

Making Sense of Growing Up with a Parent with Psychosis

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Submitted in accordance with the requirements for the degree of
Doctor of Clinical Psychology (D. Clin. Psychol.)

The University of Leeds

School of Medicine

Academic Unit of Psychiatry and Behavioural Sciences

June 2016

The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Acknowledgements

Firstly I would like to thank my supervisors Carol Martin and Anjula Gupta for their support and time dedicated to this research project. Carol, thank you for your guidance throughout and especially for taking on this project after it had already started. Your feedback and patience with me has not only helped encourage my thinking to develop but has enabled me to find a way to put my sense making into words. Anjula, I have really valued your knowledge, experience and perspective on peoples' experiences of psychosis. These insights and considerations of the wider context will remain with me after I qualify. To Sylvie Collins who supervised the first year of this project until she left the university, thank you for guiding my thinking in the beginning.

Thank you to the Max Hamilton Fund who provided extra funding to enable the last two interviews to be transcribed, this saved me valuable time.

I would like to thank my mum for the numerous amounts of drafts she has read over the course of my academic career. I have learnt a lot about language from you and appreciate all of the time you have given up to teach me.

To Tom, thank you for all your support and encouragement throughout my training and for always being there for me. You have helped remind me that there is a world outside of my thesis and given me things to look forward to. It would have been very difficult to have done this without you.

I would also like to thank my friends and family for keeping me grounded, and in particular a thank you to Alex and Fran. Without your help at the start of my career I might not have managed to achieve this.

To my housemates, I feel fortunate to have shared this journey with you all. Thank you for being there when I have needed a cup of tea and a reason to leave my computer!

Finally, I would like to thank my participants for sharing their life stories with me. I feel very privileged to have had the opportunity to hear about your experiences. Without your participation this research would not have happened and for that I am very grateful.

Abstract

Introduction: Research into the experiences of having grown up with a parent with psychosis is limited and tends to focus on the detrimental impact. Therefore, this study aimed to find out how adults who grew up with a parent with psychosis made sense of these experiences as a child and during adulthood. It was hoped that if participants were given the opportunity to speak openly about their experiences it might allow for a broader perspective to be presented.

Method: Five participants who grew up with a parent with psychosis were interviewed using a semi structured interview approach. The interviews were transcribed, and then analysed using Interpretative Phenomenological Analysis. This analysis was carried out for each participant before conducting a group analysis to identify major and subordinate themes.

Results: Four major themes were identified: *“People don’t want to care for me”*; *I’m different*; *What if people find out?*; *Finding my identity*, with thirteen subordinate themes. The findings indicated that participants felt neglected and uncared for by their parent with psychosis but also by the other people in their lives. Participants described feeling different from their peers, alone with their experiences and they wondered whether they themselves would develop unusual experiences. The research identified that to increase their sense of belonging the participants attempt to find people who they see as different from others but similar to themselves. The findings also gave insight into participants’ feelings of shame and their fear of humiliation if other people were to find out about their parents’ experiences. The research also found that the participants were able to identify ways in which their experiences had negatively impacted on them and changes which they wanted to make. Two of the participants took the opportunity to try out some of these changes between the interviews. Participants reported positive growth from their experiences but their apparent need to find the positive, possibly in order to make the experience more meaningful, is reflected on.

Discussion: The findings were considered in relation to psychological theory in an attempt to understand the participants’ experiences further. This study adds to the literature on the difficulties of growing up with a parent who experiences psychosis but provides a new element by considering the significance of developing positive growth from these experiences. The strengths and limitations of this study were considered, along with the clinical implications and areas for future research.

Table of Contents

Chapter one: Introduction	1
Introduction to the study	1
Literature review	1
<i>Developmental stages</i>	2
<i>Childhood experiences</i>	3
<i>Children with parents who have physical health difficulties</i>	4
<i>Children with parents who have mental health difficulties</i>	5
<i>Psychosis</i>	9
<i>Being part of a family where someone experiences psychosis</i>	9
<i>Prevalence of parents with psychosis</i>	12
<i>Children with parents who experience psychosis</i>	12
Differences in the impact of childhood experiences	15
Adult experiences.....	20
<i>Adults who grew up in adverse conditions</i>	20
<i>Adults who have a parent who experiences mental health difficulties</i>	21
<i>Adults who have grown up with a parent who experiences psychosis</i>	22
Conclusions.....	24
Chapter two: Method	26
Alternative methods considered.....	26
Design	28
<i>Participants</i>	28
<i>Recruitment</i>	30
<i>Final sample</i>	31
Procedure	32
<i>Pilot interview</i>	32
<i>Final interviews</i>	33
Ethical considerations	34
Analysis	36
<i>Creditability and Reliability</i>	38
Chapter three: Results	40
Pen Portraits	40
<i>Mary</i>	40
<i>Peter</i>	41
<i>Richard</i>	42
<i>Rosie</i>	43
<i>Amanda</i>	45
Group Analysis Results.....	46
“People don’t want to care for me.”	50

<i>Feeling unloved</i>	50
“Everyone looks the other way”	52
<i>Feeling burdened</i>	53
I’m different	56
<i>Becoming aware of difference</i>	56
“On my own”	57
“Am I going to end up like that?”	59
<i>In search of belonging</i>	62
What if people find out?	63
<i>Fear of shame and humiliation</i>	64
“Living a double life”	66
Finding my identify.....	67
<i>Independence</i>	67
<i>Being caring towards others</i>	68
<i>Coping through creating distance</i>	69
<i>A journey of discovery</i>	69
Chapter four: Discussion	73
Main findings	73
How do we make sense of past experiences?	75
“People don’t care for me”	77
I’m different.....	80
What if people find out?	83
Finding my identity	85
Strengths and limitations of this study	92
<i>Recruitment</i>	92
<i>The sample</i>	93
<i>Interviews</i>	94
<i>The analysis</i>	95
<i>Credibility and reliability</i>	96
<i>Gaining an adult’s perspective</i>	96
Clinical implications	97
<i>Providing more support to children who have parents with psychosis</i>	97
<i>Providing support to adults who grew up with a parent with psychosis</i>	98
<i>Reducing stigma</i>	98
Areas for future research.....	100
Conclusions.....	101
References.....	103
Appendices.....	118

List of figures

Figure 1. Child themes developed by Pölkki, Ervast and Huupponen (2005).....	6
Figure 2. Adult themes developed by Pölkki, Ervast and Huupponen (2005).....	21
Figure 3. Thematic map.....	56

List of Tables

Table 1. Participant demographics.....	32
Table 2. Distribution of themes amongst participants.....	58

Chapter one: Introduction

Introduction to the study

Throughout the course of my career in psychology I have developed an increased awareness and interest in how our childhood experiences shape the adults we become. I am particularly interested in how people respond to similar childhood experiences and how the impact of difficult childhood experiences can vary greatly amongst people.

My interest in psychosis began when I first started learning about mental health difficulties and working with people with psychosis. My own understanding of these experiences has always been that psychosis is part of a continuum of human experience. I believe that many people in society have occasional unusual experiences but for some when they are faced with other distressing life events these unusual experiences intensify, last longer and cause a greater impact. It is these people who are more likely to require support from services and are more likely to receive a label of psychosis. I was shocked when I first learnt about the way in which people with psychosis have been treated over the years, both by the medical profession and by society. However, I am encouraged by the recent movement away from psychosis being viewed solely as a biological illness which is primarily treated with medication towards considering the psychological and social elements which influence a person's experiences (BPS, 2014).

This current study combines my interest in psychosis and how we make sense of our childhood experiences in adulthood by interviewing adults who grew up with a parent with psychosis. It is useful for the reader to know that I did not grow up with a parent who had unusual experiences and I have not experienced this myself. However, throughout my life I have known family members with a variety of mental health difficulties and believe that these experiences have shaped who I am today.

Literature review

The following chapter will begin by providing an overview of the developmental stages which people pass through over the course of a life time and the challenges which are faced at each stage. The literature will then move on to consider the impact of adverse events during childhood. The research into the impact of growing up with a parent who experiences psychosis is limited and therefore a broad overview of people's experiences of having grown up with a parent with physical or mental health difficulties will be provided first. This review will then narrow to focus on the literature into the experiences of having someone in the family with psychosis and then move onto the experiences of having a parent who has psychosis. An overview into the aspects which might influence

how a child manages and makes sense of these experiences, such as their life stage, coping styles, attachment styles, self-esteem, social support and environmental factors will then be provided. The research into the impact in adulthood of having grown up with a parent who experienced psychosis is limited and therefore the literature into adults who grew up in adverse conditions will be summarised first. The review will then narrow to focus to the literature into adults who grew up with a parent with mental health difficulties, followed by the research into adults who grew up with a parent who with psychosis.

Developmental stages

When considering the impact of people's experiences it is important to also reflect on the developmental stage and associated challenges which are faced alongside these experiences. Different developmental models have highlighted stages which we move through and begin to integrate previous memories and experiences into a new identity where we are more aware of our values, desires and beliefs. For example, Erikson (1968) proposed that if we are able to resolve challenges at each stage then we develop and grow stronger from it, however if we are unable to resolve this challenge it can result in increased vulnerability and personal difficulties. The stages are described below:

Stage one; Trust vs Mistrust (0 to 18 months). During this stage the child attempts to make sense of whether the world is a safe place or not. If they receive consistency of care and their parents are responsive to their needs then they develop a sense of trust. However, if they do not receive this type of care then they will begin to mistrust others and it is thought that this links to later difficulties with peer relationships.

Stage two; Autonomy vs shame and doubt (18 months to three years). During this stage children begin to develop a sense of independence away from their parents. If parents are supportive of the child they will become more confident with their autonomy. If parents are critical or are not patient whilst the child is learning then the child will begin to develop shame and self-doubt.

Stage three; Initiative vs guilt (three to six years). During this stage children begin interacting with other children at school and use their initiative as they explore the social and physical world. If parents allow the child to explore their environment but supportively and warmly put limits on this to ensure their safety then the child will develop confidence in their ability to lead others and make decisions. If parents are controlling or critical of a child's desire to explore the world then this will result in them feeling guilty.

Stage four; industry vs inferiority (six to 12 years). The child focusses on goals which are seen as valued by their peers, teachers and parents and for which they are praised in they do well. If they are encouraged then their confidence will grow, however, if they are not then they will begin to doubt their own abilities and feel inferior.

Stage five; identity vs role confusion (12 to 18 years old). This is when an adolescent begin to develop their own sense of identity and self. It is during this period that adolescents begin to experiment with different roles in society, in order to develop their own set of values and beliefs. It is also a time when adolescents makes sense of their previous experiences in the light of the new and attempt to combine the two into one sense of self.

Stage six; Intimacy vs isolation (18- 40 years old). This is a time when people either move into an intimate relationship or an isolated position. Difficulties with moving into an intimate relationship can stem from previously unresolved earlier dilemmas.

Stage seven; Productivity vs stagnation (40 to 65 years). If during this stage people are able to be productive through having a family, developing a career and developing a sense of contributing to making the world a better place for future generations then this can be a positive experience. However, if they are unable to do this then they may feel stressed, overwhelmed or depressed.

Stage eight; Integrity vs despair (65+ years). It is during this last stage when we spend more time reflecting on our life and those who are able to accept the life we have led and what we have or have not achieved then this allows people to face death with less fear. However, if there are regrets, guilt, shame or a sense that life goals were not achieved then people are more likely to feel despairing and hopeless in their later years.

It is useful to consider the different life stages proposed by Erikson and the influence that developmental stages and associated challenges might have on how someone makes sense of their experiences. How someone manages these challenges might influence whether they are able to grow from these experiences or whether they negatively impact on them. Therefore, the following paragraphs will consider the impact of difficult childhood experiences and how this influences children's sense making.

Childhood experiences

Research indicates that those who experience adverse conditions during childhood, such as poverty, abuse, neglect and trauma, are more vulnerable to developing mental health difficulties themselves, such as depression, anxiety, but also are at

increased risk of physical health difficulties and adverse environmental factors, such as poor living conditions (Anda, Whitfield, Felitti, Chapman, et al., 2014; Hertzman, 1994; Kendall-Tackett, 2002; Kessler, Davis, & Kendler, 1997; Springer, Sheridan, Kuo, & Carnes, 2007). A child's relationship with their parent can act as a buffer for the impact of these adverse experiences, for example if a child feels safe and secure with their parent the child is more likely to learn how to express themselves healthily and to effectively regulate their own emotions (Goldberg, Muir & Kerr, 1995; Holmes, 1993). Therefore, it is important to understand how children make sense of growing up with a parent who experiences psychosis as their perception of these experiences is likely to have a lasting impact. However, there is a distinct lack of research focussing explicitly on the impact and experiences of children growing up with a parent with psychosis, as research tends to focus more broadly on physical or mental health difficulties. However, as growing up with a parent with physical or mental health difficulties has similarities to growing up with a parent who experiences psychosis, such as parent being in hospital for periods of time and reduced availability, this literature will be reviewed in the following sections to help understand the possible impact.

Children with parents who have physical health difficulties

Dura and Beck (1998) investigated the levels of self-reported depression and anxiety of children whose parents were suffering from either chronic pain, diabetes, or no medical illness. They found that there was a significant difference between the levels of reported depression for children whose parents had chronic pain when compared to the control group. However, there was no description of the number of children who reported feeling depressed, or how near the clinical threshold they were. Worsham, Compas and Ey (1997) found that adolescent girls displayed the highest levels of depression and anxiety and this increased further when it was the girl's mother who was ill, rather than her father. They suggested that this was because adolescent daughters had an increased level of responsibility at home, for example looking after younger siblings. Other studies into the effects of having a parent with a physical health problem have similar findings, such as lower levels of self-esteem (Lewis, Ellison, & Woods, 1985), increased depression and anxiety (Siegel, Mesagno, Karus, Christ, et al., 1992) and increased conduct problems at school (Rickard, 1988). However, the research into this area is limited because the course of these difficulties and how they progress over time is unclear. However, Welch, Wadsworth and Compas (1996) did carry out a longitudinal study which showed a decrease in levels of the children's distress in the months following a parental diagnosis of cancer. There is also little research into the impact of other, more

externalised levels of functioning, such as achievement at school and ability to function in peer groups.

Children with parents who have mental health difficulties

Research into the impact of having a parent with mental health difficulties uses this term to include a mixture of diagnoses, most commonly anxiety, depression and psychosis. It is important to acknowledge that when this mixed criterion is used it means it is not possible to differentiate between the impact of growing up with a parent with psychosis, or a parent who has other mental health difficulties. This research can provide us with some insight but it is possible that the mental health difficulties of the parent are likely to affect the child differently, such as increased severity of distress resulting in increased hospitalisation and unavailability.

Rutter and Quinton (1984) carried out a longitudinal study comparing 137 children with a parent who had a diagnosis of schizophrenia, manic-depressive psychosis, depression, phobic anxiety state, alcohol dependency or a personality disorder, with a control group. They found that up to one third of the children who had a parent with mental health difficulties demonstrated increased distress, hostile behaviour and difficulties regulating their emotions when compared to children who do not have parents with mental health difficulties. Further research has reported that children who have parents with mental health difficulties are at higher risk of developing problems with their behaviour and expressive language, impaired cognitive processes and a reduction in overall ability to cope (Beardslee, Schultz, & Selman, 1987; Cox, Puckering, Pound & Mills, 1987; Jaenicke, Hammen & Zupan, 1989). It has also been reported that within the family there is increased emotional and economic strain (Covinsky, Goldman, Cook, Oye, et al., 1995), restricted activity outside the home (Jenkins & Schumacher, 1999), fear of stigma (Rose, 1998b) and fear of violence (Anthony, 1986) all of which might impact on the family's ability to cope. It has also been suggested that the children of mothers who are depressed are two to five times more likely to have behavioural difficulties than children who do not have a mother with depression: they have lower self-esteem and are also more likely to develop psychopathology and depression during later life (Cummings & Cicchetti, 1990; Cummings & Davies, 1994; Downey & Coyne, 1990; Hirsch, Moos, & Reischl, 1985; Weissman, Prusoff, Gammon, Merikangas, et al., 1984; Welsh-Allis & Ye, 1988).

By contrast, Tarullo, DeMulder, Pedro and Radke-Yarrow (1994) argued that not all children with a parent with mental health difficulties go on to develop problems

themselves and suggested that there are a number of reasons why this might be. Influential factors might include the age of the child, support around the child, gender of the child, nature of the parent’s difficulties, whether the child has difficulties and how this influences the parent’s perception of and interactions with the child. The following paragraphs will review the qualitative research into children’s experiences of growing up with a parent with mental health difficulties.

Pölkki, Ervast and Huupponen (2005) interviewed six children aged between nine and eleven years whose parent had a mental health diagnosis. Five of the children had a mother with manic depression and the other child was described as having a ‘mentally ill step-father’. They used grounded theory to identify themes which emerged from the interviews and developed the model below to highlight these themes:

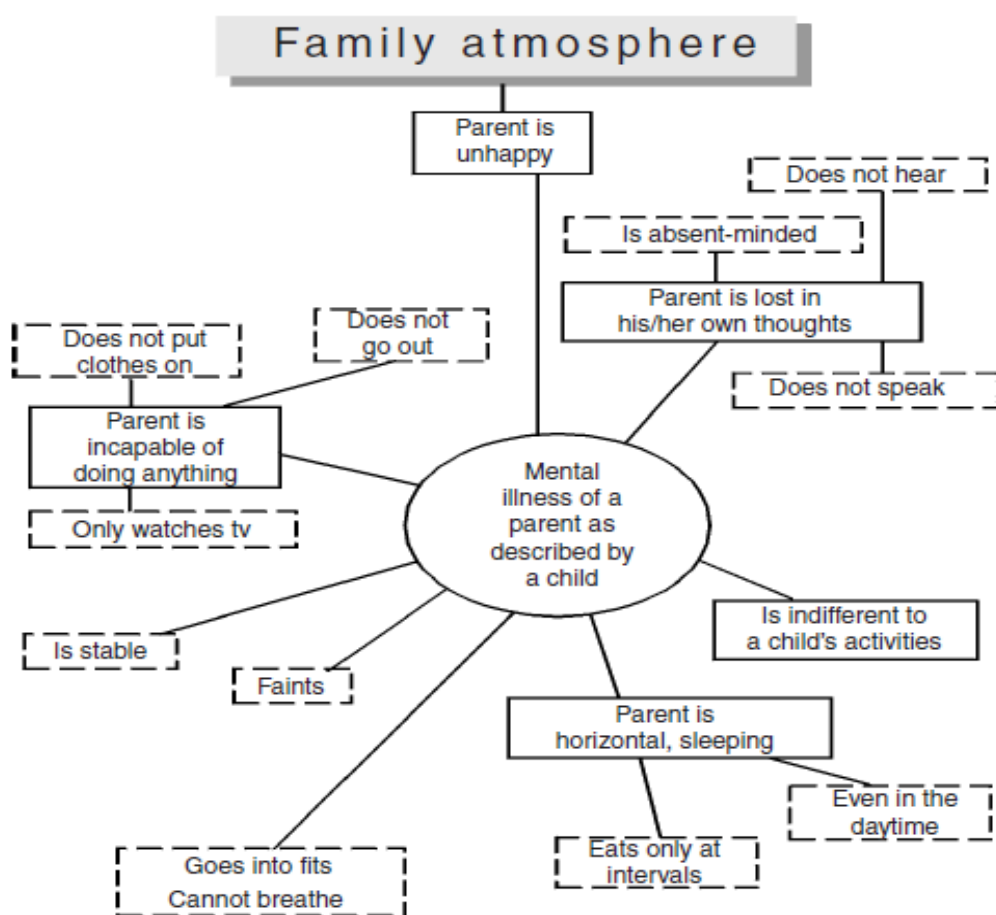


Figure 1. Child themes developed by Pölkki et al. (2005)

Pölkki et al. (2005) observed that the children had difficulty naming their emotions and some became anxious when asked how they felt about their parent’s mental health difficulties. However, it is important to consider that children of this age might

find it difficult to name their emotions. Although the themes developed in the model above suggest that the children did not have any positive experiences of their parent having mental health difficulties, all of the children reported feeling they were coping well, doing well at school, had friends and good relationships with their siblings. Pölkki noted that this could be due to the children having support from another family member or close adult. It is possible that these children were not fully open and honest about their answers because they wanted to protect their parent or please the interviewer, however they do not provide illustrative quotes to support this. Also, the sample was taken from children attending a 'rehabilitation camp', which, from the limited information described, appears to be a centre where the children spent time away from their parents and had the opportunity to see a counsellor. This is also where the interviews took place. Therefore, their families were possibly asking for, and receiving, more support than perhaps other families.

Stallard, Norman, Huline-Dickens, Salter and Cribb (2004) interviewed 24 children between the ages of six and 17 years old. There were 17 children whose mothers had mental health difficulties and seven who had a father with mental health difficulties and they were all under the care of a community mental health team. The parents experienced a range of mental health difficulties, including psychosis, affective disorders, chronic fatigue syndrome, eating disorders and borderline personality disorder. They studied the perceptions the children had of their parents and their situation and noted similar concerns as Pölkki et al. (2005). For example, they identified themes of wanting their parent to get better, being worried about the relationships within their family and also practical concerns, such as whether their parent would be able to take them to school, or whether there would be enough money for the family. The authors highlighted that their sample size was small and just under half of the parents approached refused to let their child participate in the study. Therefore, it is difficult to make generalisations as the sample might not be representative of the population being studied.

Garley, Gallop, Johnston and Pipitone (1997) carried out a series of four hour-long focus groups with six children aged between 11 and 15 years old who had a parent with mental health difficulties. Two had mothers diagnosed with depression, one had a father with depression and three had a father with manic depression. All of the children's parents were either separated or in the process of separating. They identified the following four themes as key to these children's experiences;

- *Understanding the illness*: three themes were identified; firstly, *personal concerns*, such as, participants identified being concerned about being separated,

or having been separated, from their parents and the changes in their relationship with their parent. Secondly, *illness attributions*, which included trying to make sense of what the illness meant and thirdly, *quest for information*, which involved being concerned about the possibility of they themselves developing mental health difficulties in later life and a strong desire to know all about what caused the illness and what the likely prognosis might be.

- *Recognising the signs*: participants spoke about being able to see when their parent was becoming unwell and how this could be helpful in making sense of their parent's behaviour.
- *Impact of hospitalisation*: some participants spoke about how it was a relief to know that their parent was receiving help and others spoke about how living with other relatives was a positive experience.
- *Managing their parent's difficulties*: three subthemes were identified: firstly, *coping with impact* on self, such as talking to friends or using distraction to cope. Secondly, *coping with impact of ill parent*; such as a sense of responsibility to care for the parent. Thirdly, *perceptions of help for the ill parent*; central to this theme was the importance of their parent taking their medication.

This study excluded children who had behavioural and mental health difficulties themselves, as well as children who used alcohol and drugs. Therefore, this sample excluded more vulnerable children who could have been finding living with a parent with mental health difficulties more difficult to cope with. Despite the exclusion criteria most of the themes highlighted the negative aspects of having a parent with mental health difficulties, however, the theme '*Impact of hospitalisation*' suggests that participants found making close bonds with people other than their parents protective, regardless of the circumstances.

Downey and Coyne (1990) highlighted the importance of considering the wider context which the child is growing up and not just focussing on the parents' condition, for example the wider social context and adverse conditions which the child and their parent experience. They suggested interpreting the findings from the research into the impact of having a parent with mental health difficulties with caution due to the tendency of literature to end up '*mother-bashing*' (p. 72), without considering the other contextual elements.

In summary, research into the impact of children growing up with a parent with mental health difficulties has found increased behavioural and emotional difficulties during childhood but also an increased vulnerability to developing mental health

difficulties in later life (Beardslee et al., 1987; Cox et al., Cummings & Cicchetti, 1990; 1987; Downey & Coyne, 1990; Jaenicke, et al.1989). However, research has also highlighted how this outcome is not certain and appears to depend on other external influential factors (Garley et al., 1997; Pölkki et al. 2005; Tarullo et al., 1994).

Psychosis

Before moving onto considering the literature into the impact of psychosis on families and children, first an overview of the term psychosis will be provided. The word psychosis is used to describe a range of unusual experiences which can significantly affect mood, perception, thoughts and behaviour. This includes unusual beliefs which are not universally held and voice hearing (perception in the absence of any stimulus), as well as changes which include lack of drive, social withdrawal, emotional apathy, self-neglect and poverty of speech. Individuals who have a diagnosis of psychosis can have different combinations of experiences (NICE, 2014). Approximately 1% of the general population will experience an episode of psychosis during their lifetime (NICE, 2014). Unusual experiences can have an impact on people's lives resulting in high levels of distress, unemployment and difficulties in social functioning and leisure activities (Thornicroft, Tansella, Becker, Knapp, et al., 2004). However, it is also important to note that some people have reported on the positive impact of unusual experiences, such as an increased sense of creativity or spirituality (Chadwick, 1997). As previously mentioned, the recent movement away from the medical model as a way of explaining psychosis has evolved considering unusual experiences as part of a continuum of human experience. This has allowed for the opportunity to acknowledge that not everyone who has unusual experiences becomes distressed by them.

