be unable to care for her sister effectively without caring for herself, and having distance allowed her to do that. Perhaps time away allowed her time to focus on her own needs, and live her own life.

Maintaining some emotional distance remains important for the siblings throughout their lifetime, as Susan suggests:

Susan:	that period was so intense for me then I had to do the same for myself as well really.
Interviewer :	yeah, so that's something that you do apart from your sister?
Susan:	Yes. I just, take a bit of space. My current partner, he's quite, he's quite er, he's a bit laid back, he's, he's and he kind of doesn't make himself busy at weekends so it's kind of, it's possible. Oh we could go for a walk or we could go for lunch, we could go and do this.

<div align="right">(Susan, p10)</div>

Here Susan implies that sometimes she still needs to take time for herself. Rather than for her emotional development, or to live her own life, here she implies that sometimes she needs 'a bit of space' as a way of coping short term so that she can recharge.

Susan also suggests that distance can also support her sister:

kind of just getting used to that there will sometimes be crises, so actually stepping back a bit and not launching, kind of letting her go, cos they're her crises , letting her go through those crises and finding something that I can do but supporting that.

<div align="right">(Susan, p10)</div>

Here Susan suggests that 'stepping back' and letting her sister deal with crises herself is about helping her to develop a sense of autonomy, and take responsibility for her actions.

3.3.2. The importance of developing self-care

> 'you have to look after yourself first before you can help support someone else'
>
> (Emma, p24)

This quote sums up this subordinate theme. Here, Emma suggests that a requirement for being able to care for others is to be mentally well yourself. For most of the participants this realisation developed over time:

> I think like my dad's attitude and my old attitude would have been we're tough and strong and you just plough on and you kind of deal with these things, and as I say my dad was ploughing on and then he had this heart attack. And you think you're ploughing on but in fact he was smoking himself to death and stressing out and working too hard..... Something suddenly knocks you sideways and makes you think you know you should take care of yourself or look at yourself or think about yourself or kind of, um yeah, deal with your issues I guess.
>
> (Alan, p19)

Here Alan describes how he and his father used to 'plough on', ignoring their own needs, until his father's death prompted Alan to re-evaluate this approach. He realised how unsustainable this was, and now seems to value prioritising his own needs. He seems to suggest that one needs be kind to oneself, and dedicate time to 'deal with your issues'. Emma seems to have only recently had this realisation herself:

> really I think it's only been, probably in the last five years that I've got better with dealing with, and giving my brother the support he needs. Erm, probably because I'm in a happier place.... and I had to take concrete steps to make myself happier
>
> (Emma, p14)

Here, Emma is likely referring to her recovery from the 'meltdown' she mentioned she had when she moved to London. She reflects on how she made a conscious effort to address her own needs and how doing so has enabled her to care more effectively for her brother. Perhaps this suggests that by addressing her emotional needs she now has larger emotional reserves and resilience for supporting her brother, and her happiness is no longer dependent

on or 'dominated' by his behaviour.

In terms of taking 'concrete steps' to become happier the participants described how sharing their story with others, be that their friends, other siblings, partners or counsellors appeared to be one of the most valued forms of self-care. However, sharing their situation with others could be difficult:

> I've had to work very hard to get myself to that position to be able to do that [talk to others], because in the beginning I couldn't have talked about my sister's illness at all because I had no language for it. We were dealing with it but we had no language for it, which is why it was so difficult to talk to anybody about it and that is why I think people tend to shut up about it unless they're with people who they think have had some sort of experience in the area of mental ill health, people won't talk about it because the behaviour is often so strange and off the range.
>
> (Kathy, p3)

This excerpt describes how difficult it is to talk to others about inexplicable or strange behaviour when you have no words for understanding it yourself. When Kathy was younger, in the 1960s and 1970s, information about schizophrenia was less accessible than now. It is therefore unsurprising that Kathy may have felt silenced by her inability to conceptualise or discuss it. However, she also alludes to the stigma surrounding mental health difficulties and how the unfamiliar nature of the difficulties might lead to unhelpful and unempathetic responses. Fear of these responses caused her hesitation in sharing her story. Kathy says she had to 'work very hard' suggesting a process of self-development, perhaps to learn an appropriate language but perhaps also to overcome that fear of stigma. Alice also commented on how her perception of stigma prevented her from sharing her brother's difficulties with others:

> it's a word [schizophrenia] that carries such negative connotations and such powerful stigma and misunderstanding...so I think that was really where that idea about protecting him came from. And I think that after I was formally told about this thing it was just this huge secret. It felt like, my biggest secret, kind of, burning, eating away almost, erm
>
> (Alice, p4)

Here Alice describes how she felt unable to share her story with others in order to 'protect' her brother. Keeping this secret was a huge burden for her and seemingly contributed negatively to her emotional well-being. She suggests that her family tried to protect her brother from the negative attitudes and lack of understanding people may have had towards him. However, secrets can also be related to shame. Another interpretation could be that Alice and her family felt shame and embarrassment regarding her brother's difficulties, and this impacted on Alice's ability to tell others. It was only later that she felt able to talk about her experiences with others.

Alice	'I started very tentatively started telling people, but very tentatively.
Interviewer:	And why was that, that you started telling people?
Alice:	I think I just couldn't hack it any more, I was just, I was sick and fucking tired of it, and I think my parents had reached a similar point and somehow that gave me permission?...and I very tentatively started telling some of my friends....
Interviewer:	And how was that? How was that telling your friends?
Alice:	erm, always very tearful…… (pause) and very cathartic.'

(Alice, p11)

It appears that Alice only felt able to talk to others about her experiences once she had reached a very low point. This again demonstrates how punctuating events can prompt re-evaluation. It also illustrates the negative effect the secret, and the situation, was having on her well-being; her use of expletives conveys the strength of her frustration. Alice also noted that she felt able to do this when her parents also began to talk to others. This might demonstrate how much her choices are influenced by those of her parents. Perhaps she felt she would have betrayed them by talking to others prior to this, despite her apparent growing need to do so. Her perception of the stigma around schizophrenia as discussed above likely contributed to her tentative approach to telling others, however, once she did she found that this experience, while perhaps difficult,

was rewarding. Her tears demonstrate the strength of the emotion that she was suppressing, and perhaps her relief at telling others, and might suggest that sharing her story had an immediate positive effect on her well-being. Having found the experience cathartic suggests that she will continue to talk with other friends in the future. This demonstrates how the ability to care for oneself is learnt and evolves and develops over time..

3.3.3. 'I sort of know what drives him': The value of gaining understanding

This subordinate theme demonstrates how gaining an understanding of schizophrenia and how it can present appears to play an important role in the participant's ability to build a caring relationship with their sibling. Emma describes how her parents tried to limit the information she had about her brother's difficulties:

Emma: initially I was just angry at my parents for hiding
                  their concerns for so long, which has been a bit of
                  a recurrent theme. I told them at the time, 'don't
                  hide these things from me', cos I think maybe that
                  afternoon I'd had a massive row with him, cos he'd
                  been staring at me funny while I was trying to
                  watch TV and have my dinner and I was like
                  'what's your problem?' As you might do when
                  someone is scowling at you… and then my
                  parents told me and I'm like 'oh dear god, do you
                  know how I would have felt if me being a horrible
                  sister had led to him doing something?' and they
                  understood, temporarily, and they've subsequently
                  still hidden things from me, but… (Laughs)
Interviewer: Ah, I see, so that'd been something that..
Emma: yeah, I mean I know it comes from a place of
                  trying to shelter me from some of their concerns
                  and fears, but it doesn't really make it any easier
                                                         (Emma, p6)

Here Emma explains how her parents withheld information from her. She

suggests that this was because they were trying to 'shelter' her, perhaps reflecting a cultural discourse that parents should protect their children. However, she implies that being protected in this way did not help and has only served to increase her feelings of guilt. She indicates that had she been better informed she would have reacted differently to her brother's behaviour, perhaps mediating her reaction in order to reduce his distress. Interestingly, this reflects the protective behaviour her parents demonstrated towards her. She notes that, despite pleas not to, her parents have continued to 'hide' information from her, which she finds unhelpful. It is possible that uncertainty about the validity of the information she receives from them contributes to feelings of lack of control and unpredictability. Suggesting that in contrast perhaps being more informed would help her to feel more in control.

Drawing on a psychiatric understanding of schizophrenia appeared to be very helpful for many of the participants:

> I sort of know what drives him what motivates him, you know inside and
> out really, and that's why I can tell when he's saying weird things, I just,
> I know roughly how he thinks. And, um, dunno, I mean I think we're ok,
> you know, we're, I realise it's his illness that's making him be annoying.
>
> (Alan, p16)

By referring to schizophrenia as an illness here, Alan appears to be externalising or objectifying his brother's difficulties, thus absolving his brother of blame. This appeared to help Alan reduce his frustration towards his brother, and therefore maintain a positive relationship. Unpredictability appeared to be one of the most difficult elements of schizophrenia for the participants to deal with. By externalising his brother's behaviour and understanding his 'drives' and idiosyncrasies perhaps Alan is able to rationalise his behaviour and make it more predictable, helping him to gain a sense of control. Alice demonstrated a developing understanding and ability to externalise her brother's difficulties:

> he was also very cruel, and I suspect now in retrospect that's because
> he was experiencing the world in a way that cast me in a particular light
> so maybe he believed I was saying or thinking awful, awful things about

him, and he's told me that since... So I couldn't have known that at the
time, and maybe I'm just making excuses, maybe he was mean for no
reason at all

(Alice, p4)

Firstly Alice reiterates how difficult this experience was for her. She also
demonstrates a developing understanding of her brother's difficulties by
realising that her brother's behaviour may not have been a personal attack but
an expression of his own internal difficulties. Alice wonders if she might be
making excuses for her brother, implying that it is difficult to know if
responsibility for his behaviour lies with him or the schizophrenia. Perhaps
'making excuses' is protective, allowing her to externalise and rationalise her
brother's behaviour and reduce blame in order that she can build a positive
relationship with him. Alice seems to be developing a capacity to externalise,
which the older participants, perhaps through practice, seemed to manage more
successfully. However this understanding was not always easy to maintain:

Alan   'I've been really close to saying look I'm giving up these
Mondays [weekly visits], you, you're pretty obnoxious and I
don't think I wanna... but then my sister would say it's cos
he's ill, you know, you should see him and it's doing, and I
always say yeah you're right it's cos he's ill, and two weeks
time she'll be weeping saying, 'oh and he did this' and I'm
like I'll say, it's cos he's got this illness. So you know you
constantly...

Interviewer: …. take it in turns,

Alan: yeah

(Alan, p16)

This excerpt again demonstrates how hard it can be to differentiate between the
person and the schizophrenia. Alan suggests that it was hard to maintain an
objective perspective when he felt emotionally hurt, something his sister also
struggles with at times. They support each other by helping one another to
externalise their brother's behaviour as an 'illness', which here helps Alan to
maintain his weekly contact with his brother. This demonstrates how despite
understanding the nature of schizophrenia, it can be hard to stay objective at all

times, and how important access to support is.

3.3.4. <u>Negotiating a caring relationship vs a sibling relationship</u>

As with the other subordinate themes the relationship the participants had with their sibling seemed to change over time. This subordinate theme refers to the struggle the participants described in negotiating a close sibling relationship and a more functional, caring relationship. Alan described his understanding of a sibling relationship:

> siblings you know, it's a bit more matey [than a parental relationship]
>
> (Alan, 17)

Here Alan's use of 'matey' suggests that he sees sibling relationships as fun and enjoyable, and distinctly different from parental relationships. It was important to Kathy to maintain this unique sibling relationship:

> I was always very careful with my sister to be her sister, even if I was taking on, in inverted commas, sort of 'parental responsibilities', er, I never wanted her to think or feel anything else, cos I can think of nothing more irritating than having a sibling coming along and behaving like a parent
>
> (Kathy, p15)

It was very important to Kathy that her sister never felt 'parented' by her, suggesting that she too has differing expectations from parental and sibling relationships. Perhaps she is referring to the power imbalance within a parental relationship, which she is hoping to avoid to ensure her sister does not feel 'irritated'. In contrast, Alan struggles with these more 'parental responsibilities':

> I'm having to tell him very basic things, how to clean his bathroom, how to organise your fridge, you know, all that, all that sort of stuff that's a bit odd. I mean I'm 50, he's older than me, I shouldn't have to be telling him anything like that. Very odd. '
>
> (Alan, p 16)

This excerpt also links to power, implying that a power imbalance may have

developed between these brothers. In his interview Alan described how prior to his diagnosis his brother had been successful, but now Alan is the more able and successful. This change in their dynamic may be evident for his brother, perhaps adding an extra layer of difficulty to the relationship.

