

Siblings in Early Psychosis – What Health Professionals Need to Know.

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Abstract

Siblings play an important role in human development during adolescence and early adulthood. It is during this period of life when the onset of early psychosis commonly occurs. Whilst the impact of early psychosis upon parents has been shown to result in increased burden and distress, little attention has been given to the experience of a sibling. This study seeks to provide insight into the sibling experience.

This research used a survey methodology to explore the experience of 157 siblings during the first 18 months of their brother or sister's treatment. A special-purpose survey was developed consisting of seven components. Five of these were existing questionnaires and the other two were designed by the researcher. Participants reported on their knowledge of psychosis (Knowledge About Schizophrenia Questionnaire, Ascher-Svanum, 1999), their sibling relationship (Adult Sibling Relationship Questionnaire, Stocker, Lanthier & Furman, 1997), the burden they were experiencing (The Experience of Caregiving Inventory, Szmukler, Burgess, et al., 1996), the impact of events related to their brother or sister's illness (Impact of Events Scale – Revised, Weiss & Marmar, 1997), and their quality of life (WHOQOL-Bref, WHO, 1998).

Statistical differences between groups were investigated using independent samples t-tests and a series of one-way between-groups analysis of variance (ANOVA). Correlation analyses were used to detect relationships between scales and variables. Pearson's product-moment co-efficient (r) was used as all data were normally distributed.

The findings showed that gender and birth order were important as younger sisters experienced the greatest impact. When the young person experiencing early psychosis had a period of untreated psychosis longer than 6 months, required more than one admission to hospital, had persisting psychotic symptoms, continued to use substances, and/or had a history of physical violence, the sibling relationship was reported to be less warm. When the young person with early psychosis had attempted suicide and/or had been physically violent, siblings reported being less satisfaction with their quality of life.

Living with the ill brother or sister resulted in less satisfaction in the social domain of quality of life.

Implications for practice involve sibling inclusion. The results of this research invite mental health clinicians to reflect on siblings as integral to interventions with both the identified client and the parents. Siblings require a unique approach to engagement and individualised education, specifically tailored to their unique circumstances, to reduce burden and enhance coping. Further, it is recommended that parents be educated about common sibling experiences during early psychosis. Finally, this research has identified characteristics of early psychosis that significantly affect the sibling experience. It is suggested that clinicians use these findings to identify siblings at risk. Further research in identifying targeted support options for siblings in early psychosis is recommended.

Statement of Authorship

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for another degree or diploma.

No other person's work has been submitted for the award of any other degree or diploma in any other tertiary institution.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in this thesis were approved by the The Behavioural and Psychiatric Research and Ethics Committee of North Western Mental Health Program and the La Trobe University Human Ethics Committee (See Appendix E).

Signed _____

Siann Bowman

Date _____

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Chapter One: Introduction

This study is situated in the context of adolescents and young adults with a first episode psychosis living in Victoria, Australia. Early psychosis or first episode psychosis, which is central to this thesis, refers to the first 18 months after the initial onset of a psychotic illness. This onset most often occurs during the developmental stage of late adolescence and early adulthood (McGorry, 2010; McGorry, Nelson, Amminger, Bechdolf, Francey & Berger, 2009).

In Australia, the Australian Bureau of Statistics (2009) indicates that forty-seven per cent of young Australians aged 15-29 live at home with their parents and siblings (ABS, 2009). Young Australians generally do not leave the parental home until early adulthood when education is completed and/or financial independence is achieved (ABS, 2009).

Adolescence is a complex phase of development (Arnett, 2010). The essential developmental tasks of the period include establishing relationships with peers; achieving emotional independence; preparing for a career; establishing a sense of morality; and developing a gender role (Havinghurst, 1972). With societal changes and the growth of western economies in recent decades a new phenomenon described as “prolonged transition” from adolescence into adulthood has been observed (Arnett, 2010). This is explained by greater numbers of young people continuing into tertiary education beyond secondary school; delaying full-time work, thus delaying economic independence; and young people living longer in the family home and marrying/partnering and/or starting a family significantly later (Arnett, 2010). Arnett describes this period of emerging adulthood as “the age of exploration, the age of instability, the self-focused age, the age of feeling in-between, and the age of possibilities” (2010, p.12).

Psychoses represent the most severe of the mental health disorders, experienced mostly by males, which may lead to a disability that lasts a life time (McGrath et al.,

2004). It causes severe disruption to social and psychological development which can be compounded by further risks of prolonged psychosocial decline and arrested identity formation (McGorry, 2010). Normal developmental challenges such as negotiating peer and parental relationships, and achieving educational and vocational goals may also become more difficult due to cognitive impairment, secondary morbidity and stigma (McGorry, 2010).

Intensive interventions aimed at maximal symptomatic and functional recovery and relapse prevention are delivered during the critical early years after diagnosis (Birchwood, Todd, & Jackson, 1998; McGorry, 2010). The emergence of increasing evidence and widespread national and international efforts to reform services and develop treatment approaches for early psychosis have resulted in close to 200 early intervention centres worldwide that focus on the special needs of young people and their families (McGorry, 2010).

Although early intervention programs hold the promise of better outcomes with an emphasis on the prevention of the progression of illness and minimization of the trauma experienced by the young person and their family (The Australian Clinical Guidelines for Early Psychosis, 2005; McGorry, 2010), many international and local researchers have noted that it is not uncommon for young people to experience hospital admissions, persistent symptoms, comorbid mental health conditions and a deterioration in psychosocial functioning (Lambert, Conus, Cotton, Robinson, McGorry & Schimmelman 2010; Large & Nielsson, 2008; Robinson, Cotton, Conus, Schimmelman, McGorry & Lambert 2009; Wade, Harrigan, Harris, Edwards & McGorry, 2005; Wade, Harrigan, Whelan, Burgess, & McGorry 2004). These researchers have also shown that a prolonged period of psychosis before treatment is associated with poor symptomatic and functional recovery (Conus, Cotton, Schimmelman, McGorry & Lambert, 2007; Perkins et al., 2005).

The rationale for working with families in early psychosis is clear. Because of the age of the onset of psychosis, many young people are still living with, or are in close contact with their parents, grandparents and family of origin (Addington & Burnett, 2004). The Australian Clinical Guidelines for Early Psychosis (2005) provide recommendations for early intervention services and family work is seen as playing a key role. Working with the family and others who are important in a young person's social network ensures that their difficulties are understood. Offering help at this early stage supports the family's understanding, the way in which they relate to each other, and their adjustment to the major changes they face in their lives (Addington, McCleery & Addington, 2005).

Distress and psychiatric morbidity has been reported in the relatives of families in early psychosis (Addington et al., 2003; Addington, McCleery & Addington, 2005; Tennakoon et al., 2000). Other issues raised in the literature include the ways in which families cope with grief and loss, adjust to the major changes that occur within the family, and cope with issues associated with recovery (Addington & Burnett, 2004; Corcoran, McGlashan, Gerson & Sills-Shahar, 2007; Gleeson et al., 2008; McFarlane et al., 2003). Authors Smith, Fadden and O'Shea (2009) from the United Kingdom noted that although family-sensitive practices are a recommended component of comprehensive treatment for young people with early psychosis, attention is most often directed towards parents. The rationale for including siblings in family work is straightforward: the majority of young people who develop a psychosis will still be living at home and, in many cases they will have a sibling.

There is a dearth of literature on the impact on and needs of siblings in the treatment of long term psychotic illness (Lobban & Barrowclough, 2009). However there is a large body of literature on the importance of the sibling relationship in the field of developmental psychology (East, 2009). A main contributor to this field of study is

Professor East, from the University of California in the United States, who has studied the importance of the sibling relationship and its contribution to developmental tasks of adolescents and early adulthood. Her work has covered cultural differences as well as the protective factors that the sibling relationship provides. Her work shows that sibling relationships are enduring, interpersonal ties that serve as important contexts for individual development (East, 2009).

Sibling relationships are characterised by a number of key elements. They tend to be of longer duration than most other relationships in people's lives (Bank & Kahn, 2003). Professor Goetting from the Western Kentucky University was instrumental in initiating interest in understanding the sibling relationship through her publications on the developmental tasks of siblings. She asserted that during adolescence, sibling relationships provide companionship, emotional support and practical support to one another (Goetting, 1986). The onset of psychosis may be critical in terms of potential disruption, and the potential loss of an important reciprocal relationship.

The mental health research in this area has focussed on the impact on older siblings who cope with a brother or sister with long-term psychosis (Barak & Solomon, 2005; Lively, Friedrich, Buckwalter, 1994; Smith & Greenberg, 2008); studies where siblings are a subset of a larger sample of key relatives (Gleeson et al., 2008); or retrospective studies which have asked siblings to recall feelings and events over the previous 20 years (Gerace, Camilleri, Ayres, 1993; Greenberg, Kim & Greenley, 1997; Solomon, Cavanaugh & Draine, 2005). These studies found that an individual's psychosis has an impact on the lives of siblings (Barak & Solomon, 2005).

The studies in long term psychotic ill have found that siblings are at risk of developing survivor guilt in response to a loved one's illness, (Gerace, Camilleri, Ayres, 1993; Titleman & Psyk, 1991), and may experience long-standing grief due to the lost personality of their ill brother or sister (Lively, Friedrich, Buckwalter, 1994; Riebhleger,

1991). This affects the sibling's choice of leisure interests and vocational pursuits (Barak & Solomon, 2005; Lively, Friedrich, Buckwalter, 1994; Smith & Greenberg, 2008). The literature identifies commonly occurring issues for these siblings such as stigma, fear, worry about the future, and burden of care (Gerace, Camilleri, Ayres, 1993; Greenberg, Kim & Greenley, 1997; Solomon, Cavanaugh & Draine, 2005). Researchers Smith and Greenberg from Washington University and the University of Wisconsin-Madison (2008) implemented a study that took a life course perspective to guide an investigation into the predictors of the quality of the relationship between adults with schizophrenia and their siblings. They found that long term psychotic illness negatively impacted upon the quality of the sibling relationship.

The only study to date about siblings in early psychosis was a small qualitative study ($n = 10$) conducted by psychiatric nurses, Sin, Moone and Harris (2008), in the United Kingdom. The participants in this study reported feeling overwhelmed, resentment, blame, guilt, loss and shame. The authors reported that participants had stopped inviting friends home and reported changes in their own academic and social performance. They did not confide these changes in their performance with their parents. Further, siblings in this study believed that supporting their parents and providing practical assistance was their most important role and that providing companionship to their ill brother or sister was part of the conventional sibling relationship. The authors recommended that siblings should be identified when a young person is first referred to an early psychosis clinic and provided with education and information, and other specific interventions that address the emotional impact and changed performance experienced by siblings.

Introduction to the researcher

The idea for embarking on this study came from the author's clinical experience. Recognising that early psychosis is a traumatic experience for the individual and the

family, it was evident that siblings did not attend the clinic where the researcher (SB) was employed and they were rarely discussed with the treating team. At the time of this study, a cognitive behavioural family intervention approach, specific to early psychosis, was implemented for each young person and their parents (Edwards, McGorry & Pennell, 2002). However staff (clinicians) were concerned that siblings were missing out on education about psychosis and an opportunity to express their feelings. They were concerned that they lacked strategies that may assist them in coping with their brother or sister's illness.

At the commencement of the study there were 388 young people attending the clinic which was the site for this research and 298 had at least one sibling (77%). It was evident that six siblings had attended the family education program offered by the clinic (1%). Ninety-one per cent of siblings had no contact with the treating team.

To orient the reader to this quantitative study, an outline of the way in which this thesis is organised is presented next. However it is helpful to alert the reader to the following conventions used in this thesis. Hereafter, I will refer to myself as *the researcher*. The *young person* refers to the individual experiencing early psychosis. The *sibling* refers to the brother or sister of the young person experiencing early psychosis. *The Clinic* will be used to refer to the site of the study.

Order of the thesis

A critique of relevant literature is presented in the next chapter which examines the literature and research on the sibling relationship, siblings with long term psychotic illness and the characteristics of early psychosis that may influence the sibling experience (Chapter 2). A detailed description of the methods employed in this study is provided in Chapter 3, followed by the results of the study in Chapter 4. The discussion appears in Chapter 5. The conclusion (Chapter 6) includes a brief account of the significance of this research, its limitations and recommendations for future research.

Chapter Two: Literature Review

This chapter critiques the literature on the sibling relationship, research on siblings in long term psychotic illness and the characteristics of early psychosis that may influence the sibling experience. These three topics are not commonly brought together, however to inform the background to this study it was deemed necessary to scrutinize this literature to demonstrate how this current research builds on prior knowledge. This review begins by examining the theoretical underpinnings of sibling relationships and the contributions they make to psychological and social development during adolescence and young adulthood. It will then critique the research on siblings who have a brother or sister with a long term psychotic illness. The evidence for key characteristics of early psychosis is then reviewed to examine siblings' experiences of having a brother or sister with early psychosis.

This review includes books, journal articles, and publicly available reports retrieved from database searches of CINAHL, MEDLINE, PsychLIT and PubMed. Published papers were limited to English language and year of publication parameter was set from the mid 1950s to 2011 as minimal research was reported during this time. This search captured relevant articles on early psychosis, with young people ranging from 15 to 29 years. Studies that focused on the genetic or biological aspects of siblings were excluded.

Theories pertaining to sibling relationships

Early works by developmental psychologists established that sibling relationships play a critical and formative role in human development (Bandura, 1989; Bowlby, 1969; Festinger, 1954; Kreppner & Lerner, 1989; Weiss, 1974). The work of these authors contributed to developmental theories which have been applied to understand the relevance of sibling relationships throughout the lifespan. Such theories include family

systems theory (Kreppner & Lerner, 1989), attachment theory (Bowlby, 1969), social learning and comparison theory (Bandura, 1989; Festinger, 1954) and social provision theory (Weiss, 1974). It should be noted that the selection of the theories reviewed is not comprehensive, but rather the emphasis is on perspectives that remain influential in the field of sibling research today. These developmental theories are useful in understanding sibling influences and therefore the impact that may occur with the onset of early psychosis. The theories are not presented in chronological order but are in order of the contribution they make to understanding sibling relationships. They are now discussed briefly.

Family systems theory begins this discussion as it contends that all individuals within a family impact upon and have the capacity to affect each other. This theory maintains that family members are part of an interdependent, dynamic system whereby the behaviour of each individual or family subsystem has the capacity to affect other individuals or subsystems within the family (Kreppner & Lerner, 1989; Minuchin, 1988). Developmental theorists Kreppner and Lerner (1989) and Minuchin (1988) have specifically applied this theory to understanding sibling relationships. These researchers used a system perspective to highlight the family as a “complex, integrated whole” (Minuchin 1988, p. 8) whereby individual family members exert an ongoing and reciprocal influence on one another. Each family member can never be fully understood independent of the context of that system (Kreppner & Lerner 1989, Minuchin 1988). Family subsystems refer to the marital dyad, sibling relationships and parent-child relationships. This theory contends that a change in either the individual or the family unit has an impact on the other. As applied to the study of sibling relationships, a family systems perspective posits that individual family members, as well as the dynamics of the family unit as a whole, have the potential to affect the quality and intensity of sibling relationships.