Being part of a family where someone experiences psychosis

The research into the impact of having someone in the family with psychosis tends to focus on the family as a whole, such as the impact on mothers, fathers, siblings, spouses and other significant relatives. This research will be discussed before moving onto looking more closely at the experiences of being a parent of someone who has psychosis and the experiences of being a spouse. There appears to be no research into other specific relationships of people who experience psychosis, such as siblings or grandparents.

Martens and Addington (2001) carried out research with 41 family members (which included mothers, fathers, siblings and spouses) of people who experience psychosis. They used questionnaires to measure the levels of family burden, distress, wellbeing and the impact of the number of years since first onset of these experiences. They found that

families are more likely to report high levels of distress during the initial onset of psychosis but that high levels of distress, significant burden and negative impact on their lives are also reported by families during the course of the psychosis.

Addington, Coldham, Jones, Ko et al. (2003) used questionnaires with 238 family members (mothers, fathers, spouses and other close relatives) of someone experiencing a first episode of psychosis to identify what might influence family distress, the levels of distress experienced and the impact of caring. They found that the family experienced the highest levels of distress when the person who was experiencing psychosis was younger and if there were associated functional difficulties. They also noted that if families' appraisals of the impact of the psychosis was high then they were more likely to experience higher levels of distress. The researchers also identified that distress and feelings of being burdened can occur both when the person with psychosis is living with the relative and when not. Other themes which have been identified within families were: guilt about the cause of the psychosis, anxiety about the unknown, feelings of loss and unresolved grief (Addington et al., 2003; Barker, Lavender, & Morant, 2001; Birchwood, 1992; Szmukler, 1996).

Wainwright, Glentworth, Haddock, Bentley and Lobban (2014) carried out a thematic analysis of 23 people's experiences of being a parent of someone with psychosis. They identified four themes which were as follows;

- *Psychosis from the relatives' perspective*; this theme incorporates how the term 'psychosis' can be difficult to understand because it is not a diagnosis but a label for a variety of different experiences. It can also be difficult for relatives to make sense of the experience and learn that health care professionals might not understand what has happened, it might take a long time to uncover the best course of treatment and that this understanding and treatment might remain vague. This theme also incorporated how relatives might find it hard to maintain a relationship with the person with psychosis and how this, and communication, might begin to break down.
- *Relatives' fight with the mental health system*; this theme included issues such as the feeling of having to battle against the mental health system in a number of areas, for example to gain knowledge about the care of their child, lack of empathy from services, unclear structure to services and neglect for relatives' needs and welfare.
- *Is anybody listening? Does anyone understand?*; this theme included issues such as feeling guilty, isolated and blaming themselves for not identifying that

something was wrong earlier. There were parents who blamed themselves for their child's psychosis and some felt that this was reinforced by professionals' views towards them. They spoke about feeling stigmatised by others and the lack of information available to educate others.

- *Relatives' coping*; relatives spoke about their own resilience, the importance of having support from others and of developing an understanding that it is not all their fault. They spoke about how it was helpful to talk to other parents and learn that they are not alone in their experiences.

Wainwright et al. (2014) concluded that families learnt to adapt and cope but that the main coping strategy used was to share their experiences with others who were also going through a similar experience. They noted that it would have been beneficial if services were more supportive, more empathetic and provided them with more information to enable them to adapt and cope earlier. The parents who volunteered to participate in this study might have been looking for an opportunity to share their experiences, or found sharing their story and hearing from others as more helpful than perhaps the people who did not volunteer to take part in this study and therefore it makes it difficult to know how far these findings can be applied to other people.

Carvalho, Freitas, Leuschner and Olson (2014) used the Family Adaptability and Cohesion Evaluation Scales (FACES IV) with 38 married couples with children where one adult in the relationship experienced psychosis. This measure looks into three main areas; flexibility (the expression and quality of roles and leadership within the family), cohesion (the level of emotional closeness between family members) and communication (whether the type of communication in the family is positive or not). The idea behind the model was that if there are extremes (either very high or very low) in levels of cohesion and flexibility and high levels of negative communication this will lead to unhealthy and unbalanced family functioning. They found that 72% of people with psychosis described their families as 'connected or very connected' and 82% of their partners rated their family as 'flexible or very flexible'. However, 34% of those with psychosis identified the communication as negative compared to 66% of their partners. They concluded that the findings suggested that the majority of the families viewed themselves as functioning well, despite one parent experiencing psychosis. Carvalho et al. (2014) noted that the sample size was small and that those who agreed to participate could have been more willing to talk about their experiences due to them being largely positive. Both of these factors might have influenced the findings, however, they did not report on the number of participants approached compared to those who agreed to participate, so it is difficult to conclude the extent to which this might be the case.

In summary, the research has highlighted that families report distress, burden, loss, guilt and anxiety but that it is possible for families to adapt, cope and feel connected to each other (Addington et al., 2003; Barker et al., 2001; Birchwood, 1992; Carvalho et al., 2014; Szmukler, 1996; Martens & Addington, 2001). The following paragraphs will narrow the literature review to consider the prevalence of parents with psychosis before discussing the literature into the impact that growing up with a parent with psychosis.

Prevalence of parents with psychosis

Parenthood is an important life stage for the majority of people and one of the most significant and life changing experiences (Twenge, Campbell & Foster, 2003). It is therefore also an important life stage for people who experience psychosis. However, the number of people who experience psychosis and who are also parents is uncertain. Craig and Bromet (2004) identified that 30% of people whose diagnosis included psychosis were parents at the time of their first admission and Howard, Kumar and Thornicroft (2001) reported 63% of British women who experience psychosis are mothers, compared to 50% of mother's from North America (Seeman, 2002). Women with psychosis were found to be twice as likely as men to be parents. More than half of the fathers and over three quarters of the mothers were living with their children, and most continued to do so after they were discharged. Craig and Bromet (2004) also found that on first admission nearly three-quarters of children were aged 16 and under, and over 40% of mothers had at least one child under the age of five. Meltzer, Gill, Petticrew and Hinds (1995) reported that 1.1% of single parents in the UK experiences psychosis, compared to 0.4% of people raising children in a couple. As a significant number of people with psychosis may be parents, their unusual experiences may have an impact on their children.

Children with parents who experience psychosis

Available research into how children with a parent with psychosis make sense of their experiences tends to focus on the risk of developing psychosis. For example, those who have a parent with psychosis have been recorded to have a 13% chance of developing it themselves, compared to an approximately 0.5% to 1% chance in the general population (Gottesman, 1991). Gottesman reported that this could be due to a genetic predisposition but also to the societal and family pressures experienced when a parent has psychosis. Protective factors identified included having a positive relationship with both parents and a good social network outside of the family (Erlenmeyer-Kimling & Cornblatt, 1987; Schiffman, LaBrie, Carter, Cannon et al., 2002). Walker, Downey and Bergman (1989) reported that when children have a parent with psychosis and suffer from maltreatment, it is this, rather than having a parent with psychosis, which causes the

increased vulnerability. The following sections will review the qualitative research available into the experiences of children growing up with a parent with psychosis.

Mander, Norton and Hoare (1987) reported a case study of an 11 year old girl whose mother experienced psychosis. They concluded that the parent and daughter had developed an over-dependent relationship, with the child wanting to look after her mother and being reluctant to leave her. This had a detrimental effect on the child's school attendance, independence and relationships with peers. They highlighted how there were missed opportunities for health professionals and the school to find out more about the circumstances and to identify if support was needed. Without this the mother struggled to cope and her child was eventually taken into foster care. Whilst it is not possible to generalise the findings from case studies, it does provide us with valuable information about the importance of identifying the needs of children of parents with psychosis and to identify if the family need support. However, as this study was carried out in 1987 service provision will have changed and therefore it is possible that the support available now is different.

Webster (1992) interviewed 22 children aged eight to eighteen who had a mother who experienced psychosis. The Social Behaviour Assessment Schedule (SBAS; Platt, Weyman, Hirsch & Hewett, 1980) was used to assess the level of burden the children and family experienced. She found levels of emotional disturbance and physical problems in seventeen of the children. Using the SBAS, Webster identified family burden and then categorised families into the following subgroups:

- Subgroup one (10 families): well-functioning families where the experiences appeared to have had little adverse effects on the children. The adults were viewed as in charge and the mother displayed low levels of distress.
- Subgroup two (two families): well-functioning single parent families who received support from extended family. The experiences appeared to have had little adverse effects on the children. The adults were viewed as in charge and the mother displayed low levels of distress.
- Subgroup three (three families): fathers presented as long suffering and coped by distancing themselves emotionally from their wives. Mothers appeared to be more distressed by their experiences of psychosis and were less involved in family life. The older children in this group were often left to look after themselves.

- Subgroup four (four families): single parent families who received little support from others and mothers had a higher frequency of involuntary admissions. The children provided care for their mother, themselves and for other siblings.
- Subgroup five (three families): chaotic families where the mother was extremely distressed by her experiences of psychosis and there was poor care of the young children.

As can be seen from the above groups, there is a large variation in the experiences of children growing up with a mother with psychosis. Having support from others, the adults being viewed as in charge and low levels of distress from the mother all appear to be important factors in protecting children from possible adverse effects. Webster identified a 'dawning awareness' stage during which older children spoke about coming to understand their parent's behaviour as stemming from mental health difficulties, rather than their personality or the child being responsible. Participants from this study were recruited from parents with psychosis who attended a clinic for a depot injection. Therefore, the sample has been taken from a population whose mothers were severely affected by her experiences of psychosis and excludes those managing well enough to be on oral medication or no medication. However, it is important to consider how this research offers limited insight into the other possible influential factors, such as the social economic status, environmental factors or support provided and how it offers little insight into the overall lives of those who are deemed well and less so.

Somers (2006) interviewed 20 boys and 17 girls whose age ranged from eight to 16 years. Of these participants, 26 had a mother with a diagnosis of schizophrenia and 11 had a father with this diagnosis. A control match was found for each participant, based on age, gender, type of housing, marital and employment status of parent and resident in the same mental health catchment area. They found similarities between the two groups in the areas of physical health, friends, hobbies, household chores and warmth experienced from their parents. However, they reported that the sample group were aware of the possible stigma from others and expressed feelings of embarrassment and shame. They also reported additional burdens, such as being at home alone, caring for other siblings and caring for their parent. They also expressed sadness and fear about their parent's experiences but only one child reported that they would prefer it if their parent were not living with them. Limitations of this study include the possibility of participants not fully expressing the full impact of living with a parent with unusual experiences. Somers noted that this might be because they fear the consequences if they were to do so, for example some of the participants spoke about their fear of being placed in foster care (and some had been in the past).

Differences in the impact of childhood experiences

After reviewing the literature it would appear that the degree to which having a parent with mental health or physical difficulties impacts on a person can vary greatly (Cummings & Davies, 1994; Lewandowski, 1992; Somers, 2006; Tarullo et al., 1994; Worsham, et al., 1997). The following sections aim to summarise some of the elements which have been suggested to influence how someone might cope with and make sense of difficult life experiences.

Life stage

Lewandowski (1992) noted that how a child makes sense of their parent's illness can be understood in terms of their developmental stage. For example, an older child who has increased cognitive awareness of the implications of their parent's illness might be more affected than a younger child who is less aware of the risks posed. Older children might also be required to carry out more of the practical tasks, such as household chores or caring for younger siblings. Over time, different developmental models have highlighted the different stages we move through and have begun to integrate previous memories and experiences into a new identity, which involves being more aware of one's values, desires and beliefs. For example, Erikson (1968) proposed that if we are able to resolve challenges at each stage then we develop and grow stronger from it, although if we are unable to resolve this challenge it can result in increased vulnerability and personal difficulties. It is useful to consider the different life stages proposed by Erikson and the impact this might have when growing up with a parent with psychosis. For example, if a parent experiences psychosis and they are unable to provide consistent care and this occurs during the first stage of the child's development then this may result in the child mistrusting others and later having some difficulties forming peer relationships. However, it is important that Erikson's stages are used as a description of human development, rather than an explanation of why things happen and that it is not assumed that everyone in the same developmental stage has the same experiences and challenges.

Differences in coping styles

Lazarus and Folkman (1984) suggested that the type of coping style used can influence ability to cope with difficult situations. They proposed two different types of coping style; emotion-focussed and problem-focussed. They reported that people who cope with distressing events by using emotion focussed coping strategies aim to reduce the associated emotions, such as distraction or venting frustrations on others. Those who use problem-focussed coping styles cope with distressing events by targeting the cause

itself, for example seeking information and planning ahead. Lazarus and Folkman (1984) suggested that emotion-focussed coping can be more beneficial when a person has no control over the situation but that problem-focussed coping is more useful when someone has control over the situation. Therefore, a person's perception of the overall controllability over their parent's illness might influence their coping style. For example, Compas, Worsham and Howell (1996) found that children whose parents had been diagnosed with cancer generally identified their parent's illness as out of their control and they found higher levels of emotion-focussed coping techniques, such as 'watching TV to take my mind off it'. Compas et al. (1996) also reported that there were higher levels of anxiety and depression in those who used emotion focussed coping, particularly avoidance. Nelson, Sloper, Charlton and While (1994) looked at the impact of having a parent diagnosed with cancer on children aged between 11 and 14. They observed that when the children used the coping strategies of denial and avoidance they experienced increased levels of anxiety and anger towards their parents. However, Compas et al. (1996) highlighted that these findings were based on semi-structured interviews which could have resulted in participants reporting fewer coping strategies than if they were presented with a self-report questionnaire. These findings are relevant to this research because they can be applied to someone who grew up with a parent with psychosis; for example if during childhood emotion focussed coping techniques were used because the child did not feel that they had much controllability over their parents experiences, this could result in them being more distressed. Therefore, it is possible that high levels of distress might impact on their sense making and ability to cope as a child but also during adulthood, especially if they continue to appraise the situation similarly and use similar coping strategies.

Differences in attachment styles

One influential factor in how children cope with and make sense of situations is the attachment style a child has with their caregiver. If a parent is able to understand the experiences and emotions of their child from the child's perspective, they are more likely to be able to reflect on and cope with the child's emotions. If this occurs, the child is more likely to develop a secure attachment and learn how to express themselves healthily and to effectively regulate their own emotions. However, if the parent is unable to do this, then the child is more likely to develop defences against their own emotions, have difficulty regulating them and develop an insecure attachment (Goldberg, et al., 1995; Holmes, 1993). The type of attachment a child has also impacts on how they make sense of their relationships with others, and it is thought that those who have insecure attachments have more difficulty establishing and maintaining positive relationships

(Howe, 2011). For a child to develop a secure attachment, an infant needs at least one secure attachment figure to act as a secure base which provides security and warmth and is consistently sensitive and responsive (Bowlby, 1988). More recent research has identified that this does not have to be a parent: it could be another person close to the infant (Rhodes, Grossman & Resch, 2000).

Research into parental mental health difficulties and the impact on attachment has mainly focussed on mothers with depression. Martins and Gaffan (2000) conducted a meta-analysis of studies which used the Strange Situation (Ainsworth, 1970) to identify the attachment types of infants with a mother with depression compared to a control group. They concluded that children of mothers who were not depressed were more likely to have a secure attachment, and those with a mother who was depressed were more likely to have insecure attachments. It has been suggested that this may be because the depression the mothers experience affects the quality of the relationship they have with their child. For example, mothers with depression were observed to be more negative towards their child, more intrusive and unsupportive compared to mothers who were not depressed (Field, Healy, Goldstein, & Guthertz, 1990). Other symptoms of depression might also influence interactions with a child, for example apathy, being more withdrawn from activities, increased sleep and being more irritable and aggressive towards others (Beck, 1976; Weissman & Paykel, 1974).

Cummings and Davies (1994) argued that children of mothers with depression can, nevertheless, develop positive qualities which children of non-depressed mothers do not. For example, they may become more sensitive to the emotions and needs of others and develop a strong ability to care for others. Somers (2006) also found that there were no significant differences between the control group and the children of parents diagnosed with schizophrenia in how they described their relationships with their parents.

When considering the longer term consequences of developing an insecure attachment as a child, researchers have found that adults with attachment difficulties are likely to be at greater risk to maladjustment, have difficulties coping with distress, view the social world negatively, be mistrusting of others, be more likely to view themselves negatively and become more distressed at conflict with people they were close to, compared to those who had secure attachments (Bartholomew & Horowitz, 1991; Kobak & Sceery, 1998; Mikulincer & Florian, 1998). It has been proposed that the attachment style we develop as a child is fixed because working models of attachment are likely to repeat themselves as people approach new relationships using the patterns which they have learnt (Douglas & Atwell, 1988). For example, behaving in a defensive way with

new people is likely to increase rejection from others and reinforce the defensive behaviour. However, Hesse (1996) noted that individuals did not always fit with one type of attachment style and at different times they moved between different styles; this is influenced by their experiences of the people they have formed attachments with. For example, longitudinal research into attachment style of married couples has shown that whilst the majority of attachment styles were stable over time, up to 30% of married couples changed attachment style after four years of marriage (Baldwin & Fehr, 1995). Therefore, it is possible that attachment style might change over time. Also, living with an insecure attachment style might not be as black and white as the literature suggests, otherwise a larger proportion of children of parents with mental health difficulties might have gone on to develop significant problems with their relationships and emotion regulation in adulthood (Baldwin & Fehr, 1995).

Attachment style is relevant to this research because it is possible that the experiences of having psychosis might impact on the parent's ability to foster a relationship where a child can develop a secure attachment. Therefore, if a child were to develop an insecure attachment with their parent who experiences psychosis, it is likely to impact on how they make sense of this relationship and their relationships in adulthood.

Self esteem

Self-esteem has been defined as evaluations of self-worth and comparisons to others in a variety of different contexts, for example, work, school, family, peer group and leisure activities (Mruk, 2006). Self-esteem might play an important role in the impact of childhood experiences as these experiences are made sense of and internalised. If a child's parent is accepting of their limitations and strengths and supportive of their child in obtaining high but achievable standards then they are more likely to develop high self-esteem. However, if a parent is unsupportive, inconstant, strict, abusive or rejecting then the child is more likely to develop lower self-esteem (Carr, 2010). High self-esteem has been associated with good adjustment to social, personal, occupational and education changes, as well as the ability to manage stress, be a high achiever and be more likely to be accepted by others. In comparison, those with lower self-esteem are more likely to have difficulties managing stress, have difficulties adjusting to social, personal, occupational and education changes and be more likely to develop mental health problems such as anxiety and depression (Carr, 2010). Self-esteem has been shown to be relatively stable over the course of a person's life, however, if changes occur this is most likely to happen during young adulthood (Huang, 2010). Therefore, if a parent's experiences of psychosis negatively impacts on their interactions with their child then this

can influence the child's development of self-esteem, which in turn can influence how the child feels about themselves and how they manage levels of distress. This might then impact on how they made sense of their experiences as a child and how they make sense of their experiences during adulthood.

Social support

Belonging to a group has always been important for human beings and from an evolutionary perspective belonging to a group increased our likelihood of survival (Dunbar, 1996). Social support can be defined as having a group of people, such a family, friends, co-workers, neighbours or people in the community who we have a valued relationship with and can turn to for support (Siegel, 1993). Having a support network has been linked to increased health and wellbeing, as well as lower levels of stress, anxiety and depression (Dickerson & Zoccola, 2009). It has also been reported to be linked to increased resilience to stressful situations and a decrease in the likelihood of developing mental health difficulties following traumatic life events (Southwick, Vythilingam & Charney, 2005).

A distinction has been made between the different elements of social support:

- How the social network is constructed, for example the size and frequency of contact with this network.
- Emotional support, such as the ability to share one's feelings and to receive empathy and warmth from another.
- Practical support, such as borrowing money from someone or receiving assistance with moving house.

Research has found that it is receiving emotional support from others which is more closely associated with increased wellbeing, although the other elements remain important (Charney, 2004; Dickerson & Zoccola, 2009; Taylor & Friedman, 2007). Gilligan (2000) highlighted how having support from teachers at school can also be an important source of social support which can buffer the effects of difficult parental relationships at home. In summary, if children who grow up with a parent with psychosis have a social network which they can turn to for support, especially emotional support, then this is likely to act as a buffer to stressful life events and help increase their resilience. This in turn will then impact on how they make sense of their experiences during childhood through to adulthood.

Environmental factors

It is important to consider the external factors which might influence a person's ability to cope with life experiences, for example low socioeconomic status, low family income, poor quality of housing and lack of ability to afford food and clothing. All of these factors make it harder for someone to cope with other life experiences, such as having a parent who experiences psychosis (Masten & Gewirtz 2006; Rutter, 1990; Sameroff & Seifer, 1990). It is also possible that having a parent with psychosis might impact on some of these environmental factors, for example this parent being unable to work, resulting in the family having a lower family income. Therefore, environmental factors can influence how a child makes sense of their experiences because of the impact on their ability to cope. It is also possible that these environmental factors are more likely to continue into adulthood, for example the family being unable to financially support them, and therefore these factors continue to impact on their experiences in adulthood.

In summary, there are a number of different factors which might influence how a child makes sense of their experiences which are likely to impact on how they make sense of these experiences in adulthood. The following sections will review the available literature into the experiences of adults who grew up in adverse conditions, and with a parent with mental health difficulties, including psychosis.

Adult experiences

The research into the impact on adults of growing up with a parent with psychosis or specific difficulties, such as depression or physical health problems is limited. However, it was felt that there might be an overlap of the experiences of having grown up in adverse conditions, for example the absence of a parent or their inconsistent care, which would be applicable to this current research and therefore this literature will be reviewed. The literature review will then move to report on the experiences of adults who grew up with a parent with mental health difficulties and adults who grew up with a parent who experienced psychosis.

Adults who grew up in adverse conditions

Much of the research into impact of childhood experiences on adulthood focusses on the childhood experiences of physical and sexual abuse, neglect and parental alcoholism. It has been reported that adults who went through these experiences as children are more vulnerable to developing mental health difficulties themselves, such as depression, anxiety, substance misuse, eating disorders, self-harm and personality disorders (e.g.

Anda, et al., 2014; Kendall-Tackett, 2002; Kessler, et al., 1997; Springer, et al., 2007). However, Horwitz, Widom, McLaughlin and White (2001) highlighted how research into this area often fails to include other aspects of the person's life, such as socio-economic status and social support and attempts to look at the phenomenon in isolation. It is important to highlight how growing up with a parent with psychosis does not mean that the child would automatically be abused or neglected.

Adults who have a parent who experiences mental health difficulties

Pölkki et al. (2005) carried out a thematic analysis of letters written to the Central Federation of Child Welfare on the topic of 'How my life changed after a member of my family became mentally ill'. Included in the analysis were letters from 17 people aged between fifteen and late adulthood (although they do not specify the exact age) who grew up with a father with mental health difficulties (six participants) or a mother who experienced mental health difficulties (eleven participants). Four of the participants were described as continuing to provide care for their parent and their diagnosis included psychosis and severe depression. They found the following themes from their analysis:

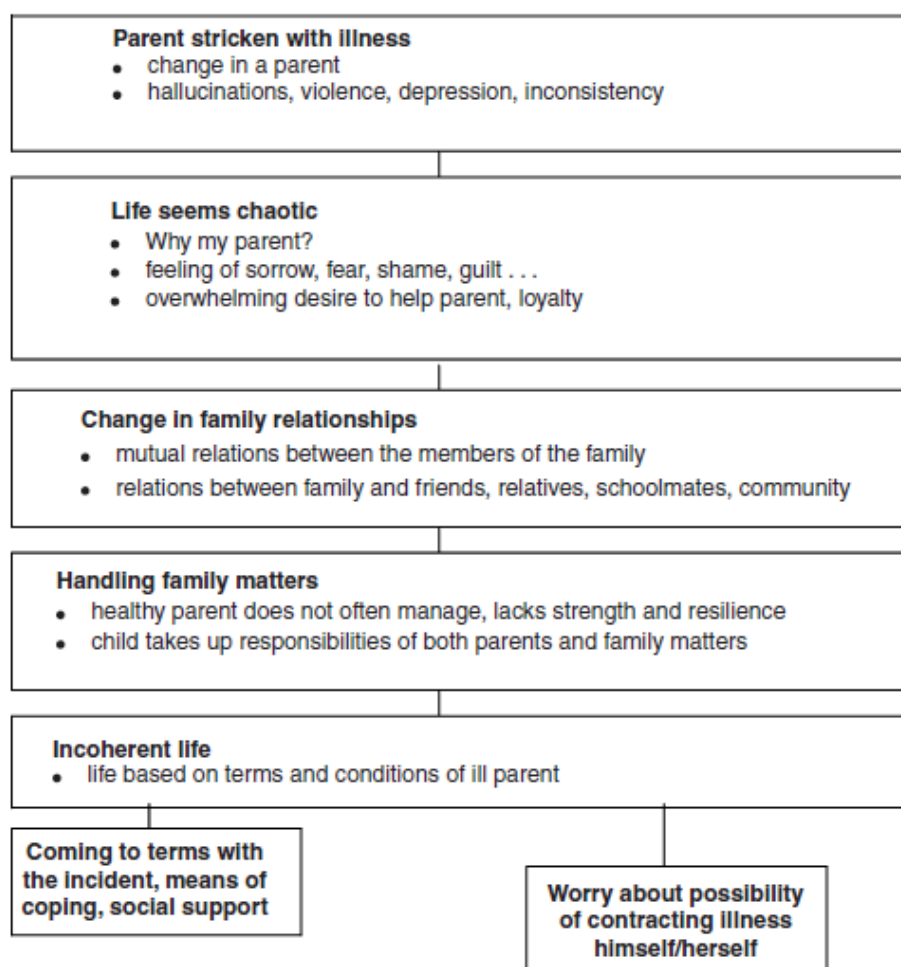


Figure 2. Adult themes developed by Pölkki et al. (2005)

Pölkki et al. suggested that the findings highlighted how some adult children of people with mental health difficulties reported managing to cope through using supports such as teachers at school, friends, their other parent or siblings. However, they also acknowledged that some found this period in their lives more difficult to cope with and developed mental health difficulties themselves. The authors' findings on how these participants made sense of their experiences in adulthood is limited and their data appears to be focussed on participants reflecting back to the impact these experiences had on them during childhood.