Alan also indicates that he did not expect to have to help his brother in this way at this age, indicating that he compares his situation to social normatives. The disparity between expectation and reality may not be easy to manage, and he implies that he finds the situation unfair. Nevertheless Alan continues to support his brother. Although, elsewhere in his interview Alan notes how 'close [he is] to not wanting to see him'. Perhaps indicating how conflicted Alan is between his frustration about the unfairness of the situation and his obligation to care. Emma also struggled to manage the emotional and functional aspects of her relationship:

> but that's most of the interactions [arguments], or he's got a problem
> that I need to help him fix. Erm, so I guess that's why I don't feel much
> of a relationship with him any more.
>
> (Emma, p18)

Here Emma's caring role has hindered her emotional connection to her brother. As a result she appears disheartened, perhaps feeling that the relationship has become one-sided, with little incentive for her to maintain it. This demonstrates how difficult it can be to maintain an emotional relationship whilst also offering functional support, and therefore how self-sacrificing the participants may need to be. This feeling was reciprocated by other participants.

In contrast to these more negative observations of their sibling relationship, Susan describes how her relationship with her sister has become closer since she became more involved:

> I think it's deepened actually [our relationship], but that's over the past,
> that's, that's since my mother died I suppose, or since both my parents
> died, it's it's kind of deepened. And I think there's I think there's an innate
> closeness there which is just about us being sisters

Here Susan confirms the assertion that the sibling relationship is unique. She also notes that her relationship has deepened since her parents have died and she became more involved with her sister in a caring capacity, indicating that there are indeed positives from caring for a sibling. This might be as now she better understands her sister and her idiosyncrasies as they have spent more time together.

3.4. Expectations for their life-cycle

This theme is concerned with more existential concepts such as the participants' expectations for their life, how these expectations may have changed due to their sibling's difficulties, whether they feel they had a choice in this, and their concerns for the future.

3.4.1. 'I had no choice': Siblings perceived choice about caring

All the participants indicated that they wanted to be involved in the caring for their sibling, but for seemingly different reasons. Kathy felt like she had little choice:

> I remember an older couple in Edinburgh saying to me "You shouldn't have to be dealing with all of this", but actually I had no choice. I was a member of the family and unless I went to Australia I, I mean I had no reason to go away.' (Kathy, p9)

Here Kathy describes how she felt obligated to care for her sister, due to her position as a family member. She implies that she did not have a valid reason to escape this responsibility and therefore asserts that she had no choice but to care for her sister. Interestingly she does not have the same expectations of her younger brother:

> I was quite determined from the, from the beginning that we'd try and get, yeah, that, that he would grow in such a way, I mean I was old enough to be perhaps slightly more maternal to him…

Here Kathy described her relationship with her younger brother as perhaps more maternal than sisterly. In this more maternal role she has tried to protect her brother, reflecting the way many of the participants describe how their parents tried to protect them. Perhaps she hoped that he would grow up free from the pressures or obligation she felt in caring for her sister. Her reasons for this seem related to her position as the older sister, perhaps also explaining why she chose to care for her younger sister. 'Chose' is used here as despite Kathy's assertion that she had no choice, she could have chosen to leave the caring role to her parents. As the eldest, female sibling she might have been accustomed to taking on caring, indeed perhaps slightly parental, roles for her sister and her brother and maybe expected to continue this role when her sister developed difficulties. This might reflect the Western cultural and gendered expectations of the role of women in caring.

While Kathy felt familial obligation soon after her sister was diagnosed, Susan only became involved after the death of her mother:

> [my sister] who'd been really really close and very dependent on my mother was kind of pushed outside that situation and then it, I, I kind of er, ducked back in to support her cos I felt that she, uh, I don't know, my brothers had a very objective distant response to her and so there was the whole kind of grieving process going on but she was very much outside it.'
>
> (Susan, p5)

For Susan it was empathy for her excluded sister, after their mother's death, which prompted her to become more involved. Susan did not appear to expect this scenario but perhaps also felt a sense of obligation when she realised her other siblings were not going to help. This might suggest that there is something different about Susan or her relationship with her sister compared to her other siblings. Again, Susan's decision to care may have been influenced by Western, gendered, societal expectations. In her position as the eldest female sibling she might have been more familiar with caring roles and thus less apprehensive of caring for her sister than her 'distant' brothers. Her brother's 'distance' might

also reflect Western cultural expectations regarding males and hesitation around intimacy. Susan also has no children. She therefore feels further obligation to help her sister, possibly as she feels, or thinks her siblings assume, that she has fewer responsibilities.

> I'm in a situation really where if I wanted to I can do it a bit more easily than my other siblings
>
> (Susan, p7)

Tom also felt a sense of responsibility:

> I think that's, that I sort of feel like I want to compensate that I've, cos maybe I've, like I've got, you get this feeling of neglect, I've, I've neglected a little, like as a sibling I feel like I've neglected her and I'm responsible for her mental health problems.
>
> (Tom, p7)

Here Tom describes how he feels responsible that he wasn't there for his sister when her mental health difficulties developed. Elsewhere in his interview he discussed his feelings of 'guilt' over this. By being involved he might have felt that he atoned for his perceived mistakes, perhaps reducing these feelings of guilt. Western cultural expectations regarding gender and birth order might also influence Tom here: Perhaps he had an expectation that as the older brother he, similar to Susan and Kathy, should care for and protect his younger sister, and that by not protecting her from the illness he has failed in that role.

Thus it appears that a sense of obligation caused the participants to become involved, however, the reasons for this feeling might be due to expectations as the older sibling, feelings of empathy, or related to reducing their own feelings of guilt.

3.4.2. Expectations regarding life-cycle transitions

The siblings also talked about how their caring role with their sibling affected the choices and expectations they had about normative transitions in the family life

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cycle. In particular their expectations around relationships and children are discussed.

3.4.2.1. Difficulties having relationships

Many of the participants talked about how having a sibling with a diagnosis of schizophrenia affected their choices relative to romantic relationships. Emma shared concerns that her circumstances might be a barrier to finding a partner:

> the idea that someone will be able to see me as an individual, and not
> be like 'oh God' you know, something like the reaction that some people
> might have to the child if you don't want to be dating someone with a
> child, and that's kind of how I see it.
>
> (Emma, p19)

Here she compares her responsibility and commitment to her brother as being similar to that of having a child, implying that it would be a huge commitment for someone to take on. She might also be alluding to the stigma surrounding mental health difficulties and concerns that she might be stigmatised much like her brother. These concerns may be partly responsible for her initial hesitance to become involved in caring for the brother or frustration towards him. She may still be grieving the loss of her expected future. Kathy similarly thought that her partner had to be 'special':

> the person I chose as a life partner had to be, he had to be pretty special.
> I wasn't with, I had been through so, so much with my sister that I
> thought, god, she's going to have to come as part of the package.'
>
> (Kathy, p11)

Here Kathy also reflects that her partner had to be understanding about the role her sister would play in her life. She implies that such a person might be rare. Therefore she seems to have also been aware that she may have sacrificed her own happiness to care for her sister. In doing so she demonstrated that she prioritised her sister's well-being over her own life expectations.

However, most of the participants were in long-term relationships which suggests that despite some expectations to the contrary, they had been able to

find partners who were able to support them and their relationship with their sibling.

3.4.2.2.   Choice to not have children

Interestingly, in this study none of the participants had children. For the most part this seemed to be a conscious decision related to the fear that, as parents, they might have children with mental health difficulties:

> So I don't want to have children, and it is possible that that will change but I've felt very clear about that for, for always really... I find the kind of parent child relationship problematic cos you have this thing that you love and you would give your life for and at times it will hate you and you might damage it, you probably will, even if you try your best, damage it somehow.
>
> (Alice, p17)

Alice seems to believe that it is inevitable that parents will 'damage' their children, indicating her fears of being responsible for recreating her brother's distress in a child. She implies she would feel guilty about this, and therefore may want to protect herself from these painful feelings. Alice noted in her interview that this was not her only reason for not wanting children, but admitted that it plays a part. Emma also discussed her feelings about children in the future:

> you already feel like emotionally you've, you're constantly putting yourself out there to help someone and support them and doing it, I think actually it's also the fear that the small child idea maybe not so scary now, particularly as I'm going into teaching (laughs) but the idea that I could end up in the same situation as my parents and….
>
> (Emma, p20)

For Emma fear that she might also have a child who is mentally unwell makes her hesitant about having children. She is already in a difficult and tiring situation and does not want to expose herself to further difficult feelings. This concern about mental health difficulties in children was shared by Susan, who also made a conscious decision not to have children. However, for a couple of participants not meeting a partner at the right time, due to the difficulties

discussed above regarding finding an understanding partner, meant that they have been unable to have children.

3.4.2.3. Concerns about the future

Only the two youngest participants had concerns about the future, centred around the death of their parents and how they might care for their sibling in the future without their support.

> I worry that I'm going to be a hard-hearted bitch by the time I'm the one
> to take control, and be like 'well tough, you did that. It's your problem'.
>
> (Emma, p17)

Here Emma implies that she is concerned she will struggle with the pressures of caring for her brother and become unsympathetic as a result. She may be worried that this will impact on his well-being and her relationship with him. She implies that this is not the person she wants to become. Alice also worries about what will happen in the future:

> There's a little bit of me that feels like you know, when my parents die,
> my other brother is not going to be, is not going to be dealing with this
> stuff, it's going to be me and I, I don't know what that life will look like,
> so there's a bit of me that's like, I have to have my life now, cos maybe
> I won't have the life I plan to have in future
>
> (Alice, p14)

Here Alice assumes that her brother will not provide any support towards the care of her diagnosed brother in the future, maybe because he has not been involved thus far. For her too, the idea of supporting her brother without any support is frightening. She assumes that this future will be difficult, perhaps because she has observed her parents struggle and expects that she will similarly struggle with her brother's difficulties. She also does not seem to expect that her brother will recover. She is preparing for the loss of her expected future, but before she reaches this point she wants to enjoy herself.

The older participants were less concerned about the future, possibly as they

had already coped with the death of their parents and therefore were already dealing with the situation the younger participants were anxious about.

4. DISCUSSION

Following the analysis of the data three super-ordinate themes were identified; The 'terrible weight' of schizophrenia, the evolution of the caring role over time, and expectations of the sibling's life-cycle. This chapter summarises these emerging themes in relation to the existing literature. It also evaluates the quality of the research, considers its limitations and implications for practice. Directions for future research will also be discussed.

4.1. Summary of findings

The research questions of this study relate to how siblings perceive their caring role over their life-cycle and whether life-cycle transitions affect their sibling relationship. The biggest finding of this study is that the participants' emotions and relationship towards their diagnosed sibling seem to change over their lifetime, with some participants initially emotionally struggling with their sibling's difficulties, but taking on a more caring role over time. The findings also show that rather than the participant's life-cycle transitions affecting their sibling relationship, in fact their caring responsibilities towards their sibling affected some of their life-cycle transitions, their expectations and the choices they made. These findings demonstrate the pressures placed on sibling carers and how choosing to care for a sibling diagnosed with schizophrenia may be related to a loss of an expected future.