A study of siblings in adolescent development also needs to consider the work of Bowlby (1969). Attachment theory describes a system of human behaviours that serve to bring an individual close to an attachment figure, often the principle caregiver, in times of stress and duress (Bowlby, 1969). The caregiver's responsiveness to a child's affective signals provides safety and security which, when experienced over time, helps children develop a sense of trust, and the ability to regulate emotional distress. Professor Brody from the Department of Child and Family Development, at the University of Georgia, applied Bowlby's attachment theory to sibling relationships and proposed that children can develop strong sibling attachments in cases where parents do not (or cannot) provide sufficient warmth or security (1998). He proposed a heuristic model that hypothesised a link between attachment roles and sibling relationships. The model was utilised by authors Bank and Kahn (2003) in understanding adolescent sibling loyalties where a sibling provides the primary care after a maternal death or when a mother is chronically ill. This compensatory role has been found in other psychological studies. For example psychologists Sears and Sheppard (2004) conducted a qualitative study to explore the experiences of adolescents (N=3) who had a parent with cancer. They found that sibling attachments assisted in their ability to maintain being a "normal teen" through the provision of emotional and practical support (p.19). Stein, Riedel, and Rotheram-Borus (1999) found similar themes in their study of 183 adolescents who had a parent with AIDS receiving case management from a service in New York city. Many adolescents had taken on parenting roles for their younger siblings such as completing the household chores, managing the finances, taking younger siblings to the doctor or other specialist services and providing emotional comfort and support. From the findings of these studies it can be suggested that siblings can fulfil successful attachment roles when parents are not in a position to do so.

Psychologist Albert Bandura's social learning theory has also been applied to the study of siblings (Bandura, 1989). This theory proposes that observational learning, or

modelling, is one of the primary methods by which behaviour is acquired. According to Bandura, there are several conditions required for learning from observation and imitation. First, a role model must possess qualities which attract attention and second, one of the most important determinants of whether a role model will attract another person's attention is the frequency of contact. Because adolescents can spend so much time with their siblings, sisters and brothers can be very salient role models.

Researchers Whiteman, McHale and Crouter (2007) utilised this theory in understanding how older siblings can influence younger siblings in the domains of risky behaviour, peer competence, and sports and art interests. The authors interviewed siblings from 191 maritally intact families in an American study. Analyses revealed that sibling influence was positively linked to a warm sibling relationship. Sibling similarities were evident when older siblings were highly engaged, competent and interested in a particular domain. They served as powerful socializing agents when they provided younger siblings with opportunities for engaging in particular behaviours and also provided vicarious reinforcement. The younger siblings had the opportunity to observe their older siblings' behaviours and actions and attend to what was reinforced by parents and peers. This finding was further developed by the same psychological team Crouter, Whiteman, McHale, and Osgood (2007), who examined the development of gender attitudes in 402 adolescent siblings. They found that the younger siblings modelled their older brothers and sisters' attitudes, interests and behaviour when developing a gender identity. The authors reported this to be due to many younger siblings looking up to and modelling their older siblings. From the findings of these studies, it is clear that social learning processes that assist in the development of identity during adolescence can exist within sibling relationships.

Festinger (1954) proposed social comparison theory which contends that there is a basic human drive to evaluate oneself relative to others. He maintained that without these comparisons people cannot assess their strengths, weaknesses or talents and the person

with whom people compare themselves can greatly influence how people view themselves. Later proponents of social comparison theory asserted that these processes can exist within sibling relationships. Whiteman and Buchanan (2002) for instance, in a study of 305 children interviewed in the United States, found that a child's expectation of adolescence was based on their older sibling's experience and consequently supported the results of a comparison hypothesis. The children in this study were asked about their expectations of risk taking/rebelliousness, prosocial behaviours, problem behaviour, classic adolescent conforming behaviours, social functioning and internalised feelings during adolescence. They were asked about their older sibling's behaviour during adolescence. Analyses showed that a more positive perception of the older sibling's behaviour predicted a more positive expectation of adolescence for the younger sibling. Feinberg, Neiderhiser and Simmens (2000) on the other hand, interviewed 516 families in the United States to assess social comparison processes between adolescent siblings. The authors found that the participants in the study placed greater importance on comparisons with their siblings rather than peers. They found that self esteem regulated whether the comparison was positive or negative. The findings of these studies show that social comparison processes can be a powerful dynamic within the sibling relationship.

Finally, social provision theory (Weiss 1974), proposes that different social relationships can serve different social needs. This theory has also been applied to the study of siblings. For instance, in a ground breaking study that influenced future research interest in sibling relationships, Furman and Buhrmester (1985) interviewed 49 children to discern the various functions of the relationship. They developed a list of fifteen primary qualities reported in open ended interviews. They found that during childhood and adolescence siblings can provide companionship, intimacy and affection, fulfil roles such as friend, competitor and role model, and can compensate for absent relationships such as same age friends or peers. Cicirelli (1989) built on this research and began to investigate the social needs met by siblings in later life. He interviewed 83 older people

about their relationships with their siblings and asked them to rate their closeness, conflict, rivalry and indifference towards each living sibling. He utilised a depression measure to rate well-being. The author found that perceived closeness of a sibling bond was related to less depression. Perceptions of conflict and indifference were related to increased depression. The findings of these studies suggest that the sibling relationship can fulfil different social needs at different points during the life course.

The preceding theories have been useful in understanding sibling influences on adolescent development during the time when the onset of early psychosis mainly occurs. In the following section, research on the function of sibling relationships during adolescent and early adulthood is discussed.

Sibling Relationships in Development

A review of the literature indicates that there are three elements of the sibling relationship regularly studied in developmental psychology (Dunn, 2007; Milevsky, 2005; Stockier, Lanthier & Furman, 1997). These elements are warmth, conflict and rivalry. They are a reason that the sibling relationship is often characterized as a love-hate relationship, and have been found to contribute to individual psychological and social development. Studies define warmth as sibling closeness and affection (Dunn, 2007; Goetting, 1986; Stocker, Lanthier & Furman, 1997); they define conflict as when one sibling does something to which the other objects (Conger & Little, 2010; Dunn, 2005; Dunn, 2007; Stocker, Lathier & Furman, 1997); and studies define rivalry as the competition for attention, affection and approval from parents between siblings. This competition helps to define who they are as individuals (Brody, 1998; Dunn, 2007; Goetting, 1986; Scharf, Shulman & Avigad-Spitz, 2005; Stocker, Lathier & Furman). Researchers have studied these elements during childhood, adolescence, adulthood and old age and have found that they are expressed with varying levels of intensity during

specific life stages. Researchers have also established the protective and compensatory effects of sibling support during development across the lifespan (Gass, Jenkins & Dunn, 2007; Milevsky, 2005; Milevsky & Levitt, 2005).

The main contributors to this research include Professor Dunn, a British psychologist from Kings College in London, who has studied the contribution siblings make during childhood and adolescence to social functioning, adjustment and family relationships (Dunn, 2005; Dunn, 2007). Through observational, naturalistic studies she has proposed that warmth between siblings contributes to greater socialisation and support (Dunn, 2007; Dunn & McGuire, 2002). In an earlier observational study, Dunn and Slomkowski (1992) suggested that sibling conflict also fostered social and cognitive development and was a powerful influence in the establishment of social understanding during adolescence. Further, Professors Conger and Little (2010) from the University of California have published observational studies of the sibling relationship during the transition from adolescence to early adulthood. They report that sibling conflict can play a role in identity formation, with sibling disputes helping to clarify self-identity, acceptable behaviour and personal boundaries.

The literature about the sibling relationship during early adulthood focuses on whether life events common to this phase of life, such as leaving home, going to university, getting a job, partnering, or starting full-time employment, impact upon the elements within the sibling relationship. For example, developmental psychologists Stocker, Lanthier and Furman (1997) from the United States, developed a measure, the Adult Sibling Relationship Questionnaire (ASRQ; Stocker, Lanthier & Furman, 1997), with 2 samples of university undergraduates and evaluated it in a quantitative study (N = 383). The factor structure of the ASRQ indicated that sibling relationships in early adulthood were also characterized by 3 independent dimensions: warmth, conflict, and rivalry. They found that the respondents characterised their sibling relationships during

early adulthood as warm and individual differences in warmth, conflict and rivalry were to some extent associated with the amount of contact between siblings and to siblings' mental health.

Another American study by Professor Brody (1998) proposed that rivalry increases during late adolescence as developmental differences diminish, with siblings becoming more alike as they get older, producing more opportunity for social learning and comparisons between siblings. The findings of these studies suggest that warmth, conflict and rivalry coexist to give children a variety of experiences in learning to deal with others, promoting social, psychological and cognitive development.

A number of studies have found that the intensity of these factors within the relationship change over time. For example, in an Israeli study, psychologists Scharf, Shulamn and Avigad-Spitz (2005) interviewed a sample of healthy adolescents and young adults (N=116) about the quality of their sibling relationships. They reported that shared leisure activities decline as adolescents' autonomy increases, leading to greater engagement with friends, peers and romantic partners, and participation in freely chosen recreational pursuits. They proposed that this is a trend of separation and individuation similar to the process children go through in separating from parents. Their analysis of narratives found that sibling relationships were warmer in emerging adulthood than in adolescence. Conflict and rivalry was also reported to be less intense for emerging adults in comparison with adolescents. From the findings it is clear that factors within the relationship can change in intensity and the way they contribute to individual psychological and social development. In summary, warmth decreases in intensity during adolescence but increases again during early adulthood. Conflict and rivalry decreases in early adulthood.

Another area of study that has been briefly mentioned, but deserves further critique is gender and birth order and its relevance to the sibling relationship. Studies have

examined whether these factors have a significant impact on warmth. For example, Dunn, Slomkowski and Bardsall (1994) implemented a study to examine the differences in sibling relationships during adolescence based on semi-structured interviews. The study included 39 sibling dyads that were assessed at different time points over seven years. The authors reported that the effects of gender composition became apparent in early adolescence with boys reporting less warmth with their younger sisters than girls. The loss of warmth was attributed to the establishment of a male peer group outside of the family. Another group of American developmental psychologists, Tucker, Barber, and Eccles (1997), examined the perceptions of adolescents ($N = 223$) about their sibling's influence on their life plans, personal problems, interests and goals and their satisfaction with sibling support. The differences between first and second born children, males and females and opposite and same sex sibling pairs were explored. Participants filled out a survey in their final year of school. Analyses revealed that females and second born children reported receiving more advice, were more influenced and were more satisfied with sibling support than males and firstborn children. Female - female sibling dyads reported receiving more advice from their siblings than those in male-male and mixed gender pairs.

In another American study by Professors Kim, McHale, Osgood and Crouter, (2006) from Pennsylvania State University, changes in sibling warmth and conflict were examined from childhood to adolescence in 200 families using a multilevel modelling strategy. The researchers also found these elements changed over time and reported that differences in the intensity of these elements could be explained by gender and birth order. For example, sibling warmth was highest for sisters, stable over time for same sex dyads and fluctuated for mixed sex dyads. They also found that sibling conflict declined after early adolescence and this had no association with gender or birth order.

The protective effects of sibling support have been investigated in several studies in the social support literature. For example, in a Canadian longitudinal study (N=192), Professors Gass, Jenkins and Dunn (2007) examined the protective effects of sibling support on psychological adjustment after stressful life events such as family deaths, accidents, illnesses and separations. The study found that sibling warmth moderated the relationship between the stressful event and the level of distress. The authors suggest that siblings, like parents, have the potential to provide security and comfort when they are experiencing stress in accordance with attachment processes discussed earlier in this chapter.

This protective effect has also been found in North American research particularly by Professor Milevsky (2005) from the Kutztown University of Pennsylvania who has published numerous studies on siblings and social support. In one study, he examined how support from siblings related to psychological adjustment and academic competence in early adolescence (Milevsky & Levitt, 2005). Participants (N = 695) were interviewed in school. The measures used included indices of support from each family member as well as measures of adjustment and ecological risk (personal poverty, low socio-economic neighbourhood, high family stress, or single parent family). Adjustment measures included indices of psychological well being and academic competence. Hierarchical regression analyses showed that a high level of support from a brother was associated with more positive school attitudes and higher self-esteem. A high level of support from a sister was found to buffer the relationship between ecological risks and school functioning.

In another study Milevsky (2005) examined the compensatory effects of social support received from siblings and how this related to psychological adjustment in early adulthood. Participants (N = 305) completed measures of social support and well being using the Adolescent version of the Conroy Mapping Procedure (Levitt, Guacci-Franco &

Levitt, 1993) . Sibling support was found to be associated with less loneliness and depression as measured by the UCLA Loneliness Scale (Russel, 1996) and the Depression Scale (Pearline & Johnson, 1977), and also high self-esteem and life satisfaction during this period of transitional development. Sibling support compensated for low parental and peer support. The author found that individuals who had poor relationships with parents or friends but reported warm relationships with their sibling were more satisfied with their well being.

Several studies have shown that sibling support is associated with positive mental health in adolescence and early adulthood. For example, Professors Ponzetti and James (1997) from the University of British Columbia examined the influence of siblings on loneliness. Measurements of loneliness and warmth, conflict and rivalry in the sibling relationship were administered to 251 university students. Correlation and regression analyses were carried out to assess the association between loneliness and the three factors. The authors found no correlation between rivalry and loneliness but a positive correlation for loneliness and conflict. That is, the more conflict in the relationship the more loneliness was experienced by the individual. High levels of warmth resulted in lower levels of loneliness.

Another study that showed a positive relationship between sibling support and positive mental health was a Dutch longitudinal study of 285 families (Branje, Van Lieshout, Van Aken, & Haselager, 2004). Family members completed a questionnaire on perceived support and problem behaviours in family members. Problem behaviours were defined as withdrawal, anxiety, depression, aggression and delinquent behaviour. Data analysis established that a high level of sibling support was related to low levels of all problem behaviours for both older and younger siblings.

Psychologists Olivia and Arranz (2005) from the University of Seville in Spain explored the sibling relationship during adolescence, focusing particularly on the

relevance of gender and positive mental health. They constructed a questionnaire consisting of nineteen different instruments related to family relationships, peer relationships, and positive mental health. They recruited 513 adolescents from various secondary schools to complete this questionnaire. The authors found that for the females in the study, a good relationship with their sibling was linked to high self esteem, life satisfaction and positive mental health (Oliva & Arranz, 2005).

In summary, the literature indicates that warmth, conflict and rivalry within sibling relationships can change over time; can promote social, psychological and cognitive development; can have protective and compensatory effects; and contribute to positive mental health during adolescence and early adulthood. As the contributions siblings make to each other may have the potential to impact on the experience of psychosis within a family system, the literature on siblings' experience of long term psychotic illness is now examined.

Siblings experiences of long term psychotic illness

The early studies on psychotic illness from 1950 to 1970, conducted by the Yale University Group of the National Institute of Mental Health, focused on the family as the etiological agent in schizophrenia (Fromm-Reichman, 1950; Meissner, 1970; Newman, 1966). Practitioners of this theoretical persuasion saw families as the source of pathology in their relatives' illness and believed that help for the mentally ill person first required treating the sick family. In the search for the nature of this pathology, these early theorists cycled through a number of explanations with each having a period of popularity. These explanations included the concept of symbiotic or rejecting mothers, marital schism, community deviance, enmeshed families, and distorted hierarchical relationships (Fromm-Reichman, 1950; Meissner, 1970; Newman, 1966).

In 1986, Dr Hatfield from the University of Maryland wrote an influential article in the *Schizophrenia Bulletin* that focused on the impact these theories had had on families. She reported that clinicians could have considerable difficulty establishing trust with families because the field of mental health carried a legacy of negative views towards them.

Personal accounts of siblings were published in the *Schizophrenia Bulletin* during the late 1980s and early 1990s. These accounts displayed their feelings of guilt, grief, stigma and fear of acquiring the illness (Bernheim, Lewine, & Beale, 1982; Brodoff, 1988; Johnson 1988; Kahn & Lewis, 1988). Evelyn Smith, a mother of four children, one of whom developed schizophrenia, published her first person account for the *Schizophrenia Bulletin* in 1991. She reported that her three children lived with ongoing and cyclic grief for their once well sibling and they did not seek help in coping with their brother's illness, especially from mental health services. Smith recorded that "the break in their sibling relationship has left a void in all of their lives" (Smith, 1991, p. 690).