Adults who have grown up with a parent who experiences psychosis

The following paragraphs will review the literature into adults' experiences of having grown up with a parent with psychosis and identify the gaps which this research aims to cover.

Dunn (1993) looked into the experiences of nine adults (five women and four men, ranging from the ages of 21 to 41) whose mothers experienced psychosis during their childhood. She advertised the study by putting notices in 'the alliance for the mentally ill', referrals by mental health providers and notices in a newspaper. The participants took part in three semi structured interviews. In the first they were asked about their family history and structure, the treatments their mother and they themselves had received and any other contact with mental health services. In the second interview they were asked questions about their relationship with their mother, other family members and friends during their childhood. They were also asked about their needs as a child and whether or not these had been met. In the final interview they were asked about their current relationship with their family, and in particular their mother, as well as their relationship with mental health providers. They were also given the opportunity to comment on anything which had not been covered. Dunn (1993) used content analysis to identify the following five main themes:

- Abuse and neglect: participants described their mothers as being withdrawn and unable to provide them with emotional and practical support. There were reports of physical abuse, and in one case sexual abuse, from their mother. Participants commented that they had to provide care for siblings and that other people outside the family did not notice what was happening.
- Isolation: participants talked about feeling isolated from their own family, their peers and their communities and feeling different from others. They reflected that

their mother's experiences were not talked about and this left them feeling confused about what was happening.

- Loyalty and guilt: participants reported that whilst their experiences were difficult they felt loyal to their mothers. Dunn linked this to feeling a sense of responsibility to care for their mother but also guilt at wanting to leave.
- Contact with mental health services: participants found their contact with mental health services to be negative, often related to not understanding what was happening when their parent was taken into hospital.
- Social supports: the participants identified one or two people in their lives who they felt were supportive when they were a child. They reflected that it was difficult to be open about their experiences because they felt like they did not belong.

When carrying out the analysis Dunn identified and sorted quotes to match the topics participants were asked about during the interview and within these categories she identified subthemes which were common to all participants. Dunn does not include an interview schedule detailing the questions asked so it is not possible to determine how closed, open or directive the questions were. This is an important factor because if the questions were closed or directive and the themes were developed from these questions, then they will only reflect the questions asked and there would have been little room for new topics and themes to emerge. The recruitment processes might also have resulted in the sample being more likely to have come from people with mental health difficulties themselves, which might mean that the findings come from a sample who needed support to cope with their experiences, or their experiences were more severe. These findings do provide some insight into the experiences of a child whose mother had psychosis. However, the only reference to adult experiences is that all but one participant entered therapy as an adult and one participant experienced psychosis in later life and therefore little is known about how these participants make sense of their experiences in adulthood.

Caton, Cournos, Felix and Wyatt (1998) interviewed 41 people aged 13 to 48 who grew up with a parent with psychosis. They used semi-structured interviews to find out about historical information, such as their living arrangements, the makeup of their family, episodes of abuse, neglect, foster care placements and homelessness. They also asked questions about current occupational status, educational achievement, relationships with family members and peers, physical health, coping skills, contact with mental health services and psychological and social adjustment. They used the DSM-III R structured clinical interview to find out about current psychiatric difficulties. The authors reported

using descriptive statistics to analyse the data. Findings highlighted that participants often had to move house, they felt that their parent was unable to support them and they felt embarrassed and also fearful of their parents' behaviour. Eight participants reported being subjected to physical or sexual abuse (however the authors did not specify where this abuse came from). They noted that only one quarter of participants had been told by a doctor their parents' diagnosis, whereas others would have liked to have the opportunity to talk about their parents difficulties and find out about ways to help them. They found that 11 of the participants identified their parent with psychosis as the most significant adult in their life, compared to 15 who said it was a grandparent. There were 23 participants who had children of their own and eight who said that they had been in violent relationships in the past. The authors found considerable variation in the current mental health of the participants and on average levels of anxiety and depression were within the low range and none had received a diagnosis of schizophrenia. It is important to note where the participants were selected from as they were the children of participants who had taken part in a previous study for people who were at risk of homelessness (Caton, Shrout, Eagle, Opler et al., 1994; Caton, Shrout, Dominguez, Eagle et al., 1995). Therefore, it might be difficult to transfer these findings to other samples because the participants came from a population that were high risk and did not include families which were deemed as coping well. The interview topics, as well as the psychiatric measures used were all designed to measure problems and deficit and therefore the results are biased towards these domains.

Conclusions

Within the literature there is a focus on the negative outcomes and consequences of growing up with a parent with psychosis, mental health difficulties, physical illness and adverse conditions. Interestingly, the research looking into how adults made sense of their experiences of growing up with a parent with psychosis mainly focusses on the impact during childhood and the only reference to adulthood is whether they themselves have developed mental health difficulties. Within the wider literature, there is an emphasis on the increased risk of developing psychological and relationship difficulties during childhood through to adulthood and an abundance of research has been carried out to support this (Beardslee et al., 1987; Cox et al., 1987; Cummings et al., 1990; Cummings et al., 1994; Downey et al., 1990; Hirsch et al., 1989; Rutter et al., 1984; 1985; Weissman, et al., 1984; Welsh-Allis et al., 1988). However, as Morss (2002) argued '*every life is different from every other*' (Morss 2002, p.2) and the approaches used for collecting evidence to support well-established theories have been questioned. For example, it is possible that there is a diverse range of different experiences amongst

individuals who grew up with a parent with mental health difficulties, but as the research generally focusses on the negative consequences, this generates more research, and therefore more evidence, in this area.

“Psychology is not just the study of disease, weakness and damage; it also is the study of strength and virtue” (Seligman, 2002, p4).

I believe that this quote highlights how the focus of research and intervention is based on the medical model of disease and concentrates on a person’s weaknesses and how to fix them, rather than focussing on their strengths and how to build upon them. Seligman also highlighted the failure of studies to identify the longitudinal context to ascertain how people’s strengths can grow, or what prevents them from doing so. Chadwick (1997) argued that psychosis can clearly cause distress for the person and their family but if the focus is solely on the negative consequences of the experiences, we are less likely to have the courage and hope to use our strengths to continue with our journey and overcome our difficulties.

Therefore, this study aims to give voice to adults who grew up with a parent who experienced psychosis, to encourage them to tell us what it was like, how they made sense of these experiences as a child and how they make sense of them as an adult. If participants are given the opportunity to speak openly it might allow for a broader perspective to be presented, rather than focussing solely on the negative aspects of their experiences. It is hoped that this more balanced viewpoint might encourage people to consider an individual’s experiences, rather than the dominant negative narrative. The findings might also help identify the needs of children and adults who have a parent with psychosis and to also identify how to support the parent with unusual experiences to reduce the likelihood of adverse impact. The aims of the study are to find out:

- What sense did people make of growing up with a parent who had psychosis or unusual experiences when they were a child?
- What sense is made of these experiences in adulthood?
- How has going through these experiences impacted on them now?

Chapter two: Method

Interpretative phenomenological analysis (IPA) was chosen as the methodological approach for this study. A qualitative method was selected because it provides the opportunity to uncover a detailed and rich account of people's experiences which are led by the participants (Lyons & Coyle, 2007). In the following paragraphs different methodological approaches are considered before moving on to a discussion of why IPA was selected. The second half of this chapter outlines the design, procedure and ethical considerations before finally describing the analysis stage.

Alternative methods considered

Discourse analysis (Potter & Wetherell, 1987), focusses on how people talk about their experiences and on the function of the language used. It had been suggested that the language people use changes depending on what context they are in and that the surrounding context and language environment can impact on how they talk about an experience (Georgaca & Avdi, 2012). However, this research aims to look underneath the language used in an attempt to develop an understanding of what sense people have made of their experiences. Discourse analysis does not attempt to understand how people make sense of their experiences and therefore was not chosen as the methodology.

Grounded theory (Glaser & Strauss, 1967b) aims to create a theoretical understanding of a given phenomenon in order to explain what impacts upon and influences that phenomenon in the wider population (Tweed & Charmaz, 2012). However, the aim of this research is to develop an insight into how people make sense of growing up with a parent with psychosis. It is not concerned with creating theory to explain why people might feel or behave in a certain way after growing up with a parent with psychosis and therefore grounded theory was not chosen.

The purpose of IPA is to gain as much of an 'insider perspective' (Conrad, 1987, as cited in Smith, 1996) as possible on how people understand and make sense of their experiences. However, Smith (1996) also acknowledges that when using IPA one will never be able to fully understand another's experiences as we are influenced by our own beliefs, values and past experiences. IPA is based on the theoretical approaches of Phenomenology, Hermeneutics and Idiography, which will each be discussed in the following paragraphs.

Phenomenology is based on trying to understand human experience; what is important to us and how we come to understand these experiences. The ideas were first

introduced by Husserl (1927, cited in Smith, Flowers & Larkin, 2009) who noted how easily humans neglect to pay attention to their experiences and highlighted the importance of reflecting on them. He commented on our tendency to examine events based on our own experiences, rather than for what they really are. He emphasised the importance of 'bracketing,' or separating our prior assumptions, beliefs, values, preoccupations etc. from those whose experiences we are trying to understand. However, Husserl also noted that it is not possible to entirely put aside one's previous assumptions, beliefs and values but that the more consciously aware we are of them and the more we reflect on how this might influence our understanding of another, the more likely we are to get to the core of another's experience. Heidegger (1962, cited in Smith et al., 2009) postulated that all experiences are subjective and that we always relate to the world based on our current context. Our experiences are always in relation to something else and are not solely confined to the person. Sartre (1948, cited in Smith et al., 2009) suggested that our sense of self develops over time and how this is a continuous journey. He also highlighted that it is not only the things which are present in our life which affect us, but also the absence of experiences. This concept is potentially relevant to the current research, as participants might experience their relationship with their parental figure as different from their peers, resulting in them feeling like they are missing something.

Hermeneutics is the theory of interpretation: it has a much longer history than phenomenology as it dates back to attempts to try to make sense of religious writings (Smith et al., 2009). Schleiermacher (1998, cited in Smith et al., 2009) highlighted that when listening to people talk about their experiences it is possible to understand them more holistically than the person understands them themselves. However, whilst IPA would not attempt to make these kinds of claims, Schleiermacher makes a valid point in that it is important to look more deeply than just the actual words used by the story teller. Therefore, in this research it was important to note the way in which participants spoke about their experiences, such as the words or metaphors they used, their tone of voice and the potential significance of pauses or incomplete sentences.

Idiography is based on an attempt to firstly understand a person's experience, before moving on to draw parallels in others. IPA attempts to understand a particular experience which is important to an individual from an in-depth and detailed perspective (Smith et al., 2009).

It was decided that IPA (Smith, 1996) would be used in this research because of its focus on how people make sense of significant events in their life. IPA stipulates that it is important for the sample to be homogeneous and for the participants to have lived

experiences of the phenomenon being studied; this allows for individual and shared sense making for experiences that are common between participants. Whilst sample sizes in IPA studies are small, findings from the analysis are rich and detailed. They allow for ‘theoretical transferability’ (Smith, 2009) which enables links to be made between the study, existing reports in the literature and a person’s experience. The results can also build upon other findings from qualitative studies, allowing for a more comprehensive picture to be built up.

Design

The following sections will outline the design for this research, including the sample, recruitment process, the procedure, ethical considerations and the analysis stage. Finally, I build upon the reflexivity statement provided in the introduction chapter to allow the reader to see how my thoughts and beliefs have developed.

This research was designed to explore participants’ experiences of having grown up with a parent with psychosis or unusual experiences. Five participants aged between 19 and 58 attended two semi-structured interviews spaced one week apart. The interviews from this research were transcribed verbatim and were then analysed using IPA to in order develop themes. Individual analysis was carried out initially, before moving onto developing major and subordinate group themes.

Participants

Smith et al., (2009) recommend interviewing between four to ten participants for a doctoral thesis: this was therefore the aim for the current thesis.

The inclusion criteria for participants were as follows:

- Aged 18 years old or over.
- As a child, lived with, or had regular contact with, a parent with psychosis, or who had unusual experiences. These experiences were determined using a screening questionnaire developed by myself and my supervisors, drawing from the Positive and Negative Syndrome Scale (PANSS) for schizophrenia (Kay, Fiszbein, & Opfer, 1987; see appendix 1).
- Not currently living with the parent who experienced psychosis.
- Does not have any children of their own.

The exclusion criteria for participants were as follows:

- Under 18 years of age.
- Currently living with the parent with psychosis.
- Has children of their own.
- Currently being supported by an NHS mental health team.

Smith et al. (2009) argued that the more homogenous the group's experiences, the deeper the understanding of those experiences. Initially I aimed to interview people who were between the ages of 18-25 because this has been identified as the stage of 'emerging adulthood', when a young person is moving from adolescence to adulthood (Arnett, 2000). This age range was chosen because older participants would have had more time to process their experiences and this might influence how they make sense of childhood experiences as a young adult (McAdams, 2001). However, as there were difficulties with recruiting enough participants from this age range then this inclusion criterion was changed to anyone over 18 years old. It was felt that whilst the number of years since participants grew up with a parent with psychosis might result in different sense making, the main focus of homogeneity for IPA is the experience being examined.

It was felt that the experiences of either continuing to live with their parent with psychosis or a participant having a child of their own might significantly alter their sense making and therefore this was made an exclusion criteria. It is possible that talking about their experiences of growing up with a parent with psychosis might have caused people high levels of distress. Therefore, currently being supported by an NHS mental health team was added to the exclusion criteria because it was felt that the interview might contribute to already high levels of distress. It was acknowledged that people experiencing distress might have still been interviewed.

Consultation

I attended the 'Everybody's Voice' service user and carers' group run by the Clinical Psychology Doctoral programme at the University twice in order to share and receive feedback on the information sheet, consent form, poster and interview schedule. I also received feedback from a group of six university students who were approached through a friend. They provided me with feedback on the language used so that it would be less clinical and more personal. They also provided feedback on how to make the poster more appealing so that people might be more likely to make contact with me.

Recruitment

Recruitment began in July 2015 and continued through to January 2016. A recruitment stand in the Students' Union at the University was held for two days during September 2015. This involved the display of posters advertising the research (see appendix 2), information sheets with details of the research being made available (see appendix 3) and the opportunity for informal conversations with me.

Posters indicating the aims of the research and detailing the inclusion criteria were placed on poster boards around the university in The Students' Union, the health centre, various academic buildings and libraries. However, as previously mentioned, initially I had difficulty recruiting enough participants and therefore, an amendment was made to the inclusion criteria and posters were placed in the following areas:

- A carer's service that provides support and organised activities for those, aged 16 and upwards, who care for another person.
- Mind: an organisation providing support and activities for people with mental health difficulties. It was felt that this would be appropriate, despite the criteria for not including those currently being supported by NHS mental health services, as a wide variety of people access the service.

Details of the study were posted on the websites of the following places:

- A charity which provides support services and also represents voluntary organisations and opportunities across Leeds.
- The University Psychology Department's internal website. An email was also sent to a list of people who have signed up to participate in research.

I approached other venues, such as community centres, supermarkets, gyms and voluntary organisations but they either did not reply, did not have poster boards for the posters to be placed, or did not wish to advertise the study.

The posters invited those interested in discussing participation in the research project to make contact via email or telephone. Once contact had been made, participants were emailed the information sheet with further details of the study and asked to make contact again if they wished to discuss it further. All participants made contact via email and an initial telephone conversation was then arranged during which I asked them questions relating to the inclusion and exclusion criteria to ascertain if their current and past

experiences were eligible or not. If I did not hear back from them within two weeks I made one further attempt to contact them via email.

Final sample

Five participants were recruited; Mary, Peter, Rosie and Amanda responded to posters they saw within the university grounds. Richard saw the advert on the website representing voluntary organisations. The following paragraph details potential participants who made contact but did not participate in the research:

- One potential participant showed an interest in the research at the recruitment stand at the university students union. However, after receiving the information sheet and thinking about it they decided that they did not want to participate. This was based on feeling disrespectful to their parents if they spoke about their experiences and being concerned about how their parent's unusual experiences would be perceived by others.
- Another potential participant made contact after seeing a poster at the university. However, they explained that their parent who experienced psychosis died whilst they were very young and therefore they had not had much contact with them or have many memories of them. It was therefore agreed that they did not meet the inclusion criteria of having had regular contact with their parent during childhood.
- Three further potential participants made contact after the recruitment phase was complete: it was therefore not possible to include them in the research and it is not known if they met the inclusion criteria.

Further details of their experiences will be presented in the pen portraits section of the results chapter. Below is a table detailing the demographics of the participants.

Table 1. Participant demographics.

Pseudonym	Age	Has a partner?	Ethnicity	Studied at university?	Parent who experienced psychosis	Identified having unusual experiences themselves?
Mary	23	No	White non-British	Yes	Mother	No
Peter	19	No	White British	Yes	Mother	No
Richard	49	No	White British	No	Mother	No
Rosie	58	Yes	White British	Yes	Father	Yes
Amanda	25	Yes	White British	Yes	Both parents	Yes

Procedure

Pilot interview

A pilot interview was carried out with a Psychologist in Clinical Training colleague who did not have any experience of growing up with a parent who experienced psychosis but role played as a participant. Through this process it was identified that having a list of questions to ask the participant restricted the flow of the interview. Hollway and Jefferson (2000) suggested that taking a more narrative approach to the interview process, such as allowing the structure of an interview to change and develop, can encourage participants to tell more of their story, unlike a traditional question and answer interview. They highlighted the importance of the types of questions we ask when trying to elicit stories from people. They suggested that it is important to avoid questions which begin with ‘why’, as this results in the participants providing an intellectualised answer. They also spoke about the importance of following the interviewee’s own words and phrasing in order to encourage further stories to be told. I therefore developed a topic guide and tailored it to avoid asking ‘why’ questions. This included a list of areas to cover

and prompting questions would allow me to gain more in-depth and participant specific information. I hoped this would allow participants to be open and for the interview to be as led by the participants as much as possible, whilst also encouraging them to consider the positive and negative aspects of their experiences. I hoped that this would allow participants to tell the whole story and provide a more balanced view than is currently in the literature.

Final interviews

Once participants had agreed to take part, they were invited to attend two face-to-face semi-structured interviews. Semi-structured interviews were chosen because they allow the participant to speak and reflect openly and freely. This approach increases the likelihood of collecting the in-depth and rich data needed for IPA, as it allows some focus on the topic but also enables the participants to introduce themes and experiences of their own (Smith et al., 1999). Having two interviews was chosen because it has been identified as having a positive impact on the interview process and allows for a greater depth of data (Macran, Stiles & Smith, 1999). Hollway and Jefferson (2000) suggested that this may be because the interviewer is able to listen to the first interview and reflect themes back to the participant during the second interview, as well as following up on areas previously discussed. This allows the interviewee to have an experience of being heard and listened to which enables trust to develop. They found that people were able to engage in the process of telling stories and built upon them through feeling safe and listened to in the researcher/ interviewee relationship. An interview schedule was developed for both interviews in collaboration with supervisors and guidance from IPA literature (e.g. Smith et al., 1999). The first interview schedule provided prompts for participants to reflect on their awareness of their parent's unusual experiences as a child, their experiences and memories, and what sense they make of these experiences now (see appendix 4). The second interview schedule encouraged participants to reflect on the first interview and to consider what it had been like talking about their experiences (see appendix 5).

Interviews took place at the University and were carried out with a one week interval between the first and second interview. The first interview lasted between approximately 75 to 90 minutes and the second ranged from 30 to 90 minutes. The interviews were recorded using an audio voice recorder. After the first interview, I noted down my reflections and subsequently listened to the audio recording of the first interview before holding the second interview. This enabled me to identify areas which had been missed or which would benefit from following up. I transcribed both interviews

from participant one and the rest were transcribed by a university approved transcriber who signed a confidentiality agreement (see appendix 6).

Ethical considerations

Ethical approval

Ethical approval for this research to take place was granted by the School of Medicine Research Ethics Committee at the University of Leeds on July 29th 2015 (see appendix 7), after some minor amendments were made to the information sheet, contact details for further support, poster and consent form. An ethics amendment to change the age range and to advertise the research outside the university and within the local community was approved on November 13th 2015 (see appendix 8).

Wellbeing of participants and researcher

Participants

Some participants might have found it beneficial and interesting to talk through their experiences. However, some participants might have found that talking through their experiences brought up painful memories or emotions, or they might have become conscious of personal distress of which they were not previously aware. If participants were observed to become highly distressed during the interview it was planned that it would be suggested to them that we have a break and then see if they wished to end the interview. They would have been advised to contact either a close family member or friend, or their GP. However, this did not occur during the research. All participants were given an information sheet with details of where they could receive further support subsequent to the interview (see appendix 9). They also had the opportunity to discuss their experience of the interview process immediately after it had finished.

Researcher

I was mindful that I was potentially being exposed to distressing information from participants and that it was important to consider my own wellbeing during the research. Also, as I have personal experience of relatives with mental health difficulties, it was possible that what I heard might impact on me personally. One of my supervisors was always available for me to contact whilst I was interviewing in case I should have any concerns about the participants or myself. I also used supervision to reflect on the impact the research was having on me personally. Prior to the research beginning it was also agreed with my supervisors that if they were concerned about me then they would raise this with me.

Consent

Before consenting to take part in the research, participants had an opportunity to read the information sheet (see appendix 3) and discuss it in further detail over the telephone or via email if they wished. Before the interview began, participants were asked to sign two copies of the consent form, one of which was kept by me and the other they took with them (see appendix 10). At the end of the interview, participants were asked if they continued to give their consent and also if there were any topics which they felt uncomfortable about being included in the research. If there were any such topics, then an agreement would have been made about the use or omission of data. All participants, however, agreed to have all of their interview material included in the research.

Confidentiality

Participants were informed that their involvement in the research would be anonymous unless there was a concern about any risk to themselves or others. This was discussed with them prior to the interview beginning and also documented in the information sheet and consent form. However, the process of breaking anonymity due to concern about risk was not needed with any of the participants. A university approved transcriber signed a confidentiality agreement in order to transcribe four of the interviews (see appendix 6). The audio recordings were transferred to the university's secure server and deleted from the audio recorder. The audio files will be deleted once the research is complete (September 2016). Participants were informed that direct quotes from their interviews would be used but any personally identifiable information would not be disclosed.

Withdrawal from research

Due to the sensitive nature of the topics being discussed, participants were informed that they could stop the interview at any point and withdraw from the research. At the end of the interview participants were asked if there were any aspects which they would like to withdraw consent. No participants asked for any part of their interview to be withdrawn. Participants were also informed that if they changed their mind they had one week in which to withdraw their information, although none did.

Token of gratitude

Participants received a £20 Amazon gift voucher at the start of the first interview. This was not advertised on the posters due to the possibility of it influencing the reasons for participation. The information about this token of gratitude was contained within the

information sheet for participants to see after they had made contact about the study. Amazon was chosen because of the wide range of available products, hopefully appealing to a variety of people. The amount of £20 was chosen as it was felt less would have been insufficient to buy something of worth: this amount would allow participants to purchase items such as books or DVDs. Alternative tokens of gratitude were considered, such as an option of donating to a charity, however, it was felt that this would put pressure on participants to have to take this option, rather than receive a token of gratitude for themselves.

Analysis

For each participant, I carried out an individual analysis using the guidelines provided by Smith et al., (2009). The steps undertaken are outlined below:

- I began the analysis phase by listening to the audio recording again and making notes on my initial reflections.
- I then moved on to reading through the transcript and becoming accustomed to the information.
- Following this, I read through the transcript twice more and made notes in the right hand margin. I used different coloured pens to identify the following areas:
 - Descriptive comments; to identify any sentences or phrases which stood out or seemed important.
 - Linguistic; to highlight any language used which seemed significant or might have further meaning.
 - Perceptual; to make interpretations from what the participant had said.
- Once this had been completed, I wrote out the participant's story in order to help familiarise myself with the participant and gain an overall sense of their experiences.
- Following this, I used the left hand margin to write themes identified as emerging from the first stage of analysis. The titles of these themes aimed to include more psychological language in order to move from what had been said towards the incorporation of psychological theory. This process was continued throughout the data set.
- Initially, once this had been completed, the themes were all collected, written on post-it notes and moved around so that connections between them could be identified. Morse (2008) emphasised the importance of ensuring that the themes developed are themes and not categories. She described a category as a 'collection of similar data sorted into the same place' which might only occur at

certain times during the data, compared to a theme which is ‘a meaningful essence that runs through the data’. I noticed that after the first stage of my analysis the themes which were developing resembled categories and therefore were not reflective of the essence of participants’ experiences. Following this, I changed the process so that after completion of the left hand side analysis, I began writing down my thoughts from the process, noting any emerging themes and adding illustrative quotes.