4.1.1. The 'terrible weight' of having a sibling diagnosed with schizophrenia

It appeared that as teenagers or young adults the participants struggled with the emotional impact that their sibling's diagnosis caused, including grief, anger, and guilt. This emotional conflict has been found in several other studies (Stalberg et al, 2004: Sin et al, 2008; Barnable et al, 2006) and was particularly pertinent for the younger participants. Some participants noted that the pressure of having a sibling with a diagnosis of schizophrenia impacted on their mental health, causing a 'break down' later on. Kinsella et al, 1996, similarly found that siblings matured faster but to the detriment of their own mental health. Guilt was

particularly salient for the participants in this study. They felt guilt that they were not doing enough, or that they may be responsible for their sibling's difficulties. Similarly, these findings have been found before (Stalberg et al, 2004; Barnable et al, 2006; Ewerton et al, 2012). Becoming involved in their siblings care appeared to reduce these feelings of guilt in some participants.

Previous research has suggested that high levels of symptomatology is the hardest aspect of schizophrenia for siblings to manage (Barnable et al., 2006; Sin et al., 2008). This contrasts with this study where the participants appeared to find the unpredictability of their sibling's behaviour and a lack of control over the situation the hardest aspect to deal with. Unpredictability has not been discussed much in other research, yet appears to have encouraged some participants in the current study to seek emotional distance from their siblings before ultimately becoming more involved in their care. However, as noted previously, it is possible that the participants in this study represent experiences of more severe presentations of schizophrenia. Therefore siblings of those with less severe presentations of schizophrenia may not experience such an impact of symptomatology or unpredictability and may not feel so affected by their relative's diagnosis.

4.2. The evolution of the caring role over time

This theme found that over time the participants' relationship with their sibling evolved into a more caring relationship. The participants appeared to go on a journey that involved creating some emotional distance from their sibling, learning to care for themselves, and gaining knowledge about schizophrenia and their sibling's idiosyncrasies, ultimately becoming more willing and more able to care for their sibling. However, the siblings still struggled at times to negotiate between a caring and sibling relationship.

In order to maintain involvement in their siblings care the participants appeared to need some emotional distance. All the participants had extended periods of time away during early adulthood, such as at university. Previous research has also found that emotional distance can help adults cope with the pressures of having a sibling diagnosed with schizophrenia (Ewertzon et al, 2012; Barnable et al, 2006). However the current findings go further, suggesting that this might

be particularly important during early adulthood, when siblings appeared to struggle most with the emotional impact of their siblings behaviour. Distance appeared to be vital in allowing the participants respite from the pressures of their siblings difficulties and in allowing them to examine and resolve their own neglected needs. Doing so appeared to better prepare them to care for their siblings in the future. Creating some distance also worked as a short-term coping strategy, let the participants live their life, and promoted building autonomy in their siblings.

For some participants emotional distance prompted a realisation of the importance of self-care. This could involve engaging in alternative activities, which has been found to be helpful for teenage siblings (Kinsella et al, 1996). However, the biggest form of self-care that the participants discussed was sharing their difficulties and feelings with others. Some participants discussed how they can be fearful of talking to others due to concerns that people may misunderstand or stigmatize their sibling, supporting the findings of previous research around hesitation to talk to others (Sin et al., 2008; Greenberg, Kim and Greenley, 1997; Ewertson et al, 2012). Some participants initially struggled to talk to others as they had been encouraged by their parents to keep their sibling's diagnosis a secret. Some parents had tried to avoid sharing information even with the participants. Ewertzon et al (2012) similarly found that parents felt less able to share their situation than siblings. This might demonstrate the influence parents may have over how the participants dealt with their situation. It may also highlight how societal discourses towards mental health may be changing, with younger generations more willing to share and discuss their experiences. Parents might fear being blamed or stigmatised themselves for having a child with mental health difficulties, as a result of previous prominent theories such as the 'schizophrenogenic' mother which place significance on family conflict for causing mental health difficulties. Interestingly, this is in contrast to how families with a physically disabled child have been found to communicate with each other, with siblings of physically disabled children noting that their parents were open about sharing information (Pit-Ten Cate and Loots, 2000; Ali and Sarullah, 2010). The difference between the style of communication in the parents of these two groups might suggest that stigma surrounding mental health difficulties can prevent families from talking about

these issues.

Once they felt able, the participants discussed how important it was to be able to share their story. In particular the siblings talked positively about the sibling support group they all attended. The positive effects of support groups for siblings have been found before (Ewertzon et al 2012; Kinsella et al, 1996). Smith and Greenberg (2008) particularly found that support groups for children and teenagers were very helpful during the period of conflicting and difficult emotions.

Once the participants had learned how to care for their emotional needs they felt more able to be involved in their sibling's life and care. As they did so their knowledge of schizophrenia and of their sibling's idiosyncrasies grew, and appeared to positively impact on their ability to care for them. As noted, some of the participant's parents tried to limit the information they were given as children. This might have led some participants to misunderstand their sibling's behaviour and might be related to their initial unwillingness to be involved in their care. However, as they developed a greater understanding of their siblings' difficulties, these participants were able to interpret previously upsetting situations from a more thoughtful perspective, and became increasingly involved in their siblings life. This supports Kinsella et al's (1996) findings that receiving knowledge about schizophrenia as a child helped children to understand their sibling's behaviour and maintain a good relationship.

In particular, externalising their sibling's difficulties as a psychiatric 'illness' reduced the frustration the participants felt towards their siblings due to the lack of control they felt their siblings had over their behaviour. Externalising is not dependent on medicalising the difficulties, but is also about understanding the idiosyncratic aspects of the behaviours.   The benefits of 'objectifying the illness' have been discussed in previous research, Johnson (2000) in particular found that siblings were more likely to provide support and care if they understood difficult behaviour as part of an illness. While the findings of the current study suggest that externalising the 'illness' became easier over time, one of the older participants, Alan, still struggled with this at times. This implies that while externalising can be a helpful strategy, a variety of strategies for managing the

difficult behaviour need to be sought.

The participants also discussed how developing a caring role led to difficulties negotiating between a sibling or caring relationship. All participants noted how the sibling bond was unique and special, however it appeared difficult to maintain that sibling relationship without also taking on a caring role, a caring role that some participants felt could take over.

4.3. Expectations for their life-cycle

4.3.1. Siblings perceived choice about caring

The current study offers some new insights into the more existential themes of the participants' choice and expectations for the future. All the participants noted that they wanted to be involved in their sibling's care in the future, something which has only recently been identified (Ewertzon et al, 2012; Barnable et al, 2006). They all noted a sense of obligation to support their diagnosed sibling, a finding that has been found to have an impact on involvement in care previously (Smith, Greenberg and Seltzer, 2007; Jewell and Stein, 2002). However, while the participants felt a sense of obligation, most of them had other siblings who appeared to not share this feeling. This suggests there is something different about these participants, compared to their siblings, that caused them to become involved while their siblings did not.

This sense of obligation seemed related to different reasons: because they were a family member; feeling empathy for their sibling; and feeling guilt that they may have caused their sibling's difficulties. Gender and birth order also seemed to play a role. Gender has previously been found to affect the amount of care a sibling might provide. The high numbers of women appearing as carers in research suggests that the socialisation of woman in Western cultures to care for others leads to sisters being more likely than brothers to care for their ill siblings (Greenberg et al, 1999; Lohrer et al, 2007). Indeed in the current study not only were there more female participants in the sample, one female participant described her brothers as 'distant and objective' (Susan, p5).

The current literature suggests that younger siblings take on more of a caring

role than older siblings (Smith et al, 2004), with younger sisters more likely to care than older brothers (Bowman et al, 2014). The current study certainly lends support to these previous findings as three of the participants are younger than their diagnosed siblings and two of these participants are female. Younger siblings may be at home for longer with their unwell older siblings and therefore become accustomed to the pressures associated with their difficulties. However, this study also has three older participants, which fits with earlier findings that older children take on parental roles and responsibilities in families, such as caring for the younger children (Bossard and Boll, 1956). Therefore further research must be completed to further explore feelings of obligation in siblings.

Previous research has also found that the quality of the sibling relationship in childhood affects the level of caring the siblings are willing to provide (Jewell et al, 2009). All the participants in this study noted that they had been close to their sibling prior to their diagnosis, which might support Jewell et al's (2009) finding. However, some participants did note that the lack of gratitude they received from their siblings impacted on their desire to care. Previous research has similarly found that the amount of reciprocity felt by the well siblings affects the amount of care and support they provide (Smith, Greenberg and Saltzer, 2007;Smith and Greenberg, 2008; Greenberg et al, 1999; Smith et al, 1997). However, one participant, Susan, described how her relationship with her sister had become closer as she gave more support. This reinforces the importance of supporting families to build strong emotional relationships in order that the siblings can provide emotional support for their sibling without feeling resentful.

4.3.2. Choices regarding life-cycle transitions

While the life-cycle transitions of the participants did not appear to impact on their relationship with their sibling, caring for their sibling did appear to impact on their choice to pursue life-cycle transitions. Surprisingly, none of the participants had children and all bar one were not planning to have children. This is a departure from the expected life-cycle suggested by Carter and McGoldrick (1980). Rather than a rebellion against societal expectations, some participants were fearful that they might have a child with mental health difficulties and find themselves in the same situation as their parents,

corroborating previous research by Schmid et al (2009). For other participants their involvement with their sibling and their increasing caring role seems to have impacted on their ability to find a partner and therefore start a family. Some participants spoke about their partners having to accept their siblings as part of the 'package'. However, while some participants indicated that their decision to not have children was directly related to concern for the distress a child of theirs would feel if they developed a mental health difficulty there may be other factors that influence this decision. For example one participant noted that she was aware of the distress having a child with mental health difficulties had caused her father. This indicates that watching their parents' difficulties coping with having a son or daughter with a diagnosis of schizophrenia, and therefore what they might experience in the future, may also have influenced the participants' decision, not just fear of the distress of the child. There may also be other factors that influence the decision not to have children. Indeed, the fact that many of the participant's other undiagnosed siblings had families demonstrates that it is possible to do so, and that the participants made a choice not to pursue this. Perhaps these participants have made these decisions as they have been exposed to and experienced severe presentations of schizophrenia, perhaps siblings of those with less severe presentations of schizophrenia would not have made similar life choices and decisions. Despite the possible impact of caring for a sibling diagnosed with schizophrenia seems to have on the expected life-cycle of their undiagnosed sibling, these more existential themes have not been fully explored in the literature thus far.

4.3.3. <u>Concerns about the future</u>

In this study it was the younger participants who had greater concerns about the future. They worried about their future caring role after their parent's death, and described a sense that they should enjoy their life now before they were constrained by caring for their older siblings. This concept has also been found in recent research (Ewertzon et al, 2012). However, the older participants appeared to live more in the present. This may reflect the fact that the older participants parent's had already died and therefore they were already in the situation that the younger participants feared.

Previous research suggests that there is an expectation that siblings are able to take on the caring role when parents are unable to (Horowitz, 1993). However, this role may be secondary to the mental health system, rather than the prolonged contact that is more characteristic of parental relationships (Smith, Greenberg and Seltzer, 2007). Our findings might reflect this suggestion as the younger participants appeared hesitant to take on the primary caring role, and the older participants described only periodic input and contact, such as Alan's Monday evening meetings with his brother,

4.4. Evaluation

4.4.1. Quality of the research

As mentioned in chapter 2, Yardley's (2000) principles for quality in qualitative research have been used to evaluate the validity and quality of this research. Each principle is discussed below.

4.4.1.1. Sensitivity to content

Yardley (2000) recommends that qualitative studies are sensitive to their context and grounded in the previous research in the area. Close reading of the previous research in this area guided this study, particularly the lack of research into the existential aspects of caring. This influenced the selection of existentialist-informed hermeneutic phenomenology as a methodology to explore this area further. The sample in this study were deemed to be 'representative' (Englander, 2012) as they were recruited from a support group for siblings of those with mental health difficulties and through the interviews demonstrated that they had the experiences sought by the researcher. That is experience of caring for a sibling diagnosed with schizophrenia. In addition to this, Yardley (2008) recommends being sensitive to the socio-cultural context of the participants and how this might influence their beliefs and expectations. This study has considered cultural influences throughout as can be seen in chapter 3 where Western cultural values about gendered caring roles, and how this might have affected the participants decision to care for their diagnosed siblings, have been discussed at length. This study has also been careful to relate the findings back to the current research, as can be found above in the summary of findings, at times supporting previous findings and at others offering new understandings

or alternative views that have come from the participants.