Although the early theories were based on limited scientific evidence, they are reported to have resulted in widespread stigma and fear of mental illness. For example, an opinion piece by Professor Rowe (1992) in the *Journal of Child and Adolescent Psychiatric Nursing*, proposed that in accordance with family transmission theory, sibling relationships were either conceptualised as a subsystem that supported the pathological family that caused the psychotic illness, or the sibling was isolated from the family in an unhealthy manner. He proposed that as a result, siblings feared their level of risk for the illness, and their role in the onset of it (Rowe, 1992).

Later studies published during the nineties and the beginning of the new century from the United States and Sweden were implemented by several disciplines, medicine, social work, psychiatric nursing and psychology departments from various universities (Gerace, Camilleri & Ayres, 1993; Greenberg, Kim & Greenley, 1997; Horowitz, 1993; Lively, Friedrich & Buckwalter, 1995; Riebhleger, 1991; Titelman and Psyck, 1991).

Key issues relevant to the current study included guilt, grief, burden, care giving, and violence, as they directly relate to the impact on the sibling relationship and siblings' quality of life. These issues will now be reviewed.

Guilt

Guilt was found to be a major theme for siblings in long term psychotic illness in two studies (Gerace, Camilleri & Ayres, 1993; Titelman and Psyck, 1991). These studies found that siblings felt guilty for not becoming ill themselves, for not being able to help their parents enough and for succeeding in their own lives. Clinical Psychologists from the Swedish Psychoanalytic Society, Titelman and Psyck (1991), reported on Titelman's psychotherapeutic experience and clinical impressions of three siblings of individuals with schizophrenia in the Bulletin of the Menninger Clinic. Titelman reported that these high functioning siblings were evasive and frequently withdrew from engagement in family treatment. He reported that they experienced survivor guilt which comprised of sadness, shame, anxiety, self blame and as a result, they restricted themselves from enjoying their own lives. He also believed that the siblings found it difficult to witness a parent's pain and helplessness and inevitably the parent, pre-occupied by the fate of the ill child, tended to neglect the sibling who tried to hide the need for appreciation and reassurance.

These results were considered by Gerace, Camilleri, and Ayres (1993), from the Department of Psychiatric Nursing, University of Illinois, who conducted a qualitative case study design to explore 14 siblings' experiences with their chronically psychotic ill brother or sister. The recruitment process favoured siblings who took an active role in their brother or sister's illness situation, with the majority of the participants being female ($n = 11$). The researchers reported that guilt was a common theme expressed by the siblings and this had an impact upon their level of involvement with their ill brother or sister. During the interviews, one sibling described the illness as having a "pervasive,

dampening influence” (Gerace et al., 1993, p. 645) on his life. In other studies of illnesses or impairments such as intellectual disability, family members have acknowledged that some good has come from the illness situation, such as drawing the family closer together (Seltzer, Greenberg, Orsmond, & Lounds, 2005). Gerace et al suggested that for siblings in mental illness research, it was “difficult to portray schizophrenia as a cloud with a silver lining of any kind” (p.645).

Grief

There is literature that reports on siblings’ experiences of grief and loss for their once well brother or sister following a diagnosis of a psychotic illness. For example, Riebhleger (1991) conducted semi structured interviews with 20 adult siblings of chronically psychotic individuals at a community mental health centre in the United States (11 females and 9 males, with a mean age of 35 years). Interview questions solicited information from siblings about their emotional responses, coping strategies, and the effect the illness had had on their life as well as historical and current interactions with the mental health system. The major theme identified was grief and loss. In describing the sibling grief reactions in this study, Riebhleger believed it was in accordance with Kubler-Ross’s (1969) well known emotional continuum of denial, anger, bargaining, depression and acceptance. The cyclical illness pattern of psychosis was reported to be a barrier to grief resolution. Other concerns of siblings in this study included: feeling excluded and being contacted only when there was an emergency; not being assisted in dealing with their own trauma; and a genuine concern about the lack of resources provided to their brother or sister in order to help them get well. The author proposed that in contrast to the grief one experiences following the death of a family member, “siblings experience chronic, unending grief” (Riebhleger, 1991, p. 235).

Lively, Friedrich, and Buckwalter (1995), from the College of Nursing, University of Iowa, conducted a descriptive field study and used verbal administration of

questionnaires to examine the impact of long term psychotic illness on adult siblings, specifically the impact on their relationships, roles and health (N = 30; mean age = 37 years). The respondents' brothers and sisters had been ill for an average of 18 years. The researchers developed and implemented a quantitative scale and open ended questions were transcribed verbatim for qualitative analysis and themes. One of the study participants said, "In many ways it was like having an ongoing funeral for a brother we had known. He was the brightest and the most sensitive. After he became ill it was a bit like watching somebody go through Alzheimer's. The brother I had known died and we now have somebody who looks a little bit like him but he's a stranger" (Lively et al., 1995, p. 230).

Quantitative data from the questionnaire were analysed by descriptive and nonparametric testing. The results showed that having a brother or sister with long term psychotic illness (schizophrenia) brought about changes for siblings in all relationships and the relationship most affected was that with the ill brother or sister. Further, leisure, school and work performance were reported to have been negatively affected by their experience. The authors also found that the illness had had an impact on the mental health of the siblings in the study (66%). Siblings expressed an impaired sense of self, sadness and stress. For instance, one participant commented, "I cried and cried all the time, no matter what was going on. My dad and I would sit down and cry together. As time passed, acceptance of the illness and its limitations became a little easier" (Lively et al., 1995, p. 234).

Grief was reported to be associated with difficulty communicating with their ill sibling and resulted in distancing within the relationship, anger at the unfairness of it, and ongoing stress related to an unending problem. The authors concluded that the experience reported by the siblings in the study was like a traumatic grief process.

Burden

The care giving literature shows that burden is a common experience for families of individuals with a long term psychotic illness. The literature defines burden as the impact and consequences of an individual's psychotic illness on a carer or family member (Barak & Solomon, 2005; Greenberg, Kim & Greeneley, 1997; Szmukler, Burgess, Hermann, Colusa, 1996). In addition to the emotional, psychological, physical and economic impact, the concept of burden includes feelings of shame, embarrassment, and self-blame. It is often recognised in the literature as having two distinct components (objective and subjective) (Greenberg, Kim & Greeneley, 1997). Objective burden indicates the effects on the household such as taking care of daily tasks, whereas subjective burden indicates the extent to which the care giver perceives the burden of care (Barak & Solomon, 2005; Greenberg, Kim & Greeneley, 1997; Szmukler, Burgess, Hermann, Colusa, 1996). Although there are many studies on families living with schizophrenia, a critique of this literature reveals that the term 'families', in fact refers to mothers or fathers and husbands and wives. There is only one major study that has explored burden in a sample of siblings. Professors Greenberg, Kim, and Greenley (1997) from the School of Social Work at the University of Wisconsin, conducted a cross-sectional study to determine the burden experienced by 164 siblings (70% female; mean age 45 years) of individuals with schizophrenia attending a public mental health clinic. Telephone interviews were conducted using the Wisconsin Family Burden and Services Questionnaire (Greenberg & Greenley, 1991). They were asked about their experience of various types of burden, including stigma, fears, worries, the amount of care they provided, and the psychiatric symptoms their ill brother or sister exhibited. Regression analyses were used to investigate the predictors of burden. The results showed that birth order and gender had a relationship with the amount of burden reported. For example, older siblings ($n = 131$) reported less burden than younger siblings. Further, sisters

reported more burden than brothers. Persisting psychotic symptoms resulted in more burden and stigma for siblings.

There were limitations in this study. They included having a sample of siblings who were active in their relationship with their ill brother or sister; who were supported by their spouses (81%); who were mostly women (70% women; 80% older sisters); and who had experiences of their brother or sister's mental illness for at least 20 years. Their experience cannot be generalised to young siblings early in the course of the illness.

In a later study, Barak and Solomon (2005) from Tel Aviv University in Israel also examined the impact of burden on siblings who had a brother or sister with schizophrenia. Their sample consisted of a study group of 52 siblings and a control group of 48 individuals with no mental illness in the family, matched by similar socio-demographic features. Self report questionnaires were utilised and included the Burden Assessment Scale (Reinhard, Gubman, Horowitz & Minsky, 1994). Participants were asked about their sibling relationship, their social environment and their coping strategies. Following statistical analyses, the results showed that siblings of individuals with schizophrenia felt more negative about their sibling relationship than the control group. They reported feelings of helplessness, sadness, pity and worry. The study group was found to have higher levels of burden than the control group. The findings also showed that siblings of those with schizophrenia were less ready to share their experiences with others due to shame, embarrassment and stigma. Again in this study, sisters reported greater burden than brothers as did single siblings living at home who took more responsibility and performed more care giving tasks.

Care giving

Directly related to burden are the tasks involved in providing care. Only one study was found in a comprehensive data-base search of the literature. This study was commissioned by the National Institute on Aging in the United States and aimed to

investigate how much care giving siblings provide to brothers and sisters who have schizophrenia (Horowitz, 1993). This exploratory study obtained information via telephone interview from 108 siblings who attended a community mental health program in New Jersey. These data therefore represent siblings whose relationships are warm and close and are also involved in care giving. Over half the participants were sisters (57%; mean age 40 years). The siblings in this study described their care giving responsibilities as transportation (48%), lending money (45%), providing support in a crisis (43%), keeping up with household tasks and shopping (50%).

The interview contained questions about attitudes towards family obligation and found that this was a motivator for siblings especially as their parents aged. They also asked siblings to state what care their ill brother or sister provided to them. Results showed that ill brothers and sisters did reciprocate care in terms of lending money (6%), doing household chores (20%), participating in family activities (78%), and providing emotional support (84%). This study found that when the sibling relationship was reciprocal, there was more willingness to provide care giving services. Birth order and gender were not found to be significant factors in care giving.

Violence

Research has found that in long term psychotic illness family members are likely targets of violence. For example, Professors Solomon, Cavanaugh and Gelles (2005) reviewed the limited research on violence of adults with psychotic illness against their families and found that studies reported between 10% and 40% of families experienced violence. Most relevant to this research is a longitudinal cohort study by Estroff and colleagues (1998). The authors followed a sample of 169 individuals with psychotic illness. Data were collected in five face to face interviews at six monthly intervals over 30 months. Logistical regression was used to calculate the impact of participants' characteristics and their victims' characteristics. The results showed that 55% of

participants had been violent to individuals within their social network. Further, immediate family members, particularly mothers (30%), living with the participant who had schizophrenia and concurrent substance use, were at greatest risk for being the target of violence. The second most reported target was siblings (19%).

The sibling relationship

Only one study has researched the quality of the sibling relationship in long term psychotic illness. Smith and Greenberg (2008) from the Department of Psychiatry at Washington University School of Medicine conducted a longitudinal study of families of adults with schizophrenia. This study surveyed 136 siblings of people with a long term psychotic illness. These siblings had a mean age of 44.5 years and 55% were female. The Positive Affect Index (Bengtson & Schrader, 1982) was used to measure the quality of the sibling relationship. Predictors were measured using the Family Environment Scale (Moos & Moos, 1981), and the Schizophrenia Outcome Module (Cuffel, Fischer & Owen, 1997) which evaluated the frequency of psychiatric symptoms exhibited by their brother or sister over the previous month. Participants were asked to indicate whether their ill brother or sister had been violent towards them. Multiple regression was used to estimate the predictors of the relationship quality. The results of the study showed that sister dyads did not show closer relationships than brother dyads or mixed dyads. Siblings who reported growing up in a cohesive family rated a better relationship. Violence resulted in siblings reporting a poorer relationship with 23% being the victims of their ill brother or sister's violence. Persisting psychotic symptoms also resulted in a poorer relationship.

In reviewing the literature it is evident that most siblings participating in these studies are a supportive, involved and interested cohort. It is also evident that married older sisters mostly participate in research (Gerace et al., 1993; Greenberg et al., 1997; Horowitz, 1993; Lively et al., 1994; Smith & Greenberg, 2008; Titleman & Psyk, 1991).

Overall, there is very little literature on siblings in long term psychotic illness and no intervention studies.

However, studies located for this research indicate that long term psychotic illness can impact upon the sibling relationship and sibling quality of life. In order to further inform the research, the issues arising during early psychosis are examined. It is important to draw on this field of research in order to establish what siblings experience early in the course of the illness.

Early Psychosis

As this research seeks to understand the sibling experience, this section of the chapter focuses on common characteristics associated with a diagnosis of early psychosis. Even though intervention in early psychosis promotes reason to hope for a good outcome from this debilitating illness, the literature indicates that the experience can consist of the following characteristics: long periods of untreated psychosis due to difficulty accessing treatment and resisting help; hospital admissions; being non-compliant with treatment; having persisting psychotic symptoms; engaging in ongoing substance use; attempting suicide and being physically violent (Addington, & Addington, 2007; Coldham, Addington, & Addington, 2002; Farrelly et al., 2010; Lambert, Conus, Cotton, Robinson, & McGorry, 2010; Lambert et al., 2005; Perkins, Gu, Boteva, & Lieberman, 2005; Power et al., 2003; Robinson et al., 2009; Wade, Harrigan, Harris, Edwards & McGorry, 2006; Wade et al., 2004).

This study seeks to understand whether these characteristics affect the sibling relationship and their quality of life and if so, which of these impacts the most. Each characteristic will now be reviewed and linked to how they may relate to the sibling experience.

Duration of Untreated Psychosis

Over the past ten years, quantitative studies from Norway, the United Kingdom and Australia have found that the length of time someone is ill before receiving treatment is an independent predictor of the likelihood and extent of recovery from early psychosis (Larsen, Johannessen, & Opjordsmoen, 1998; Marshall, Lewis, Lockwood, Drake, & Jones, 2005; McGorry et al., 2009). A further example is an American study by Perkins, Gu, Boteva and Lieberman (2005) from the University of North Carolina who conducted a critical review of the literature on the association between the duration of untreated psychosis and treatment outcome. They conducted a meta-analysis examining these relationships. The researchers found that shorter duration of untreated psychosis was associated with greater response to antipsychotic treatment and resolution of symptoms within three months. A prolonged period of psychosis before treatment was associated with lower rates of symptomatic and functional recovery, more incidences of suicide attempts and physical violence (Perkins et al., 2005).

In order to ascertain the median length of the duration of untreated psychosis of a large Australian sample, a study by Schimmelmann et al (2008) from the Orygen Research Centre in Melbourne, conducted an analysis of data from 636 medical files of individuals in their first 18 months of treatment for an early psychosis. The median duration of untreated psychosis (DUP) was found to be 8.7 months. The authors found that 84% of participants had a DUP of less than 12 months ($n = 532$) and 16 % had a DUP of more than 12 months ($n = 104$). In another similar study conducted at the Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne, Australia, Conus, Cotton, Schimmelmann, McGorry, and Lambert (2007) conducted a file audit for 661 individuals experiencing early psychosis and found the mean duration of untreated psychosis was also eight months.

A long duration of untreated psychosis may indicate that siblings have witnessed their brother or sister becoming unwell. This may lead to sibling experiences indicated in

long term psychotic illness such as guilt, grief, burden, care giving and a changed sibling relationship.

Hospital admissions

Regardless of whether a person has experienced a long duration of untreated psychosis, the literature indicates that most individuals who experience early psychosis require a hospital admission. For example, in an Australia study by Wade, Harrigan, Harris, Edwards and McGorry (2006), 104 young people accepted consecutively into an early psychosis program for treatment, agreed to participate in a quantitative study that investigated their rate of hospital admission over the following 15 months as measured by electronic data of psychiatric service use. They found that eighty of 104 participants (84%) required a hospital admission within the first three months of treatment. Fifty-nine (57%) had a single admission and 21 (20%) had multiple admissions over the course of the 15 months. Correlation analyses indicated that multiple admissions occurred due to problems with risks to self or others, ongoing substance use and medication non-compliance. Multiple admissions predicted persisting symptoms at 15 months. The authors reported that individuals were often discharged from hospital without full resolution of psychotic symptoms. They would therefore often require readmission soon after discharge owing to a lack of treatment response, the recurrence of risks to self or others, poor engagement with outpatient services, or a combination of these factors. (Wade et al., 2006).