- I then went back to the transcript, reading through the themes which had been identified and adapting the theme names accordingly, thus ensuring that I had covered all the areas previously highlighted.
- I then shared and discussed my initial themes, illustrative quotes and transcripts with my supervisors. This enabled the themes to develop further as by discussing them and talking aloud about them the final themes became clearer.

I carried out this process with each participant’s transcripts. After the analysis of the second participant’s transcripts, I also began a document detailing my reflections on the similarities and differences between the participants. I subsequently built upon this once I had completed the analysis for each participant. This document was also discussed with my supervisors to help develop clarity about emerging themes. See appendix 11. for an example of a transcript after analysis.

Once this process had been completed for all participants, I began the group analysis, attempting to highlight the connections between the participants to create the major themes. I used the following process:

- I printed out each participant’s themes and illustrative quotes and separated them. I then used these separated items to try to place similar themes together. However, I found that, similar to my previous experiences, I began categorising the themes again and the connections therefore lacked depth.
- In an attempt to connect to the themes of the participants’ experiences I audio recorded myself talking about the similarities and differences whilst looking through the themes and illustrative quotes. I found listening back to this helpful in making sense of the connections and differences between the participants’ themes.
- I then used this audio recording to add more meaning to the themes which were emerging and from this I was able to build the major and subordinate themes.
- I created a map of the themes and a table to identify which participants experienced which subordinate themes and which did not.

- During the process, I discussed the themes and illustrative quotes several times with my supervisors which enabled them to develop further.

Creditability and Reliability

Qualitative research has been criticised for the possibility that the researchers' interpretation of the data might be subjective, their beliefs and experiences possibly influencing the outcome (Lyons & Coyle, 2007). Elliott, Fischer and Rennie (1999) wrote about the importance of '*owning one's perspective*' (p.221) when carrying out qualitative research in order for the reader to learn about the researcher's own beliefs, values and experiences related to the topic being studied. This then enables the reader to consider how the researcher's assumptions influence the findings and allows them to consider alternative explanations. During this research I wrote in a reflective diary and have included reflective statements throughout this document. I hope that these reflections will allow the reader to understand my perspective on the topic and for them to consider whether this has influenced the findings from this research. Elliott, Fischer and Rennie (1999) also highlighted the importance of providing detailed information about the participants and providing extracts from interviews in order for the reader to consider the link between the findings and the data. The pen portraits outlined in the results chapter aim to provide insight into the personal experiences of each participant. The extracts from the interviews throughout the results and discussion chapters aim to demonstrate the link between the findings and the data. It is also important to ensure that the themes developed are valid and credible. The following steps were taken to increase credibility:

- My academic supervisor read sections of one of my transcripts to ensure that she could see the themes which were emerging from my analysis.
- After the initial stages of each analysis were complete, I discussed each participant's story with my supervisors. With reference to the illustrative quotes, together we examined the emerging themes to ensure they resonated with us all.
- Before the group analysis, I discussed my initial thoughts with both of my supervisors and reflected on the themes which I had identified thus far.
- On several occasions during the group analysis stage, I discussed with my supervisors the themes which were emerging and the illustrative quotes. We reflected on the similarities and differences between the participants in order to build on the major and subordinate themes.

Reflexivity

The following paragraphs will outline my personal experiences related to this area of research and reflections on some of my values and assumptions. I have also kept a research diary to capture my thoughts and feelings along this journey and throughout this thesis I will provide a summary when appropriate.

At the start of this research I felt that the impact of having someone with mental health difficulties within a family always had a negative impact and caused a great deal of distress within a family. Whilst carrying out the literature review I initially agreed with the findings of the negative consequences and this research strengthened my beliefs. However, as my understanding of research developed I learnt to critique the literature and I began to see the story as one sided. I began to reflect on the aspects of my identity which I value and which might not have developed had I not grown up with family members with mental health difficulties; for example, being caring towards others and attuned to their thoughts and feelings. It brought to my attention mine and society's natural inclination to focus on the negative consequences and how this might prevent research from considering alternative perspectives of people's experiences. Therefore, when developing the interview topic guide I felt it important to include prompts to encourage thinking about the positive as well as negative aspects of participants' experiences. However, it was also important to ensure that I did not dismiss the more difficult experiences which participants might have wanted to talk about. I also felt that reflecting on what I had gained from my experiences was positive for me and I might be at risk of trying to encourage participants to go through a similar process as me. To manage this it was important that I was aware of my own perceptions and during the interviews monitor how I reacted to the stories which I heard. I found it helpful to listen back to the audio recordings and discuss the interview with my supervisors before the second interview. For example, on listening back to the interview with Amanda I noticed that at times I had avoided asking questions about how she was feeling. I reflected that this stemmed from our telephone conversation where she spoke about feeling anxious that she would become overwhelmed with emotions and therefore I had avoided topics which might cause her distress without realising at the time. I wrote my thoughts and reflections from each interview in my research diary to help inform my analysis and sense making.

Chapter three: Results

The following chapter will provide a summary of my interpretative phenomenological analysis of people's experiences of growing up with a parent with psychosis. Firstly, in the pen portraits section I will describe each participant, their experiences of growing up with a parent with psychosis and significant points about the interview process. I will then provide a diagrammatic representation of the major and subordinate themes, followed by details of each theme and extracts from transcripts. Lastly, I will provide my reflections on this process.

Pen Portraits

Mary

Mary comes from a white middle class family and upholding an appropriate image to reflect this status was important in her community whilst she was growing up. Her parents lived together with Mary and her younger sister until they separated when Mary was 10. She then continued to live with her mother and sister until her father gained custody of both children: they moved to live with their father when Mary was 17. Mary values being independent and she recently moved to university from abroad to study for a master's degree; before this she completed her undergraduate degree in another country. She has limited contact with her family.

Mary's mother had unusual experiences whilst Mary was growing up. Mary said that she was never told of a diagnosis but her mother had two admissions to psychiatric hospitals when she was in her late teens. She described her mother as often being suspicious and anxious. For example, she thought that someone was trying to harm the family and someone was watching her through the television. Mary provided a significant amount of emotional and practical support for her mother after her father moved out, such as reassuring her when she was feeling anxious and encouraging her to pay the bills. She described herself as her mother's caregiver but she appeared exhausted from this role and angry towards her mother. Mary's sister also relied on her for support and would go to Mary when she was concerned about their mother. Mary was in a five year relationship after she moved away to university which was based on her providing care for her partner and Mary felt this care was not reciprocated. It seems that this has added towards her need for independence which appears to be based on not trusting other people to look after her. She also spoke about how she finds it hard to ask others for help because of her past experiences.

Mary came across as confident when she spoke about her experiences, however she talked quickly throughout the interviews. This appeared to be because she had not had

much opportunity to talk about her experiences and did not want to miss anything out, rather than because she was highly anxious. I was surprised that Mary never mentioned feeling angry towards her father for leaving the family as I felt angry towards him for abandoning them. She spoke about feeling grateful that he did help them in the end which left me feeling confused. I was also confused by Mary's relationship with the people in her community and how on the one hand she appeared to be angry towards them for *'keeping things hush hush'* but she also spoke about how grateful she was for what they did do. I noted that all the hurt and anger about what she had to endure appears to be targeted towards her mother, which leaves her with little sympathy for her mother.

Peter

Peter described his family as coming from a white middle class background. His father left the family when he was a baby and he lived with his mother, an older brother and two older sisters until he was seven, when social services became involved and he and his siblings moved in with their father. Peter also has four other siblings from his father, although he does not have contact with them. When Peter was 12 he decided to move back in with his mother on his own. He said he has always had difficulties sleeping but when he was about 12 this became significantly worse and his symptoms are similar to non-24 sleep wake syndrome. This lack of sleep impacted on his ability to attend school, which resulted in his staying at home and missing a few years of secondary school. He described spending this time largely in his bedroom on his own. He lost contact with his friends from school, but made friends with people online. Peter managed to achieve GCSEs and afterwards attended sixth form. He continued to live on his own with his mother until he recently started university to begin an undergraduate degree. He described himself as a self-made person which appears to be important to Peter because he is proud of what he has managed to achieve and how successful he is now. He has recently legally changed his name to the name he uses with his online friends. He said that this change reflects the identity which he has developed himself.

Peter's mother was diagnosed with schizophrenia when he was about seven. He said that she had unusual experiences, believing that others were trying to harm the family and hearing voices, which she found very distressing. Peter's mother was also superstitious, for example if he had a bad dream she would worry that this dream would become true. Peter provided support for his mother, such as reassurance when she was distressed or trying to help her see an alternative view to her experiences. Peter had lost contact with his father until recently. He said that his mother would have been paranoid about why he was meeting his father and therefore it was easier not to make contact with him. As Peter is the only one of his siblings to live with his mother for any extended

period, he feels a sense of responsibility to look after her and she continues to turn to him for support.

During the first interview Peter spoke quickly and moved quickly between different topics. He appeared to be anxious and struggled to make eye contact which he later said is something he has always had difficulties with. At times he reported finding it difficult to know what he was feeling and felt more comfortable answering questions which I asked him. During the second interview we spoke about how he had jumped between different topics. He said he thought this was because he had been trying to make sense of his experiences during the interview. In the second interview, Peter reported that after speaking about his experiences in the first interview, his memories seemed to be more ordered. I felt sad when Peter spoke about the years he spent isolated at home and that no one tried to change things for him. I also found myself wanting to challenge Peter when he blamed himself for the difficulties he had whilst he was growing up, such as the sleeping problems and not attending school as it was hard to hear him take full responsibility for everything. I was pleased when Peter said that because his experience of talking about his mother in the first interview was not as difficult as he had anticipated. He reported that between our interviews he had developed the courage to speak to one of his friends about his experiences and that this went well and is something he plans to try and do more of. Peter also reflected that through talking about his life in the interview he recognised that he is currently over-socialising. He said that this is because he is afraid that he might revert back to the isolated, lonely person he was in the past and how he needs to find a balance in the future.

Richard

When Richard was growing up he lived with his mother, father and older sister. The family were financially poor and there was insufficient money for new clothes, TV or new toys. He described the family as coming from a working class background, which was in contrast to the white middle class community around him. His father was in work and his mother had a succession of jobs such as cleaning, but he described her as being unreliable and the jobs not lasting. His parents have now both died and his contact with his sister is limited. He described himself as a solitary person who is content in his own company which he believes stems from spending a lot of time alone as a child.

It was Richard's mother who had experienced psychosis whilst he was growing up. When he was in his early twenties he found out from his sister that she had been diagnosed with schizophrenia. He described feeling unloved by her and did not recall any affection from her. She was also unpredictable; she could become aggressive and violent towards his father, or she would be absent from the home for hours at a time. Richard's

mother died as a consequence of an accident in hospital when he was 12 years old. Richard spoke about how after she died her friends told him that she had really loved him and I felt sad at how confused this left Richard. They also told him how different she had been before he was born and I felt frustrated they had told him this after she died because Richard was left with lots of unanswered questions and feeling like it might have been as a result of his birth.

When we spoke on the phone before the first interview, Richard was reluctant to meet twice as he was concerned that he could not remember many details and would therefore not have much to talk about. However, during the first interview he gave detailed answers and at the end he agreed to meet for the second interview. Richard found it difficult to make eye contact but as this did not change over the course of the interviews I wondered if this was something which he always struggled with, rather than based on the anxiety of the interview. During the second interview I noticed that we often covered the same stories several times over, which left me feeling frustrated at times. I felt sad when Richard described his childhood and how cold his mother was towards him. I also found myself feeling sorry for Richard when he spoke about how he was surprised he had not married and had children because other people see him as '*unconventional*'. I also noted that Richard appeared reluctant to end the second interview and began speaking more about the loss of his mother. I wondered whether this was due to not having told anyone about his experiences before, or whether the increased reference to his mother's death was symbolic of our relationship ending. I found myself torn between wanting to continue the interview because our relationship appeared to be providing him with some form of care which he was lacking, but also knowing that the interview should end because this was not my role. At the end of the second interview Richard reflected that he said that he found it interesting and absorbing to talk about his experiences and as a result of the interviews he wants to find out more information about his mother. He reported not previously having talked to his sister about their experiences in much detail. However, he now plans to because she might be able to provide him with some information to help him make sense of his experiences.

Rosie

Rosie grew up living with her mother, father and her younger sister, seven years her junior. She described having a good relationship with her parents when she was younger and living in a middle class family. When Rosie was about 17 years old, her mother left the family, taking Rosie's sister with her and moving in with a man with whom she had been having an affair. Rosie was told by her mother that it would be better if she stayed living with her father because it was near the school where she was

completing her A Levels. Whilst in her early twenties, Rosie experienced two episodes of psychosis herself and was admitted to hospital. She currently lives with her husband in a white middle class rural community. Rosie reported that her husband is similar to her, having also grown up with '*social problems*' within his family and therefore they have an understanding of each other's difficulties.

Rosie's father experienced two episodes of psychosis, the first coinciding with Rosie's younger sister being born and the second occurring about five years later. She described him as becoming paranoid that others were spying on him and that he and the family were at risk of being harmed. He was a policeman, which Rosie described as a valuable job to have because it was well thought of in their community. Her father's first episode of psychosis resulted in his losing his job and their family home. Rosie had to move away from school and her friends and felt isolated, as well as having increased responsibility to look after her younger sister. Her father does not now live nearby and her contact with him is through letters and telephone conversations. This appears to add to her concerns about him as she knows very little about his current life and is often worried about him and how he is coping. Since her own experiences of psychosis Rosie feels more connected with her father, as she understands what he has been through: this is, however, also an isolating factor for her. She no longer has contact with her mother and sister and Rosie believes this to be related to her own unusual experiences, as they do not want to be reminded of the difficult time they had with her father. There is also a strong narrative of a genetic link of psychosis within her family and a lack of control over inheriting these experiences.

During both interviews Rosie talked openly and freely about her experiences and did not need much prompting which I felt was related to not previously having had the opportunity to talk about her experiences. She became upset when talking about how worried she is about her father and also about how distant she feels from her other family members. I felt sad when she spoke about how she feels lonely and abandoned by her family and also how she feels like she is a reminder for them of the possibility of their own family members developing psychosis. The way I understood it at the time was that Rosie has always felt powerless in her life and that things happen to her which she has no control over and this has left her feeling sad and confused. During the second interview, Rosie reflected that the interview process had not been as difficult as she had imagined and that in the future she would consider being more open with people she felt she could trust. Between the first and second interview she had also started searching on the internet for support groups and said that she would like to be able to use her experiences to help others.

Amanda

Amanda comes from a white middle class background and is an only child who lived with both parents until she was 11 years old. She and her mother then moved into a hotel and subsequently into a one bedroom apartment with a shared bathroom. When she was about 11 years old, after hearing her friends discussing their home lives with a school counsellor, she began to realise her family was not like other families. Amanda had an eating disorder from the ages of 12 to 17. She said this developed because she did not feel able to tell others how she was feeling and therefore it was a physical expression of her fragility. Despite her parents trying to stop her from moving away to university she managed to achieve this. However, completing her undergraduate degree has been a difficult process as she has had to work at several jobs whilst studying. Amanda has also had to take out a restraining order on her father and stopped contact with her mother. Amanda currently lives with her partner and works full time.

Both of Amanda's parents experienced psychosis. Amanda described how her mother used to be fun, caring and like a friend to her. However, when she was about six years old her mother started to become quite controlling and she became frightened of her. When Amanda was around nine years old, her mother began alternating between behaving in a controlling way or becoming detached and telling her to leave her alone. She described her mother as having a fear that something 'bad' would happen to herself or to Amanda, as a consequence of which she was obliged to come straight home from school each day and was not allowed to speak to boys. Amanda described her father as always being frightening, scary, controlling and manipulative of her and her mother. Her parents both had unusual beliefs, such as being able to communicate with God and angels. They also referred to a child who did not exist and would do things for this child such as buy clothes or set it a place for dinner. Amanda is confused by her parents' behaviour because it seems more unusual than anything she has ever heard of. She is also hurt by the way they treated her and fearful that they will come back into her life and destroy the stability and safety which she has created without them.

Whilst talking on the phone to Amanda before the interview, she was concerned that she might become upset during the interview and wanted to ensure that she would be able to leave if she wanted to. The first interview was more descriptive and when listening to the audio recording before the second interview, I noticed that we had both avoided talking in much detail about her sense-making and her feelings. During the second interview we discussed this in relation to her finding it hard to open up to people about her feelings and how I was unknowingly avoiding asking about her feelings because of what she had said to me on the phone. The second interview was therefore

more focussed on how she made sense of her experiences and what she felt about them. During both interviews I found myself feeling incredibly sad for Amanda and angry towards her parents for what she had been through. I found it hard to end the interview and wished that I was seeing her in a therapy capacity, rather than as a researcher. I also noted that I had a strong desire to tell her how courageous she had been and how well she had done to escape, as this was something which she only fleetingly acknowledged. I sensed her fear of her current life collapsing and her fear that she was in real danger. I found it hard to let go of this after the interview because I wanted to protect her and know that she would be ok. Amanda said that the experience of opening up was not as difficult as she thought it might be. I was encouraged to hear that in the interval between the two interviews she had started to talk to some close friends about her experiences and that this had gone well. I hoped that in the future she would turn to others for more support.

Group Analysis Results

An individual analysis was carried out for each participant before moving onto a group analysis to explore participants' experiences of growing up with a parent with psychosis. Four major themes were identified, with a total of 13 subordinate themes, represented figure three below. Table two highlights which participants experienced each subordinate theme. The following section will provide more details of each theme and subordinate themes, with illustrative quotes from participants.

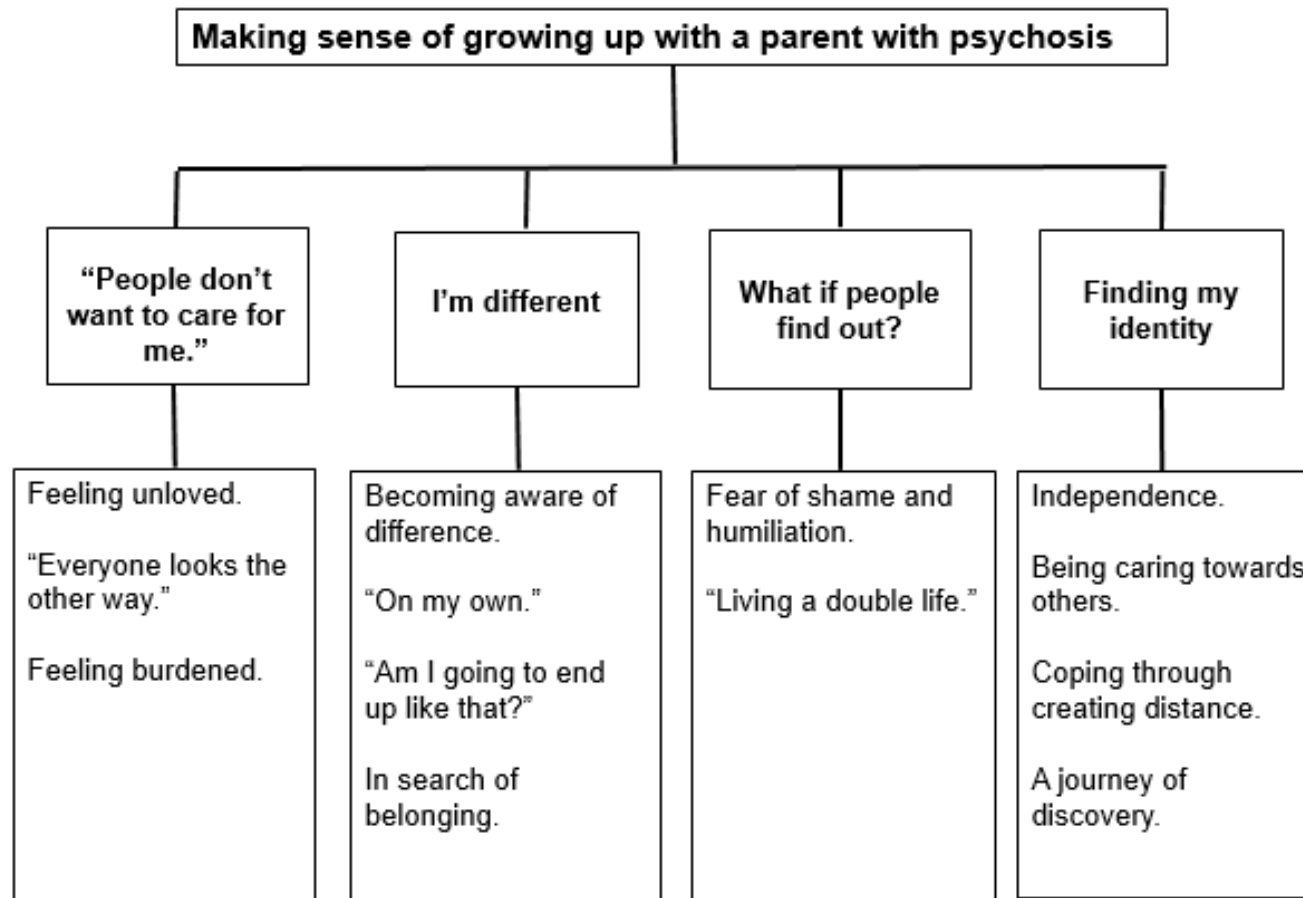


Figure 3. Thematic map.

Table 2. Distribution of themes amongst participants

Theme	Mary	Peter	Richard	Rosie	Amanda
“People don’t want to care for me.”					
<i>Feeling unloved</i>					
<i>As a child</i>	✓	✓	✓	x	✓
<i>As an adult</i>	✓	✓	✓	✓	✓
“Everyone looks the other way”					
<i>As a child</i>	✓	✓	✓	✓	✓
<i>As an adult</i>	✓	✓	✓	✓	✓
Feeling burdened					
<i>As a child</i>	✓	✓	x	✓	✓
<i>As an adult</i>	✓	✓	x	✓	✓
I’m different					
<i>Becoming aware of difference</i>	✓	✓	✓	✓	✓
“On my own.”					
<i>As a child</i>	✓	✓	✓	✓	✓
<i>As an adult</i>	✓	✓	✓	✓	✓
“Am I going to end up like that?”					
<i>As a child</i>	✓	✓	✓	✓	✓
<i>As an adult</i>	✓	✓	✓	✓	✓
In search of belonging	✓	✓	✓	✓	✓

Theme	Mary	Peter	Richard	Rosie	Amanda
What if people find out?					
<i>Fear of shame and humiliation</i>					
<i>As a child</i>	✓	✓	✓	✓	✓
<i>As an adult</i>	✓	✓	✓	✓	✓
<i>“Living a double life.”</i>					
<i>As a child</i>	✓	✓	✓	✓	✓
<i>As an adult</i>	✓	✓	✓	✓	✓
Finding my identity					
<i>Independence</i>	✓	✓	✓	✓	✓
<i>Being caring towards others</i>	✓	✓	x	✓	✓
<i>Coping through creating distance</i>	✓	✓	✓	✓	✓
<i>A journey of discovery.</i>	✓	✓	✓	✓	✓

“People don’t want to care for me.”

This master theme captures participants’ accounts of feeling neglected and unloved by their parent with psychosis and of their difficulties being ignored by other people in their lives. It also reflects their experience of feeling burdened by their responsibilities, and of having to care for their parent with psychosis without receiving any support. The subordinate themes have been divided into sense making as a child and sense making as an adult, to acknowledge the changing process.

Feeling unloved

All the participants apart from Rosie described feeling unloved by the parent who had unusual experiences at some point during their childhood. All four participants spoke about this in terms of their parent not showing them that they loved them and not being there to care for them emotionally and practically. The emotional consequences of this included feelings of hurt and anger towards this parent. All four participants also described that, as a consequence of not being loved and looked after, they had to care for themselves.

Mary: “When we got older, as soon as we hit puberty and our identities grew outside the family, she couldn’t handle that at all. It started making her feel really anxious because she felt like her identity as a mother was being threatened. It took her years to really accept my sister and I for who we were essentially”.

Richard: “Well I have been told that she really loved me, you know deeply and passionately, but I can’t say I ever noticed it to be honest.”

Peter’s description of care from this mother is slightly different to the other participants. He was very close to his mother: she took his views seriously and listened to him. However, her lack of care for him was more subtle, for example, a failure to define boundaries and his non-attendance at school for many years. He did not receive support from his mother in managing these areas of his life, which has left him feeling responsible for these events.

Peter: “Because of not being well she didn’t really make the best parent, so we were always you know, staying up until whatever time we wanted, we weren’t going to school, a lot of freedom, watching whatever we wanted, stuff like that.”