4.4.1.2.   Commitment and rigour

In order to achieve commitment and rigour Yardley recommends prolonged engagement with the topic. Not only has this been achieved through the extended engagement with the previous research and analysis of the data, but the researcher's personal experience of the subject matter reflects prolonged commitment. Rigour has been achieved through thorough data collection from participants who have been well placed to provide the sought information, as discussed in chapter 2. A contemplative, in-depth analysis has been completed, providing interpretation of the data, and which has addressed the complex variation observed within and between the participants' narratives such as conflicting or different understandings. An example of this would be the difference between the younger participants and the older participants in terms of their expectations for the future.

4.4.1.3.   Transparency and coherence

Transparency and coherence relates to the clarity of the presented arguments. The process of data collection and analysis has been transparent and explanation for how this has been done can be found in chapter 2, and an example of how the themes were constructed can be found in appendix B. Yardley (2008) also notes that there must be a fit between the research question, the methodology, and data collection. This study chose to use the existentialist-informed hermeneutic phenomenology approach to the analysis as this enabled the researcher to answer the research questions regarding the impact of the passing of life-cycle transitions on the sibling relationship, and the participants' expectations for their life. This approach appears to have been a good fit and has allowed the researcher to make meaningful interpretations of the data, leading to novel insights. However, by choosing this methodology the researcher may have closed down other avenues of interpretation, including consideration of how societal discourses may have informed the participants' reactions to their sibling's difficulties and informed their choice to be involved in their sibling's care. This might have considered the societal discourses of stigma and family responsibility that were noted and discussed by some of the

participants. This approach may also have neglected some of the psychoanalytic aspects of the participants' stories, such as Emma's dream about her father's reaction to her conflicted emotions towards her brother. This study could arguably also be suited to narrative analysis which would help us understand how the participants construct meaning and make connections between the past and present; however this would not have been able to tell us about how the events affected the participants at the time. Overall using the existentialist-informed hermeneutic phenomenological approach allowed the researcher to gain a rich understanding of the participants' world in order to answer the existential research questions, and uncover many new insights.

In order to be fully transparent the researcher must reflect on how they and their beliefs may have shaped the research. As suggested by Gadamer (1975) the researcher kept a diary where they reflected on their own presuppositions in order they did not impose their own interpretations on the data. As discussed below in 'personal reflexivity' the researcher has reflected on these presuppositions and the relationship they had with the participants and how this might have influenced the participants' stories and how the data was interpreted and presented. An excerpt of this can be found in appendix A.

4.4.1.4. Impact and importance

This principle refers to whether the study has been able to provide further insights and understanding of the subject area. This research has achieved these aims. This study has uncovered new insights, such as the realisation of the importance of emotional space away from the diagnosed sibling and the impact caring can have on the life choices made by the undiagnosed siblings. The clinical implications of the research are discussed below in more detail. It is hoped that this information has been presented in a way that resonates with the reader and helps to expand their understanding of the research area

4.4.1.5. Personal reflexivity

Throughout this research attempts have been made to consider and reflect on the impact of the researcher's personal background and relationship to the subject matter. This has been accomplished through keeping a diary of the

researcher's responses to the process of analysis and regular discussions and meetings with the director of studies. An excerpt of this diary can be found in appendix A. A reflexive note considering how the presuppositions of the researcher and their experiences interviewing and analysing the data might have influenced the findings is provided below.

4.4.1.6. Reflexive note

I found that carrying out this research was a very rewarding experience and I am pleased that I was able to bring new sibling experiences to light. I have had to be flexible throughout this research process, remaining aware of the presuppositions and assumptions I was bringing to the research. Whilst interviewing the participants my experiences as a trainee psychologist helped me to understand the participants on a professional level, for example considering theory in relation to their emotional needs, but I also identified with them and their stories on a personal level and found I shared a number of their experiences. The siblings were aware of my background as a sibling in a similar position to them and this may have affected the way they responded to me. For example, our similar experiences may have led to assumed shared understandings which may not have been clear or obvious to other interviewers. This might have affected the clarity of the answers gained from the participants. This may have also impacted on the presentation of the arguments in this study as I may have assumed a certain understanding in the reader due to my personal experiences.

During the analysis I found myself relating deeply with the reflections and experiences of the two younger participants, Alice and Emma, whose raw emotions felt most similar to my own experiences of having a sibling with mental health difficulties. I agreed with them about a number of points, but was wary of assuming that our experiences were the same. I was therefore careful to ensure that I considered and included the thoughts and reflections of the other participants in order to build a fuller understanding of the experiences of siblings across the life-cycle.

At times recalling some of their experiences was upsetting for the participants,

and equally reminded me of my own experiences, thoughts, and expectations. Keeping a reflexive diary helped me to record these concerns or feelings, and supervision was helpful in considering the impact of these reflections on the research.

Throughout the analysis I ensured the focus was on the existential aspects of participants experiences, how they thought about the future, their expectations and whether they had been able to make choices about their life. These issues are covered in the themes 'evolution of the caring role', and 'Concerns about the future'.

4.4.2. Limitations

Despite attempts to ensure good quality qualitative research there are still a number of limitations to this study. These concern the methodology and the sample, and are discussed below.

4.4.2.1. Methodology

Being qualitative in approach allowed this study to explore the impact and experiences of siblings across their life cycle. Being exploratory by nature qualitative research cannot make any causal links, and cannot be generalised further than the sample. Although this study has replicated many of the findings found in other studies, and therefore has good grounds to expect that these findings can be generalised to some extent.

Unfortunately, all qualitative research is dependent on the quality of the participants and their ability to be articulate. While most of the participants in this study were thoughtful and articulate in their responses to questions, one of the participants was less expressive. This made it difficult to make use of his quotes and thoughts, and his experiences did not bring about any further themes.

This study asked participants to retrospectively recall their emotions and feelings from several years, even decades, ago. Although lengths were taken to promote recall, such as using timelines and genograms the participants'

perspective may have changed over time, and therefore this study cannot assume full veracity of their statements.

4.4.2.2. Sample

All the participants were from the same support group. It is possible that this group of participants represent a distinct group within siblings; by choosing to join a support group they have demonstrated that they have sought support and that they are happy to talk about their experiences with others. This attitude towards sharing their experiences may not be common among adults with a sibling with mental health difficulties, indeed some siblings report feeling shame and difficulty discussing their experiences (Sin et al, 2008). In addition, seeking support from others may suggest that these participants may have only experienced more severe presentations of schizophrenia in their siblings. Their experiences may not be representative of siblings whose relatives are leading more independent lives. It is therefore important to consider that these participants may only represent a specific group of siblings, and may not be representative of sibling groups in general. This support group might also be unique due to its location and the demographics of the people who attend.

In addition to the difficulties small sample sizes can bring, the participants in this study were all White-British from a similar background. Therefore this study struggles to be generalised to other ethnicities and cultures that might have a different understanding of mental illness and schizophrenia. This study reflects the beliefs and experiences of White Western, British siblings, and therefore can only offer recommendations based on this cultural group.

4.5. Implications for clinical psychology

This study has demonstrated the vast impact that having a sibling with a diagnosis of schizophrenia can have on siblings. It also demonstrates the valuable role that they perform, not only in reducing the strain on ageing parents, but also providing support that might otherwise be provided by the NHS. Considering how protective sibling relationships can be (Gass et al, 2007), this research highlights how much support these unidentified and overlooked carers need, and should be entitled to, in order to continue to offer

such valuable input into their sibling's care.

The experiences of these participants show how support should be provided soon after the diagnosis of schizophrenia. Many of the participants noted how they felt hugely burdened by the diagnosis of their siblings. Support could be provided by services during this difficult and pressured time, not just to the parents of the family but also to the siblings. This study has shown how valuable knowledge about schizophrenia is to making sense of their sibling's behaviour and difficulties, helping them to understand and externalise their sibling's difficulties. This is particularly important as other studies have found that believing that diagnosed relatives have control over their symptoms is related with high EE environments and increased risk of relapse (Greenley, 1986). However, some parents of the participants tried to limit the information given to the siblings. Not only did this lead to frustration, but other research has shown this is also linked to high EE environments (Ruane et al, 2004) increasing risk of relapse. Therefore it seems important that information and knowledge regarding behaviours associated with schizophrenia should be shared with the whole family, including siblings, soon after diagnosis.

Family therapy could be used to facilitate this understanding also involving the person with schizophrenia and ensuring that they do not feel excluded from the rest of the family. Additionally, facilitating open and honest conversations with the family may also help to encourage parents and siblings to share their situation with others, which this study indicated is cathartic and beneficial to the ability of families to care for a diagnosed family member. Several family therapy models exist and seek to support the family through diagnosis, including Multiple Family Group therapy (MFG) which has been found to be very helpful for families (Jewell et al, 2009; McDonell et al, 2003). Open Dialogue is also a successful therapeutic practice that encourages open conversations and embraces multiple perspectives in the expectation that difficulties can be reduced through increasing communication and dialogue within families (Seikkula et al, 2001; Seikkula and Olsen, 2003). Working with the whole family in this way and sharing knowledge and information with all family members might help the sibling and their family to feel less pressured and emotionally conflicted allowing more space for them to care for their sibling. This approach

could help improve conversations in families where family members have different views in a curious and respectful way. Clinical psychology can play an important role in setting up these services, and supporting staff within these services.

In order to further facilitate understanding within families, an information sheet could be produced for parents with age appropriate versions for children. This would help to share information and ensure each family member is informed and would provide a way for parents to approach conversations with the siblings. This leaflet could include information about available therapies in addition to information about medications.

This study also demonstrates how siblings need emotional space away from the difficulties of their sibling. Sharing the need for this emotional space with families and sharing the pressures also faced by siblings might encourage parents to share information with the whole family rather than excluding their children from the process. This might also encourage parents to organise space for the siblings to allow them time to emotionally mature without the stress of their siblings difficulties, and not rely on their other children for support.

The participants in this study also noted how sharing stories with other siblings was hugely helpful for them. They felt it was important to have a space to talk and share stories, and knowledge, and it helped to normalise their sibling's behaviour and their own experiences. It therefore seems important to ensure that siblings are receiving peer support through the form of sibling support groups regularly and soon after diagnosis. This is of particular importance as it appears that the sibling support group through which the participants in this study were contacted is one of only a handful in the country, despite siblings regularly stating that they would like access to support groups (Ewertzon, et al, 2012). Clinical psychologists could play a particular role in getting such groups running.

This study also indicates that siblings' relationship with their diagnosed sibling will change over time, related to their own emotional development and their transition through the family life-cycle. The participants noted how although

caring for their sibling did bring some positives, such as an increased closeness in the relationship, it can be especially hard to offer support for their sibling when they were going through their own life transitions. It is useful for services and clinical psychologists to be aware that there can be stressful periods of time for the siblings and through maintaining communication with the family services can provide extra support during these periods.

4.6. Future research

This study has demonstrated the vast impact that having a sibling with a diagnosis of schizophrenia can have. However the exploratory nature of this study necessitates that further research be carried out. The most interesting avenue of enquiry would be why some siblings become more involved in the care of their diagnosed sibling and others do not. This study suggests that the position in the family, sense of responsibility either through social or family discourses, and gender has some influence on sibling's choices. In addition, this study has been unable to explore the reasons why siblings might choose not to be involved in their diagnosed sibling's care. Further exploration is needed to further elucidate how these factors affect the choices made by siblings.