This research found those who required more than one admission probably had persisting psychotic symptoms, may have attempted suicide, most continued to use substances and were non-compliant with treatment. The other issue relevant to the sibling experience is that even though their brother or sister had been hospitalised for treatment, they may have returned home still unwell.

Compliance with treatment

A major cause for readmission to hospital is a relapse of symptoms often due to individuals independently ceasing their antipsychotic medication (Wade et al., 2006). Professors Coldham, Addington, and Addington (2002) from the Calgary Early Psychosis Service in Canada conducted a longitudinal study with 186 participants. They implemented a compliance scale every three months in the first year of treatment, every 6 months in the second year and once in the third year. They found that 41% of the sample were compliant, 20% had fluctuating compliance (skipping doses but not for longer than two weeks); and 39% were non compliant. Those who were non-compliant were found to have more ongoing symptoms, more relapses, ongoing substance use and a poorer quality of life.

Lambert, Conus, Cotton, Robinson and McGorry (2010) implemented a file audit study to assess compliance in an epidemiological cohort of 605 individuals attending an early psychosis centre in Melbourne (EPPIC), Australia. During the 18-month treatment period, 34% of participants were fully compliant, 48% had fluctuating compliance, and 19% refused medication. Substance use and having poor insight into their illness predicted fluctuating compliance and medication refusal. Those who were non-compliant were still unwell.

Medication compliance has the potential to prevent relapse, hospitalisation and reduce poor functional outcomes (Lambert et al., 2010). Non-compliance has an impact on recovery outcomes and this is relevant to the sibling experience.

Persisting psychotic symptoms

Prolonged recovery is when remission of psychotic symptoms has not occurred. Edwards, McGorry and Pennell (2002) from the early psychosis program in Melbourne, Australia, screened 1388 people with early psychosis and found that 40% had ongoing positive symptoms at nine weeks after entry into treatment and 20% had persisting

symptoms at 12 weeks. Lambert et al. (2005), also from Australia, examined the clinical characteristics of 643 individuals with early psychosis at the beginning of treatment, during treatment and at 18 months via data file audit. The authors also found that 20% had persistent psychosis at 18 months. Further, Schimmelmann and colleagues (2008), at the EPPIC program in Australia collected further data from the medical files of 636 young people and found that at 18 months, 42% continued to exhibit persisting psychotic symptoms. This research shows that for siblings, many of their brothers or sisters experiencing early psychosis may continue to have psychotic symptoms at 18 months after treatment has begun.

Substance Use

High rates of substance use are reported in early psychosis samples throughout the world, with cannabis and alcohol as the most commonly used substances (Edwards, Hinton, Elkins, & Athanasopoulos, 2006; Lambert et al., 2005; Mazzoncini, Donohue, Hart, Morgan, & Doody, 2010). For example, in a finding by Lambert et al., (2005), 74% of individuals who completed 18 months of treatment had persisting substance use (N = 643). Other studies have reported different results. For example, Addington and Addington (2007) implemented a longitudinal study with 203 young people over three years. Assessments obtained data on the frequency of their substance use. After three years of treatment, the prevalence of substance use was high at 51%.

A number of quantitative studies in Australia, Canada and Germany have found that persisting substance use over the course of treatment can result in higher rates of relapse, persisting psychotic symptoms and non-compliance with treatment. For example, in an Australian study, Wade, Harrigan, Whelan, Burgess and McGorry, (2004), conducted a prospective investigation to examine the effects of substance use in 103 young people receiving treatment for early psychosis over a 15 month period. They implemented the Royal Park Multi-diagnostic Instrument for Psychoses (McGorry,

Copolov & Singh, 1990) and the Chemical Use, Abuse and Dependence Scale (McGovern & Morrison, 1992). These assessments were used at the beginning of treatment, 3 months into treatment, at nine months and again at 15 months. The authors found that substance use was independently associated with more relapses, more hospital admissions, more severe and persisting psychotic symptoms and co-morbid depression.

Studies that examine the impact of substance use on early psychosis samples have several limitations: prospective studies require individuals to consent to assessment, however this often excludes those with severe substance use and or severe psychosis as they are the most difficult population to recruit. Therefore substance use may in fact be under reported. For siblings whose brother or sister continues to use substances the prognosis can be poor (Lambert et al., 2005; Wade et al., 2004).

Suicide attempts

It is established in the literature that schizophrenia carries a 10% lifetime risk of suicide with the highest risk in those who developed the illness during adolescence and within the first couple of years after diagnosis (Beautrais, 2003; Harris, Burgess, Chant, Pirkis, & McGorry, 2008; Nordentoft et al., 2002; Siris, 2001). Studies have explored the frequency of suicidality in this population and it has been found to be a common feature in early psychosis samples. For example, Power et al (2003) implemented a clinical audit to ascertain the prevalence of suicidal ideation in all individuals attending an early psychosis clinic in Melbourne, Australia (N = 312). Data were used from the Health of the Nation Outcome Scale (HoNOS) ratings. Individuals' suicidality was rated by case managers fortnightly during a three month study period on the HoNOS scale. Descriptive statistics showed that forty-six percent were rated as persistently suicidal throughout the three month period.

Robinson et al. (2009), also from Australia, implemented a retrospective file audit to examine the prevalence of suicide attempts in the first two years of treatment (N =

661). The results showed that 22% had attempted suicide and 10% of those had attempted multiple times. One per cent had died by suicide. Further, Farrelly and colleagues (2010) in Melbourne, Australia, conducted a naturalistic, prospective study to examine the prevalence of suicide attempt in an early psychosis sample over 7 years (N = 413). They found that 221 had made no suicide attempt over that time (53%) but that 24 had made one attempt (6%), 26 had made more than one attempt (6%), and 12 had died by suicide (3%). This study suggests that suicide risk can remain high for at least seven years following the commencement of treatment for early psychosis and a key predictor of future attempts is previous attempts.

A Norwegian study has been included in this critique as it provides valuable insights into the sibling relationship when a suicide occurs. Clinical psychologists Dyregrov and Dyregrov (2005) from the Centre for Crisis Psychology in Bergen Norway, implemented a mixed method study to explore the needs of siblings after losing a brother or sister to suicide. Data were collected from 70 siblings divided into two subsamples. The first subsample consisted of 11 adolescents with a mean age of 17.7 years who lived at home with their parents at the time of the death. There were five females and six males in this younger sibling subsample. The second subsample consisted of 59 siblings with a mean age of 28.4 years who lived either alone or with their own core family at the time of the death. There were 39 older sisters and 20 older brothers in this subsample. The Impact of Events Scale (Horowitz, Wilner & Alvarez, 1979) was employed to measure post traumatic stress and an Assistance Questionnaire was developed for the study to obtain information about where siblings received support. Four younger siblings and five older siblings were then interviewed in-depth. The interviews aimed to further understand the siblings' experiences, as well as the qualitative dimensions of support and coping strategies.

For instance, the findings showed that one third of younger siblings had been aware of previous suicide attempts and knew the triggers. They kept this from their

parents which burdened them with ongoing guilt. Whilst the parents in the study reported finding it difficult to understand why the suicide had happened, the siblings had different information and knowledge. This enabled them to have their own theories as to why it happened. Siblings in this study avoided talking about this with their parents in order not to reveal information given to them in confidence. They felt this information could add to their parents' suffering. The siblings in the study reported that they did not communicate their own grief in order to protect their parents. As a result they felt alone. The parents also confirmed that the bereaved siblings were “forgotten” in the days following the death (Dyregrov & Dyregrov, 2005, p. 719).

Quantitative data showed that birth order was relevant to the level of distress experienced by the participants (Dyregrov & Dyregrov, 2005). The researchers found that older siblings living on their own experienced less post traumatic distress than the younger siblings. Younger siblings scored high on the post traumatic stress assessment and reported symptoms of depression, and anxiety, especially those who lived at home with family of origin. The authors proposed that age, marital status, and life circumstances may protect older siblings as they can avoid intimate exposure to their parents' despair. Older siblings often have their own core family and peer group available for support. All siblings felt only partly looked after by the family's network and professionals because most of the attention was directed toward their parents.

It may be that suicide attempts for siblings in early psychosis result in similar feelings of being forgotten, keeping secrets about triggers and therefore feeling burdened, guilty for holding knowledge that parents were not aware of, and experiencing distress, depression and anxiety (Dyregrov & Dyregrov, 2005). This appears to be relevant for younger siblings in particular.

History of violence

It is important to acknowledge that there are two methodological deficiencies in studies on violence in early psychosis: the varying definitions of psychosis which may misrepresent the true risk of violence; and the inclusion of a wide spectrum of violent acts from simple assault to homicide in the definitions of violence. However, the following studies from the United Kingdom, Ireland, Canada and Australia have found that a history of physical violence is not uncommon in early psychosis samples.

Milton and colleagues (2001), from the East Midlands Centre for Forensic Mental Health, in the United Kingdom examined incidents of physical violence in a first episode psychosis group (N = 168). They implemented clinical interviews and obtained information from the participants' medical files over three years. The authors found that one-third of participants exhibited physical violence. Many were violent prior to contact (18.5%) but it was more common after service contact (31%).

Other studies have found similar rates of violence in early psychosis samples such as in an Irish study by Foley, Browne, Clarke, Kinsella, Larkin, and O'Callaghan (2007), who implemented a retrospective case design study (N = 157) and found that 29% of the sample had been physically violent. In another study, Spidel et al (2010) implemented a cross sectional study and conducted in-depth interviews with a sample of 118 individuals in British Columbia, Canada. Violence was measured using the Modified Overt Aggression Scale (Kay, Wolkenfeld & Murrill, 1988) which is a self-report measure that asks participants to report incidents of their physical violence over the past 12 months. The authors found that 42.7% reported being physically violent within the past year. All three of these studies conducted correlation analyses and were consistent in finding that a long duration of untreated psychosis, persisting substance use and persisting psychotic symptoms contributed to acts of physical violence (Milton et al., 2001; Spidel et al., 2010).

Studies have also shown that the risk of homicide is greatest during the first episode of psychosis. For example, Large and Nielssen (2008) from Sydney, Australia, conducted a systematic review of 71 studies and implemented a multiple linear regression to examine the relationship between duration of untreated psychosis and homicide in early psychosis. A long duration of untreated psychosis was associated with homicide committed prior to receiving treatment. This was in agreement with other studies (Appleby & Shaw, 2006; Meehan, Flynn, & Hunt, 2006; Nielssen et al., 2007; Spidel et al., 2010).

This research indicates that approximately one third of individuals experiencing early psychosis may exhibit violent behaviour. It is not clear how or if this may impact upon the sibling relationship and their quality of life.

Family

A significant amount of evidence has demonstrated that families experience long term stress following the onset of early psychosis. The subjective effects on families such as guilt, grief, helplessness and distress have been established in studies from Australia, Canada and the United Kingdom (Addington, Coldham, Jones & Addington, 2003; Sin, Moone, Wellman, 2005; Tennakoon, et al., 2000). Objective effects including financial difficulties, effects on work performance, constraints on social activities, disruption to households activities, and effects on their own health, have been established (Addington et al., 2003; Sin, Moone, Wellman, 2005; Tennakoon, et al., 2000). The research has found that families experience psychological distress and their lives are significantly changed (Addington et al., 2003; Tennakoon et al., 2000). Even though these studies focus mainly on parents, a brief critique is important to include in this review. In accordance with Family Systems Theory discussed earlier in this chapter, it is acknowledged that all individuals within a family impact upon each other. Therefore, even though the results of these family studies cannot be generalised to the sibling

experience, it is to be expected that parental experiences will have an impact upon the siblings.

In a Canadian study by Martens and Addington (2001), 41 family members (4 siblings) of individuals experiencing early psychosis agreed to complete a questionnaire that measured their feelings of burden and their experience of care giving. These standardised measures were used to predict psychological wellbeing. Regression analyses showed that the family members experienced helplessness, exhaustion, frustration, confusion, constant worry, anger, despair and anxiety. Participants also reported frequent conflict between family members about what to do. The most challenging experiences of care giving were reported to be dealing with negative symptoms of the illness and difficult behaviours such as ongoing positive symptoms and physical violence. The authors proposed that families of individuals with early psychosis were less likely to have had previous contact with mental health services and so were inexperienced in how to cope with the different symptoms and behaviours. They were also likely to have limited knowledge of medication, the structure of the mental health system and the process of recovery.

Other researchers have also acknowledged that early psychosis presents unique challenges and issues for family members. For example, Addington et al (2003) implemented a quantitative study to determine the level of distress families were experiencing. Two hundred and thirty-eight participants in this study completed a questionnaire. Most were mothers (73%). There were no siblings included in this study. Family members were assessed with the Psychological Wellbeing Scale and the Experience of Caregiving Inventory. Results showed that poor psychological wellbeing of family members was associated with having a young child with a first episode of the illness, with a young age of onset. Further, even though most family members lived with their ill child, those who lived separately were equally distressed and concerned. Ongoing symptoms were associated with high levels of distress for families. (Addington et al.,

2003). Further, in a study by Chen and colleagues (2005) from the University of Hong Kong, 131 family members completed semi-structured interviews based on the retrospective assessment of the onset of psychosis. This instrument was designed by the authors and sought to gather data about early symptoms and initial onset. The majority of family members reported that they interpreted early changes in the behaviour of their family member as normal adolescent behaviour and hence did not seek help as early as possible, adding to their feelings of guilt.

In a recent Australian study by McCann, Lubman and Clark (2011), a qualitative methodology was used to understand the experience of family members living with a young adult experiencing early psychosis. They employed interpretative phenomenological analysis to inform data collection with 20 family members of individuals with early psychosis. The sample was mostly female (85%) and parents (90%) and other family members included grandparents and aunts. Themes derived from data analysis included *burdensome responsibility*, which relates to reflections of the changed life for the family member and their child. The experience was described as frightening as well as physically, emotionally and mentally straining. As one participant said, “It’s hard work, 24 hours a day, 7 days a week; you’re on call.” Another theme was *feeling responsible for their illness*. Several family members felt a sense of personal responsibility. “You feel responsible for everything that happens in your son’s life. So you have all the weight on your shoulders ... its very hard because when he tried to kill himself my husband blamed me, ‘Where were you?’ he said. I said, ‘What do you mean where were you? Where were you?’” This exploratory study provides a rich understanding of family members’ experiences through the themes of burden, grief and guilt.

There have been studies about families in early psychosis where siblings have been a small subsample. For example, a qualitative study by Corcoran, McGlashan, Gerson, and Sills-Shahar (2007) examined the impact on families of the lead up to a first episode psychosis (N = 13). Interviews focused on changes observed, effects on family,

explanatory models, help-seeking patterns and future expectations. The results showed that social withdrawal and changes in mood were noticed first; inpatient admissions were traumatic for families and expectations for the future were diminished. Twelve participants were parents and only one was a sibling. It was reported that the sibling participant had been the primary caregiver for his younger brother for several years as both parents had moved to another part of the country. No other details regarding this sibling's experience were discussed. This study therefore provides little insight into the unique experience of siblings.