Amanda has always experienced feeling unloved from her father: however this experience with her mother started when she was about six. She described how her mother changed suddenly and it being like the mother who previously loved her had died. She felt sad about this loss and confused about the changes and during her childhood she hoped that one day her original mother would return.

Amanda: "There is like different versions of my mum in history when I reflect, and like the one version was when I was in primary school and she picked me up when my dad went away for several months, and we walked through the park, and she would get me some nice juice, you know, things like that, and she was like nice. And everyone was like oh, that is your mum, she is great. And then the next version of her, she just lay on the sofa one day and said don't talk to me you are giving me a headache. And she just lay there and didn't get up, didn't work, didn't do anything around the house, didn't talk to anyone, didn't make friends, and she just lay on the sofa."

In adulthood, all of the participants continue to feel unloved by their parent and like they would not be able to turn to them for support and care if it were needed. Their relationships with their parent who experience psychosis is based around their providing love and care for their parent, rather than receiving it.

Mary: "I've very much been used to being someone who doesn't have a relationship with their mum. Someone who can't really rely on their mum."

Some of the participants spoke about their current lack of love in a more detached manner than when reflecting on it during childhood. This is perhaps as a way of coping, or because they have more distance from their childhood, or perhaps because the consequences were more significant during childhood.

Peter: "We weren't talking so much when I lived there anyway... we don't have a lot in common...we get along, we don't have to be super close. Now, it is much the same except I leave it to her to text me."

Amanda is fearful that if her parents were to come back into her life they would control her again and she does not feel emotionally strong enough to manage this. She is also fearful of being physically harmed by her father and because of this her current life feels fragile like it could disappear at any point.

Amanda: "I remember feeling so suffocated when I had to deal with the harassment order, and I felt like my dad could actually come and kill me. And I just felt so terrified, and not just terrified but so depressed."

During childhood and adulthood, participants have experienced feeling unloved and uncared for by their parent who experiences psychosis. These relationships have often been based on providing support for their parent which has meant that they do not feel able to turn to their parent when they need them.

"Everyone looks the other way"

All of the participants felt that during childhood other people knew about their experiences but the care which they received from others was superficial. For example, they had some positive relationships with the wider family, teachers or people in the community, however, they would only ask surface-level questions and made no attempts to find out if they were really managing, or whether something needed to change.

Mary: "Well it's like a, it's like a town which is a very stereotypical town where you would never want to admit that anything is wrong. Erm, so a lot of it was hush hush. So like, we'll give you a little extension on your homework. If you need someone to talk to you can go and talk to somebody. But we're not going to like, raise any flags."

Peter: "The secondary school that I was attending before I dropped out, I never officially left the register. I just didn't go and told them that I wasn't coming in...so three years went by, and then they reached out to me and said we will do this online with you, we will enrol you in this online account thing. And that was to get me to do my GCSEs."

Participants reflected that as a child they did not ask others for help outright because they would have felt guilty about letting their parents down and feared their rejection as a consequence. They also considered that as others did not help them this indicated that they should be able to manage and they would have been a failure if they needed extra help. Some participants just did not realise that there might have been an alternative and were angry that other people did not help them to discover this.

Mary: "At that point we were still at the level where everyone looks the other way and everyone pretends it doesn't exist."

Amanda spoke about developing an eating disorder during her adolescence as a way of trying to communicate to others how *'fragile'* she was feeling. However, as the extract below demonstrates this did not result in the consequences she wished for but further fuelled her belief that no one in her life cared about her.

Amanda: "It felt like people didn't care, and that this physical display wasn't actually amounting to anything, so I felt more hopeless, because I thought well I tried talking and it is not working, and I tried this and it is not working, and people still think that there is nothing wrong."

These feelings that others did not really care about them has continued into adulthood. The participants feel like people are not really being interested in what it was like for them to grow up with a parent who experiences psychosis and how this might impact on them now.

Rosie: "I thought about the fact that nobody had ever asked me about this. The question had never even arisen, what effect dad having that illness had on the family."

They feel as though other people do not try to understand what they have been through and how this might have impacted on them. Participants also acknowledged that they continue not to tell people in detail about their experiences or to ask others for help.

Amanda: "It is like sometimes people just assume everything is just ok and say things, and they don't mean to be dismissive of you...a girl in my office whose mum died and everybody was like 'Oh, let's look after you, let's make a big cake on your birthday', and like of course I am sad that her mum died....but I feel like my mum has died, and I feel like my dad has died... I think I feel jealous that people don't want to care for me."

Throughout childhood and adulthood, participants have felt that other people do not really want to find out about their experiences and their care and interest in their difficulties is superficial. Participants acknowledged that they did not ask for help as a child, for fear of rejection or feeling like a failure and this way of coping continues with them into adulthood.

Feeling burdened

During childhood, Mary, Peter, Rosie and Amanda all described feeling burdened during childhood and sometimes overwhelmed by their sole

responsibilities to care for their parent who experiences psychosis or for other family members.

Mary: "I guess I had internalised the idea that I was the caretaker, or whatever, I mean there was just something again that I was told I was good at so I was supposed to be the caretaker but I had literally reached the end of my rope and I felt like I couldn't control the irritation at all and that made me feel kind of bad."

Mary and Peter felt it was their individual responsibility to care for their mum and both felt burdened by this and the impact this had on their life, for example being unable to socialise with peers or missing school. This resulted in them feeling angry towards their mother at times but also guilty about these feelings.

Peter: "Over time it does take its toll and you get tired of being the one that has to handle it all the time. Like I have already got burdens. I was missing a lot of lessons, I was constantly on the catch up. I have missed days because I have stayed at home to make sure she doesn't do anything weird that day because she was acting weird or something. You are fine with that at first but then you start to feel like it is a burden."

Richard did not describe feeling burdened by caring for his mother, but this might be because his mother died before he reached the age when the other participants describe this. Rosie did not describe feeling burdened with caring for her father: however, she did feel burdened with caring for her sister and her mother. Whilst she was growing up Rosie often had to look after her younger sister and felt like her mother turned to her for emotional and practical support.

Rosie: "I was very often almost always put in a position where I had to look after her (sister), even when I didn't really want to."

Amanda did not feel able to leave her mother and go into care because she felt responsible for her mother's wellbeing. On numerous occasions Amanda's mother told her that she might end her own life and Amanda worried that she might carry this out. Amanda also feared that her mother's life would be meaningless if she were to go into care and so therefore did not act on this possibility. She also felt responsible for providing for her mother, for example despite fearing her father she continued to visit him as he gave them money when she did.

Amanda: "I always felt really guilty about leaving my mum, and I knew that my mum didn't have anything in her life that she was happy about. She wasn't happy about me, but she felt like there was actually something if she had a child, but she didn't really show it in a very nice way. And I just thought what if that purpose of her life suddenly disappeared, was she going to commit suicide? Because she said things like that quite a lot when I was growing up."

Mary, Peter and Rosie currently feel responsible for caring for their parent who have unusual experiences and are concerned about their welfare.

Rosie: "I think he has done incredibly well to still be alive, but I still worry about him. I worry more about his rights and whether he is getting the right sort of treatment, and if he falls ill again, you know if there is any medication he is taking or anything."

Mary and Peter feel burdened by this responsibility, as despite no longer living with their parent they provide care through phone calls and text messages. This can be stressful and they cope with this by distancing themselves from their parent.

Peter: "For a while it did feel like quite a burden to be honest, it is a big deal to try and be responsible for someone else who should be...for the rest of your life has been responsible for you. My other siblings don't live with her, so it is all on me to keep her under control and it is quite stressful to be honest with you."

Amanda has had to stop the contact with her parents due to her fear of their doing her physical harm and trying to control her life again. She has had to take out a restraining order against her father to try to gain some control over his contact with her. However, she continues to feel burdened by the weight of their existence and the possibility that they might destroy her current life.

Amanda: "If I did talk to her then everything would collapse, and she would want to be in there manipulating me and controlling every aspect of my life, and I am just not ready for that, so I have just not spoken to her....I just can't afford for them to come back into my life."

During childhood and adulthood participants have felt burdened by their responsibility to care for their parent who experiences psychosis. As a child this

meant that they missed out on childhood activities, such as playing with peers or school. As an adult they continue to be expected to support their parent and manage unrealistic requests, such as moving back in with them, or try to 'control' their parents experiences. However, they are now able to manage this burden by distancing themselves geographically and by not seeing or speaking to their parent as regularly, which helps reduce feelings of being burdened and associated levels of stress in the short term.

I'm different

This major theme captures a process which participants have all experienced in relation to feeling different from other people. Firstly, during childhood they came to realise that their family is different to other families which led them to feeling alone during childhood and adulthood. Following this, participants tried to make sense of why their family was different and what this might mean for them. Finally, participants have sought friendships and relationships with people who they see as different too, such as people who have come from a background with 'social problems' or who they see as 'weird'. Two of the subordinate themes were divided into sense making as a child and sense making as an adult because of the change in sense making over time.

Becoming aware of difference

All five participants went through a stage of realising that their families were different to their peers' families during their childhood. This realisation led them to question their parent's behaviour. For Peter and Richard this realisation began when they started school and began visiting friend's houses; they realised that their parent's behaviour was different to their friends' parents' behaviour.

Richard: "Sometimes I would call into a friend's house, you know and it was like a totally different environment, you know, a good natured mother asking if you want tea, which was kind of a shock to me."

Mary began to notice that her mother had unusual experiences when she recognised that some of what her mother said did not make sense. This appears to have stemmed from when Mary was in her early teens and had gained enough knowledge about the world to question what her mother was telling her.

Mary: "I realised, like, you know, it wasn't exactly true and it switched actually a few times before you know, I finally like understood on my own that what I was hearing from my mum wasn't true at all."

Rosie described her father's behaviour changing on the two occasions when he experienced psychosis. Amanda also spoke about becoming aware of a sudden change in her mother's behaviour when she was about six but that she never reverted back to how she had been previously. When Amanda was about 11 years old the school counsellor asked her and some of her peers about their home lives and it was then when she learnt how different her parents were from her peers.

Amanda: "And the two girls that I had went with were sort of quite normal, the stuff that they were complaining about, like my brother annoys me, or my sister makes me get her a drink every day, or whatever, and then when she asked me she was quite taken aback because my experiences were quite different to theirs. And I also realised that the things that they were complaining about were really of no consequence."

There is some variation in this subordinate theme about when participants noticed that their parents' experiences, and how they interacted with their parent, were different to their peers. This is perhaps related to whether they visited peers' houses, or whether they spoke to their peers about their family life and their parents, or in Rosie's case, there being a change in their parents' behaviour.

"On my own"

All the participants described how during childhood they felt different, and had different responsibilities from their peers resulting in them feeling alone and isolated. Mary, Peter, Rosie and Amanda all spoke about having to move house as a consequence of their parents' experiences and therefore being further away from friends, adding to their feelings of isolation.

Mary: "My dad came to take us...and got emergency custody that never went away...my dad was living a few towns over. It was a half hour car ride to go to my school...for me that meant I ended up being a lot more isolated from my classmates because I didn't have a car and no one is really going to drive a half hour both ways when everyone else is in town 5 minutes away. So I just ended up being more isolated away from my senior class."

Rosie: "We moved around quite a lot when I was young...we lived about half a mile away, so there weren't really any other children around, so I didn't really have anyone I could talk to about it."

For Mary her responsibilities to care for her mother impacted on her ability to spent time with her peers and this added to her feeling different and alone.

Mary: "It was an isolating factor, you know, it's like I'd be pulled away from my friends."

Peter lost contact with his peers when he stopped going to school and became isolated at home but no attempts were made to help integrate him back into school. He felt too embarrassed at the situation to keep in contact with his previous friends.

Peter: "So I spent about three years in my room just not speaking to anyone, and I became quite unsociable. So for those three and a half years I was just on my own in my room."

Richard spoke about how his father did not allow him to bring friends home after school which meant he would often play by himself. However, he also spoke about how he was reluctant to bring friends home because he was worried about what they might think about him if they found out about his mother's experiences.

Richard: "The biggest barrier was that you can't invite your friends back because you think that they are going to think that there is someone berserk in your family. You know you don't want them to think that there is someone cuckoo in your family. Because you know, kids are prone to bullying and teasing."

Rosie and Amanda felt that there was no one else going through similar experiences to them and this separated them from others and made them feel alone.

Rosie: "One of the problems when that happens in a family is that the family tends to feel incredibly isolated and lonely, and you know, you feel like you haven't got a friend in the world, as a family. You feel sort of cut off from your neighbours and your friends."

Amanda: "But I think even within that I have not experienced anyone having anything like me, so I feel quite...I don't know...I still feel quite alone with it, and I still feel like people can overlook it."

As adults the participants continue to experience feeling alone in the sense that their friends have not had to go through similar experiences to them which leaves them feeling like they cannot relate to anyone else.

Rosie: "And it gets worse, when you get to university and you make friends with people who have parents in managerial professions, like some of our neighbours actually, who are people of about our age whose parents were local farmers or quite wealthy professional people. And when you compare your dad with their dad that is very painful."

Amanda: "Even in the circumstances of people who have had difficult families I just can't relate to anyone."

Richard describes himself as a solitary person and believes that this has stemmed from spending large amounts of time on his own during his childhood. He appears content in his own company and does not seek out others.

Richard: "I am not very sociable to be honest, I am sort of quite happy being by myself and getting on with my hobbies and interests, and I think that sort of stems from spending a lot of my childhood by myself."

During childhood participants were isolated from their peers for a number of factors, including their carer responsibilities, fear of what others might think and having to move house. These feelings of being alone and isolated have continued due to participants ongoing feelings of being different and like no one else understands what they have been through.

"Am I going to end up like that?"

During childhood, all of the participants made attempts to try to understand why their family was different from others but their sense making varied. When Mary was a child, she thought that if she were able to provide the right kind of care for her mother then she would get better and they could be like other families. Peter spoke about how as a child he did not know that she experienced psychosis and believed that the way she behaved was related to who she was and this made him angry.

Peter: "Back then, I didn't understand why she was like that and the maybe it was her illness that was making her that way. So I was quite angry."

After Richard's mother's death, people began telling him how different his mother had been before he was born. It was at this point that he began questioning why she might have changed and wondered if it was as a result of his birth.

Richard: "When I was younger growing up a lot of her friends would come up to me and you know, put their arms around me and cuddle me and say 'It

is tragic what has happened to your mum', and they would say to me 'I remember when she was a bonny lass', you know sort of dancing every night and every other night and being really happy, and I realised my mum wasn't always the way she was when I knew her.'

Rosie's mother made attempts to explain to her that her father had mental health difficulties and the family narrative was based around this being an illness over which he had no control. This perhaps reflects the more medicalised model of explanation at the time.

Rosie: "When he came out of hospital, my mum sat down with the crossword puzzle, and said 'let's finish this off shall we', just to give him something to do. And he couldn't remember doing the crossword puzzle at all. Because I think my mum had got a clue, and she wanted to go through it, and I remember as a child that was actually something that stuck in my memory as being, you know, it helped me understand that the treatment was helping him to get better, because it was doing things to his memory."

As a child Amanda did not understand why her parents behaved in the way they did and she could not find an explanation for it. She was too frightened of them to talk to them about their experiences and therefore she remain confused about the cause.

Amanda: "I just found it really baffling, but I didn't really feel able to challenge it, because I didn't really know what they were doing."

All five participants spoke of their current attempts to try to find an explanation for their parents' experiences and consider what their parents' experiences might mean for them in the future. Mary's sense making has changed over time and she puts more of an emphasis on her mother being able to change than she used to. She sees her mother's experiences as a 'mental illness', however, she is angry that her mother chooses not to make any changes. Mary has thought about whether she will become like her mother, but sees herself as very different and much more able to cope with life and therefore less likely to develop mental health difficulties. There appears to be a contradiction in Mary's account as to whether she believes these experiences are based on an 'illness', or whether they are based on her mother's ability to cope, in which case Mary does not feel she will develop her mothers' experiences as she sees herself as stronger than her mother.

Mary: "I understand that I am very low on neuroticism, which actually also helps with worries about like, could what my mum has affect me? It make me feel like absolutely no way because, again she was having panic attacks in college, whereas, if my partner trying to kill themselves doesn't give me a panic attack, I'm not sure what will."

Peter spoke about how once his mother had received a diagnosis it helped him to understand her behaviour more and he was less angry towards her. He saw a difference between how she normally is and how she is when she experiences an episode of psychosis. However, he also considered a link between her past traumatic life events and her unusual experiences. Peter described himself as 'not atypical' but rational, which he described as being different from his mother. This might be why he does not overly talk about fearing developing unusual experiences himself.

Peter: "So she will ask me if someone is hacking me, and obviously I don't have a lot of things to say to that except 'Mum, I don't think that is a normal thing to think, I think you are having an episode'."

Amanda continues to search for an explanation but finds her parents' behaviours too unusual and too different to other people's unusual experiences to be able to explain and she remains confused. Amanda has also had some unusual experiences and worries about this and the connection between her parents' experiences.

Amanda: "You know, both my parents were mental so maybe I have got some kind of mental streak where I just see funny things. But I find it scary to be honest, and I still don't understand why it has happened."

Richard feels confused about his mother's unusual experiences and regrets that he is unable to find out more information about her experiences. He considers some traumatic life events, such as sexual assault, which might have been influential in the changes to her behaviour which her friends described. However, his explanations are mainly based on a biological and genetic understanding, as are Rosie's.

Richard: "You know, when you have got a history of mental illness, like years later, you end up thinking 'Well am I going to end up like that, you know, in my 50s?' Sometimes I get that, because I can be quite moody at

times, and sometimes when I get moody I wonder if it is a genetic condition and if I should see my doctor.”

Richard and Rosie both described psychosis as an illness over which they have no control. Their biological understanding is perhaps linked to their being older than the other participants and having grown up in a time when this was the only explanation for unusual experiences in the mental health profession. Due to Richard's fear of a genetic link he is worried that that he may become like his mother, he fears he has no control about inheriting mental health difficulties and as a result is hypervigilant to possible symptoms. Rosie has experienced psychosis herself and the fear of a possible genetic inheritance is present within her family. There is also a fear of a lack of control over whether either Rosie or her father will have psychotic experiences again in the future. In the past Rosie feared that her father would kill himself and the extract below highlights Rosie's belief that there is a genetic explanation and a link between suicide and psychosis.

Rosie: “After it happened to me a couple of times growing up, it was quite clear that there was good evidence of a genetic condition happening here. And years later...I became quite interested in my family history, the way a lot of people do....and I started looking into my grandma, my dad's mum's family... and the most amazing thing came out. Which was that my grandma's grandma killed herself, drowned herself.... When I read this, you could have knocked me over with a feather, because I just thought bloody hell, this is what happened to dad, and this is what happened to me....there is probably this gene for something in our family, that lay dormant for over a 100 years, and then suddenly, was realised in my dad, and was then realised in me.”

During childhood and adulthood all of the participants have been searching for an explanation as to why their parents had unusual experiences and what this might mean for them in the future. Their explanations differ and change over time which perhaps reflects their confusion over why it is their family who has these experiences.

In search of belonging

Mary, Peter, Rosie and Amanda all spoke about trying to find people, or having made relationships with people, who they see as different from what they perceive as normal but who are similar to them. This appears to have stemmed

from feeling like an outsider and wanting to find people who they can identify with to help them feel more connected with other people and less alone.

Peter: "I have found quite a few people on my course who I can relate to, who are mature, so that is nice. In 6th form and secondary school I didn't quite have that. It wasn't quite as much of a problem at secondary school, but when I distanced myself from people that was when I grew up at a different pace. Also the extra responsibilities I was given, having to take care of my mum and stuff, probably helps in that regard."

Amanda: "I really want to meet weird people like me. But I think I kind of met some of them, and that was alright eventually."

This subordinate theme only occurs during adulthood, which is possibly a result of participants moving away from home and having the opportunity to meet a wider variety of people.

Peter: "I didn't make many friends in sixth form, didn't really go out very often, but since coming to uni I have got a lot of friends, I have become quite social. My social life is a real thing now."

Richard identifies himself as being different, he leads a solitary life, rather than finding people who he sees as similar to himself. Although when he was a young adult he describes becoming involved in the punk scene and this was perhaps a way of trying to find a way to relate to people who society sees as different.

Richard: "That need to look different, I don't know where that came from, but maybe I already thought I was a bit of an outsider because I was coming from a bit of a broken home, so rather than cover it up I used to make the most of it, and put safety pins in a jacket and wear it with jeans, and just sort of try and look as different as possible."

What if people find out?

This master theme covers a fear which all the participants experienced as a child and as an adult regarding the consequences of other people knowing about their parents' experiences. As a result of not wanting other people to find out, the participants have not felt able to be fully open with others about their experiences. As sense-making changes over time, the subordinate themes have been divided into sense making as a child and sense making as an adult.

Fear of shame and humiliation

Peter, Richard, Rosie and Amanda spoke about how during childhood they would feel ashamed if other people, and in particular peers at school, found out about their parents' experiences. They feared that if others found out then others would treat them differently, be cruel towards them and they would become an outcast.

Richard: "I was not able to develop close friendships at school because I had this fear of them coming home with me and seeing what it was like and then telling everybody at school and I would be a laughing stock. It does sort of spread, and you know kids can be really malicious can't they?"

Rosie: "You know, what do you say to someone? I suppose it was fear of...fear of rejection really, or fear that I might lose...that is probably what it was actually, I was afraid that I might lose friends if I told someone about my parents, about my family."

Mary's experiences were a little different, as to cope with her shame and embarrassment she sided with her peers against her mother. When she spoke about this it felt like it was a way of protecting herself from others thinking that she was like her mother and therefore avoiding humiliation and rejection.

Mary: "I learnt to distance myself from my mum, she (sister) felt more the need to protect her at that age. So I erm, so yeah people would say, 'oh look, crazy women is walking down town' and my sister would feel very isolated, whereas it wouldn't really bother me. I didn't hear that very much either but I generally agreed with them because at that point I was really frustrated with her."

Richard, Rosie and Amanda continue to be concerned about what other people might think about them and if they would be treated differently if other people found out about their parents' experiences.

Rosie: "Madness in the family is terrible....Nobody wants to marry into a family where there is a history of mental illness, you know."

Mary continues to manage her feelings around what other people might think about her mother similarly to how she did as a child; she creates a distance between her and her mother by siding with others.

Mary: "I just wanted to go on vacation and she wouldn't get on the plane. I was as pissed off with her as the people who were trying to get her on the plane."

Peter remains concerned about what other people might think if they were to see her whilst she was distressed, however, he feels comfortable that his close online friends would not treat him differently if he told them about his mother's experiences. In the second interview Peter reported that he had found the experience of talking about his mother in the first interview more helpful than he had imagined. This gave him the courage to talk to one of his friends about his experiences between the two interviews.

Peter: "So I thought I'd see what she thought about it, because she is my friend, she will tell me directly what she is thinking. She finds it really interesting because psychology students are interested in that kind of stuff."

He reported that this went well and that it is something which he will try more often in the future. Peter's reference to his friend being a psychology student and being interested in the area highlights his need to find people who are more likely to understand his experiences and not humiliate him.

The participants' experiences of shame about what others might think also manifested itself during the interview over their concerns about what I might think about them. With all participants I felt that during the first half of the first interview they were more guarded but as our relationships developed they become more open and trusted me with more personal information.

Rosie: "You know, that is the embarrassment that is attached to remembering. You are really kind, you look like the sort of unflappable person that you can tell something like that to and it doesn't matter, but a lot of people I can't imagine telling things like that to. And I wouldn't expect anyone else to tell me something like that, you know something embarrassing."

Amanda: "I guess you are doing research and so you have got to talk to lots of people about this sort of thing, so you are probably not judgemental, but I feel like you could be thinking 'oh she is really weird', or...I don't know...it is just...it is so personal, and it is so formative to who I am that it is a really weird experience to just let it all out in an hour and a half to

somebody that I have only met for this purpose and to think that you could be thinking something bad. I mean I am sure that you are not but you could be thinking badly of me, or I don't know."

Throughout their lives participants have experienced feelings of shame and humiliation around their parents' experiences. They have remained concerned that other people would find out and as a result they would be humiliated and others would be cruel towards them.

"Living a double life"

During their childhood all participants felt unable to tell people about their experiences fully, or at all, or they felt a need to lie about their current lives because they feared the consequences of people finding out. Mary and Rosie felt unable to be fully open about their experiences with their friends and teachers.

Rosie: "I did have one best friend at the time, but I couldn't have talked to her about it I don't think. I was desperate to make a good impression and get on."

Peter felt like the only people he could be more open with were two online friends who did not know his real name and had not met him.

Peter: "There were a lot of friends I wouldn't talk to about that kind of thing.... But online it is more separate, because you are not actually in the same room. You are talking online, and you are segregated almost."

Richard and Amanda missed out details of the truth about their family life or made up alternative stories as a way of keeping their experiences a secret.

Amanda: "I just made stuff up. Like I made up oh I have got a brother, and I made up oh we are living in a house and have got a cat, and my parents are nice. And people sort of said 'oh, your brother sounds interesting, what is he like', and I didn't know whether to say oh I just made him up, or...and lots of people were talking about their houses, and going up the stairs or down the stairs, and I was like oh, we are just living in one room. And I didn't tell anyone about it."