This study has also highlighted the existential impact of having a sibling with a diagnosis of schizophrenia, especially the choices of siblings in relationships and decisions to have children of their own. Further research could explore if these views are representative of other siblings, and how siblings can be supported to fulfil the expectations they have for their lives, such as having relationships and families if they wish. This might involve evaluating which support structures are the most helpful for siblings, and effectiveness of new services such as Open Dialogue which might be able to support siblings earlier.

This study has only explored the views of White-British siblings. Yet London is a diverse, multicultural population. Therefore future research should aim to explore the themes found in this study within other cultural communities in order to understand the particular difficulties faced by these populations and how they can be better supported. In order to recruit a more diverse sample future

research could target support groups in diverse communities, or target the siblings of NHS patients from ethnic minorities.

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6. APPENDICIES
APPENDIX A: Reflexive diary excerpt

August 2015

I met with Alice today. Alice is 27, so not much younger than me, and I really connected with her story. She was taken aback by just how incredibly articulate she was and emotive in the way she told her story. I felt for her and the story that she has been through. Again, I was struck with how open she was and how willing she was to share her story with me. She seemed nervous to begin with but at no point held back from telling me the most distressing aspects of her story. I reflected on how actually, the same is true for me. I am also very open with my story of having a sibling with mental health difficulties. It can feel like a release of anxious energy at times, as if you hand the troubling emotions to someone else. It can feel incredibly important for someone to truly understand my experiences and how I felt. I wondered if that was the same for Alice, that it was important that I really understood where she was coming from, and that I really joined with her in understanding of her story. Their story is so often overlooked and I wondered if perhaps this research was giving the participants an important opportunity to tell their story, and give it the significance it deserves. I found myself feeling frustrated about that. Frustrated that in the past Alice felt she had to hold all this pain in, and how very difficult that was for her. It has made me realise how I must respect her story, and the stories of all the participants and ensure that I'm representing their experiences correctly. I also wondered if this reflects just how necessary support for siblings is.

Alice spoke about her frustration with her brother, how she conflicted she felt at times. Scared, angry, sad and guilty. At one point Alice was very tearful and I found myself feeling those emotions with her. I wondered if my reaction was purely due to her story, as I often find that I respond to strong emotion in others. However, I also think I was particularly moved by Alice because I could really relate to the emotions and experiences she was describing. I felt that I had been through very similar experiences. Talking to her brought many memories to mind, and how difficult that period of my life had been.

However, these emotions seem more current for Alice than for me, as if she is still struggling with them. I wondered why this was, as we are so similar in age. I wondered if it was because she has only just left moved away from her family and brother, and she has only recently started to talk about her experiences with her friends. Maybe this is the first time that she has really been able to confront and start to deal with these emotions and expectations. I contrast I've felt able to talk about my experiences for a number of years, and have shared my story with nearly all my friends. In fact, whereas in the past I have had a burning need to share my experiences, it does not even feel important to tell people any more, unless something particular has happened. I wonder if this reflects the importance of being able to share ones story, and how important it is to feel heard. Perhaps once you feel you have been heard or have been able to do this it is easier to deal with the difficult emotions? Perhaps you need time away in order to manage and deal with your own emotions and needs? Now I feel more able to help my sister and have a relationship with her without feeling angry or sad, or frustration that this happened to me. Perhaps Alice is going through this process at the moment.

The fact that these points resonated so much with me helped me realise how helpful my own personal experience might be when I come to analyse this data. I feel that I have an innate understanding of where these participants are coming from. I also wondered if I connected with Alice's story so much as we are such a similar age and at a very similar point in our lives. It has made it very clear to me that I am very connected to this research, and therefore just how careful I am going to have to be when writing this up to not impose my own personal experiences and understandings onto the data,

but to be thoughtful about what the participants are communicating.

205   56: it's really tough. I think it's really, it's a really tough situation and I   *hard situation*

206   think that my mum she didn't really call on outside help, or maybe at the   *— mum didn't ask for*

207   time there weren't support services in the way there are, I don't know. I   *help.*

208   can't really judge if mental health is really much better understood now   *lack of support servces in past?*

209   than it is then, I imagine that it really must be, but um, my mum really   *mum*

210   kept it a lot of it to herself in a way and I think she, I think because of her   *— dealt with on own*

211   own mental health issues she felt guilty about it or whatever and so it was   *↳ shame?*

212   contained but not necessarily in a good way. But um, my mother died   *guilt?*

213   about 5 years ago and it was, and she died at home, she had cancer and

214   she, but it was at that point that I realised, there was a lot of care for my   *— moment of realisation*

215   mother but my sister had been going through, who'd been really really   *— able to consider sisters POV*

216   close and very dependent on my mother was kind of pushed outside that   *— empathy?*

217   situation and then it, I „I kind of er, ducked back in to support her cos I   *= Sense of obligation?*

218   felt that she, uh, I don't know, my brothers had a very objective distant   *— Brothers - objective + distant*

219   response to her and so there was the whole kind of grieving process going

220   on but she was very much outside it. It was really, and actually the   *— ostracised by family*

221   hospice services were kind of, they were saying things objectively to one   *↳ lonely?*

222   of my brothers, oh well she's she's going to be really upset she's going to

223   need to be hospitalised but that direct conversation with my sister never   *— Considering sisters POV*

224   went on, and she felt very much distant from it and I just thought it was   *— empathy?*

225   really unfair and not helpful for her so she was, well we all were not in a

226   good way but she was in a particularly bad way after that so that's when I

227   really kind of really engaged with her and started and actually she'd kind

228   of been on the outside and her life was really precarious in terms of her

229   living situation and in terms of practical things so then I kind of ducked

230   back in but I, well both in support and I suppose that I needed to be   *own needs to be connected*

231   connected into the family, it was also my need you that family connection   *to family after death*

232   to be a bit closer. So we shared all that, and I'd been able to support her a   *of mother prompted*

233   bit more practically as well and do things that my mother couldn't do cos   *caring for sister.*

234   my mother couldn't use the internet and didn't, do you know what I

235   mean, it's kind of and so that's been, that's been good. And I've been   *— positve for helping*

236   doing that for the last five years and now we're kind of, yeah, we're   *↳ helps to maintain input)*

237   much, yeah, we've got a close, we've got a close relationship and...   *Close relationship*

       ↳ Related to caring?

238   I: sorry I'm jus writing that in cos I'd realised I hadn't....

239   56: yes, that was before, that was a key, that was a key moment. I mean

240   before my 20s and 30s obviously I kept a connection with her but   *— less connected in 20's+30's*

241   obviously it was a, she was living independently she had a place she had   *— more distance.*

242   with her boyfriend, whatever, I had a partner and stuff like that, but I

243   haven't had children so but, she knew my partner and thigns like that so... *No children.*

244   I: and would you say that her difficulties have impacted on some of the

245   choices that you've made in your life or have you been free to do what

246   you wanted to do as well?

247   56: I have, yes I have, but that's because my mother she lived close to my   *mothers support allowed*

248   mother and my mother supported that really and she kind of supported   *her to live own life.*

249   me... a bit from it, when I suppose I suppose I could have done a bit more

Left margin notes:
copy of mum (near 205–207)
reason for caring ↳ sense of obligation/support (near 220–224)
reasons for caring (near 232–234)

250   at that point but my mum she didn't really want at that point that and she   *mum allowed her*
251   left me to live my own life which I;m really, very very gratefull actually,   *to live her own life.*

252   I: yeah

bres vs sibling

253   56; but now it's impacting a lot more and now I am in this kind of carer   *more impact as a*
254   role and there is a lot to sort out.   *carer*

255   I: and how has that been? how has it been since your mother's death and
256   you've been taking on this role?

257   56: well all this stuff is tough, but actually it kind of um, I guess it focussed   *+ve?*
258   me a bit. And sometimes being practical support to someone else it   *caring practically allows time for*
259   seems to kind of, and we were able to talk about things to do with my   *conversations*
260   mum and what it was like in the end and what it was like for her and
261   actually it's lovely it's really lovely to have those kinds of conversations   *+ve of caring.*
262   and that's that's you know, that's quite important and she was umming
263   and aahhing about going to the funeral and she came and her boyfriend
264   came and also she came when we went to scatter the ashes, it was a real   *appreciating effort of*
265   effort for her cos she's quite, she doesn't go out much but she did and she   *sibling.*
266   came and did it with all my brothers and sisters so that was really, that   *Connection with family*
267   was really, that was really good, and it's, for me it's, now I'm into a sort of
268   situation with her of actually sort of tackling, trying to get the right   *practicalities of caring.*
269   support services for her cos she's struggling with independent living, I'm
270   kind of that's where it's become a bit more formal really, yeah, and I
271   struggle with that, plus there are occasional crises, and so my current
272   partner he doesn't kind, he doesn't really understand he doesn't sort of   *partner struggling to*
273   understand the kind of commitment I've got to her, and I see her   *understand.*
274   fortnightly and I talk to her most days, and so sometimes that feels   *Regular commitment*
275   pressured a bit cos I've got, but it makes a difference to her so it's, yeah,
276   it's difficult and I think getting the right, the support services that she   *Need for proper support*
277   needs just aren't there, I don't think, independent living and so that a,   *services*
278   that's a real frustration for me so I have a lot of, I do a lot of emailing to   *impact on her due to*
279   make sure certain things are happening, blah blah blah, this that and the   *lack of support services.*
280   other so, that gets, rather than her actually, that gets, that gets tiresome.   *tiring.*
281   because a lot of talking happens with services but actually getting a care
282   plan and action on the ground, it takes so long, and you know, so..   *difficulties of working with services.*

283   I: and how is all that impacting on you, I know that you said it's tough, but
284   how is it impacting on you in your life.

285   56: er, I've kind of built it into my life a bit, erm, after my mother died I so,   *Built caring into life*
286   I also changed jobs and then I also worked part time so, I had a bit more   *part of life*
287   free time and I needed time to do that, there were other changes I   *needing time to care?*
288   needed to make as well for work, now I'm back to sort of full time work.
289   so sometimes it gets, it gets difficult cos you're just reliant on the daily
290   conversation and so (laughs) I like to have a daily conversation that's not   *daily convos can be*
291   all about nuts and bolts and sort of domestic things ,and the stuff that   *too practical/dull?*
292   needs to be done, or whatever, just a conversation so that's ok, and she's
293   getting, so sometimes I'll do things in the evening and I'll say actually I'm

294 not in this evening so but I'll talk to you another, you know what I mean,
295 another talk to talk so

able to tell sister has other plans

296 I: yeah.

didn't realise it was wearing down

297 56: it's ok, the only time I realise actually it was wearing me down a little
298 bit was when I went on holiday this summer and the holiday just felt
299 amazing even a kind of complete weeks break felt amazing, so oh well, ok
300 maybe there is some pressure around this, so I find it hard but it's very
301 hard to judge really. And there isn't an option, sometimes there's crisis
302 situations which my sister, she can ,she can sort of go into quite
303 unpleasant mode and it's quite, and then she really pushes you away, and
304 she'll apologise and say sorry, if you push too much on getting a situation
305 changed or anything cos she really wants to continue with a sometimes
306 negative situations and this is particularly relating to something that she,
307 she kind of has a long term friendship with who semi lives in her house
308 who causes lots of chaos who's extremely, who's got a lot of mental
309 health issues, so that's really, that's pretty difficult so sometimes I think
310 it's just cos she's my sister it's difficult to draw the boundary, so it's you
311 know it's if this happens then I can't be involved in this situation anymore,
312 and that's kind of quite tough but I have, I mean I try not to be, I have
313 very open conversations with her and stuff but she finds it very difficult to
314 take into account my life and my needs and that's just part of the
315 syndrome I think

feeling of break
Break felt amazing
pressure
Behaviour can be unpleasant
knowing when to push + when not to push.
caring vs sibling
→ drawing boundaries difficult.
open convos
→ difficult for sisto understand her needs.