A randomised control trial was conducted in Melbourne, Australia, by Gleeson and colleagues (2008) from the Early Psychosis Prevention and Intervention Centre (EPPIC) to evaluate the effectiveness of adding cognitive behavioural therapy (CBT) for relapse prevention to usual treatment and included a family therapy component (Gleeson et al., 2008). The study provided an opportunity to examine outcomes for families who received family CBT compared to family participants who received treatment as usual within a specialist program. This study recruited only individuals who had reached remission from positive symptoms of psychosis. Thirty-two family members were recruited to the relapse prevention group and 31 were recruited to treatment as usual. All family participants were parents, except for one sibling in each group. The findings showed that a high rate of depression and anxiety symptoms were evident as was a high level of burden amongst family members. As there were only two siblings in the study and no specific information is provided about them, their unique experience is still not known.

As outlined in the introduction, there is only one qualitative study, conducted by nurses Sin, Moone and Harris (2008), from the United Kingdom that used a phenomenological approach to capture the lived experiences of siblings. Ten siblings were interviewed (two men, eight women; 16-30 years of age, mean = 22.8 years). The sample included six younger sisters, two older sisters, one younger and one older brother

of nine individuals diagnosed with first episode psychosis. Only one participant was living with their ill brother or sister. Individuals with early psychosis had a mean age of 24.2 years (eight men, one woman) and had one to three years' duration of illness with a mean of 21 months.

Three themes were reported by Sin, Moone and Harris (2008). They were *emotional impact*, such as feeling overwhelmed, resentment, blame, guilt, loss and shame; *relationships in the family*, that reported the participants' belief in the importance of supporting their parents but not sharing their own feelings; and *sibling roles*, which discussed the practical support and companionship provided by siblings. Methodological flaws existed in this study. An example of this is that researchers did not state whether they revisited participants to clarify meanings and verify interpretations thus providing confidence that findings were faithful to the lived experiences of the participants. The dependability of interpretations is therefore threatened by the premature closure of analysis before data saturation had been achieved (Lincoln & Guba, 1985). However, as a first study into siblings in early psychosis, it shows that there may be a significant impact on the sibling relationship and quality of life.

Conclusion

A lot is not known about siblings in early psychosis, such as the impact upon their health and well being, their understanding of the illness, the roles they play in help seeking and care giving, the burden they experience, if and how the illness impacts upon their relationship and their quality of life. Studies with parents suggest the burden and impact upon their lives presents significant challenges. One qualitative study has shown that siblings can experience changed relationships and roles within the family and emotional impact. Clear characteristics of early psychosis can be identified in the literature such as the duration of untreated psychosis, hospital admissions, non-compliance with treatment, persisting psychosis, substance use, suicidal attempts and

violence. The impact of these characteristics of early psychosis on the sibling relationship and their quality of life is not known.

Aim of the study

To obtain quantitative data on the experience of siblings who have a brother or sister with early psychosis.

Research Questions

Research question 1: Does the gender and birth order of a sibling with a brother or sister experiencing early psychosis, result in: different levels of knowledge of psychosis; different levels of warmth, conflict and rivalry within the relationship; a different quality of life; different levels of burden and post traumatic stress symptoms?

Research question 2: What is the sibling relationship like in early psychosis and how does it compare to normative data?

Research question 3: What is the sibling quality of life like in early psychosis and how does it compare to the Australian normative data?

Research Question 4: Are there specific characteristics of early psychosis that are associated with a less warm sibling relationship?

Research Question 5: Are there specific characteristics of early psychosis that are associated with lower satisfaction of quality of life for a sibling?

Chapter Three: Methods

This study employed a survey methodology to explore the experience of siblings in early psychosis in the state of Victoria, Australia. This chapter will describe the methodology utilised in this research. It will consist of a detailed description of the design of the survey and the procedures undertaken to recruit participants, collect, manage and analyse data. For the remainder of this chapter, these siblings of young people experiencing early psychosis will be referred to as *participants* or *siblings*.

At the time of the study, the Clinic in Melbourne had a catchment area of approximately 880,000 inhabitants (ABS, 2004), covered a geographical area of 45 suburbs, and had a mandate to treat all young people aged between 15 and 29 years with a first episode psychosis. At the time of recruitment, it was the only facility for the target population in Victoria (Edwards, McGorry & Pennell, 2002).

The program included a comprehensive early intervention treatment program with a usual treatment period of 18 months. The program encompassed extensive psychiatric assessments, outpatient case management, cognitive behavioural therapy, low dose antipsychotic therapy, access to a specialised inpatient unit for acute care during crisis admissions if required, a mobile crisis intervention and community treatment team, group programs, family support groups and a specialised consultation group for the treatment of enduring positive psychotic symptoms (Edwards, McGorry & Pennell, 2002; McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996).

Participants

Siblings were eligible to participate in the study if they had no previous history of psychotic illness; were able to provide informed consent or, if under 18 years, their parents would provide consent; were able to speak and understand written English; did not have a diagnosis of intellectual disability; were aged between 15 to 29 years of age;

they had a brother or sister attending the Clinic for treatment of an early psychosis; and their brother or sister attending the Clinic provided informed consent for their participation.

The characteristics of the 157 siblings who participated in the study are presented in Table 1. The mean age of the sample was 21.7 years (S.D = 4.4).

Table 1 Descriptive summary of sibling participant, characteristics as reported by them.

Characteristics (<i>n</i> = 157)	Study sample <i>n</i> (%)	
Male	81	(51.6)
First born	65	(41.4)
Second born	52	(33.1)
Biological sibling	154	(98.1)
Living with ill brother or sister	99	(63.1)
Employed full time	91	(58)
Completed year 12	115	(73.2)
Completed a tertiary degree	15	(10)
Older brother to person with early psychosis	42	(26.7)
Younger brother to person with early psychosis	39	(24.8)
Older sister to person with early psychosis	44	(28)
Younger sister to person with early psychosis	32	(20.3)
Parents divorced	69	(43.9)
Moved out of home due to their brother or sisters illness	8	(5.1)
Brother or sister required admission due to illness	123	(78.3)
Visited their brother or sister when in hospital	104	(66.2)
Believed their brother or sister remained psychotic	88	(56.1)
Length of duration of untreated psychosis as stated by sibling		
1-6 months	42	(26.7)
7-12 months	61	(38.8)
≥ 13 months	54	(34.3)
Attended family services offered by mental health clinic	6	(3.8)
Happy with treatment brother or sister receives	113	(72)
Any contact with brother or sisters treating team	27	(17.2)

The age range of this group was 15 to 29 years with 51.6% being male. Most siblings were either first born (41.4%) or second born (33.1%) with only 6.4% being later then fourth born children. Nearly all were biological siblings (98%). Most of the siblings had completed secondary school ($n = 115$) and 10% had completed a tertiary degree. Nearly two thirds of the sample lived with their ill brother or sister (63.1 %). Six siblings had not lived with their ill brother or sister for two years; 24 siblings had not lived with them for three years and 17 had not lived with them for four years. Eight siblings reported they had moved out of home because of the illness (5.1%). Two thirds of siblings did not visit their brother or sister in hospital during their admission (66.2%). Over half believed their brothers or sisters continued to experience psychotic symptoms (56.1%). There were more males (81) than female (76) and more older siblings (86) than younger siblings (71) in this study as shown in Table 2.

Table 2: Descriptive summary of sibling dyads ($n = 157$).

Young person with early psychosis	Participant Older Brother	Participant Younger Brother	Participant Older Sister	Participant Younger Sister	Total
Male	30	29	27	27	113
Female	12	10	17	5	44
Total	42	39	44	32	157

The young people experiencing early psychosis

Individuals were eligible for treatment at the Clinic if they: exhibited symptoms of psychosis in accordance with the Diagnostic and Statistical for Mental Disorders (DSM-IV; American Psychiatric Association [APA], 2000) (schizophreniform psychosis, schizoaffective disorder, schizophrenia, drug induced psychosis, psychotic depression, bipolar affective disorder, brief psychotic disorder, psychosis not otherwise specified); had experienced less than 6 months of treatment with antipsychotic medication; lived in the demographic catchment area; and were between the ages of 15 to 29 years of age.

There were 388 young people recorded on the Clinic's data base during the study period. Of the 388 young people attending the Clinic for treatment of their early psychosis, 64 were lost to follow up, 32 were ineligible due to the exclusion criteria, 24 did not have a sibling, and 53 were reported by their case manager or doctor to be too unwell to approach due to acute psychosis. Two hundred and fifteen young people were therefore eligible to request consent for their sibling to participate in the research. One hundred and twenty-three young people provided consent for 157 siblings to participate. Twenty one young people consented to having more than one potential sibling participate in the study.

The sociodemographic characteristics for the one hundred and twenty three young people with early psychosis who provided consent for their sibling to participate are presented in Table 3. The mean age of young people with early psychosis was 21.4 years (S.D = 3.5).

Table 3: Sociodemographic characteristics of young people with early psychosis obtained from medical record (n = 123).

Characteristics	Study sample	
	N	(%)
Male	87	(70.7)
First born	41	(33)
Second born	56	(45.5)
Employed full time	33	(26.8)
Unemployed	71	(57.7)
At school or university	19	(15.4)
Diagnosis		
Schizophrenia	51	(41.5)
Schizophreniform	47	(38.2)
Schizoaffective	6	(4.9)
Bipolar affective disorder	13	(10.6)
Post traumatic stress disorder	5	(4.1)
Post partum psychosis	1	(0.8)
Persisting psychosis	64	(52)
Length of time in treatment		
1-6 months	47	(38.2)
7-12 months	54	(43.9)
13 -18 months	20	(16.2)
>18 month	2	(1.6)
Number of admissions		
No admission	29	(23.6)
1 admission	40	(32.5)
2 admissions	29	(23.6)
=/> 3 admissions	25	(20.3)
Compliant with medication	98	(79)

Attempted suicide	45 (36.5)
Completed homicide	2 (1.6)
Past history of substance use	96 (78)
Current substance use	34 (27.6)
Australian nationality	76 (61.7)

Participating young people with early psychosis ranged from 15 to 29 years of age with 70.7% being male. Most were either first born (33%) or second born (45.5%) with only 5% being later than the fourth born children. The majority lived with their parents (53%). Others lived alone (3%) and the rest lived with friends or partners (43%). Two individuals in the sample were homeless.

Over half the young people with early psychosis were unemployed (57.7%). Over a quarter were employed full time (26.8%) and the rest were either at school or university (15.5%). Thirty one percent had completed year 12, and 10% had completed an apprenticeship. Nine young people had obtained a university degree (7%).

The ethnicity of this group reflected the multicultural nature of the western region of Melbourne where the study's catchment was located. There were 22 different nationalities within this group of 123 individuals. The majority were born in Australia (48%), with Vietnam the second most common place of birth (11%), followed by Italy (5%), Greece (5%) and Lebanon (4%). Other backgrounds reflected the immigration from countries that had experienced war such as Sudan ($n = 2$) and Croatia ($n = 5$).

Seventy-nine percent of young people with early psychosis were reported in the medical file by their treating team to be compliant with medication. Over a third (36.5%) had attempted suicide. Two young people had murdered a family member during a psychotic episode. Nearly 80% had a past history of substance use. Over one quarter of young people in the study (27.6%) remained current users of illicit substances, mainly

cannabis. More than half were reported in their medical file to have persisting psychosis and had not yet obtained remission from symptoms (52%).

The sample of young people with early psychosis who agreed for their sibling to participate in this research was compared to samples from previous early psychosis studies. This was to ascertain whether the sample was a reasonable representation of those with early psychosis. In summary, there were more male participants in this study when compared to other studies but the mean age of participants was the same (Schimmelmann et al., 2007; Wade et al., 2006; Lambert et al., 2005). Employment rates were lower than seen in other studies (20%), more lived out of home (10%) (Schimmelmann et al., 2008), and more young people had a diagnosis of schizophreniform psychosis, indicating a shorter period of active psychosis (less than 6 months) (Schimmelmann et al., 2008; Schimmelmann et al., 2007; Wade et al., 2006; Lambert et al., 2005). This sample had a longer mean length of duration of untreated psychosis (DUP) (10 months compared to 8 months) (Schimmelmann et al., 2008; Conus et al., 2007). Similar rates existed of young people not requiring hospital admission but higher rates of multiple admissions were found in this study sample (24% more) (Wade et al., 2006). Young people in this study sample were reported to be more compliant with treatment (Lambert et al., 2010); they had a higher incidence of persisting psychosis (Schimmelmann et al. 2008; Conus et al., 2007); were reported to have less incidence of substance use (Addington & Addington, 2007; Lambert et al., 2005; Wade et al., 2004); and had a higher incidence of suicide attempts than other studies (Robinson et al., 2010; Robinson et al., 2009). The incidence of physical violence was comparable to the study by Milton, et al (2001).

Research Design

Influences on choice of study design

Obtaining feedback from young people about their view on health care or their experiences can be challenging (Arnett, 2010). There were three questions that influenced the choice of survey as the design for the study:

1. Siblings rarely attended or engaged with clinicians from the mental health clinic so how would the researcher engage them in this study?

From professional experience the researcher was acutely aware of attitudes held by both the community at large as well as the mental health sector in regard to psychosis. In discussions over the phone with siblings (which had been initiated for case management reasons, such as asking a younger brother in Year 12 if he needed a medical certificate, or a special consideration letter following the traumatic police admission of his ill brother), the researcher tried to gauge the worthiness and usefulness of this study. The siblings expressed their subjective views on mental health settings, their negative attitudes towards such clinics and their fear of being perceived as ill themselves. Just as young people with early psychosis are hard to engage in treatment (McGorry, 2007), their siblings were also considered to be reluctant to participate in research. The study design therefore needed to be accessible and non-threatening in order for siblings to participate.

It is widely acknowledged that data from a randomly selected sample are more representative of a population, than a sample of those who attend meetings, speak loudest, volunteer to respond, or happen to be convenient to research (DeVaus, 2004). It was not possible for the sample to be randomised, but if as many siblings as possible were to be recruited, the sample would reflect those with different levels of involvement, different attitudes, beliefs and experiences. This would assist in having a sample of siblings of different genders, different birth orders, and different levels of involvement, which earlier

research lacked (Gerace et al., 1993; Greenberg et al., 1997; Horowitz, 1993; Riebhleger, 1991; Smith & Greenberg, 2008).

2. What if the researcher found during the interactions with siblings, that some individuals may require therapeutic follow up?

As this research was the first reported study to actively engage the involvement of siblings in Victoria, it was unclear if they would accept or benefit from therapeutic support. Therefore the information package given to potential participants included a detailed explanation of specific programs within the Clinic available to all siblings of young people attending the youth mental health service (family services) (See Appendix A).

3. How can the researcher involve siblings in research and not breach confidentiality or offend the young person with psychosis?

Confidentiality is an important factor in all research and is particularly important for effective engagement of young people with early psychosis. The researcher had some experience of clinical situations where crisis teams and inpatient units had broken confidentiality agreements with young people. The consequences of such incidents had proven to be detrimental to both the recovery of the individual, the family relationships and the therapeutic relationship with the treating team. As a result and in order for the sibling to participate, the young person experiencing early psychosis was asked to provide informed consent. Consent also included the researcher reviewing the young person's medical file to obtain information about their illness. This gave the young person control in deciding whether or not they wanted to give permission for their sibling to be involved in the study.

Survey methodology

A survey is a systematic method for gathering information from a sample of people for the purpose of constructing quantitative descriptions of the attributes of a larger population (DeVellis, 2003). Surveying a sample of a target population of interest is a common research method that is cost effective and offers a systematic way of obtaining feedback about people's experience (Groves et al., 2004). It is well recognised that the perspective of patients, family members, health professionals and health authorities often differ, and attempts to measure these perspectives in a consistent and systematic way has been the subject of much research (Baker, 1990; Poulton, 1996). Clinical research surveys are concerned with describing attitudes and values, levels of knowledge or experience, current practices, or characteristics of a specific group (Groves et al., 2004; Liangputtong, 2010). Portney and Watkins (2009) reported that for psychological variables such as perceptions, fears, motivations, and attitudes, there is no more direct way to obtain information than a survey.