Richard: "You feel like you are living a double life, when you go to school, or your friends start talking, you can't just sort of be honest about it, so you do feel a bit like you are leading a double life."

All of the participants continue to be concerned about what other people think and because of this they continue to feel unable to be completely honest and open about their experiences with others.

Rosie: "I'm frightened to talk about it because there is just this huge stigma about madness in the family, psychosis in the family, so it is really really difficult to talk to people."

Peter described continuing to talk to two of his online friends when he is feeling stressed, however, they know him by his online name, which until recently was not his true identity. However, he is able to continue to use and build upon the identity which he feels he developed himself and is not associated with his family.

Peter: "When I first got on to the internet, I thought having an alias would be a good idea for safety reasons. And I used that name, and I was using it for years, and made a lot of friends. So my friends knew me as (name omitted). And eventually, because the friends I made I keep on talking to, and when you go by a name for a few years that is who you identify as, and that is what my friends know me as."

Due to participants' shame and fear of humiliation if others were to find out about their parents' experiences they have had to develop a way of hiding their experiences. Throughout their lives this has resulted in participants feeling like they are living a double life.

Finding my identify

This major theme captures participants' reflections on the impact that growing up with a parent who experiences psychosis has had on the adults they have become. For example, being an independent person, finding it hard to ask others for help, being caring towards others and coping through distancing themselves from difficult situations. This theme also incorporates some of the participants' identification of these patterns and their attempts to make changes. This section ends with a reflection on why it might be important for participants to identify positives from their experiences.

Independence

Mary, Peter, Richard and Amanda talked about having developed a sense of independence and an ability to look after themselves because they had to do this as a child. However, they all commented that this has resulted in their finding it difficult to ask others for help. It is possible that this is because they have

developed a sense of pride at managing to cope on their own and this makes it more difficult for them to turn to others for support.

Mary: "I feel like definitely independence has become a huge thing. I don't like feeling dependent on people. It's an independent streak of mine where it's to a fault. Erm, it probably is to a fault."

Richard: "It kind of made me more resourceful. As I said you get used to having long periods by yourself, you know if you are home you would be by yourself, so you would find things to keep you occupied or amused. You know, it just made you a bit more able to stand on your own two feet I think."

Being caring towards others

Mary, Peter, Rosie and Amanda all spoke about how they are more aware of others' needs because of their experiences of caring for their parent as a child. They see themselves as naturally more caring towards others compared to how they would have been if they had not had these experiences.

Amanda: "I think a big motivator for me in my career is that I want to actually help somebody and I don't know if I would have had that if I hadn't have been a person that needed help."

At times, this has resulted in some of the participants forming relationships with others based on providing them care, rather than it being balanced.

Mary: "I had spent so much time taking care of my mum I felt like I could actually, well it's essentially I saw this other person was struggling with something so much and I felt like I can actually take care of you by just giving you a lot of support and gentle affection and I just ended up getting stuck in this pattern again."

This theme also manifested itself within the interviews where one of the reasons Mary, Peter, Rosie and Amanda gave for wanting to take part was around helping me with my research and to find a way of using their experiences to help other people.

Peter: "I figured you probably wouldn't get that many respondents because it is a pretty specific area, so I thought I might as well help out."

Rosie: "I feel privileged to have had that experience, although at times it has been extremely painful for me, but you know, I feel that I have a duty to

share it really, somehow, to help other people going through the same thing.”

Coping through creating distance

All five participants have developed a way of coping with difficult feelings, memories and experiences by distancing themselves from it. This way of coping appears to have developed through having to face challenging experiences but not being able to talk to people about it or about how it made them feel. They use this way of coping to manage the stressful demands of their relationships with their parent who experiences psychosis.

Mary: “I have just given up on my mum essentially and like she does what she does, I don’t really care, I just, I will answer her phone calls once a week and if she continues to call me more than that, because that’s one thing that she would used to do, she would call 50 times a day, erm I just won’t answer.”

Peter: “So she was mentioning people at random, switching topics kind of erratically, and I guess that day I was kind of stressed, I was dealing with a lot of stuff that day, and so I kind of, I feel bad about it but sometimes I ask her not to text me when she is like this. I feel bad about doing it.”

A journey of discovery

I felt as though all five participants are continuing along a journey of discovery about themselves and how they relate to other people. Mary, Peter and Amanda are acting on this learning, such as trying to develop relationships outside of caring, beginning to open up to others and be less secretive or asking for help from others.

Mary: “I mean to some extent I still do have sense of accomplishment through caretaking, as long as it’s not the same person all the time but I also recognise that about myself now and I try to avoid getting into patterns and I try to avoid heavy caretaking.”

However, this is a journey and they are still testing out this new learning and revising it as they go along.

Peter: “I realised that recently I have been struggling with coursework deadlines and stuff, basically due to the fact that I feel the need to socialise. If someone offers to go out, I will probably join them, just because. My

reasoning behind that is, for why I do this, as far as I can tell, is that I really don't want to go back to being that guy that doesn't hang out with anybody. And I feel like if I don't hang out with people, I will kind of just relax back into being that guy, which doesn't seem like a good idea to me."

Richard and Rosie appear to have developed knowledge about how their experiences have shaped them: however, it appears that they have not made attempts to make changes, even when they allude to not being fully satisfied with how they are living their lives.

Richard: "I mean I am not married now yet, which is a bit surprising...If I had followed the path of most males my age I would have probably met someone my age at quite a young age and probably settled down and got married and bought a house together."

The areas which Richard and Rosie identified as wanting to change were focussed on wanting to build more relationships with others. Their explanations for the causes of psychosis are heavily focussed on biology and genetics and they grew up in a generation where this was also the main narrative. It is possible that because of this they experienced more stigma or were more ashamed of their parent's experiences, resulting in them finding it more challenging to make changes and connect to others. It is also possible that when they were at the life stage the younger adults are currently in then they were more driven to make changes; perhaps it is a process which occurs over time, or perhaps it fluctuates over time or perhaps it depends on the individual.

After discussing their experiences in the first interview all of the participants reflected that this had been a more positive experience than they had expected. As a consequence of this positive experience Peter and Amanda both developed the courage to speak to some of their friends about their experiences between the interviews. They both reported that this went well and is something which they will continue try to do more of in the future.

Amanda: "It was quite amazing to mention it, almost like I had at least like two people that I didn't have to sort of hide this horrible secret thing with, which was nice, and their response was really mature and intelligent, and they are really nice people anyway, so I should have kind of known that they would be like that. But it was liberating."

Richard and Rosie have made plans to talk to their family about their experiences in an attempt to try to help them make further sense.

All participants spoke about how their experiences have shaped them in a positive way, for example being more independent, more caring towards others, knowing that they can cope with difficult life events. However, the way they spoke about it made me feel like it came from the need to find something good from a difficult situation. It seemed to be that if there was nothing positive to take from the experiences then it would have just been a meaningless painful experience and therefore finding the positive is a protective factor.

Rosie: "I try as hard as possible to think about it as a blessing rather than a curse if you see what I mean, that it happened for a reason, and that there is more to be learned from seeing it as something that was bound to happen, rather than as something that wasn't, if you see what I mean."

Reflexivity

As previously discussed, I hoped that whilst carrying out this research I might enable participants to consider some of the positive aspects of their experiences. During the first interview, Mary spoke about some of the positive personality traits which she valued about herself which she had taken from her experiences, such as being caring towards others and being independent, which fitted with my beliefs about myself. However, as the research progressed and I carried out the second and third interviews, I started to consider the way in which the participants were talking about these positive traits and how I felt when they spoke about them. I noticed my own need for them to talk about the positive aspects and reflected on why this was. I noticed that I struggled with being in a researcher position as opposed to one of a Psychologist in Clinical Training because, whilst I am used to hearing people's stories of distress and hardship, I am normally in a position where I can offer psychological therapy. I felt powerless hearing people's stories, in particular when they were having current psychological difficulties, and not being able to do anything about it. Therefore, I was biased towards hearing and following up on the positive outcomes from their experiences as a way of trying to find meaning in their difficult experiences. When listening to some of the language the participants used to describe their experiences and the positive outcomes, it felt as though they were on a similar journey to me; if they did not find positive aspects of their experiences then they would feel more hopeless and the experience would have been meaningless and painful. The themes

I have tried to capture a balanced view of their experiences; I aimed to elicit some of the positive outcomes which participants have taken from their experiences, but to also reflect how painful some of these experiences have been. I also aimed to highlight how finding the positive outcomes is a protective factor but how this does not mean that they are not valid.

Chapter four: Discussion

This study was designed to explore how adults make sense of having grown up with a parent with psychosis or unusual experiences. The following chapter will summarise the key findings in relation to the research questions:

- What sense did people make of growing up with a parent who had psychosis or unusual experiences when they were a child?
- What sense is made of these experiences in adulthood?
- How has going through these experiences impacted on them now?

Five participants were interviewed twice and interpretative phenomenological analysis identified four major themes: *“People don’t care for me”*; *I’m different*; *What if people find out?*; *Finding my identity*. A summary will be provided of the main findings with a focus on what is unique about the findings from this research. Following this the factors which might influence sense making of past experiences will be considered, after which each theme will be discussed in relation to psychological theories and the literature reviewed in chapter one. I will then discuss the strengths and limitations of this research, followed by clinical implications and recommended areas for future research.

Main findings

During childhood, participants in this research experienced a lack of love and care from their parent with psychosis. The experiences which created these feelings varied, Richard, Rosie and Amanda felt rejected by their parents, Peter felt that his mother did not provide him with emotional or practical support and Mary’s relationship with her mother was based on providing care for her. Whilst all of the participants reported having some other positive relationships, such as with teachers at school, they felt that these relationships were superficial and people did not provide them with the care they felt they needed. During childhood participants went through a process of realising that their family was different to their friends’ families, which appeared to coincide with their increased contact with others through school and visiting friends’ houses. This new knowledge about their family left participants feeling different and alone and led them to consider if they will end up developing unusual experiences like their parent. Participants feared that other people would find out about their parents’ experiences and as a result they would be ostracised or bullied. To try to prevent this from happening, participants felt unable to tell people about their parents experiences and either made up elements

of their family life or they did not fully open up to others. For some participants this resulted in them feeling like they were leading a double life.

During adulthood participants continue to feel uncared for by their parent with psychosis. They also continue to feel different from others and concerned that others will find out about their parents' experiences. The participants reflected that it would have been helpful if someone, such as a family member or someone within the mental health care system, had helped them to make sense of their parents' experiences. They appeared to want to support their parent as a child but did not want to ask others for help. However, on reflection in adulthood the participants described feeling that if they had received more support they would not have felt so burdened by their responsibilities. They highlighted how events occurred but they did not understand what was happening because no one explained them to them, for example being made to move house or the other parent leaving the family home. At the time the participants were confused but did not feel able to ask questions. However, on reflection in adulthood some of the participants feel that more could have been done to help them makes sense of their experiences.

Peter: "So we went to my dad's, and it was a few weeks before I was kind of realising that I was going to be there for years. I thought it was like a temporary thing perhaps. Nobody told me, it wasn't really communicated well. I think social kind of dropped the ball on that."

The participants in this research fall into two age categories; young adulthood and middle adulthood and therefore there are similarities and differences across the two age groups. The young adults have not long moved away from living with their parent with psychosis and Mary and Peter are more involved in providing support for their parent with psychosis, such as phone calls and text messages. However, all three of them have created distance from their parent with psychosis as a way of coping with the burden they experienced as a child. The participants within the middle adulthood age range differ in that Richard's mother is no longer alive and Rosie has limited contact with her father.

During the interviews the participants were able to reflect on the impact of their experiences and some of the participants became aware of elements of themselves which they were previously unaware of. For example, Peter identified that he had been over socialising because he feared becoming the isolated lonely person he was in the past. He reflected on the importance of gaining a balance in

the future. All of the participants continue to feel like they are unable to be fully open about their experiences, even with people they have identified as different to others but similar to themselves. However, following the first interview Peter and Amanda reported that this had not been as difficult as they had anticipated. Between the interviews they both spoke to friends about their parents' experiences and had positive responses. This has resulted in them feeling relieved that others did not reject or shame them as feared and has encouraged them to be more open with others in the future. After the first interview, Richard and Rosie also spoke about finding the process of talking about their experiences helpful and considering doing more of this in the future. Richard reflected on how he has led a solitary life which he believes stems from having had to look after himself whilst he was younger. He identified that perhaps if he had experienced a different upbringing he might have sought out the company of others more which might have resulted in him marrying and having a family.

The findings from this research are unique in that they highlighted an overlap between sense making during childhood and sense making during adulthood for people who grew up with a parent with psychosis. For example, during childhood and adulthood participants have felt as if care from others was superficial, that they are different from others and the fear of other's finding out about their experiences resulting in the feeling like they are leading a double life. This research attempted to do something different by trying to capture the full impact of someone's experiences of having grown up with a parent with psychosis, rather than just focussing on the negative outcomes. This gives rise to the unique finding of participants identifying some positive outcomes from growing up with a parent who experienced psychosis, such as participants identifying themselves as being independent and more caring towards others. This research also considered the significance of participants identifying this positive growth in order to make their experiences more meaningful.

How do we make sense of past experiences?

It is acknowledged that participants were asked to reflect on their childhood experiences and therefore how they make sense of these experiences will be influenced by life events and sense making which has occurred since this time. The following sections will review how this might have influenced the themes which were developed during this research. McAdams (2001) argued that making sense of life experiences is a normal process and to make our life more meaningful we

create 'life stories'. He described these as narratives of our lives which place more or less emphasis on certain aspects of our experiences in order to make it meaningful. He highlighted how the people in our lives and the culture we live in influence the elements of the story which we embellish and the parts which we overlook. As such, they take on cultural, gender, class and historical assumptions and values. He suggested that our life stories help us to express and make sense of who we are within different periods of time. He also reported that a person's life story provides in-depth information in their overall sense making and purpose of their life. He said that as we get older our life stories develop and we become more concerned about the lasting impact we might leave, such as on our children or on the community. We also begin to move towards defining ourselves by overarching themes, such as our community position, job or parental role. Therefore, as three of the participants are within the young adulthood stage and two are within the middle adulthood stage, it is likely that this will influence how they make sense of their experiences. For example there are cohort effects which might impact on their experiences, such as the participants who are within middle adulthood grew up in a time when there was a greater divide between social economic status, less people were middle class and there was a lack of technology which would have been more present during the younger adults childhood. As previously noted, as the explanation for psychosis, treatment and provision of services has changed over time, it is possible that this has also had an impact on how the different age groups make sense of their experiences.

Boothe, Von Wyl and Wepfer (1999) suggested that the language we use to tell the story of our emotional experiences can be influenced by the reality which we have consciously decided upon. They proposed that when someone tells a story of their experiences it is similar to an actor performing on stage: that is, they are choosing to present a version of the events in a way which will captivate the listener, including more emphasis on some parts than others. In turn, the listener is likely to identify with one or more of the characters in the story which is influenced by the listener's own experiences. Boothe et al. (1999) suggested that it is possible for the listener to mould the story so that it becomes more meaningful for them and, like the storyteller, they can place more emphasis on some parts than others, to a point where the story differs from the original version. This is one of the reasons why reflexivity and credibility checks are so important because it could be possible for me to have become focussed on a certain version of the story, for example the positive outcomes, if I did not make attempts to manage this. They reported that

narrating stories serves a psychological function in that it can update these stories, help with social integration and help to cope with anxiety and wish fulfilment. Therefore the more time which has elapsed and the more times the story has been told the more it is likely to change. For example, the updating aspect allows the expression of emotion by imagining oneself back in the situation and the coping with anxiety stage allows the narrator to take control of the story and the anxiety they experience due to unresolved mental conflict. How we make sense of our experiences depends on how often we have told the story, the cultural context in which the story was created and to whom the story is being told. Therefore, it is important to be aware that sense making from the participants in middle adulthood, who are further away from their childhood experiences, might have changed over time and altered from the original narrative.

What we pay attention to and what we remember also influences our life story and what we recall is influenced by our current wishes, needs, values and aspirations (Conway & Pleydell-Pearce, 2000). Howe (2004) reported that this autobiographical memory begins to form before a child can speak and that the development of language and the ability to articulate memory might strengthen or possibility distorts it. He suggested that our autobiographical memories begin to be influenced by our social world where our life stories include sense making of ourselves in relation to others and providing others with a description of who we are. Howe (2004) also suggested that our recall of events from our past can change based on gaining new knowledge, new experiences and a reorganisation of information already present. Memories are more likely to be altered if they fit with our current values and ideas about ourselves. Therefore, it is possible that when trying to recall childhood experiences, the participants in middle adulthood will have had more time to have had other life experiences which may have influenced their life story. It should also be noted that how children understand and make sense of their experiences will differ from how an adult make sense of experiences but the further away from these experiences the harder it is to remember them. Bearing this in mind, the following sections will review the major themes and consider psychological theory to explain the findings, as well as considering the differences and similarities between these findings and previous research.

“People don’t care for me”

This master theme captures participants’ lifetime experiences of feeling unloved and neglected by their parent with psychosis and other people in their

lives, as well as feeling burdened by their responsibility to look after their parent. Attachment theory will be revisited to explore the impact of feeling unloved and uncared for as a child. Then the differences and similarities between previous research into children's experiences of growing up with a parent with psychosis which were discussed in chapter one will be reviewed before moving onto the research into adults' experiences.

If a child's parent is unable to provide them with a secure, safe and nurturing environment then a child is more likely to develop an insecure attachment (Bowlby, 1988). If a child develops an insecure attachment they are more likely to have difficulties with emotion regulation and relationships during adulthood (Howe, 2011). Therefore, it is important that a child should have a relationship with an adult that feels safe, secure and nurturing. However, it is also important to note that recent research has identified that the attachment figure does not have to be a parent; it could be another person close to the child (Rhodes, Grossman & Resch, 2000). This is an interesting finding as participants reported that other people '*turned a blind eye*'. Participants felt that others knew about their parents' experiences but no one tried to find out if they needed extra support or if anything needed to change. This left them feeling neglected by the adults in their lives and therefore it would have made it difficult for them to develop a secure attachment. Perhaps if there were other people in their lives, such as their other parent, the wider family, or people within the school system, who could have provided them with care which did not feel superficial this might have helped them to feel more nurtured by others. However, it is possible that there were people in their lives whom they felt attached to but they were too young to have a memory of this. This finding is unique to this research as whilst other research into the area has commented on children's feelings of neglect from their parent (Webster, 1992) they do not comment on their experiences of feeling neglected by other people in their lives. Some research did report that children who grew up with a parent with mental health difficulties found that support from other people in their lives, such as teachers, can act as a buffer against stress (Gilligan, 2000; Pölkki et al., 2005). However, this research does not comment on the level of support provided by others or the questions asked by these people. Therefore, it is difficult to identify the similarities or differences between these experiences and the experiences of the participants in this research.

The findings that the participants in this research felt burdened by their sense of responsibility to care for their parent with psychosis was also found in other research in this area (Garley et al., 1997; Somers, 2006; Webster, 1992). Research into adult carers for those experiencing psychosis also reported feeling distressed, burdened and overwhelmed by their responsibilities (Gutiérrez-Maldonado, Caqueo-Urizar & Kavanagh, 2005; Kuipers, Onwumere & Bebbington, 2010).

Research into how adults made sense of their experience of growing up with a parent with psychosis is limited; however, Dunn (1993) and Caton et al. (1998) both reported adults having felt neglected through a lack of supervision and care and that their parent was unable to support them. However, they both also reported the theme of physical and sexual abuse, which was not present in this current study; this perhaps reflects the different experiences captured when working with small sample sizes. It is important to note that in this research no specific questions were asked related to abuse and therefore it is possible that some of the participants did have these experiences but did not talk about them. Also, the sampling was notably different between these studies and this current research. One of the ways in which Dunn recruited participants was through referrals made by mental health providers and participants in Caton et al.'s (1998) research were selected from children who had previously taken part in a study for people who were at risk of homelessness. Therefore, both samples were more likely to have come from people with mental health difficulties themselves or circumstances that made them more vulnerable than others and who therefore might be more likely to have had distressing childhood experiences than the general population. Neither Dunn nor Caton et al. comment on participants' continued feelings of being unloved and uncared for by others in their lives which was a theme for adults in this research. Participants also continued to feel burdened by a sense of responsibility, even if their contact with their parent is now limited.

It would appear that children who grow up with a parent who experiences psychosis are vulnerable to feeling neglected not only by their parent but also by others who could provide them with care; for example teachers, social services or the wider family. This research found that these feelings continue into adulthood, as do the feelings of being burdened.

I'm different

This master theme captures participants' journeys of becoming aware of their family being different to their peers', feeling alone and wondering if they will develop psychosis themselves. It appears that in order to cope with these feelings and develop a sense of belonging they try to find people who they see as different but like themselves. The following sections will focus on social comparison theory to help explain these experiences.

Festinger (1954) said that human beings have a natural drive to compare their abilities and their opinions against others. He developed social comparison theory to explain how we compare ourselves against other people in order to find out knowledge about ourselves. The comparison to people who we see as doing well and whom we aspire to emulate is known as an upward social comparison (Festinger, 1954). Buunk et al. (2013) highlighted the difference between this type of social comparison to a downward social comparison, in which one compares oneself to those who are perceived as similar but worse off. Lazarus and Folkman (1984) noted that when faced with an uncertain and stressful situation, there is a tendency to revert to using the emotion focussed coping strategy of downward social comparisons. This process reduces negative feelings about one's own situation and enables people to feel more positively about themselves (Wills, 1981). However, as noted in chapter one, the use of emotion focussed coping can result in higher levels of anxiety and depression in the longer term (Compas et al., 1996). There were a number of ways in which participants in this current research compared themselves to others; they made comparisons with their peers, they considered if their responses were similar to other participants in this research and they made comparisons with their parent with psychosis. All of these different comparisons will be discussed in more detail below.

The subordinate theme of *becoming aware of difference* captures the time when participants began comparing themselves to peers and seeing themselves and their parent's experiences as different. The comparisons they made appeared to begin when participants became more immersed in a social world, both at school and when visiting friends' houses. Through making comparisons, it appears as if participants were trying to understand themselves better in order to make sense of their experiences. Social comparison theory suggests that we are only able to make comparisons using the information we have (Krueger, 2000) and therefore prior to beginning school and going to friends' houses, participants would have been

unable to make these comparisons. The development of peer relationships is vitally important during the transition from childhood into adulthood: it has been referred to as an adolescent replacement of parental attachment (Berndt, 1979).

Adolescence is an important time for the development of independence away from the family and the establishment of one's own identity (Harrop & Trower, 2001). Therefore, if people perceive themselves as different, or are treated differently and are unable to make peer relationships as a consequence, this is going to have a lasting impact on how they feel about themselves and how they relate to others (Carr, 2010). As discussed in chapter one, low self-esteem results in someone feeling negatively towards themselves. The literature in this area supports the idea that the more different we feel, the more negatively we compare ourselves with others and the worse we feel about ourselves (Carr, 2010; Mruk, 2006). During childhood and adulthood, participants in this research compared themselves negatively with their peers and this resulted in them feeling isolated and different. They manage these feelings by finding people who they see as different from others but more like themselves. It is possible that this helps them to feel more positive about themselves as when they made social comparisons they felt less different and more able to connect to others.

The subordinate theme *'in search of belonging'* emerges as the participants transitioned into adulthood. It is possible that this was at the time when they were able to meet a wider variety of people, for example at university, and therefore had more opportunity to find those whom they viewed as similar to themselves. Social comparison theory highlights the tendency to choose to be with those whom we see as similar to ourselves: it reports that this reduces levels of distress and anxiety (Buunk et al., 2013). Schachter (1959) noted that the more stressful a situation is for someone, the more they desire to be with people who are undergoing a similar experience. He concluded *'misery doesn't just love any kind of company, it loves only miserable company'* (p24). Barrett (1987) suggested that people seek others who have had similar experiences to themselves in an attempt to reduce feelings of 'uniqueness' or difference. Maslow (1954) highlighted the need for belonging as one of the basic human needs. Research into sense of belonging in support groups for those who have gone through similar experiences has highlighted the beneficial effects of being with others who we see as similar to ourselves; this can lead to a normalisation and validation of the experiences and reduce social isolation (Hagerty, Lynch-Sauer, Patusky, Bouwsema, et al., 1992; Lieberman, 1993). This drive for a sense of belonging and of finding others who are similar to themselves

appeared to happen with participants in this research when they attempted to compare themselves to other participants in the study:

Amanda: "I thought the fact that somebody is researching this area will mean that other people will have had my experiences, and I thought that was a quite comforting thought."

Other research has suggested that when facing stressful life events, people want to associate with those who have the most information, rather than those in a similar situation to themselves. For example whilst waiting for surgery, people are more likely to want to meet others who have been through surgery, rather than meeting those who are also waiting (Kulik and Mahler, 1989). However, findings from this current research tend to suggest that participants compare themselves to, and seek out, people who they see as different but similar to themselves in order to reduce their feelings of isolation and increase their sense of belonging. Whilst previous research has reported that children who grew up with a parent with psychosis felt different from others and isolated (Dunn, 1993) the finding that as a result of this they actively seek out those who they see as similar to themselves is unique to this research.