316 I: and how is that, if you're feeling that you're not having maybe the
317 support back?

318 56: well I suppose occasionally I just loose it with her and I just do that
319 because I suppose, the relationship we've got I can do that and I think she
320 needs to, she needs to hear it from the other side as well, so it's, yeah it is
321 tricky. Do you know what I mean? I know at her core there's a really, a
322 sound and loving relationship there but the kind of things that, how her
323 personality manifests sometimes through the illness it's quite, it's quite
324 difficult and I phone, it's quite recently that I've been able to sort of
325 distinguish the cycles with her up to three week injection and when things
326 might start to go a bit haywire with her and some of the things she says,
327 she's very articulate about it but actually you actually realise it's not real
328 or it's a kind of, or it's something that comes from fear that it, it's sort of
329 something that's slightly off that sounds like it's actual practical reality
330 and that's quite tricky but I'm learning how to do deal with that

externalising knowledge?
Sometimes get angry
Relationship strong enough to withstand anger.
Loving relationship
personality diff from illness - externalising?
Understanding cycles helps - knowledge.
Learning idiosyncrasies

331 I: yeah, it sounds like you're her routines almost, not her routines but her,

learning
learning how coping

332 56: well yes there is a kind of cycle and I mean she hasn't been, she hasn't
333 been in hospital for a long long time, I'd say for at least 20 years? So she's,
334 she's actually quite stable in the situation she's in. but the prob, the
335 problem side is the long term impact of lithium as well so there's you
336 know, the weight gain and the mobility problems and dental problems
337 and things like that. So it's, she's quite good about her medical

cyclical
other probs associated with medicines

8

APPENDIX C: Example theme development

The expectations for their life-cycle

Choice in caring?

Choices regarding life-cycle transitions

Expectations for the future

Sense of obligation

Decision to not have children

Difficulty having relationships

Reducing guilt

Dear of damaging child

Needing to find a 'special partner'

Fear of taking on caring responsibility from parents

Family responsibility

Fear of producing a mental unwell child

'package' too much to take on

Fear of becoming a 'cold hearted bitch'

Empathy for siblings' experience

Fear of having to care for a mental unwell child into old age

Partner's difficulty understanding siblings needs

Trying not to think about the future – living in the present

Role of older sibling to care for younger sibling

PARTICIPANT INVITATION LETTER

UNIVERSITY OF EAST LONDON

School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator
Katy Stillwell
Siblingresearch2015@gmail.com

Consent to Participate in a Research Study
The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate a research study. The study is being conducted as part of my Clinical Doctorate in Psychology at the University of East London.

Project Title
Caring across the life cycle: Experiences of caring for a sibling with a diagnosis of schizophrenia.

Project Description
The project aims to explore and better understand the relationships between adults with a diagnosis of schizophrenia and their siblings, and how the relationship may change at different times in their lives. Particularly when there are big changes in the lives of the sibling, such as getting married, having children etc.
To do this siblings of adults with a diagnosis of schizophrenia will be interviewed by a researcher and asked to describe their relationships with their sibling over the course of their life, and how, if at all, it has changed during this time.
There is no risk to the participants and it is not expected to cause any distress, however all participants will be offered contact details of organizations that may be able to offer support, and participants are welcome to ask any questions they may have.

Confidentiality of the Data
All information will be anonymised and all identifying information, including names, will be omitted. The data will be securely kept in password protected files on a password protected computer. Once the study has been completed the audio recordings will be destroyed. The anonymised transcripts of the recordings will be kept for five years, in password protected files.

Location
The interviews will be held in a location convenient to both the participant and the researcher. There are rooms available at the UEL campus.

Disclaimer
You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. Your data will not be used in the final analysis.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Dr David Harper, School of Psychology, University of East London, Water Lane, London E15 4LZ.
or
Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.
Yours sincerely,
Katy Stillwell
23.02.2015

APPENDIX E: Participant consent form
UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Caring over the lifespan: Experiences of caring for a sibling with schizophrenia

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Participant's Signature

…………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

…………………………………………………………………………………..

Researcher's Signature

……………………………………………………………………………………

Date: ………………….……

APPENDIX F: Interview schedule

Tell me about you and your family? Can you describe them?
    (Complete a genogram with the participant)

How was your relationship with your sibling when you were:
- Children?

- At school?

- Teenagers?

- Moving out of home?

- Married or in a serious relationship?

- Had children?

- Parents illness?

Prompts: how did that (transition) impact on you?
    Can you give me an example?

How has your relationship with your sibling evolved over time?
How do you think your sibling has experienced your relationship?

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

SUPERVISOR: David Harper   **REVIEWER:** Meredith Terlecki

STUDENT: Katherine Stillwell

Title of proposed study: Caring across the lifespan: Experiences of caring for a sibling with Schizophrenia
Course: Clinical Doctorate in Psychology

DECISION *(Delete as necessary)***:**

*APPROVED

APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer)*:

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*
Student number:

Date:

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

	HIGH
	MEDIUM
x	LOW

Reviewer comments in relation to researcher risk (if any):
The student has an appropriate safety plan in place for interviews occurring at non-UEL, non-NHS sites.

Reviewer *(Typed name to act as signature)*:   Meredith Terlecki

Date: 2 March 2015

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)

PLEASE NOTE:
*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: http://www.uel.ac.uk/gradschool/ethics/fieldwork/

APPENDIX H: University of East London registration document

APPLICATION TO REGISTER FOR A POSTGRADUATE RESEARCH PROGRAMME
(TO BE COMPLETED IN CONSULTATION WITH THE DIRECTOR OF STUDIES)

In completing this form, the applicant should refer to the relevant sections of the Part 9 of the Manual of General Regulations, the Code of Practice for Postgraduate Research Degrees and, where necessary, the Code of Practice for Research Ethics and Governance.

This form must be signed and dated in advance of submission to School Research Degrees Sub-Committee (SRDSC).

> ***What Now?*** *This form should be completed by the applicant in consultation with the Supervisory Team. Following formal approval at Research Degrees*

1. STUDENT'S DETAILS

FULL NAME	**Katherine Stillwell**	
UEL STUDENT NUMBER	**U1331793**	
PROGRAMME FOR WHICH YOU ARE CURRENTLY ENROLLED *(Please Tick)*	**MPHIL**	
	MPHIL BY PUBLISHED WORK	
	PHD VIA MPHIL	
	PHD DIRECT	
	PHD BY PUBLISHED WORK	
	PROF DOC	**X**
TITLE OF PROFESSIONAL DOCTORATE PROGRAMME (IF APPLICABLE)	**Professional Doctorate in Clinical Psychology**	
DATE OF FIRST ENROLMENT FOR CURRENT PROGRAMME	**September 2013**	
HAS THE PERIOD OF ENROLMENT INVOLVED A SUSPENSION OF STUDIES? (DELETE AS APPROPRIATE)		**No**
IF THE PERIOD OF ENROLMENT HAS INVOLVED A SUSPENSION OF STUDIES, PLEASE INDICATE THE DURATION IN WHOLE SEMESTERS.		

CURRENT MODE OF STUDY (DELETE AS APPROPRIATE)	**FULL TIME**
NUMBER OF MODULES CURRENTLY REGISTERED FOR *(For Professional Doctorates only)*	**One**
REQUESTED DATE FOR START OF REGISTRATION *(Registration must occur within 6/12 months of the date of enrolment for FT/PT students respectively and may be backdated to that date.)*	**October 2013**
DECLARATION OF PREVIOUS REGISTRATION. *(If a previous period of registration exists elsewhere this may be transferred to form part of the registration period at UEL. Evidence confirming the dates and location of this registration must be provided.)*	
SCHOOL	**Psychology**
1) NAME OF COLLABORATING ESTABLISHMENTS (IF ANY) **2) PLEASE LIST YOUR UNDERGRADUATE AND/OR POSTGRADUATE QUALIFICATIONS**	1. **N/A** 2. **Upper Second Class BSc Psychology, Merit MSc Forensic Psychology**

RELATIONSHIP BETWEEN WORK TO BE UNDERTAKEN IN THE COLLABORATING ESTABLISHMENT AND THAT TO BE UNDERTAKEN AT THE SPONSORING ESTABLISHMENT OR ELSEWHERE (IF RELEVANT)
N/A
DETAILS OF FACILITIES AVAILABLE FOR THE INVESTIGATION, INCLUDING FUNDING AND LOCATION
INTERVIEWS WILL NEED TO BE RECORDED AND TRANSCRIBED SO A DIGITAL RECORDER. AN INTERVIEW ROOM AT THE STUDY LOCATION IS ALSO REQUIRED.
IF THE STUDENT WILL BE DOMICILED OUTSIDE THE UK WHILE THE RESEARCH IS BEING CONDUCTED, PLEASE PROVIDE DETAILS OF PROPOSED ARRANGEMENTS FOR SUPERVISION, SPECIFICALLY THE NATURE AND FREQUENCY OF CONTACT. PLEASE NOTE, PARTICULAR ATTENTION SHOULD BE PAID TO THE DEMANDS PLACED ON CANDIDATES WHILE NOT IN ATTENDANCE AT UEL, AND GUARANTEE THAT APPROPRIATE SUPERVISORY SUPPORT IS MAINTAINED.

N/A		
IN THE EVENT THAT THE STUDENT INTENDS TO UNDERTAKE THE MAJORITY OF THEIR RESEARCH AT A HIGHER EDUCATION PROVIDER OR RESEARCH INSTITUTION ABROAD, HAVE SPLIT-SITE ARRANGEMENTS BEEN CONSIDERED BY SCHOOL RESEARCH DEGREES SUB-COMMITTEE (SRDSC)? (DELETE AS APPROPRIATE)	**YES**	**NO**

2. THE PROGRAMME OF RESEARCH

PROPOSED TITLE OF THESIS
CARING OVER THE LIFESPAN: EXPERIENCES OF CARING FOR A SIBLING WITH SCHIZOPHRENIA
AIM OF THE INVESTIGATION
THIS STUDY AIMS TO INVESTIGATE HOW SIBLINGS OF ADULTS DIAGNOSED WITH SCHIZOPHRENIA RETROSPECTIVELY PERCEIVE THEIR RELATIONSHIP WITH THEIR SIBLING ACROSS THEIR FAMILY LIFE CYCLE. **RESEARCH QUESTIONS** - **HOW DO SIBLINGS OF ADULTS WITH A DIAGNOSIS OF SCHIZOPHRENIA DESCRIBE AND PERCEIVE THEIR CARING ROLE, CURRENTLY AND RETROSPECTIVELY?** - **HOW DO SIBLINGS OF ADULTS WITH A DIAGNOSIS OF SCHIZOPHRENIA RETRO-SPECTIVELY DESCRIBE THEIR SUBJECTIVE EXPERIENCE OF HOW LIFE CYCLE TRANSITIONS EFFECTED THEIR RELATIONSHIP?**
DETAILS OF PROPOSED RESEARCH IN LAY TERMS
THIS RESEARCH AIMS TO INVESTIGATE HOW SIBLINGS OF ADULTS WITH SCHIZOPHRENIA UNDERSTAND AND CONSIDER THEIR CARING ROLE WITHIN THE RELATIONSHIP WITH THEIR SIBLING, IN THE PAST AND THE PRESENT. **SIBLINGS PROVIDE A LOT OF PEER SUPPORT FOR EACH OTHER, AND I AM INTERESTED IN HOW SIBLINGS OF ADULTS WITH A DIAGNOSIS OF SCHIZOPHRENIA DESCRIBE AND MAKE SENSE OF THEIR EXPERIENCES OF HAVING AND CARING FOR A SIBLING WITH SCHIZOPHRENIA. I AM ALSO INTERESTED IN HOW AND IF THE CARER SIBLING'S ABILITY TO CARE FOR THEIR SIBLING CHANGED DURING THEIR LIFE, PARTICULARLY DURING PERIODS OF TRANSITION WITHIN THEIR LIFE, SUCH AS AT SCHOOL, AS A TEENAGER, WHEN THEY HAD THEIR OWN FAMILY ETC. THIS MAY HELP US UNDERSTAND HOW TO SUPPORT SIBLINGS IN THIS ROLE.** **I HOPE TO EXPLORE THIS BY CARRYING OUT 8-10 SEMI-STRUCTURED INTERVIEWS WITH ADULT SIBLINGS OF ADULTS WITH A DIAGNOSIS OF SCHIZOPHRENIA (LASTING 50-60 MINS). INTERVIEWS WILL BE CARRIED OUT SEPERATELY IN A PRIVATE SETTING EITHER AT UEL OR IN PUBLIC AREAS SUCH AS COMMUNITY CENTRES, OR NHS BASES. INTERVIEWS WILL BE AUDIO-RECORDED AND TYPED UP FOR ANALYSIS.**

THE PARTICIPANTS WILL BE RECRUITED FROM THE MENTAL HEALTH CHARITY 'RETHINK' WHICH RUNS SUPPORT GROUPS FOR SIBLINGS OF ADULTS WITH MENTAL HEALTH DIFFICULTIES. AN ADVERT WILL ALSO BE PLACED IN LOCAL NEWSPAPERS FOR THE STUDY. ANYONE WHO IS INTERESTED IN TAKING PART WILL BE GIVEN AN INFORMATION SHEET AND BE ASKED TO CONSENT TO THE INTERVIEWS.