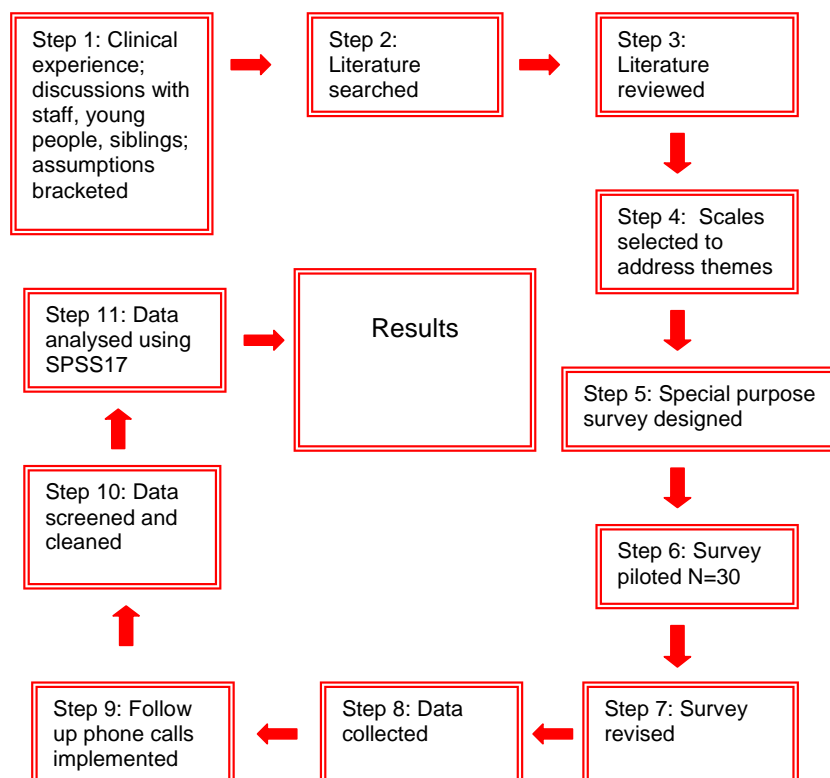
Surveys have the following characteristics: Information is gathered primarily by asking people questions through questionnaires, by having people read questions and record their own answers. Information is collected from only a sample of a defined population (Groves et al., 2004; Portney & Watkins, 2009). Surveys are self-administered using pen and paper, and consist of standardised scales, so that everyone is exposed to the same questions in the same way, reducing the potential for bias from interactions with an interviewer. The researcher does not directly observe the participants' behaviour or attitudes, but records the participants' report of them. Participants can take their time to think about their answers and to consult records for specific information. Surveys provide anonymity, encouraging honest and candid responses, and they enable simultaneous data collection from large samples (DeVaus, 2002). They are also a means for low cost data collection in comparison to other methods (Stange & Kyzanski, 1998).

There is always potential for bias or inaccuracy in self-reports, for example, when questions concern personal or controversial issues. There is however evidence to suggest that when a topic is sensitive, survey participants are more likely to give honest responses via self-report questionnaires (Portney & Watkins, 2009).

The researcher considered that if siblings were not inclined to attend the clinic or were reluctant to meet with other siblings, and the research demanded the recruitment of as many participants as possible, a hand delivered survey, collected three to five days later, where the sibling only had to engage with the researcher and not attend the mental health clinic, would fulfil this goal.

The research process undertaken in this study is represented in Figure 1.

Figure 1. Research eleven step design



As noted in Figure 1, this research began with informal discussions with staff, young people with early psychosis, parents of young people and their siblings. Step Two consisted of searches of databases including CINAHL, MEDLINE, PsychLIT and PubMed. Published papers were limited to the English language. The resulting literature was critiqued and clinical impressions were compared with the literature on the topic. The breadth of content, questions, scales and psychometric instruments were selected in Step Four. Step Five and Six consisted of designing and piloting the survey design. Piloting is an essential step in determining whether a survey is user friendly, and collects the required data in order to answer the research questions (DeVaus, 2002). Items were adjusted or eliminated to improve the survey and consequently it was refined and finalised. Step Eight involved the recruitment of 157 siblings across an 18 month period. All participants completed a hand delivered survey. Follow up phone calls were implemented in Step Nine. Trustworthiness was enhanced during Step Ten by cleaning and screening data to enhance accuracy. The final step before obtaining results involved the procedures for coding, data entry and data analysis. The results of data analysis are presented as findings (Chapter Four - Results). Conclusions were then drawn from the survey results (Chapter Five – Discussion, Chapter Six - Conclusions).

Designing the Survey

A special-purpose survey was developed consisting of seven components. Five of these were existing questionnaires and the other two were designed by the researcher. This survey aimed to address the issues found in the literature that were problematic for siblings of the long term mentally ill and therefore may impact upon the sibling relationship and quality of life in early psychosis. Such issues included experiences of guilt, grief, burden, care giving and a changed relationship with their ill brother or sister (Berheim, Lewine & Beale, 1982; Gerace et al., 1993; Greenberg et al., 1997; Horowitz, 1993; Kahn & Lewis, 1988; Lively et al., 1994; Riebhleger, 1991; Sin, Moone & Harris,

2008; Smith, 1991; Smith & Greenberg, 2008; Soloman et al., 2005; Titelman & Psych, 1991). The survey was designed to be age appropriate (See Appendix B).

Selection of Existing Scales

It was important for the study to select scales that were reliable and had good internal consistency. Internal consistency refers to the degree to which the items that make up the scale effectively measure the variable. One of the most commonly used indicators of internal consistency is Cronbach's alpha coefficient. Pallant (2007) reports that ideally the Cronbach alpha coefficient of a scale should be above 0.7. A procedure for checking the reliability of each scale selected for this study was implemented. The overall Cronbach alpha coefficient is therefore reported for each scale to show its internal consistency. The Cronbach alpha coefficient for each subscale is further reported in Appendix C.

The instruments selected were: The Knowledge about Schizophrenia Questionnaire (KASQ; Ascher-Svanum, 1999) which was utilised to measure stigma and knowledge about psychosis; The Adult Sibling Relationship Questionnaire (ASRQ; Stocker, Lanthier & Furman, 1997) which was used to measure the warmth, conflict and rivalry within the sibling relationship; The Experience of Caregiving Inventory (ECI; Szmukler, Burgess, et al., 1996) was utilised to measure the burden experienced by participants; The Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997) was used to measure the emotional impact; and the World Health Organisation Quality of Life Scale (WHOQOL-Bref; WHO, 1998) was used to measure the participant's satisfaction with their quality of life.

The selection of scales was influenced by consideration of their psychometric properties, the concept being measured and the variable being produced when the standardised scale was scored. The following section provides an overview of each instrument including data reduction.

1) The Sibling Participant Profile

The researcher designed a self report demographic data form consisting of 31 questions that covered such aspects as age, gender, living situation, birth order, contact frequency, educational and work history. Some items required a written response (e.g., ‘How many years you have known about your brother or sisters illness?’). Other questions were multiple choice in design. This demographic data were entered into the SPSS Statistics 17.0 data file for descriptive statistics.

2) Pathways to Care and Current Care Questionnaire

The Pathways to Care and Current Care Questionnaire was adapted from Early Detection and Optimal Treatment in First Episode Psychosis (McGorry, 1995) and aimed to establish recognition of sibling involvement in pathways to care and their opinion of the current treatment provided to their brother or sister. The values scored for this 6 item multiple choice scale were rated 1 (yes), 2 (no), 3 (unsure). No Psychometric properties were applicable to this assessment; answers were recorded in the SPSS data file for descriptive statistics.

3) The KASQ (Ascher-Svanum, 1999)

Knowledge about psychosis can be studied as a correlate of attitudes and stigma towards individuals experiencing psychosis (Ascher-Svanum, 1999). The most reliable and appropriately worded scale was found by the researcher to be the KASQ (Ascher-Svanum, 1999). As this research was directed to an early psychosis population, the label *schizophrenia* was changed to *psychosis* throughout the instrument as this was the word used to describe the illness at the study site and was therefore familiar to siblings.

The KASQ is a valid and reliable 25 item multiple choice test that covers diagnosis and prevalence of psychosis, aetiology, course, prognosis, medication and side

effects, non-medication treatments, stress factors and legal issues. The KASQ yields one score. Scores are calculated by the summation of the number of correct responses for 25 multiple choice items. Higher scores indicate a better knowledge of psychosis. It has a Cronbach alpha coefficient reported of $\alpha = 0.85$ (Ascher-Svanum, 1999). In the current study the Cronbach alpha coefficient was $\alpha = 0.73$ therefore showing good internal consistency (Pallant, 2007).

4) *The ASRQ (Stocker, Lanthier & Furman, 1997)*

Researchers Stocker, Lanthier and Furman (1997) developed a valid and reliable self report measure that assesses qualitative features of sibling relationships in young adulthood. The ASRQ assesses participants' perception of their own behaviour and feelings toward their sibling, as well as their perceptions of their brother or sisters' behaviour and feelings towards them. These perceptions can influence patterns of interaction. The items were developed on the basis of a conceptual analysis of previous research on sibling relationships in childhood and adulthood.

The questionnaire consists of 81 items conceptually grouped into 14 scales. The items on the 14 scales were combined to form three higher-order factors: warmth (intimacy, affection, knowledge, acceptance, similarity, admiration, emotional support, and instrumental support), conflict (dominance, competition, antagonism, quarrelling), and rivalry (maternal rivalry and paternal rivalry). Warmth is defined as sibling closeness and affection (Dunn, 2007; Goetting, 1986; Stocker, Lanthier & Furman, 1997); conflict is when one sibling does something to which the other objects (Conger & Little, 2010; Dunn, 2005; Dunn, 2007; Stocker, Lathier & Furman, 1997); and rivalry is defined as the competition for attention, affection and approval from parents between siblings (Brody, 1998; Dunn, 2007; Goetting, 1986; Scharf, Shulman & Avigad-Spitz, 2005; Stocker, Lathier & Furman).

For all ASRQ items participants rated how each item was characteristic of themselves and their sibling. Weighting of items was used and ranged from 1-5 on a Likert scales ranging from *hardly at all* (1) to *extremely much* (5). Maternal and Paternal Rivalry items were rated on a 5-point Likert scale (1 = *participant is usually favoured*, 2 = *participant is sometimes favoured*, 3 = *neither participant nor sibling is favoured*, 4 = *sibling is sometimes favoured*, 5 = *sibling is usually favoured*). These items were recoded as absolute discrepancy scores (0 = neither child is favoured, 1 = parents sometimes favour one child over the other, 2 = parents usually favour one child over the other, in accordance with guidelines (Stocker et al., 1997).

Scores for the ASRQ are calculated by summing responses within each subscale and dividing the total number of items in each scale to obtain a simple mean. Higher scores indicate more warmth, conflict or rivalry experienced within the relationship.

The ASRQ was reported by Stocker, Lanthier and Furman (1997) to have good internal consistency with a Cronbach alpha coefficient reported for warmth of ($\alpha = .97$), for conflict ($\alpha = 0.93$) and for rivalry ($\alpha = 0.88$). In the current study the Cronbach alpha for warmth was ($\alpha = 0.98$), for conflict ($\alpha = 0.92$) and for rivalry was ($\alpha = 0.91$). Further details of the subscales are provided in Appendix C, Table 1.

5) The ECI (Szmukler, Burgess, et al., 1996)

Szmukler and his colleagues (1996) developed this self-report measure of the experience of care giving for family members with a person with a serious mental illness in their family. It assesses both the negative and positive aspects of care giving in this context. Care giving is conceptualised within a stress-appraisal-coping framework. The ECI is a 66 item measure that yields 2 scores – Negative Aspects of Caregiving Subscale (8 items: difficult behaviours; negative symptoms; stigma; problems with services; effects on family; need to backup; dependency, loss) and Positive Aspects of Caregiving Subscale (2 items: rewarding personal experiences; good aspects of relationship with the

patient). Items are scored on the basis of how often the individual has thought about various statements (e.g., ‘during the past month how often have you thought about feeling unable to tell anyone about the illness?’). The care giver rates these statements from 0 (never) to 4 (nearly always). Scores are calculated by adding responses within each subscale and dividing this score by the total number of items to obtain a simple mean (Szmukler, Burgess, et al., 1996). A high rating on the negative subscale reflects a high level of burden experienced. A high rating on the positive subscale reflects a high level of positive experiences.

This measure of care giving has been found to be a strong predictor of the psychological well-being for people who have a family member with schizophrenia (Szmukler, Burgess et al., 1996). The Cronbach alpha coefficient statistics are provided for the eight negative scales and two positive scales in Appendix C, Table 2, for both the Szmukler et al (1996) sample and this study sample. High internal consistency is evident.

6) IES – R (Weiss & Marmar, 1997)

This scale was developed to parallel the Diagnostic and Statistical Manual for Mental Disorders criteria for post traumatic stress disorder (DSM-IV; American Psychiatric Association [APA], 2000). It is a self report assessment designed to assess current subjective distress for any specific life event. It is based on clinical studies of psychological responses to stressful events, and on Horowitzs’ (1976) theory about stress response syndrome which offers understanding of how people proceed through trauma.

The IES-R has 22 items and yields three scores: Avoidance Subscale (8 items: denial of consequences of events and awareness of emotional numbness); Intrusion Subscale (7 items: troubled dreams, thoughts, images, feelings) and Hyperarousal Subscale (7 items: anger, irritability, heightened startled response, difficulty concentrating, hypervigilance and dissociative experiences such as flashbacks). Participants rate the frequency of their experience of each item over the past seven days

on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), and 4 (extremely often). Scores are calculated by adding responses within each subscale and dividing this score by total numbers of items to obtain the mean (Weiss & Marmar, 1997). The overall score is calculated by the sum of the three subscales. Higher scores indicate a higher level of post traumatic stress symptoms experienced.

The IES-R showed high internal consistency with a Cronbach alpha coefficient reported of $\alpha = 0.96$ by the authors. As outlined in Appendix C, Table 3, in the current study the Cronbach alpha coefficient also showed high internal consistency for each subscale.

7) The WHOQOL-Bref (WHO, 1998)

The Constitution of the World Health Organisation defines health as “a state of complete physical, mental and social wellbeing not merely the absence of disease...” (WHO, 1998, p.1). The WHO defines *quality of life* as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1998, p.3). The WHO, with the aid of 15 collaborating centres around the world, developed an instrument for measuring quality of life that can be used in a variety of settings whilst allowing the results from different populations and countries to be compared.

The WHOQOL-BREF is a 26 item self-report measure and produces a quality of life profile consisting of four domain scores: Physical Domain (7 items: energy, enthusiasm, endurance, sleep and rest that a person has in order to perform the necessary tasks of daily living), Psychological Domain, (6 items: feelings of contentment, balance, peace, happiness, hopefulness, joy, enjoyment, despondency, guilt, sadness, tearfulness, despair and anxiety), Social Domain (3 items: support from family and friends and who they depend on in a crisis) and the Environment Domain (8 items: a person’s sense of safety, security from physical harm and their sense of freedom).

All items are rated on a 5-point scale assessing intensity, capacity, frequency or evaluation of people's satisfaction. The mean scores of items within each domain are used to calculate the domain score. Mean scores are then multiplied by four in order to make domain scores compatible with the scores used in the WHOQOL-100 (scale range 0-100) (WHO, 1998). This scale required reverse scoring of items 3, 4 and 26. The method for converting raw scores to transformed scores is provided in the WHOQOL-BREF user manual (WHO, 1998). Domain scores are scaled in a positive direction with higher scores denoting higher quality of life.