All of the participants also compared themselves to their parent with psychosis, which appeared to be in order to identify the likelihood of their developing unusual experiences. These findings are similar to that of Garley et al. (1997), who found that people try to make sense of their parent's experiences and what they might mean for them. Drawing from the literature on physical illnesses, Buunk et al. (2013) suggested that when people want to know how at risk they are of developing an illness, they are likely to compare themselves to those who they see as similar. Therefore, it is possible that participants might compare themselves to a peer who is a similar age, gender and culture but who does not have a parent who experiences psychosis, concluding that they are more vulnerable to developing psychosis themselves. As previously mentioned, the conclusions which are made from these comparisons can only be based on the knowledge which we have (Krueger, 2000), which might help explain some of the discrepancy between the participants' fear of developing unusual experiences. For example, Richard and Rosie were both brought up in a generation where the explanations for psychosis were largely based on the medical model. Therefore when they make comparisons against their peers they see themselves as having '*a gene that lies dormant*' (Rosie)

which their peers do not have and therefore they see themselves as more likely to develop unusual experiences. However, Mary, Peter and Amanda are all younger and brought up in a generation where the understanding of psychosis is changing to include more of a biopsychosocial model of explanation. This is perhaps why when these participants compare themselves to others they are not so concerned about developing psychosis themselves.

What if people find out?

This master theme captures participants' fear of being shamed and humiliated if other people find out about their parent's experiences and their attempts to keep these experiences a secret. The following sections will describe the psychological literature on social construction theory and stigma as a way of understanding participants' fear of what others think. It will also link this theme to the literature outlined in chapter one.

Social construction theory suggests that language creates realities, rather than discovering them (Brown, 1995). It highlights how 'mental illness' is a socially constructed concept which has negative connotations attached to it (Stout, Villegas & Jennings, 2004). The media has been identified as playing a large role in portrayal and maintenance of this negative view which results in those experiencing mental health difficulties, or people connected to them, feeling stigmatised (Stuart, 2006). The following section will review the research on stigma and the impact this can have on people.

The origin of the term stigma is from the Greeks who cut or burnt signs into a person's body to signify that they were a criminal, a slave or a traitor and someone to be avoided (Goffman, 1963). Today the term stigma is used to describe someone who is treated differently in society because their personal characteristics or beliefs go against cultural norms. Corrigan and Miller (2004) identified the difference between personal stigma and public stigma. Public stigma involves the following three components:

- Negative stereotypes which are endorsed by the general public
- A negative emotional reaction or belief related to this, known as prejudice.
- A resulting negative behaviour, such as avoidance or abuse, known as discrimination.

Personal stigma involves the same three processes but is turned in towards the self and is closely linked to feelings of shame and the wish to avoid others (Corrigan & Miller, 2004).

Findings from research into stigma have found that those who experience mental health difficulties are at an increased risk of experiencing discrimination from others (Penn & Frankfurt, 1994; Martin, Pescosolido & Tuch, 2000). This can be in the form of verbal or physical abuse, or exclusion, such as people not wanting to socialise with or employ them (Corrigan & Watson, 2002). Read and Baker (1996) carried out a survey of people with mental health difficulties and identified half of the 778 people who responded had experienced harassment or abuse. They also found that 24 per cent of the respondents who were parents reported that their children had been teased or bullied because of their parents' experiences. Further research highlighted family members of those who experience mental health difficulties have reported stigma from friends and their wider family. They indicated that relationships with family members and friends become strained or people try to avoid them (Ostman & Kjellin, 2002; Shibre, Negash, Kullgren, Kebede, et al., 2001). Farina (2000) suggested that this occurs because people assume that family members are similar to the person with mental health difficulties, or because if someone decides to align themselves with a person who is stigmatised there must be something unusual about them. Corrigan and Miller (2004) reviewed five studies examining families' perceptions of stigma when a family member experienced mental health difficulties. They found that between a quarter and half of the families were ashamed of what other people thought and believed that the person's experiences should be kept a secret.

Participants in previous research also reported feelings of shame and stigma associated with having a parent who experiences psychosis (Somers, 2006). It is possible that this is similar to the psychological consequences of those who experience psychosis themselves. Research has found that following a first episode of psychosis, people experienced feelings of shame, loss, humiliation and entrapment (Birchwood, Iqbal & Trower, 2000; Gilbert, 2003; Jackson & Iqbal, 2000). Jones et al. (1984) and Corrigan and Miller (2004) wrote specifically about the personal stigma which children of those who have parents with mental health difficulties can experience. They referred to it as contamination, that is a fear that their parents' experiences will pass to them and they will become like their parent. This was something which participants in this research referred to:

Amanda: "I just felt like that whole house and my dad and everything was contaminated".

Both Richard and Rosie spoke about how others are reluctant to marry into families where someone have experienced psychosis. This is a similar finding to Shibre et al. (2001) who reported that family members expressed concern that their chances of marrying in the future would be reduced because of the stigma associated with their family members' mental health difficulties. This was something which did not arise for the other participants, perhaps because they are not considering marriage at their current life stage.

Participants in this research also experienced personal stigma, for example the extract below highlights Rosie's stigmatised view of psychosis and her shame at being linked to people with these experiences:

Rosie: "I mean psychosis is terrifying...there is a danger to the sufferer, but there is also a danger to people close to the sufferer. There is also a danger to the public, obviously, because you know, sort of the knife wielding maniac thing that you read about in the newspapers, where suddenly a total stranger gets killed...Every time it happens I feel terribly embarrassed."

In summary, because of the public and personal stigma associated with psychosis, participants in this research remain concerned about what others will think of them and how others will treat them. Therefore, their way of coping with this is to try to hide their parents' experiences from others in an attempt to protect themselves from this stigma but this adds to their feelings of being alone and being unable to turn to anyone for support. However, between the interviews some of the participants reported having spoken to others about their experiences for the first time and because this went well they are considering doing so again. Therefore, by some of the participants in this research talking to others about their experiences, this might influence other people's understanding and reduce stigma.

Finding my identity

This major theme covers participants' reflections on how their experiences have shaped who they have become. It also covers their continued journey of learning about how their experiences have shaped them. Interestingly, participants were more likely to reflect on the positive aspects of themselves which they

believed developed because of their experiences, for example being independent and being caring towards others. However, during the interviews it felt as if there was a need for participants to take away something positive from the experience and I wondered if this was a way to make a painful experience more meaningful. The following sections will review the psychological theories and literature into the impact of our experiences on our identity, the importance of searching for a meaning and the findings from the post-traumatic growth literature. Finally, whether there were more painful aspects to participants' experiences which did not arise during the interviews will be considered.

Firstly, it is important to acknowledge that there is no perfect way to be a parent and there are no perfect parent child relationships. All parents will have some degree of negative impact on their children which might influence their sense of self and identity (Utting, 2007). This is not unique to people who experience psychosis.

As outlined in the introduction chapter, Erikson (1968) proposed that we continue to develop our identities as we move through adulthood and he proposed three stages which occur in adulthood: 'intimacy vs isolation' (18 to 40 years old), 'productivity vs stagnation' (40 to 65 years) and 'integrity vs despair' (65 plus years). He suggested that during these stages we continue to be faced with conflicts and crisis which impact on our sense of self and our identity. It is useful to consider the different life stages the participants are currently at and the possible influences which might have had on the impact of their experiences on their identity. Three of the participants fall within the young adulthood 'intimacy vs isolation' stage, whilst the other two fall within the middle adulthood stage of 'productivity vs stagnation'. Erikson suggested that during young adulthood people focus on developing loving and strong relationships but if this does not occur it can lead to isolation and loneliness. The three young adult participants did report difficulties developing loving and strong relationship and feelings of isolation and loneliness. For example, Mary spoke about having been in a relationship for five years but how she provided all of the care and did not feel that this was reciprocated. However, these feelings are not unique to these participants as they are something which was felt by all of them. For example, Richard spoke about his isolation and how he is surprised that he never married. Richard and Rosie are within the middle adulthood stage where the focus is on creating feelings of accomplishment and usefulness through nurturing children, caring for others or creating a lasting positive change

which benefits others. However, failure to do so results in dissatisfaction with life and stagnation. Rosie and Richard differed with regards to their drive towards productivity. For example, Rosie spoke about wanting to use her experiences of psychosis to help others and had been in contact with a support group, whereas Richard appeared to achieve accomplishment through repairing and making things around his house. I felt like Richard's description of his life appeared as if he had stagnated and this is perhaps a reflection on his lack of productivity in relation to nurturing others. Interestingly, this stage and its focus on accomplishment through making contributions for future generations does not arise for the participants in young adulthood. It is possible that themes related to isolation and loneliness occurred because the young adults are currently in crisis within this stage and Richard and Rosie were unable to pass through this stage successfully and therefore these feelings continued. However, it has been noted that these psychosocial dilemmas or conflicts can occur throughout life and may be prioritised at certain points when key tasks are expected, for example deciding whether to marry or not. These dilemmas are never achieved as a one-off, but are continually, potentially, reworked through life (Nemiroff & Colarusso, 1980).

The following section will review psychological theory and literature looking into the importance of the search for meaning and the shared experiences of the participants. Throughout history, humans have tried to find the meaning of life and of human existence (Batthyany & Russo-Netzer, 2014). The study of existentialism has looked at the impact of questions, such as 'why are we here?', 'what is the purpose of my life?' and the struggles humans have in trying to find meaning in a seemingly random and meaningless universe (Yalom, 1980). The positive psychology movement has also focused on meaning in life and has highlighted the importance of identifying 'what makes a life worth living' in order that people might feel fulfilled and find increased happiness, strength and resilience (Carr, 2011; Seligman, 2002). Batthyany and Russo-Netzer (2014) noted that rather than these two approaches being viewed separately, by combining them, it is possible to increase our understanding of how important for humans is the search for meaning in life is. Both approaches identify that a lack of meaning in life can lead to low mood, higher levels of anxiety and a higher risk of suicide, whereas having a meaning in life can act as a buffer against stressful life events and help people to cope (Batthyany & Guttman, 2005; Mascaro & Rosen, 2006; Reker, 2000). Therefore, searching for meaning is an ordinary process that we are all engaged in, however, particularly relevant to the findings of this research is that this search for

meaning increases following traumatic life events (Janoff-Bulman & McPherson, 1997).

The following paragraphs will review some of the literature into people's search for meaning following traumatic life events. Bulman and Wortman (1977) interviewed people following paralysis due to a spinal cord injury, using the question 'why me' to determine how people made sense of their experiences. They found that explanations ranged from; it was God's will, it is repayment for something bad I did, or trying to find meaning through searching for the positives. Interestingly, when Silver (1982) replicated the study she found a relationship between an increased search for meaning amongst those who blamed another for their situation and felt themselves to be a victim. This is perhaps why searching for a meaning for participants in this research was so important because they felt like they had no control over the situation and some blamed their parent.

Silver, Boon and Stones (1983) interviewed women who had been sexually abused during childhood and found that 80% were still searching for an answer as to why it happened to them and reported continuing to search for a meaning as being important. They found that the women in this study tried to find meaning in similar ways to those in Bulman et al.'s (1997) study. However, there was less emphasis on a religious explanation and approximately 20% made sense of their experiences by focussing on the positive outcomes, such as knowing that they can survive anything they are faced with.

Casey and Long (2003) noted that people who experience psychosis are likely to search for meaning as to why it happened and people can often have difficulties making sense of their unusual experiences (Smale, 2000). Fowler (1999) suggested that people can make sense of their experiences through attributing it to something external, such as being at risk of being harmed or through finding a positive personal meaning, such as God is speaking to me.

When summarising the findings in this area, Silver and Updegraff (2013) highlighted that having more time to search for meaning does not necessarily result in an increased likelihood of finding it. Also, searching for meaning is not necessarily always helpful because it can result in rumination with associated low mood and increased anxiety. Janoff-Bulman and McPherson Frantz (1997) suggested that when someone experiences a traumatic life event their sense making brings about a reappraisal of their life and whether it is of value and worth living.

They suggested that this is on a more existential level, where someone who has experienced trauma might consider whether or not their life is worth living and can move from life being meaningless to life being meaningful.

In summary, when people positively appraise their experiences this has a positive impact on their mood (Sears, Stanton & Danoff-Burg, 2003) and finding an answer to the question 'why me' is a protective factor because it has resulted in reduced anxiety, anger and improved mood (Silver 1982). Therefore, participants' search for meaning in this current study may be a way of coping with their experiences of feeling neglected and different to find a way of improving their mood. However, contrary to the findings described, none of the participants from this study ascribed their experiences to either religion or wrongdoing. They attributed their parent's experiences to either a genetic/biological cause, or as resulting from some traumatic life event, or they were confused and still searching for a meaning. Positive aspects taken from the experiences were reported by all of the participants. The following section will introduce the concept of post traumatic growth which helps explain this phenomenon further.

The concept of post traumatic growth suggests that after a traumatic event, it is possible to do more than just recover or survive: some may 'thrive' by developing from the experience in a positive way. Calhoun and Tedeschi (1999) suggested that there are three main areas of development; changes in relationships with others, changes in perception of self and changes in overall outlook on life. There has been debate over why some people experience post traumatic growth and others do not and it has been suggested that personality traits play a part. For example Peterson Park, Pole, D'Andrea, and Seligman (2008) carried out a study of 1739 adults and found that for those who had experienced traumatic life events, there was a relationship between satisfaction in life and character strengths, such as creativity, bravery, and appreciation of beauty and kindness. Other factors such as locus of control, self-confidence and dispositional optimism are also seen as influential personality traits (Tennen & Affleck, 1998). Saakvitne, Tennen, and Affleck (1998) argued that it is important that research look into how post traumatic growth occurs, not just to focus on what might influence it happening. Woodward and Joseph (2003) in a study of how life can be changed by a traumatic event, invited written testimony from 29 participants, ranging in age from 22 to 72. All wrote about a traumatic childhood experience, which included emotional, physical and sexual abuse, as well as neglect. The authors used thematic analysis to identify the

following themes: identifying the will to live, awakening of responsibility, love and nurturing, mastery and control, validation and acceptance, liberation and freedom, belonging and connection, changes in relationships, gaining new perspectives on life and changes in self-perception. There are some similarities between these findings and the experiences reported by participants in this research, in particular gaining a new perspective on life and changes in self-perception. There are some similarities between these findings and the experiences reported by participants in this research, in particular gaining a new perspective on life and changes in self-perception. Woodward and Joseph (2003) suggested that their study highlights the importance of people's perceptions of their ability to have control over changes in their life, which impacts on their ability to cope. They noted that this research found relationships with others to be important, for example feeling validated and nurtured helped make positive changes. They also acknowledged that little is known about the experiences the participants had undergone. For example, other external influences, such as psychological therapy, might have impacted on their growth. However, they were able to identify a broad range of experiences which people reported as bringing about these changes, ranging from kind words from someone, to buying a house or loving their children. They suggested that it was the individual's appraisal of the life event which changed them, and not a particular type of event itself. Their findings suggest it is possible to develop positive growth from traumatic experiences and that external influences and internal appraisals can impact on how we make sense of these experiences.

The findings from post-traumatic growth appear to fit with this current study, where participants identified positive growth following their difficult childhood experiences. However, there was something about the way in which participants spoke about this concept and after considering the research which highlights the reduction of anxiety and the improvement of mood when people make sense of their experiences in this way, I wondered if there was something protective about it. Perhaps taking something positive from the experience protects the person from the distress of it being a meaningless, painful experience. The following sections will further explore the idea that there is something protective in identifying the positive aspects of experiences and avoiding talking about the painful ones.

Hollway and Jefferson (2000) identified that when interviewing participants, researchers can come up against the following difficulties:

- In attempts to protect themselves from a vulnerable aspect of themselves, participants might be invested in portraying themselves a certain way.
- The participant might ascribe a different meaning to a question than the researcher or other participants.
- Participants will have a, mostly unconscious, drive to keep some of their emotions protected.
- Participants may not know why they think and feel the way they do.

They suggested using knowledge from clinical case studies can also help us to understand the research interview process further (Hollway & Jefferson, 2000). Kvale (1999) noted the importance of considering psychoanalytical theory when carrying out qualitative research, as this helps address the influence of the researcher's presence during the interview process. A researcher is unable to facilitate an interview without their own prior experiences, beliefs and assumptions and therefore it is crucial to try to understand one's bias. This is something which I noted during the interview with Richard, where towards the end of the interviews he spoke increasingly frequently about the death of his mother. This resulted in my finding it difficult to end the interview because of my drive to look after him. The feelings which we have during the analysis stage can be useful indicators for understanding the dynamics of the relationship and understanding these processes which might occur allows us to consider any feeling which the participant is avoiding expressing (Hollway & Jefferson, 2000). During the interview with Peter there were times when he distanced himself from how he felt about his experiences by using nonconcrete examples and speculation. In the extract below, he talks about the positive influences of going to live with his father. However, he reported that he did not have a positive relationship with his father and being a self-made person is important to Peter. Therefore, his repetitive use of the word 'probably' could highlight his underlying conflict of not wanting to attribute some of his achievements to his father and not wanting to acknowledge how this would make him feel.

Peter: "I lived with my dad for a few years, because that was necessary. So I had a few years away, and that probably helped a lot with, because dad, he doesn't have any weird beliefs, he is not weird at all mentally. So being around my dad probably influenced getting rid of all that stuff. So I probably asked my dad at some point if he believes in God, and he was probably like 'No of course not'. And that was probably at the time something of a shock maybe."

The language used during the interview process by some participants highlighted a strategy to avoid difficult feelings. For example, Richard, began the first interview with saying “*I tend to not dwell on my childhood too much to be honest, I keep it a bit buried.*” Also, during the interview with Richard it was difficult to move him away from descriptions of events towards thinking about how they made him feel, without him repeating another description of an event.

In summary, it is possible that participants avoided talking about some of the painful feelings associated with their experiences. The reporting of positive outcomes could be a way of protecting themselves from opening up to these painful feelings. However, it is also possible that moving away from a parent who experiences psychosis and the difficulties associated with this has resulted in participants’ lives becoming more meaningful, therefore leading to a focus on the positive aspects of their lives. It is also possible that due their fear about what other people might think about them having been through these experiences they did not feel able to be fully open about their more painful feelings during the interview.

The following sections will review the strengths and limitations of the research, followed by the clinical implications and suggested areas for future research.

Strengths and limitations of this study

Recruitment

Four out of the five participants responded to the advert on a poster at the university, which might mean that the sample is limited and it would be difficult to transfer the findings to other populations. I wanted to capture a sample of people who were not highly distressed or needing support from mental health services and were able to live their lives independently. Therefore, I initially tried to recruit people from the university in an attempt to capture people who met this criterion. However, as the areas where recruitment took place expanded to include people from the wider population it was hoped this might broaden the sample to include new characteristics but unfortunately these attempts were not all successful and only one of the participants was recruited in this way. Therefore, other avenues of approach to gain participants from the wider population would have been beneficial, for example putting adverts in different newspapers.

The sample

The sample size was small which means that it did not capture a wide variety of people who grew up with a parent with psychosis who might have brought a different approach to the findings. However, having a small sample size has meant that it is possible to go into more depth, for example during analysis, being able to spend more time considering the meaning of what participants were saying and being able to conduct two interviews with each participant. People who grew up with a parent with psychosis are underrepresented in the literature. This study was able to give voice to some members of this population and to find out what their experiences were like. It has also provided the opportunity to consider how to support children of parents with psychosis in the future, for example being aware of the possible impact of their feelings of responsibility, burden and feeling different from others. It has also highlighted the need to support parents with psychosis and to help them make sense of their experiences in order for them be in a position to support their children.

This research was initially aimed at young adults aged 18-25 years old. The difficulty of attracting enough people to participant from this age category resulted in a change to including adults over the age of 25. The sample then appeared as being divided into two age groups; three participants who were younger adults and two participants who were middle aged adults. There were thus some differences in how participants made sense of their experiences, for example the middle aged participants' model of explanation for psychosis was based on the medical model, which resulted in their experiencing a greater fear of developing psychosis themselves. The age gap may also have meant that reported childhood experiences were less homogenous than if all participants had been the same age, for example as health services and education systems change over time, the provisions available might also have changed. However, this is not apparent during the interviews because all of participants spoke of a lack of care and support from others. Four of the participants identified themselves as university educated and middle class and all of the participants were white, four being white British. Therefore, the diversity of cultural experiences and social economic status within this sample is limited.

All the participants in this research volunteered to take part and often identified themselves as doing so because they wanted to help me with the research. This led me to think about whether there might be something about their experiences which resulted in their being more caring towards others and thus more likely to

volunteer. I considered the potential participants who did not make contact with me and how different their experiences might have been. I reflected on an interaction that occurred whilst I was putting up a poster advertising the study and what I might learn from this. This person was very angry towards me for putting up the posters, saying they had grown up with a parent with psychosis but would not ever want to talk to anyone about it: they left before I was able to respond. This highlights the possibility of there being other potential participants with different reactions and ways of coping with their experiences to the participants in this study. Their inclusion in the research might have influenced the findings.

Interviews

By interviewing people about their experiences it is assumed that they are able to access their thoughts and feelings on the topic in order to be able to talk about them. However, the level of ability to recall and reflect on their experiences varied amongst the participants. It is not always possible for participants to access some of the more painful feelings associated with their experiences because in order to cope with them they have had to avoid thinking about them. This was reflected in the use of language by participants, such as *“I imagine I felt like”* or *“I’m not sure how I was feeling”*. It is also possible that participants’ concerns as to what I might think about them influenced what they told me.

The power dynamic during the interview might have influenced what participants were willing to share (Maynard & Purvis, 1994). Attempts can be made for the interviewer and interviewee pair to be more evenly matched, for example the same gender (Hollway & Jefferson, 2000). However, this brings with it an assumption about the type of matching which will facilitate a more open discussion, whereas research has suggested that it is not always an obvious pairing which is helpful. For example women have been found to talk more openly about sexual violence to a male interviewer than a female interviewer (Currie & McLean, 1997). During this research it was not possible to consider changing the pairing of interviewer and interviewee as I was the only person carrying out the interviews. Therefore, it is possible that some of my personal characteristics, such as age, gender, or the university setting, influenced the power dynamic of the relationship and the openness of the participants.

I found that during the second interview participants appeared to be less anxious and often told me more sensitive information than in the first. It is possible

that this is because it allowed for a trusting relationship to be built and this has been shown to be important in helping participants feel comfortable enough to open up (Hollway & Jefferson, 2000). Reid, Flowers and Larkin (2005) suggested that rapport can be developed if the researcher is able to “*allow participants to think, speak and be heard*” (Reid, Flowers, & Larkin, 2005, p.22). Participants also used the time in-between interviews to experiment with changes to their behaviour which provided valuable information which was incorporated into the themes.

From the very beginning of this research I have been concerned about the large amount of literature which focusses solely on the negative consequences of growing up with a parent with physical or mental health difficulties: these preconceptions may well have influenced the way data is collected. I hope that through avoiding ‘why’ questions and developing an interview schedule which encouraged participants’ to be as open as possible it allowed for a more balanced view than is currently in the literature.

The analysis

Whilst IPA is able to produce rich in-depth data, the interpretation of the data is open to influence by the researcher’s own assumptions and beliefs (Lyons & Coyle, 2007). Attempts were made to ‘bracket off’ my own prior assumptions, but it is not possible to do this entirely. I made use of a reflective diary, supervision and quality checks in an attempt to ensure that I stayed as grounded as possible in the participants’ experiences. For example, during supervision towards the end of the group analysis, we discussed my emotional reactions to each of the participants, identifying that there was something about Mary and Amanda which had resonated more strongly with me. Initially, I considered that their interviews were more laden with emotion, (Mary’s anger and Amanda’s fear and sadness), whereas the other participants’ expressions of emotions were more fleeting, for example Rosie became upset briefly. However, the more I reflected on my emotional reaction, the more I realised that there was something about Mary and Amanda with which I identified; they are both a similar age to myself, the same gender and have both been through university and both identified themselves as being more caring towards others because of their experiences. They also identified their experiences as making them stronger and more determined to be successful. This was unlike the other participants, for example Rosie and Richard, who have withdrawn from other people. Being more aware of this enabled me to identify the possibility that I might be more biased towards focusing on Mary and Amanda’s experiences and be

overlooking the other participants' experiences. To manage this I ensured that the other participants were equally thought about during the analysis stage and equally written about and quoted in this report.

Credibility and reliability

As previously stated, in an attempt to ensure that my analysis was an accurate reflection of the data I carried out credibility checks. This process involved one of my supervisors reading a transcript and the emerging themes and both of my supervisors discussing sections of transcripts and emerging themes with me. Creswell (2013) suggested that to further increase the validity of the themes produced, it is helpful to go back to the participants and discuss the findings with them to see if they feel they are an accurate reflection. Therefore, this is something which could have been carried out which might have increased the validity of the findings. However, it is important to note that not all of the participants' experiences are reflected in all of the themes and some of the themes are interpretations of what participants said. Therefore, how this process is carried out would need some careful consideration to ensure that increased distress was not caused. Elliott, Fischer and Rennie (1999) also suggested that it might be helpful to share the themes and the data with someone who has been through similar experiences but has not participated in the research. Therefore, if this has been carried out it might have increased the validity of the research.