ONCE ALL INTERVIEWS HAVE BEEN CARRIED OUT, EXISTENTIALLY-INFORMED HERMENEUTIC PHENOMENOLOGICAL ANALYSIS WILL BE USED TO LOOK AT THE INTERVIEWS IN MORE DETAIL AND TO REALLY TRY TO UNDERSTAND THE INDIVIDUAL EXPERIENCES OF THE PARTICIPANTS, AND ALSO SEE IF THERE ARE SOME COMMON THEMES. THE RESEARCH QUESTIONS MENTIONED IN THE PREVIOUS SECTION OF THIS DOCUMENT WILL BE KEPT IN MIND DURING THIS ANALYSIS.

PROPOSED PLAN OF WORK, INCLUDING ITS RELATIONSHIP TO PREVIOUS WORK, MAXIMUM 4,000 WORDS. *Please include in the discussion a description of the research methodologies and explain why these methodologies are the most appropriate for the task. Include a list of references for all works cited. Gantt charts should be included, where appropriate, to reflect research planning.*

1. Abstract

The impact of caring for a relative with schizophrenia is great. However, much of the research into 'carers' focuses on the parents, very little considers the impact on the siblings. The research that does consider the experience of siblings fails to consider the impact of their life cycle on the relationship with their diagnosed sibling. This study aims to investigate this through semi-structured interviews and existentially-informed hermeneutic phenomenological analysis.

2. Introduction

Approximately 220,000 People in England and Wales are diagnosed with Schizophrenia (Royal College of Psychiatrists, 2012), 55% of whom continue to live at home with their families 15 years after diagnosis (Brown and Birtwistle, 1998). Families report that this puts them under pressure, as they feel unable to leave their relative alone for even a few hours (Creer et al, 1982), or they feel responsible for their medication adherence (Armstrong, 1995). However, the families or 'carers' described in research are primarily mothers, or parents. The research has rarely referred to, or considered, the sibling's role in caring.

Experience of siblings

Siblings hold a unique position in the family; they offer peer support within a long lasting relationship with common social, genetic, and cultural heritage (Lamb and Sutton-Smith, 1982). It therefore seems unsurprising that positive sibling relationships are predictive of greater quality of life for adults with a diagnosis of schizophrenia (Greenberg et al, 1999). Considering that a large proportion of

siblings expect to become primary carers after the death of their parents (Smith, Greenberg and Seltzer, 2007) the importance of the sibling relationship cannot be ignored.

Stalberg, Ekerwald and Hultman (2004) interviewed adults about their responses to their sibling's illness and found that the participants often struggled with feelings of anger towards their diagnosed sibling who could be 'mean', but also felt guilt that they were not as supportive towards their diagnosed sibling as they felt they should be. Similarly, Sin et al (2008) interviewed siblings of individuals diagnosed with first-episode psychosis and also found mixed emotions of resentment and guilt. Interestingly, both studies found that the participants reported some form of envy or loneliness as they saw the support and attention continuously focused on their diagnosed sibling rather than themselves.
Adult siblings appear to deal with these difficult emotions either by becoming actively involving in their diagnosed sibling's care, being crisis-orientated, or being detached and avoidant (Gerace et al, 1993; Friedrich et al, 2008). Those that are able to develop an involved and caring relationship with their diagnosed sibling manage this by conceptualising their difficulties within the context of an illness (Friedrich et al, 2008).

This previous research describes the emotions individuals feel towards their diagnosed sibling, and demonstrates how the relationship they develop affects the amount of support they provide. However, these studies only describe cross-sectional themes, such as avoidant or involved coping strategies or emotions such as anger and guilt, and so fail to truly engage with the subjective experiences of the participants. Therefore we are unable to understand *why* some participants were avoidant while others were involved, and what effect, if any, their emotions had on the type of relationship they developed with their diagnosed sibling. These studies also focus on the difficulties inherent within the relationship, suggesting that caring relationships are only a burden. This could be seen as pathologising for the diagnosed sibling and fails to appreciate any positives within these relationships. The studies also have limited age ranges within their samples, or are based within early intervention services associated with younger adults, and so fail to consider development of the caring relationship over time and across different stages of the family life cycle.

The impact of the family life cycle on sibling relationships

Family life is a changing and evolving process, the concept of the 'family life cycle' is an attempt to capture this process and chart the developmental stages that families tend to go through. Carter and Goldrick (1980) suggested the family life cycle can be broken into six stages with accompanying key principles of the transition; the unattached adult, the newly married couple, the family with young children, the family with young adolescents, launching children and moving on, and the family in later life. Although the traditional concept of the nuclear family has evolved to also include single families and communal living, this model still influences our expectations and behaviours of family life (Dallos and Draper, 2010).

Family stress is believed to be highest during transitions between stages, particularly when the life cycle is interrupted or fails to adapt (Hayley, 1973). Considering that the stress felt at transitions is likely to affect how much care and support family members are able to provide it is interesting that few studies have investigated the impact of life cycle stages on the caring relationships between siblings of adults with mental health difficulties, such as schizophrenia. Stress combined with the different coping strategies mentioned above could drastically impact how much care or support a sibling provides. One of the few studies investigating the impact of life cycle stages on siblings caring indeed found that those with multiple role commitments, such as marriage, parenthood and a career,

felt more strain and were less involved in their sibling's lives (Greenberg et al, 1999). However, this study used questionnaires and therefore is unable to capture the full complexity of the sibling relationship. It therefore begs the question how is this relationship experienced by the caring siblings? Do they feel able to support their diagnosed siblings, and what impact does this have on them?

3. Research Aims and Relevance

Research aims

This study aims to investigate how siblings of adults diagnosed with schizophrenia retrospectively perceive their relationship with their sibling across their family life cycle.

Research Questions

1. How do siblings of adults with a diagnosis of schizophrenia describe and perceive their caring role, currently and retrospectively?
2. How do siblings of adults with a diagnosis of schizophrenia retrospectively describe their subjective experience of how life cycle transitions effected their relationship?

Relevance

The peer support and care provided by carer siblings towards a sibling with a diagnosis of schizophrenia is unique to that of the support provided by a parent. The care that they can provide can be seen as a resource, but as the carer sibling negotiates their own family life cycle the amount of care they can provide for their sibling will vary. This is likely to have an effect on services, as adults with a diagnosis of schizophrenia may need extra support from services if this care is not provided by their sibling. Therefore, services may benefit from understanding how and when best to support carer siblings

4. Epistemology and Method

Epistemological Considerations

Primarily this study will take a constructivist approach. The study is not concerned with 'truth-finding', indeed the participants' perception of their relationship is likely to have changed over time and be affected by retrospective recall, and therefore this study cannot adopt a 'realist' approach. Instead this study is more interested in in the subjective experience of the participants and how they participants perceive their relationship with their sibling, and placing this within a social and historical context.

Methodology

This study is interested in the embodied experiences of the participants, and will therefore be using an existentialist-informed hermeneutic phenomenological methodology. This qualitative approach focuses on how the participants interpret and construct meaning from their own experiences (Willig and Billin, 2011). Within this approach the researcher aims to understand the meaning and significance of the participants experiences by locating them within the wider social and historical context (Langdridge, 2007). This approach seeks the narratives of the participants, and lends itself to research questions about how it feels to undergo life events, and transitions between life stages (Willig and Billin, 2011), such as in the proposed study.

Participants

The participants will be 8-10 siblings of adults who have lived with a diagnosis of schizophrenia for much of their life. This should allow for saturation of the data to be achieved. It is hoped that the participants will be around 50 years old in order for the study to explore how the relationship with their siblings changes through a number of life cycle stages. It is expected that the participants will include a range of ethnicities, genders, and socio-economic status', reflective of the diversity that exists within a city such as London. However, adults with a diagnosis of schizophrenia will not be included, as this might affect their ability to take on a caring role. Those with a sibling who has recently been diagnosed will also be excluded as they will not have held the caring role for a sufficient period of their life.

Participants will be recruited from both the general population and through visiting siblings support groups. The charity 'Rethink Mental Illness' runs groups for siblings of people with Schizophrenia and has been contacted in the hope that the author will be allowed to attend group meetings to explain the study and hopefully recruit participants. In addition an advert will be run in local newspapers describing the study to encourage potential participants to become involved. A new email address will be set up for the study to communicate with the participants.

Data collection

A semi structured interview schedule (Appendix B) will inform the questions asked during the interview, however in order to best understand the experience of the participants, follow up questions may be asked. The open questions will ask about the participant's life stages and how their caring relationship with their sibling was at those times. The overarching questions will be around the evolution of the relationship over time, and the impact of transitions such as birth of children. The interviews will last about 50-60 minutes and will be audio-recorded and transcribed for analysis.

As this research is qualitative some participants may have difficulties with retrospective recall. The participants' perspective may have changed over time, and therefore this study cannot assume some veracity in their statements. However, the flexible nature of the existentially-informed hermeneutic phenomenological approach helps facilitate the participants' recall by focusing on creative engagement (Van Manen, 1990). Therefore creative methods of engagement, such as genograms and timelines, will be used in addition to semi-structured interview questions.

As far as possible the interviews will take place in public spaces, either UEL property or NHS properties. As the interviews will not take place in participants home but in public buildings, there will be little risk of harm to the interviewer. All interviews will be confidential, with efforts made to ensure that the conversations cannot be overheard.

5. Ethical Considerations

Informed consent

Participants will be given an invitation letter for the study if they show interest in taking part. This will outline the purpose of the study, their right to withdraw, confidentiality, and how their data will be stored (See appendix C). If they agree they will be given a consent form (Appendix D). It was considered whether consent should be sought from the individual with the diagnosis, since they will be

discussed in the interviews. However, it is not their experience that this study is concerned with, and there will be no questions asking directly about their history. Rather, the questions will ask about the sibling relationship and the participant's perception of this. Further, steps will be taken to disguise or remove all identifying information from the transcripts, such as names and locations. An alternative method of interviewing could involve the diagnosed sibling in the interviews, however this was rejected as it is possible that having their sibling present for the interviews may affect the answers given by the participants. In other circumstances carers are often provided private therapeutic space. These interviews may offer a similar therapeutic effect, to which the participants are entitled. For these reasons consent will only be sought from the participants. They may wish to tell their relative about the study, but this can negotiated verbally.

Confidentiality and anonymity

The recordings will be transcribed after the interview and the files will be password protected and stored on a password protected computer. No identifying details will be kept with the files. These files will be kept for 5 years, and the recordings will be deleted after the viva. The participant details will be kept separately from the transcripts.

Ethical approval

Ethical approval will be sought from the University of East London (UEL). NHS approval is not required as the participants will not be gathered from NHS services.

6. Resources, Supervision and Execution

Supervision

The study will be supervised by a Dr David Harper, Clinical Psychologist within the University of East London.