As seen in Appendix C, Table 4, The WHOQOL-Bref (WHO, 1998) has good internal consistency with a Cronbach alpha coefficient range for each domain: physical domain $\alpha = 0.70$, psychological domain $\alpha = 0.79$, social domain $\alpha = 0.79$ and environment domain $\alpha = 0.79$.

Young Persons Medical File Review Form

A demographic information sheet was designed by the researcher to review the medical file of the young person with early psychosis (See Appendix D). This form aimed to record information on the length of treatment, current medication, number of hospital admissions, compliance with treatment, current drug use, suicide attempts, physical violence, and whether the psychosis persisted or was in remission. This information was gathered in order to ascertain if certain characteristics of early psychosis affected the sibling relationship or their quality of life. They were kept separately in a locked cabinet at La Trobe University. Each file review form was allocated a unique ID number and coded in order to match with their sibling's survey.

Ethical approval

Ethical approval was obtained from the Behavioural and Psychiatric Research and Ethics Committee of North Western Mental Health Program reference number E/03/008 and the La Trobe University Human Ethics Committee (Appendix E).

Ethical considerations

Ethical issues were considered throughout the planning and implementation of this study. Further ethical considerations not dealt with elsewhere in this chapter are now considered.

A number of measures were implemented to ensure privacy and confidentiality. A plain language information sheet included with the survey informed siblings of any potential risks and also outlined data collection and storage procedures (See Appendix A). There were also assurances that data collected would be de-identified. The plain language statement informed participants of the source of funding for the research, listed the institutions involved in the study, and outlined how the results of the study would be disseminated. The contact details of the Executive Officer, Human Research Ethics, North Western Mental Health Program and La Trobe University Human Ethics Committee were listed in the information sheet should participants have any concerns with the conduct of the research. All participants were informed verbally, and on the information leaflet that their participation in the study was voluntary, and that they were free to withdraw their participation in the study without any consequences.

Pilot testing of the survey

The services of a graphic designer were employed for consultation on the visual design of the survey. The seven parts of the survey were collated into an instrument that aimed to be youth friendly and easy to use. Font, wording and layout were considered in order to assist in the engagement of siblings in the research (see Appendix B).

The survey was piloted with a sample of 30 siblings during the first 6 months of this study. The inclusion/exclusion criteria for the pilot study were the same as the criteria used for sibling participation in the main study (see page 46). The first 30 siblings recruited were requested to participate in the pilot study. Subsequent to that, the following 157 siblings were recruited to the main study. The Young Persons Medical File Review Form was also piloted by the researcher to ensure all relevant information was collected.

Recruitment for the pilot test was made in collaboration with case managers and doctors at the study site during fortnightly case management and clinical review meetings to identify possible participants. The researcher met with each case manager and doctor individually who reviewed their case list to identify young people who had a sibling. If the young person agreed, the researcher attended the next appointment at the discretion of the case manager and doctor. The Information Sheet and Consent Form for Young People Attending EPPIC (See Appendix F) was provided and read through with each young person to ensure they understood the aims, procedures and risks of the study. Once consent had been obtained from the young person, the sibling was contacted and asked to participate in the pilot test. The researcher met with the sibling and provided them with the Information Sheet and Consent Form for Siblings, reading it through to ensure they understood the aims, procedures and risks of the study (See Appendix A). The researcher met with 30 siblings and they all agreed to participate. They were informed that the results of their survey would not be used in the final study results.

The survey was hand delivered and collected by the researcher three to five days later in order to make the experience non-threatening, easy, safe and engaging, therefore enhancing the response rate. Included in the survey package was a form with questions about their response to the survey and their comments (See Appendix G).

Siblings reported that the survey did address issues relevant to them. Participants provided positive feedback on the design and structure of the tool. They pointed out minor spelling mistakes, ambiguous or repeated questions, questions that did not make

sense due to some minor grammatical errors, and questions that were difficult to understand.

Twenty-three participants stated that the ASRQ (Stockier, Lanthier, Furman, 1997) was the hardest part of the survey because they found it “confronting”, “sad” or “difficult to think about”. Others reported that the Knowledge of Psychosis Questionnaire component was hard and they requested the correct answers be provided to them for their future reference.

All recommendations made by siblings were considered and the survey was subsequently changed to reflect their requests. These changes may have made the survey more user friendly and may have enhanced the response rate. The researcher became more aware of the ASRQ and made a point of asking about this part of the survey during participant follow up. The results of the KASQ component of the survey were provided to all siblings during survey collection following the pilot study recommendation. With minor modifications the survey was finalised.

Data Collection

Sampling

Convenient purposive sampling was used to recruit siblings from the Clinic in Melbourne. The research literature recommends this design can be used when participants with particular experiences and characteristics are intentionally sought (Portney & Watkins, 2009).

Sibling recruitment

Recruitment of siblings involved three stages:

1. engaging the case managers and doctors to identify young people on their caseload who had a sibling;

2. engaging young people with early psychosis in the research and obtaining informed consent for sibling participation; and
3. inviting the sibling to participate in the research and gaining their informed consent for participation.

The recruitment of siblings occurred over an 18 month period from August 2003 until January 2005. The three stages of recruitment are outlined next.

1. Engaging the case managers and doctors to identify young people who had a sibling:

The researcher attended the fortnightly case management and weekly clinical review meetings to outline the research and provide a Clinician Information Sheet explaining the study aims (See Appendix H). The case managers and doctors reported that the most efficient way to provide the required information would be to meet individually with each young person with early psychosis.

Sixteen case managers of multidisciplinary backgrounds, three psychiatric registrars and three consultant psychiatrists were working at the Clinic. They reviewed their case list to identify young people who had a sibling. During these individual meetings, case managers provided the researcher with clinical updates, with comments such as: “It’s probably best you don’t contact this boy at this time, he’s too unwell.” In order to ensure no potential participants were missed, the researcher met regularly with each consultant psychiatrist, psychiatric registrar and case manager. This meeting process occurred every three months during the recruitment period to ensure new referrals to the Clinic were included in the sampling frame.

2. Engaging young people with early psychosis in the research and obtaining their informed consent for sibling participation:

Once the presence of a sibling was identified, the researcher requested the case manager or doctor to ask the young person during their next appointment if they would

consent to their sibling's participation in the study. If the young person agreed, the researcher would attend the next appointment at the discretion of the case manager and doctor. The timing of the approach to the young person was determined by the treating case manager or doctor. This was to avoid an insensitive or inappropriate approach that might compromise the mental health of the young person. Clinicians used their judgement when setting up appointments for information and consent. From the list of 388 young people attending the early psychosis clinic for treatment, two hundred and fifteen were eligible to approach. Of these, 84 refused to participate and 131 agreed to meet with the researcher.

During the meeting arranged by the case manager or doctor, the researcher went through the Information Sheet and Consent Form for Young People (See Appendix F) and answered any questions that were raised. Many reported they were glad to have their sibling receive 20 dollars for participating, a common response being, "at least I can do something for him". They also wanted to know what would happen to the information they provided. Eight young people experiencing early psychosis did not provide consent following the interview. This, they explained, was associated with their need to protect their sibling. They made comments such as "I really don't think they want anything to do with this place and I don't want to force them", or "I think I've caused enough disruption to their life". Other comments included, "I'm interested in the study but I don't talk to them anymore", or "He put me in hospital last time, he will just say bad things about me in the survey". If the young person had more than one sibling in their family, consent was required to approach each individual sibling.

From the 131 young people who agreed to meet with the researcher, 123 agreed for their sibling to participate. They provided the researcher with information regarding the best way to contact their sibling. Some said, "I'll ask them first and get them to ring you"; most said "You can ring them, here's their phone number". Once consent had been obtained from the young person with early psychosis, the sibling was contacted.

3. Engaging the sibling in the research and gaining their informed consent for participation:

During the first phone contact with siblings, the researcher's interview style was aimed at optimising engagement with each individual. The researcher provided as much information as possible about the study during the first contact to optimise the chance that siblings would complete the survey. The researcher read through the Information Sheet and Consent Form for Siblings (See Appendix A) with 157 siblings and they all agreed for the researcher to meet with them at their home in order to review the Information Sheet again, sign the consent form, and accept a survey for completion.

Survey delivery

During the first phone call a meeting time that suited the sibling was arranged. All siblings declined the offer of attending the mental health clinic. They requested that the researcher attend their home to gain informed consent and that the survey be left with them for completion. They agreed for the researcher to collect it at their home three to five days later.

In meetings with siblings the information package and consent form were reviewed to the participant's satisfaction and signed. This researcher asserts that face to face contact and individual engagement enhanced the response rate. The researcher went through the survey with each participant clarifying any aspects that were unclear.

Survey collection

Three to five days after survey delivery, the researcher rang the sibling to make a time for collection. This meeting consisted of sitting down with the sibling, reviewing the completed instrument, providing the opportunity to clarify any aspect of the research or survey, checking for illegible answers, crossed out or skipped questions, and clarifying

answers so that nothing was missed or misunderstood. Results for the KASQ were provided for the participants. Siblings were then paid for their participation in this study. The payment was in no way intended as an inducement to participate but was made in recognition of their valued contribution of expertise, experience and time (Ryan & Bamber, 2002). They were paid 20 dollars for the completion of the survey. Funding for the payments was made available by the Anita Morawetz Family Therapy Scholarship, University of Melbourne.

Each participant was asked about the experience of the survey. This meeting went for approximately 30 minutes. Support options were offered. No sibling accepted or requested any further support. Siblings were reminded that the researcher would be providing a follow up phone call in a week to see if there were any further comments they would like to make about their experience of the survey.

Follow up

The week that followed the survey collection allowed the researcher to read the participant's responses. During the follow up phone call approximately 7 to 10 days after survey pick up, the researcher acknowledged their individual experience. For example, if a sibling rated on the WHOQOL-Bref (WHO, 1998) component of the survey that they felt depressed all the time and that they were having difficulty eating or sleeping and having nightmares, then the researcher would raise this in the follow up phone call. Their comments included "yes I've been thinking about it and I really don't sleep since that violent outburst happened"; "maybe I am a bit down"; "what does it mean if I'm not interested in things anymore, will I get sick like my brother?" The follow up phone call provided the opportunity for education, problem solving and normalising of their reactions to traumatic events. Siblings were offered options as stated in the information package. Phone calls lasted up to one hour.

Of the one hundred and fifty-seven follow up phone calls, the researcher identified forty-five siblings who indicated that they may benefit from the support services within the Clinic. Of the 45 siblings, 39 accepted the offer and were therefore formally referred to the support service by the researcher as per the ethics approved protocol. Twenty-five of these individuals attended the first appointment, 14 accepted the referral but did not attend and six rang within a week after the follow up phone call to report they had changed their mind and did not want any formal support.

Data Management and Statistical Analysis

The data management process followed the procedures outlined in Pallant (2007). A code book was prepared to code responses and a data file was created using SPSS Version 17.

Coding

Returned surveys were stamped and allocated a unique ID number. Young people's IDs comprised three digit numbers (e.g. 001, 002, 003) and the ID of the sibling (e.g. sibling ID 02, 03) was used as a prefix. This enabled identification of the ill brother or sister with their sibling. To ensure consistency of coding and to reduce coding error, a coding schedule was developed for the survey. The researcher undertook data entry of coded surveys. All survey responses were entered twice ensuing discrepancies were identified and corrected.

Cleaning and screening the data

The procedures for cleaning and screening data as described by Pallant (2007) were followed to ensure that the data file was free from error. All participant responses were checked twice against the data entered alongside their case number in the SPSS version 17 data file.

Data Reduction

The total scores for all scales were calculated according to published instructions.

Data Analysis

The SPSS-17 statistical package was used for all data entry and management. Once data were entered, cleaned and screened, descriptive statistics were generated to establish the characteristics of the participants in the study and the young people experiencing psychosis. Means, standard deviations and 95% confidence intervals (95% CI) were calculated to represent the preliminary population norms. Scales were investigated for normality prior to statistical investigation of relationships within the data. As described by Tabachnik and Fidell (2007), scales require exploration to determine normality, linearity and homoscedasticity of residuals during routine pre-analysis screening and this occurred for all scales. The reliability of each scale was assessed using internal consistency (Cronbach alpha). After the data were reduced and explored, the research questions were addressed.

Statistical techniques applied to the data

This section briefly describes the main statistical analyses that were completed. This study was concerned with relationships among variables including correlations and the significance of group differences. Categorical variables provided identification of sub-groups within that population, and differences between groups were investigated using continuous variables (Pallant, 2007). Correlation analyses were used to detect relationships between scales and variables. Statistical differences between groups were investigated using independent samples t-tests and one way analysis of variance (ANOVA). T-tests were used to compare the mean score on a continuous variable. One-way between-groups ANOVA were used to compare the mean score of two or more

groups on a continuous variable (Pallant, 2007). Post-hoc comparisons were implemented to ascertain which groups were significantly different from one another. Given the number of analyses conducted, a conservation alpha level ($p < 0.05$) was used to assess statistical significance in all analyses.

Pearson's product-moment co-efficient (r) was used to detect relationships between variables in the study as all data were normally distributed. Pearson correlation analyses were used to explore the direction and strength of the relationship between variables (Pallant, 2007). The significance of the strength of correlation was interpreted in accordance with guidelines proposed by Cohen (1988). Correlations were considered to be small or weak below 0.29; moderate and significant between 0.30 and 0.49; and strong from 0.5 to 1.0.

Each research question required specific statistical analyses. The following section describes the techniques used to explore each question.

Research question 1: Does the gender and birth order of a sibling with a brother or sister experiencing early psychosis, result in: different levels of knowledge of psychosis; different levels of warmth, conflict and rivalry within the relationship; a different quality of life; different levels of burden and post traumatic stress symptoms?

Descriptive statistics were used to establish the results for the KASQ (Ascher-Svanum, 1999), the ASRQ (Stockier, Lanthier & Furman 1997), the ECI (Szmukler, Burgess, et al., 1996), the IER-S (Weiss & Marmar, 1997) and the WHOQOL-Bref (WHO, 1998). A series of one-way between groups ANOVA were conducted to explore the differences between sibling groups in terms of gender and position.

Research question 2: What is the sibling relationship like in early psychosis and how does it compare to normative data?

Descriptive statistics were used to establish the results for the ASRQ (Stockier, Lanthier & Furman 1997) for the warmth, conflict and rivalry subscales. These results were then compared to the norms established by the authors of the instrument using a one sample t-test to establish whether there was any difference within the sibling relationship as a result of one member experiencing early psychosis (Stockier, Lanthier & Furman 1997).

Research question 3: What is the sibling quality of life like in early psychosis and how does it compare to the Australian normative data?

Descriptive statistics were used to establish the results for the WHOQOL-BREF for the four domains: physical, psychological, social and environment quality of life subscales. These results were then compared to the preliminary Australian norms established in the study by Hawthorne et al (2006) using a one sample t-test to establish whether there was any difference in the quality of life of siblings.

Research Question 4: Are there specific characteristics of early psychosis that are associated with a less warm sibling relationship?

Independent samples t-tests, ANOVAs and Pearson product-moment correlations were conducted on nine of the most commonly experienced features of early psychosis to analyses their effect on the sibling relationship in terms of warmth, conflict and rivalry. The ASRQ scores were presented together with the 95% confidence intervals. Post-hoc comparisons using the Tukey Honestly Significant Difference Test were undertaken to

determine significance between groups and identify the differences that occurred between the groups.

Correlation analyses were conducted to explore results of the KASQ, the ECI, the IES-R, and the WHOQOL-Bref with the ASRQ to establish the strength and direction of the relationship between them.

Research Question 5: Are there specific characteristics of early psychosis that are associated with lower satisfaction of quality of life for a sibling?