Gaining an adult's perspective

Developing an insight into what it might be like to grow up with a parent with psychosis from an adult's perspective is beneficial because of the possibility of children being more guarded in their discussion. Aldridge (2006) and Meredith (1991) suggested that children may not open up fully because they want to protect their parent, they fear what might happen if other people find out about their parents' experiences or they might fear being rejected by their parent if they tell other about their experiences. They might also feel guilty about their parent's experiences and blame themselves or they could feel responsible for what might happen to their parent if people knew what it was like for them. Interviewing adults who are not so dependent on their parents' care and are not so fearful of the consequences, for example being taken away from their parent, allows for a more open account.

Clinical implications

Providing more support to children who have parents with psychosis

Participants identified feeling burdened by their responsibilities: other people only asked them superficial questions and did not provide them with support. They identified that support would have been helpful in order for them to understand and to learn how to manage their parent's experiences. They indicated that they would also have benefitted from more emotional and practical support.

Peter: "I found a leaflet that someone had given her about how to cope with voices and stuff, and it had a page in there about how family members should deal with it. And there were things in there that I had generally never considered, like don't tell a schizophrenic person that they are being paranoid, that is not a good thing. And I had been doing that for years, saying 'Mum, you are being paranoid', trying to reason with her... I was kind of annoyed...I had never been sat down properly and said hey, you know, we can tell you these things that might help you manage it better."

Therefore, it would have been helpful to participants if they had been offered support and the space to talk about their experiences with their wider family, teachers at school and people within their community. Perhaps if their experiences had been noticed by others and they were helped by others this would have increased the likelihood and opportunities for them to feel less isolated and burdened and perhaps develop some secure attachments.

Participants identified wanting help understanding their parents' experiences and this might have been a role for mental health professionals if they are supporting a parent. It is important that mental health professionals consider the whole family system and identify if people they are working with have any children. It would then be crucial to identify any needs of the children, such as identifying further support, or talking to them about unusual experiences. However, fear on the part of both the parent and child of the consequences of talking to a mental health professional about their experiences might result in their not being fully open (Meredith, 1991). Therefore, it would be important to validate these concerns, be open about the possible outcomes and speak to the children away from their parent. It would also be beneficial to support parents with psychosis and to help them make sense of their experiences in order for them be in a position to support their children. Encouraging parents to help their child to make sense of

their experiences with support and perhaps through the use of age appropriate information is important. Including them in family support groups or referring them to a young carers support network might also help them to feel more supported and less alone. A further opportunity for support and intervention can occur at school: this will be discussed further in the section below.

Participants reported feeling health care professionals could have provided them with more support and information on their parent's experiences. Therefore, it might be helpful to provide training for mental health workers in order to increase awareness of the importance of addressing the needs of the whole family when they are working with someone with unusual experiences. In order to help increase understanding of psychosis it would be important for this training to highlight the psychological explanations, including normalising unusual experiences through the idea of them being on a continuum of human experience.

Providing support to adults who grew up with a parent with psychosis

In adulthood, participants continue to feel burdened by their sense of responsibilities, unable to talk to others about their experiences and fearful of developing psychosis themselves. It would be helpful if support were available to adult children of people who experience psychosis if they felt that they needed further this. Part of this process might involve increasing society's understanding and willingness to talk about unusual experiences, which is discussed in more detail below. For those who might have more difficulties making sense of their experiences and feel more isolated, further support could be through connecting to others who have had similar experiences, either through support groups or through the internet.

Reducing stigma

One of the areas which had prevented participants opening up to others about their experiences was fear of what other people would think about them. This has resulted in their feeling alone and having to manage these difficulties on their own. Research into how to reduce stigma for family members of those with mental health problems is not currently available. Lessons can, however, be learnt from the literature about reducing the stigma of those with mental health difficulties. Helpful strategies which have been suggested include increasing education about mental health difficulties for the general population (Penn, Kommana, Mansfield,

& Link, 1999); if schools provided more education about mental health difficulties then this might allow children to develop more understanding and feel more able to speak about their own and their relatives' experiences without feeling ashamed or humiliated. Ensuring the negative media coverage of mental health difficulties is challenged with the aim of stopping its production has been identified as being helpful in reducing stigma (Wahl, 1995). There has also been more recent movements of involving social media to help increase people awareness and understanding of mental health difficulties, for example the 'Only Us Campaign'. This campaign states the following:

"There's 'Them' and there's 'Us'. We are well, happy and safe. They are mentally ill and dangerous. Is this really true? Or is the uncomfortable truth that there's a continuum, a scale along which we all slide back and forth during our lives? When we separate ourselves we hurt those labelled as sick, ill, even mad, but we also hurt ourselves" (from <https://www.talkforhealth.co.uk/the-only-us-campaign/>).

This campaign highlights the importance of developing awareness about the negative impact of labelling people as 'mentally ill' and of the importance of increasing people's understanding of the continuum of human experience. If the general population had increased knowledge and understanding of unusual experiences and it was talked about more often, this might help increase understanding, reduce fear and ultimately reduce stigma. Corrigan and Miller (2004) suggested that to help with this, individuals with mental health difficulties and their family members need to become more open to talking about their experiences in order for the general population to develop a greater understanding. However, as Read and Baker (1996) found, people with mental health difficulties have reported experiencing harassment or abuse because of their mental health difficulties and therefore being more open about their experiences would be a difficult step to take. This is similar to the participants in this research who did not feel able to talk to others about their experiences because they feared the possible consequences. Therefore, perhaps the task of people becoming more open about talking about unusual experiences should be shared across society; if everyone was more willing to talk about peoples' unusual experiences and ask questions in a caring manner this might reduce some stigma and increase empathetic understanding. If society were to become more aware of the idea that unusual experiences are on a continuum and that for some this can intensify and cause a

greater impact when they are faced with distressing life events, this might help reduce society's stigma towards unusual experiences.

Areas for future research

Throughout this research a question has remained regarding the reporting of positive outcomes by participants and whether these aspects of their experiences are held alongside the more painful feelings; or if it is a protective factor to ward off the more painful feelings, or if there are no painful feelings being avoided. It would be of benefit for future research to explore people's experiences of post traumatic growth and to find a more systematic way to understand the different outcomes to difficult experiences. Perhaps using a different data collection method, such as a free association, might allow access to some of the emotions which are not in participants' conscious awareness, or it might highlight that both experiences are held alongside each other. Hollway and Jefferson (2000) suggested the use of free association as potentially allowing indirect expression of emotions which are not in participants' conscious awareness. It might also be useful to include other sources of data collection, such as diaries, or observations of interactions with others, including their parent. This might help to overcome the possibility that participants avoided talking about how they were feeling. The interviews were also held in a university building which might have created a power dynamic between myself and the participants, making them more concerned about what they should say. Therefore, if future research were to take place somewhere more neutral, such as community centre this might make participants feel more comfortable and allow them to talk more freely.

As previously mentioned, the participants in this research fall into two categories; young adults and middle aged adults. It was noted that this had an impact on their sense making of a parent with unusual experiences and to influence their willingness to make changes. For example, Richard and Rosie identified how their experiences had impacted on them, such as feeling isolated and lonely but they also did not suggest ways in which they might change this. However, the other participants identified areas where they would like to make changes and Peter and Amanda practiced making some changes between interviews. Therefore, it would be interesting for further research to carry out longitudinal study to identify if these experiences are stages people go through, or if it is less fluid and more dependent on the person. It would also be interesting for further research to interview older

adults who grew up with a parent with psychosis in an attempt to see how they have made sense of their childhood experiences over the course of their life.

It would be useful for future research to find out if providing further support and an increased understanding of psychosis helps children and adults who have parents with psychosis to feel more supported, less isolated and less fearful of developing psychosis themselves.

Future research would benefit from interviewing participants from a wider variety of backgrounds, for example this sample identified themselves as mostly university educated white middle class and therefore it would be beneficial to gain a perspective from different cultural and social economic status. The participants in this research were not supported by mental health services and it is possible that the participants in this research volunteered to participate because they experienced positive growth from their childhood experiences and those who did not were less likely to participate. Therefore, it might be useful for future research to look into the experiences of those growing up with a parent with psychosis who have developed mental health difficulties themselves, in order to ascertain the possibility of their experiences being different. It might also be useful for future research to carry out a survey to identify the numbers of adults who grew up with a parent with psychosis. This might help to identify the number of people who have transitioned into adulthood well but who might continue to have painful feelings associated with these childhood experiences.

Conclusions

This research explored how adults made sense of growing up with a parent with psychosis during childhood, how they make sense of this experience now and considered how these experiences have impacted on them. The findings indicated that participants felt neglected and uncared for by their parent with psychosis but also by the other people in their lives. This research highlighted how participants felt different from their peers and alone with their experiences. It found that participants wondered if they would develop unusual experiences like their parent and how they have a tendency to try to find people who they see as different but like themselves to increase their sense of belonging. The findings also gave insight into participants' shame and fear of humiliation if other people were to find out about their parents' experiences and their attempts to keep their experiences a secret as a result. This research also found that participants reported positive

growth from their experiences but reflected on their apparent need to find the positive, possibly in order to protect themselves from the thought that the experience had been painful and meaningless. The findings highlight the importance of society to find out how these children are really managing and to identify possible areas of support, such as helping them to understand their parents' experiences or providing emotional and practical support to lessen the burden. It also emphasised the negative impact stigma has on people who grow up with a parent with psychosis. It reinforced the importance of society to become more open in talking about psychosis and of considering the idea of psychosis being on a continuum of human experience.

Closing reflections

This research has highlighted the complexity of the experiences of growing up with a parent with psychosis and the different conflicting feelings it raises. What resonates with me most is how different and alone the participants felt during childhood but how they continue to do so in adulthood. This research strengthens my beliefs of the importance of society talking more openly about unusual experiences and of increasing people's awareness and understanding in order to reduce the associated stigma. In the past I hoped to work with people with psychosis but had not fully considered the importance of working with their family members. This research has shown me the importance of giving a voice to children of parents with psychosis and to provide support, not only for the person with psychosis, but for those close to them.

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Appendices

Appendix 1. Screening questionnaire.....	119
Appendix 2. Recruitment poster.....	121
Appendix 3. Participant information sheet.....	122
Appendix 4. Interview one topic guide.....	124
Appendix 5. Interview two topic guide.....	126
Appendix 6. Transcriber confidentiality form.....	127
Appendix 7. Ethics approval letter July 2015.....	128
Appendix 8. Ethics amendments letter November 2015.....	129
Appendix 9. Information sheet for further support.....	130
Appendix 10. Consent form.....	131
Appendix 11. Example of a transcript after analysis.....	132

Screening questions

Over 18?

Not involved in community mental health services?

Do you know if your parent had a diagnosis such as Schizophrenia or Schizoaffective disorder, or if anyone ever mentioned they had psychosis?

I'm going to ask you a few questions about your parent's experiences and whether when you were growing you noticed any of the following. Let me know how frequently this happened:

1. They had beliefs which seemed unrealistic or perhaps a bit eccentric.

2. Their thinking seemed confused or muddled.

3. They saw or heard things which others could not see or hear.

4. There were times when they were really hyperactive and appeared to have more energy than normal.

5. They had mood swings which seemed extreme.

6. They had beliefs which seemed unrealistic, such as they thought they were superior to others, for example they might have thought they had extraordinary abilities, wealth, knowledge, fame or power.

7. They were concerned about others intentions towards them, such as feeling suspicious that others might harm them.

8. They did not appear to be connected to their emotions, for example they didn't show many facial expressions or express much emotion.

9. They lacked interest in and involvement with events going on in their life, including hobbies and social interactions.

10. If they ever had to go into hospital because of these experiences they found it hard to understand why they needed to and did not see themselves as having any difficulties.



11. If they were on medication there were times when they were reluctant to take it because they did not believe they needed it.

What was *growing up* like for you?

UNIVERSITY OF LEEDS
Leeds Institute of Health Sciences
Faculty of Medicine and Health

Study title: *Making Sense of Growing Up with a Parent with Psychosis.*

This study has been reviewed and given a favourable opinion by the Central of Human Research Ethics Committee (CHREC) on 20/07/12, ethics reference: 2012/01/0071.



Version 3.18.11.13

Your information will be kept confidential. Please tear off my details below and contact me if you have any questions or would like further information. I look forward to hearing from you, Mel.

To take part in this research you need to be 18 or over and as a child have either lived with or had regular contact with a parent who had *unusual experiences*, such as *psychosis, hearing or seeing things*, or had a diagnoses of either *Schizophrenia or Schizoaffective disorder*.

Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816	Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816	Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816	Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816	Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816	Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816	Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816	Melanie Parkins Email: ummpa@leeds.ac.uk Telephone: 07949557816
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Participant Information Sheet

Research title: Making sense of growing up with a parent with psychosis.

I would like to invite you to take part in a research study which I am completing as part of my Psychology Clinical Training at the University of Leeds. The aim of the research is to find out about the experiences of people who grew up with a parent with psychosis, what sense they made of it at the time and what sense they now make. This research will also look at whether talking about these experiences has an impact on how people make sense of them. However, before you decide whether you would like to participate in this study it is important for you to know what this will involve and why the research is being done. Please take time to read the following information thoroughly and ask me if there is anything which is not clear or you would like to know.

What is the purpose of this study?

The term psychosis is used to describe unusual experiences that people may have like significant alterations to mood, perception, thoughts and behaviour, including voice hearing, unusual beliefs or suspiciousness. Whilst we have some understanding of the experiences of children who grow up with a parent with psychosis we have little understanding about how they make sense of this as an adult. I am interested in what it was like to have grown up with a parent who had ongoing unusual experiences and hope that these findings will provide important considerations for people who come into contact with children in similar situations. I am also interested to find out whether this has any impact on the journey into adulthood. To do this I aim to interview approximately 5-10 adults who grew up with a parent with psychosis.

Who can take part in this research?

People who grew up with, or had regular contact with, a parent who had ongoing unusual experiences as described above or was diagnosed with either Schizophrenia, Schizoaffective disorder or psychosis. To take part you must not currently be supported by a community mental health team and need to be 18 years old or over.

Do I have to take part?

It is your decision whether you would like to take part in this research. If you take part but then change your mind you have the right to withdraw from the study up until one week after your interview took place.

What happens if I decide to take part?

Firstly, if you decide to take part I will answer any questions you have about the research via telephone. During this telephone conversation I will ask you a few questions about your parent's experiences to ensure that they match the inclusion criteria described above. We would then agree a date and time to meet for the first interview. This will take place at the University of Leeds during the day on a week day and will last approximately 1 ½ hours. The interview will involve talking about your experiences and answering a few questions to aid this discussion. If you become distressed we can either take a break or we can end the interview at any point. Some people might find that the interview makes them think about their experiences in more detail and therefore I will invite you to attend a second interview the following week for the opportunity share these reflections. I will record the interviews on an audio recorder to enable me to transcribe our interviews and ensure I do not miss any details.

What are the potential benefits of taking part in this study?

By participating in this study you will be providing information to help further the understanding of people's experiences of growing up with a parent with psychosis. You may also find it beneficial and interesting to talk through your experiences. There will be a £20 Amazon gift voucher available for anyone who participates.

What are the potential disadvantages of taking part in this study?

You might find that talking through your experiences brings up painful memories or emotions, or you become aware of personal distress that you were not previously aware of. I will give every participant a sheet of information on where you can access further support.

Will the information I provide be confidential?

All information I receive from you will be kept confidential unless I am concerned about any risk to yourself or any other people. If this were to happen then I would discuss my concerns with you and talk to you about who I would need to speak to, such as my supervisors. A university approved transcriber will be appointed to transcribe the recording but they will work under the same confidentiality rules. None of the transcripts will contain personal information, such as names or addresses and any reference made to particular individuals will be made anonymous so that they are not recognisable. The transcripts will be uploaded onto the university's secure server and the audio-recordings deleted from the device. These will then be deleted when the research is complete (September 2016). The transcripts will be printed out but will be kept in a locked cabinet and archived for three years after the research is complete.

What will happen to the results of the study?

If you would like to know the outcome of this study I can provide you with a summary of the findings once the research has been completed. The results will also be written up into a doctoral thesis, submitted to journal for publication and may also be presented at conferences. I might use some extracts from the transcription of your interview during these processes but at no point will any information which would make you identifiable be disclosed.

Who is funding this research?

This research forms part of my training as a Clinical Psychologist and is therefore supported by the University of Leeds. This study has been reviewed and given a favourable opinion by the School of Medicine Research Ethics Committee (SoMREC) on 29.07.15, ethics reference SoMREC/14/078.

What happens next?

If you have any further questions or would like to take part in this study please contact me on the details below. If you do not wish to take part in this study you do not need to do anything further.

If you would like to discuss this research further with another member of the team please contact Dr Carol Martin, (Senior Lecturer in Clinical Psychology and Clinical Psychologist) or Dr Anjula Gupta (Consultant Clinical Psychologist) on 01133432732 or the address below. If you have any concerns about this research please contact Clare Skinner, Faculty Head of Research Support, Faculty of Medicine and Health Research Office, Worsley Building, University of Leeds, Leeds. LS2 9NL.

Thank you for taking the time to read this information sheet.

Contact details: Melanie Parkins, University of Leeds, Charles Thackrah Building, 101 Clarendon Road, Leeds, LS2 9LJ. Email: ummjpa@leeds.ac.uk Telephone: 07949557616

Version 6: 12.11.15

Appendix 4.

Topic Guide

What was it that interested you in taking part in this study?

Experiences and sense making as a child

When you were a child what were the unusual experiences you noticed your parent had?

How did you feel about these experiences?

What did you think about them?

What was it like having a parent with unusual experiences?

Find out information about:

Relationship with both parents Relationships with others – friends/siblings

School life

Sense of self

Experiences and sense making an adult

How do you make sense of these experiences now?

What do you feel about these experiences?

What do you think about them?

Do you think these experiences have shaped who you are in anyway? – Sense of self

What would you do if these experiences were happening to you now?

Do you think you would do anything differently?

How might your life be different if you hadn't had these experiences?

Find out information about:

Relationship with both parents Relationships with others – friends/siblings

Independence University life

Is there anything else which you think is important or useful for me to hear?

Prompts: I noticed that is different to how you spoke about your experiences as a child, could you tell me more about that?

Pick up on comments which seem to have meaning and significance e.g. can you tell me more about X? What sense did you make of X? What sense do you make of X now?

Pick up on feelings: either though noticing what is happening in the room or when feelings are referred to.

Ask for examples of experiences.

Appendix 5.

Second interview topic guide

How was the last interview for you? How did it affect you?

Was there anything in particular you noticed yourself thinking about/feeling/doing afterwards?

Have you noticed any differences in the way you think or feel about your experiences?

Was there anything we didn't touch on or anything that you want to talk about today?

What has it been like talking about your experiences in both of these interviews?



Confidentiality Statement for Transcribers

Doctorate in Clinical Psychology Training Programme

The British Psychological Society has published a set of guidelines on ethical principles for conducting research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.

As a transcriber you have access to material obtained from research participants. In concordance with the BPS ethical guidelines, the D.Clin.Psychol programme requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

General

- 1) I understand that the material I am transcribing is confidential.
- 2) The material transcribed will be discussed with no-one.
- 3) The identity of research participants will not be divulged.

Transcription procedure

- 4) Transcription will be conducted in such a way that the confidentiality of the material is maintained.
- 5) I will be supplied with the audio-recordings on an encoded USB and will work directly from this USB, not downloading the audio-recordings onto my computer.
- 6) I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
- 7) All materials relating to transcription will be returned to the researcher, and no copies will be made.

Signed K. White Date 7/12/15

Print name KIARA WHITE

Researcher MELANIE PARKINS

Project title MAKING SENSE OF GROWING UP WITH A PARENT WITH PSYCHOSIS

Appendix 7.



UNIVERSITY OF LEEDS

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 10, 111b, level 10
Worsley Building
Clarendon Way
Leeds, LS2 9NL
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29 July 2015

Miss Melanie Parkins
Psychologist in Clinical Training
Programme in Clinical Psychology
Leeds Institute of Health Sciences
Charles Thackrah Building
Clarendon Road
LEEDS LS2 9LJ

Dear Mel

Ref no: **SoMREC/14/078**

Title: **Making sense of growing up with a parent with psychosis**

Your research application has been reviewed by the School of Medicine Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documentation received from you.

Document	Version	Date Submitted
MP Ethics form v3	3	20/07/2015
Appendix1 Participant Information Sheet v4	4	20/07/2015
Appendix2 Contact Details for Further Information v2	2	17/06/2015
Appendix3 Topic Guide	1	01/05/2015
Appendix4 Poster v4	4	20/07/2015
Appendix5 (Interview Questions)	1	01/05/2015
Appendix6 Consent Form v3	3	20/07/2015

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhresearchethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

Appendix 8.



UNIVERSITY OF LEEDS

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 10.111b, Level 10
Worsley Building
Clarendon Way
Leeds, LS2 9HL
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13 November 2015

Miss Melanie Parkins
Psychologist in Clinical Training
Programme in Clinical Psychology
Leeds Institute of Health Sciences
Charles Thackrah Building
Clarendon Road
LEEDS LS2 9LJ

Dear Mel

Ref no: SoMREC/14/078

Title: Making sense of growing up with a parent with psychosis

We are pleased to inform you that your amendment to your research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documents received from you and subject to the following condition:

- Evidence of organisational managerial permission must be provided from all the locations/venues where you intend to display recruitment posters

Document	Version	Date submitted
Amendment Form	1	02/11/2015
CommunityCentresLessedNovember2014	1	02/11/2015
Consent form V4	4	02/11/2015
Information Sheet V6	6	12/11/2015
Lone working policy V1	1	02/11/2015

Please notify the committee if you intend to make any further amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmh.urethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

Appendix 9.

Contact details for further support

Below are the contact details of services available.

GP services

If you feel you need further support please contact your GP as they will be able to identify the most appropriate support for you.

Samaritans

Phone: 08457 90 90 90/ 0113 245 6789

Email: jo@samaritans.org

Location: 93 Clarendon Road, Leeds, West Yorkshire, LS2 9LY

Description: Samaritans is a registered charity aimed at providing support to anyone in emotional distress or struggling to cope.

Improving Access to Psychological Therapies (IAPT)

Phone: 0113 843 4388.

Email: leedsiapt@nhs.net

Website: <http://www.leedscommunityhealthcare.nhs.uk/iapt/home/>

Description: IAPT provides psychological treatments, sometimes called talking treatments, to help people who are stressed, experiencing low mood (depressed) or are very nervous (anxiety).



Consent form

Research title: Making sense of growing up with a parent with psychosis.

Please read the following statements and place your initials in the box next to it if you agree.

I have read and understood the information sheet for the above study.	
I have asked any questions which I might have about participating in this study and the answers have been to my satisfaction.	
I understand that participation in this study is voluntary and that I am able to withdraw my information up until one week after my interview took place. I understand that I do not have to give any reasons and there will be no consequences	
I understand that all personally identifiable information will be kept confidential, unless the researcher is concerned about any risk to myself or any other people in which case the researcher will discuss it with her supervisors.	
I agree to anonymised quotes being used in any written report.	
I consent to my interviews being recorded and transcribed by a university appointed transcriber.	
I consent to take part in this research.	
If you would like to be provided with a summary of the findings once the research has been completed then please provide your contact details below:	

Name of Participant

Signature

Date

.....

.....

.....

Name of Researcher

Signature

Date

.....

.....

.....

519 someone else would like shove it under the table and they'd look like the
 520 person who cried wolf. I know that there was an incident where like my mum
 521 called the police, on one of her delusions. I don't remember which one it
 522 was exactly but it was something to do with my dad which is how he knows
 523 about it because he was called into this too. But when the police officer
 524 came and listen to what she was saying he was like, oh crap, this isn't
 525 actually like same behaviour. So they actually tried to have her medically
 526 examined to see, like, you know, do we need to actually have something
 527 done? But the examiner literally only asked what year is it, who's the
 528 president and then left. So it wasn't really pushing, can you really take care
 529 of your children? Erm, is there something really wrong here? So most
 530 people just didn't want to get involved. They would do what they could to
 531 help out the kids, but not really try to make much of a mess of things
 532 (and what do you make of that at the time?)
 533

534 I personally appreciated it really, I mean as much as it was like, as much as
 535 it was tough sometimes, I mean I was handling it, I didn't want to like have
 33 Bye, bye, getting checked
but I was not able to cope

536 I could not ask for help
 community would
 dismiss it was
 whiff bad
 really bad

537 Community did
 not want to
 know if I was
 ok

538 I had to cope
 on my own

539 My role as a
 carer is
 important to me

540 It wasn't a real
 serious problem
 they'd look like the person
 who cried wolf
 they wouldn't be there when
 things were really bad +
 really needed help
 - I need to wait
 until it's really
 dangerous

541 No one asked if we
 can really take care of
 our children
 others did not want to
 know the real problem
 things would get messy if others
 got involved
 it felt good to
 cope

542 I appreciated it it was my
responsibility
 I was handling it to me
 my role which means
 valued how to cope + can't say it