Resources

The study will require an audio-recorder, computer, pen, paper, and email address specific to the study.

Execution

1. UEL Ethics Committee Approval sought (see Appendix A).
2. If approved, approach Rethink about talking at one of their meetings for siblings of adults with a diagnosis of schizophrenia.
3. Advertise the study in local newspapers
4. Recruitment, consent-gathering and interviews.
5. Interviews transcribed by researcher within three months.
6. Analysis, literature review and write-up.
7. Submission to UEL Clinical Doctorate Programme.
8. Erasure of audio recordings after examination.
9. Dissemination - submission to peer journal.
10. Transcripts destroyed after five years.

7. References

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SUMMARY OF THE ELEMENTS OF THE INVESTIGATION THAT ARE NOVEL, ORIGINAL OR CREATIVE AND THAT MAY CONSTITUTE PRODUCTION OF ORIGINAL KNOWLEDGE OR AN ORIGINAL INTERPRETATION OF EXISTING KNOWLEDGE.
ONLY A LIMITED AMOUNT OF RESEARCH FOCUSES ON THE SIBLING RELATIONSHIP BETWEEN ADULTS WITH A DIAGNOSIS OF SCHIZOPHRENIA AND THEIR NON-DIAGNOSED SIBLING. TO THE RESEARCHER'S KNOWLEDGE THERE ARE NO OTHER STUDIES THAT HAVE INVESTIGATED HOW THE SIBLING OF AN ADULT WITH SCHIZOPHRENIA PERCEIVES THE RELATIONSHIP OVER THEIR LIFE CYCLE.

RISK ASSESSMENT AND OVERSEAS TRAVEL

A RESEARCH RISK ASSESSMENT IS REQUIRED FOR ANY PROPOSED LABORATORY EXPERIMENTS AND/OR FIELDWORK TO BE CONDUCTED OFF-SITE. WHERE THE FIELDWORK INVOLVES OVERSEAS TRAVEL, SEPARATE APPROVAL FROM VICE-CHANCELLOR'S GROUP (VCG) MUST BE OBTAINED IN ADVANCE OF THIS ACTIVITY.

DOES THIS INVESTIGATION REQUIRE LABORATORY EXPERIMENTS AND/OR FIELDWORK? (DELETE AS APPROPRIATE)	YES	
IF LABORATORY EXPERIMENTS AND/OR FIELDWORK ARE INVOLVED, HAS THE RESEARCH RISK ASSESSMENT BEEN CARRIED OUT? (DELETE AS APPROPRIATE)	YES	

If the proposed research involves overseas fieldwork, has a request for approval of this activity, via form RFA(2), been submitted to Vice-Chancellor's Group (VCG)? (Delete as Appropriate)	N/A	

NOTE: Where the proposed research involves overseas travel for the fieldwork, the registration arrangements may be approved subject to the understanding that such activity may only be carried out with advance approval from Vice-Chancellor's group (VCG) via form RFA(2) HTTP://WWW.UEL.AC.UK/QA/RESEARCH/FIELDWORK.HTM

The completion of a risk assessment for the research is the primary responsibility of the applicant and the Director of Studies. School Research Degrees Sub-Committee (SRDSC) should receive confirmation that the risk assessment is complete. Where is it apparent that the risk assessment has not been carried out, this should be reflected in the accompanying minute from SRDSC, clarifying required action to ensure its completion.

RESEARCH ETHICS

Does the proposed research design include parameters requiring ethical approval? (Delete as Appropriate)	YES	
If ethical approval is required, has the requisite application been submitted to University Research Ethics Committee (UREC)? (Delete as Appropriate)	YES	
Has the applicant sought ethical approval from an external REC in advance of submitting an application to UREC? (Delete as Appropriate)		No

NOTE: Where the research involves human participation (i.e. human participants, human material or human data) prior approval from a research ethics committee is mandatory. Applicants should be aware that conducting any form of research involving the above parameters without appropriate ethical approval may result in disciplinary action and/or the cancellation of the research.

INTELLECTUAL PROPERTY RIGHTS

Do the proposed arrangements include a transfer on to a UEL postgraduate research degree following registration with another Higher Education Provider? (Delete as Appropriate)		No
Will the programme of research lead to output(s) which will have commercial form(s) and/or intellectual property of potential value? (Delete as Appropriate)		No
If output is of potential value, has the Office of Intellectual Property Development been consulted? (Delete as Appropriate)	N/A	

3. PROPOSED SUPERVISORY TEAM

NOMINATION OF DIRECTOR OF STUDIES (DoS)	
NAME AND TITLE	Dr David Harper, Academic course director
SCHOOL	Psychology

CURRENT POSITION, DEPARTMENT AND INSTITUTION	
PREVIOUS POSTS HELD	
EMAIL ADDRESS	**D.Harper@uel.ac.uk**
QUALIFICATIONS	
CURRENT RESEARCH OR PROFESSIONAL PRACTICE	

NOMINATION OF SECOND SUPERVISOR			
NAME AND TITLE	N/A CURRENTLY REGISTERED AS A GREE PROGRAMME AT ANY HEI?		No

PLEASE LIST UP TO SIX PUBLICATIONS WHICH ARE OF MOST RELEVANCE TO THIS PROPOSAL. IF THERE ARE NO PUBLICATIONS, PLEASE INDICATE THE RELEVANT PROFESSIONAL EXPERIENCE.

STUDENT ON A RESEARCH DEGREE PROGRAMME AT ANY HEI? (DELETE AS APPROPRIATE)			**No**
PREVIOUS POSTS HELD	**MPHIL**		
	PROFESSIONAL DOCTORATE		
EMAIL ADDRESS	**PHD**		
QUALIFICATIONS			
CURRENT RESEARCH OR PROFESSIONAL PRACTICE			

NUMBER OF HEI RESEARCH DEGREE STUDENTS CURRENTLY SUPERVISED	**MPHIL**	
	PROFESSIONAL DOCTORATE	
	PHD	
NUMBER OF HEI RESEARCH DEGREE STUDENTS SUCCESSFULLY SUPERVISED TO COMPLETION	**MPHIL**	
	PROFESSIONAL DOCTORATE	
	PHD	

NOMINATION OF THIRD SUPERVISOR (IF APPLICABLE)	
NAME AND TITLE	**N/A**
SCHOOL	
CURRENT POSITION, DEPARTMENT AND INSTITUTION	

PREVIOUS POSTS HELD	
EMAIL ADDRESS	
QUALIFICATIONS	
CURRENT RESEARCH OR PROFESSIONAL PRACTICE	

IS THE PROPOSED SUPERVISOR CURRENTLY REGISTERED AS A			
NUMBER OF HEI RESEARCH	**MPHIL**		
PLEASE LIST UP TO SIX PUBLICATIONS WHICH ARE OF MOST RELEVANCE TO THIS PROPOSAL. IF THERE ARE NO PUBLICATIONS, PLEASE INDICATE THE RELEVANT PROFESSIONAL EXPERIENCE.			
NUMBER OF HEI RESEARCH DEGREE STUDENTS SUCCESSFULLY SUPERVISED TO COMPLETION	**MPHIL**		
	PROFESSIONAL DOCTORATE		
	PHD		

OVERALL SUPERVISORY EXPERIENCE AND ACTIVITY OF THE PROPOSED SUPERVISORY TEAM		
HAS EVERY MEMBER NOMINATED TO ACT IN A SUPERVISORY ROLE COMPLETED THE REQUISITE UEL SUPERVISOR TRAINING PROGRAMME? (DELETE AS APPROPRIATE)	**YES**	
COLLECTIVE NUMBER OF RESEARCH DEGREE STUDENTS SUCCESSFULLY SUPERVISED TO COMPLETION	**MPHIL**	
	PROFESSIONAL DOCTORATE	**30+**
	PHD	**5**
IF THE COMBINED EXPERIENCE AND ACTIVITY OF THE PROPOSED SUPERVISORY TEAM DOES NOT MEET THE REQUIREMENTS STIPULATED IN UEL'S RESEARCH DEGREE REGULATIONS, PLEASE PROVIDE A SHORT STATEMENT JUSTIFYING WHY CONSENT IS SOUGHT AND WHY THIS PARTICULAR SUPERVISORY TEAM IS MOST SUITABLE FOR THE PROGRAMME OF RESEARCH.		

4. NOMINATION OF ADVISOR

NAME AND TITLE	
CURRENT POSITION, DEPARTMENT AND INSTITUTION	
FULL POSTAL ADDRESS	
EMAIL ADDRESS	
PREVIOUS POSTS HELD	
QUALIFICATIONS	

5. STUDENT'S DECLARATION

PLEASE NOTE THAT ELECTRONIC SIGNATURES ARE ACCEPTABLE.

I CONFIRM:
1. **THAT I WISH TO APPLY TO BE REGISTERED AS A STUDENT FOR THE POSTGRADUATE RESEARCH AWARD AS INDICATED ABOVE;**
2. **THAT THE DETAILS GIVEN IN THIS FORM ARE, TO MY KNOWLEDGE, CORRECT;**
3. **THAT ANY WRITTEN COMPONENT OF THE PROGRAMME WILL BE SUBMITTED IN ENGLISH;**
4. **THAT I AGREE TO UNDERTAKE ORAL EXAMINATION IN ENGLISH;**
(REQUIREMENTS 3. AND 4. MAY BE WAIVED WHERE SEPARATE ARRANGEMENTS ARE APPROVED BY RESEARCH DEGREES SUBCOMMITTEE)
5. **THAT I HAVE READ AND AGREE TO THE PROPOSED SUPERVISION ARRANGEMENTS.**
6. **THAT I WILL OBTAIN PRIOR APPROVAL FOR ANY OVERSEAS FIELDWORK, IN ADVANCE OF THE COMMENCEMENT OF SUCH ACTIVITY, FROM VICE-CHANCELLOR'S GROUP (VCG).**

STUDENT	**SIGNED:**
	DATE: 19.02.2015

6. SUPERVISORY TEAM'S DECLARATION

PLEASE NOTE THAT ELECTRONIC SIGNATURES ARE ACCEPTABLE.

WE CONFIRM:
1. **THAT WE SUPPORT THIS APPLICATION AND CONFIRM THAT THE STUDENT HAS DEMONSTRATED THE POTENTIAL TO COMPLETE THE PROPOSED PROGRAMME OF WORK;**

2. **THAT NO MEMBER OF THE SUPERVISORY TEAM IS CURRENTLY REGISTERED ON A RESEARCH DEGREE PROGRAMME AT ANY HEI;**
3. **THAT, IF APPLICABLE, WE AGREE TO THE REQUEST FOR THE BACKDATING OF REGISTRATION;**
4. **THAT WE RECOMMEND THAT THE APPLICANT BE REGISTERED FOR A RESEARCH DEGREE PROGRAMME AT UEL.**
7. **THAT WE HAVE BRIEFED THE APPLICANT ON ALL REQUIREMENTS RELATING TO RESEARCH ETHICS AND RESEARCH GOVERNANCE, RELEVANT TO THE PROPOSED RESEARCH.**

DIRECTOR OF STUDIES	**SIGNED:**	
	PRINTED:	**DATE:**
SECOND SUPERVISOR	**SIGNED:**	
	PRINTED:	**DATE:**
THIRD SUPERVISOR (IF APPLICABLE)	**SIGNED:**	
	PRINTED:	**DATE:**

7. DEAN OF SCHOOL'S DECLARATION

PLEASE NOTE THAT ELECTRONIC SIGNATURES ARE ACCEPTABLE.

I CONFIRM THAT OUR UNIVERSITY AND SCHOOL FACILITIES AND RESOURCES DETAILED IN THIS FORM, INCLUDING ACADEMIC STAFF INVOLVED IN THE STUDENT'S SUPERVISION, WILL BE AVAILABLE FOR THE DURATION OF THE PROGRAMME OF RESEARCH.		
DEAN OF SCHOOL *(or nominee)*	**SIGNED:**	
	PRINTED:	**DATE:**