Independent samples t-tests, ANOVAs and Pearson product-moment correlations were conducted on nine of the most commonly experienced features of early psychosis to analysis their effect on quality of life in terms of the physical, psychological, social and environment domains. The domain scores are presented together with the 95% confidence intervals. Post-hoc comparisons using the Tukey Honestly Significant Difference Test were undertaken to determine the significance between groups and to identify the differences that occurred between the groups.

Correlation analyses were conducted to explore results of the KASQ, the ECI, the IES-R and the ASRQ with the WHOQOL-BREF to establish the strength and direction of the relationship between them.

Chapter 4: Results

This chapter will present the statistical analyses that were completed to address the research questions.

Research question 1: Does the gender and birth order of a sibling with a brother or sister experiencing early psychosis, result in: different levels of knowledge of psychosis; different levels of warmth, conflict and rivalry within the relationship; a different quality of life; different levels of burden and post traumatic stress symptoms?

This section presents the siblings' experience of early psychosis by reporting their self-assessed ratings of their knowledge of psychosis as measured by the KASQ (Ascher-Svanum, 1999), their sibling relationship as measure by the ASRQ (Stocker, Lanthier & Furman, 1997), their experience of care giving as measured by the ECI (Szmukler, Burgess, et al., 1996), the impact of events associated with their brother or sister's illness as measured by the IES-R (Weiss & Marmar, 1997), and their quality of life as measured by the WHOQOL- Bref (WHO, 1998). Siblings are divided into four groups: older brother, younger brother, older sister and younger sister. Total scores are also provided (See Table 4, p.82).

Knowledge of psychosis

Table 4 reports the results of the siblings' knowledge of psychosis as measured by the KASQ (Ascher-Svanum, 1999). A one-way between-groups analysis of variance (ANOVA) was conducted to explore the significance of the differences seen between sibling groups for knowledge of psychosis, as measured by the KASQ (Ascher-Svanum, 1999). No statistically significant difference was found at the $p < .05$ level between the mean scores of the four groups in their knowledge of psychosis $F(3, 153) = 0.61, p = .609, \eta^2 = 0.01$.

The sibling relationship

Younger sisters scored highest for levels of warmth and rivalry. Younger brothers had the lowest scores in warmth and rivalry. Older sisters scored highest for conflict. Older brothers reported the least conflict (See Table 4). A series of one-way between-groups ANOVA were performed to explore the significance of the differences seen between sibling groups. There was no statistically significant difference found between the four groups for warmth $F(3, 153) = 1.08, p = .356, \eta^2 = .02$, conflict $F(3, 153) = 2.28, p = .081, \eta^2 = .04$ or rivalry $F(3, 153) = 0.90, p = .440, \eta^2 = .01$.

Quality of life

Older brothers reported the most satisfaction in each domain of their quality of life. Younger sisters reported the least satisfaction in each domain of their quality of life (See Table 4). A series of one-way between groups ANOVA were performed to explore the significance between sibling groups for the WHOQOL-Bref (WHO, 1998). Post-hoc comparisons using the Tukey's Honestly Significant Difference test were undertaken to ascertain which groups were significantly different for each quality of life domain.

There was a statistically significant difference found for the physical domain between the four groups $F(3, 153) = 3.66, p < .05, \eta^2 = .07$. Older brothers were significantly more satisfied with the physical domain of their quality of life than younger sisters. A statistically significant difference was also found in the psychological domain $F(3, 153) = 5.75, p < .05, \eta^2 = .10$. Older brothers were significantly more satisfied than both older and younger sisters. Younger brothers were also found to be significantly more satisfied with their psychological quality of life than younger sisters.

In the social domain $F(3, 153) = 3.97, p < .05, \eta^2 = .07$, the mean score for older brothers was significantly higher than younger sisters. In the environment domain

between the four groups, $F(3, 153) = 3.93, p < .05, \eta^2 = .07$, the mean score for older brothers was again significantly higher than younger sisters.

The experience of care giving

Older brothers reported the lowest total score for negative experiences. Younger brothers reported the lowest score for positive experiences. Younger sisters had the highest negative score of the four groups and reported the highest levels of burden on six of the eight subscales (See Table 4). They also reported a greater number of positive experiences than the other sibling groups. A series of one-way between groups ANOVA were performed to explore the significance between sibling groups for the ECI (Szmukler, Burgess, et al., 1996). Post-hoc comparisons using the Tukey's Honestly Significant Difference test were used to identify which groups were significantly different for each aspect of burden.

For overall burden reported by the total negative scores between groups, $F(3, 153) = 2.94, p < .05, \eta^2 = .05$, older brothers scored significantly lower than younger sisters. For total positive experiences, $F(3, 153) = 5.25, p < .05, \eta^2 = .09$, older and younger brothers again scored significantly lower than younger sisters.

The impact of events

Older brothers reported the lowest levels of avoidance, intrusions and hyper-arousal symptoms as a result of events associated with their brother or sister's illness. Younger sisters reported the highest number of symptoms (See Table 4). A series of one-way between groups analysis of variance were conducted to explore the significance between sibling groups for the IES-R (Weiss & Marmar, 1997). Post-hoc comparisons using the Tukey's Honestly Significant Difference test were used to identify which groups were significantly different.

There was a statistically significant difference for both avoidance, $F(3, 153) = 3.24, p < .05, \eta^2 = .06$, and intrusions, $F(3, 153) = 4.01, p < .05, \eta^2 = 0.07$. For older

brothers the mean score in both was significantly lower than for older and younger sisters. The hyper-arousal subscale, $F(3, 153) = 3.27, p < .05, \eta^2 = .06$, was found to be significantly lower for older brother than younger sisters.

Key findings for gender and birth order

Statistical analyses of this data show that gender and birth order did not result in different levels of knowledge of psychosis for this sample. There was no significant difference in levels of warmth, conflict and rivalry within the relationship. Statistical analyses did show that older brothers were more satisfied with all domains of their quality of life in comparison to young sisters. Older brothers were found to be statistically more satisfied with the psychological domain of quality of life than older sisters. Older brothers reported significantly lower levels of burden and post traumatic symptoms than both older and younger sisters.

Table 4

Results of the KASQ , ASRQ, WHOQOL-Bref, ECI, IES-R .

Scores are presented for sibling gender and position (older brother (OB), younger brother (YB), older sister (OS), younger sister (YS), and for total numbers (total siblings(T)).

	OB N=42 <i>M (SD)</i>	YB N=39 <i>M (SD)</i>	OS N=44 <i>M (SD)</i>	YS N=32 <i>M (SD)</i>	T N=157 <i>M (SD)</i>
KASQ*	17.50 (3.82)	16.86 (3.29)	18.81 (2.95)	17.67(3.93)	17.76(3.52)
ASRQ					
Warmth	3.37 (0.80)	3.08 (0.91)	3.29 (0.97)	4.43 (0.94)	3.29 (0.91)
Conflict	1.39 (0.45)	1.52 (0.58)	1.70 (0.61)	1.63 (0.64)	1.56 (0.58)
Rivalry	0.53 (0.58)	0.46 (0.61)	0.59 (0.70)	0.71 (0.69)	0.57 (0.64)
WHOQOL-Bref					
Physical	87.24 (13.84)	81.41 (17.24)	78.32 (17.43)	75.33 (17.31)	80.86(16.89)
Psychological	63.59 (10.41)	61.53 (9.81)	57.10 (9.90)	53.77 (14.79)	59.26 (11.67)
Social	77.97 (15.15)	67.52 (20.83)	69.69 (18.51)	64.06 (18.98)	70.22 (18.92)
Environment	81.69 (14.97)	78.20 (16.72)	73.65 (14.78)	70.01 (18.69)	76.19 (16.60)
ECI					
Total negative score	87.62 (4.70)	93.30 (5.30)	103.24 (4.86)	108.4 (6.10)	97.66 (5.30)
Total positive score	28.09 (1.55)	27.07 (1.30)	32.40 (1.45)	35.6 (1.53)	30.58 (1.52)
IES-R					
Avoidance	1.28 (0.39)	1.65 (0.83)	1.17 (0.91)	1.75 (0.77)	1.59 (0.77)
Intrusions	1.18 (0.32)	1.51 (0.79)	1.59 (0.78)	1.67 (0.66)	1.48 (0.68)
Hyperarousal	1.17 (0.28)	1.54 (0.90)	1.46 (0.73)	1.69 (0.90)	1.45 0.75)

* Knowledge scores range from 0-25, with higher scores indicating higher levels of knowledge.

Research question 2: What is the sibling relationship like in early psychosis and how does it compare to normative data?

The total study sample was compared to the participants in the study by Stocker, Lanthier, et al (1997) who examined sibling relationships in undergraduate students at two universities in the United States in order to establish norms (See Table 5). A one sample t-test was conducted for each subscale and no significant difference was found between the two samples.

Table 5
Participant results of the Adult Sibling Relationship Questionnaire (ASRQ) compared to results from the Stocker et al. normative data (1997).

	Study Sample	Stocker et al. 1997
	N=157	N=383
	Mean (SD)	Mean (SD)
Subscales		
Warmth	3.29 (0.91)	3.30 (0.70)
Conflict	1.56 (0.58)	2.20 (0.70)
Rivalry	0.57 (0.64)	0.70 (0.60)

Research question 3: What is the sibling quality of life like in early psychosis and how does it compare to Australian normative data?

Quality of life scores for the 20-29 year old respondents in the study sample were compared to the participants in the study by Hawthorne et al (2006) who established norms for age groups within the Australian population. The current study showed lower satisfaction in the psychological domain for both male and female participants. Males in the study scored higher satisfaction in the social and environment domains. Females in the study had lower satisfaction in the social domain. A one sample t-test was conducted for each domain and no significant difference was found between the two samples.

Table 6
WHOQOL-Bref (WHO, 1998) results of participants compared to the preliminary Australian normative data established in the study by Hawthorne et al. (2006)

Quality of Life Rating	Study Sample 20-20 years		Hawthorne et al. Study (2006) 20-29 years	
	Male N=49 <i>mean (SD)</i>	Female N=40 <i>mean (SD)</i>	Male N=17 <i>mean (SD)</i>	Female N=30 <i>mean (SD)</i>
Physical Domain	86.3 (15.4)	79.8 (16.9)	88.7 (9.8)	83.6 (11.3)
Psychological Domain	63.6 (10.6)	57.2 (9.8)	74.3 (16.8)	69.7 (17.9)
Social Domain	76.8 (18.4)	72.5 (17.2)	68.1 (23.4)	75.6 (15.3)
Environment Domain	82.0 (16.2)	75.0 (16.6)	77.2 (10.6)	72.7 (15.6)

Research Question 4: Are there specific characteristics of early psychosis that are associated with a less warm sibling relationship?

Independent samples t-tests, analysis of variance (ANOVAs) and Pearson correlations were conducted to examine the effect of key characteristics of early psychosis on the sibling relationship (warmth, conflict and rivalry) as measured by the ASRQ (Stockier, Lanthier, et al., 1997). The characteristics of early psychosis examined were suicide attempts, persisting psychotic illness, duration of untreated psychosis, history of violence, compliance with treatment, persisting drug use, living with the ill brother or sister, and the number of admissions required since the onset of illness. The mean ASRQ scores are presented together with the 95% confidence intervals and the significance levels. The guidelines for interpreting the effect size, eta squared (proposed by Cohen, 1998) are: 0.01 = small/weak effect; 0.06 = moderate effect; 0.14 = large/strong effect. Correlation analyses were also conducted with the ECI (Szmukler, Burgess, et al., 1996) and the IES-R (Weiss & Marmar, 1997). In order to determine the strength of the relationships, Cohen's (1998) guidelines are used: $r = .10$ to $.29$ or $r = -.10$ to $-.29$ small/weak; $r = .30$ to $.49$ or $r = -.30$ to $-.49$ moderate; $r = .50$ to 1.0 or $r = -.50$ to -1.0 large/strong. Please note that only significant findings are presented in the following chapter. This decision was made given the volume of analyses required to find the answer to the research question. Complete findings of all analyses for this research question can be found in Appendix I. Tables 7 to 12 show the individual results for each high order factor as measured by the ASRQ (Warmth 7 & 8; Conflict 9 & 10; Rivalry 11 & 12).

Warmth

Table 7

The impact of the characteristics of early psychosis upon the self assessed warmth within the sibling relationship (ASRQ)

Warmth	Mean (SD)	(95%CI)	<i>p</i>	eta squared
Persisting Psychosis			0.001	-0.058
Yes N = 88	3.03 (0.86)	2.84-3.21		
No N = 69	3.62 (0.87)	3.41-3.83		
Duration of untreated psychosis (months)			0.016	0.052
1-6 N = 42	3.49 (0.86)	3.22- 3.76		
7-12 N = 61	3.03 (0.93)	2.79- 3.27		
≥13 N =54	3.42 (0.86)	3.19- 3.67		
History of violence			0.001	-0.083
Yes N = 15	2.09 (0.91)	1.60-2.58		
No N = 142	3.42 (0.80)	3.29-3.56		
Compliance			0.005	0.050
Yes N = 124	3.39 (0.88)	3.24-3.55		
No N = 33	2.89 (0.92)	2.56-3.22		
Persisting drug use			0.001	-0.058
Yes N = 42	2.80 (0.94)	2.50-3.09		
No N = 115	3.47 (0.83)	3.31-3.62		
Number of admissions			0.001	0.114
0 N = 41	3.37 (0.77)	3.13-3.62		
1 N = 49	3.62 (0.79)	3.39-3.85		
2 N = 36	3.19 (1.04)	2.84-3.54		
≥3 N = 31	2.76 (0.86)	2.45-3.07		

Suicide attempts, having divorced parents, or living with the ill brother or sister were found to not be significant factors affecting warmth within the relationship.

Persisting psychotic illness, the duration of untreated psychosis, a history of violence, non-compliance with treatment, persisting drug use and having more than one hospital

admission were found to be significant. These factors reduced warmth within the sibling relationship.

An independent-samples t-test showed a significant difference in warmth scores for participants whose brother or sister had persisting psychosis ($M = 3.03$) and those who did not ($M = 3.62$). The magnitude of the differences in the means was moderate ($\eta^2 = .06$).

A one-way between-groups analysis of variance showed a significant difference at the $p < .05$ level for the duration of untreated psychosis (1: 1-6 months, $M = 3.49$; 2: 7-12 months, $M = 3.03$; 3: >13 months, $M = 3.43$) $F(1, 155) = 5.50$, $p < .05$, $\eta^2 = .05$. Post-hoc comparisons using the Tukey Honestly Significant Difference test were undertaken to determine significant differences between groups and identify between which groups the difference occurred. The comparisons showed that sibling warmth for a brother or sister who had been ill for 1- 6 months was significantly higher than those who had been ill for more than 13 months.

Independent samples t-tests showed significant differences in warmth scores for participants whose brother or sister had a history of violence, were non-compliance with treatment and continued to use drugs. There was a significant difference in scores for participants whose brother or sister had a history of violence ($M = 2.09$) and those who did not ($M = 3.42$, $SD = 0.80$; $t(155) = -6.170$, $p < .05$). The magnitude of difference was moderate (eta squared = 0.08).

There was also a statistically significant difference found in scores for compliance with treatment ($M = 3.39$) compared to non-compliance ($M = 2.89$, $SD = 0.92$), $t(155) = 2.87$, $p < .05$, $\eta = .05$, and for persisting drug use ($M = 2.80$) compared to no drug use ($M = 3.47$, $SD = 0.83$), $t(155) = -4.305$, $p < .05$, $\eta^2 = .06$. The presence of non-compliance and persisting drug use resulted in less warmth within the relationship.

A one-way between-groups analysis of variance was conducted to explore the impact of the number of hospital admissions on participant warmth. There was a statistically significant difference between the four groups (0: no admission, $M = 3.37$; 1: 1 admission, $M = 3.62$; 2: 2 admissions, $M = 3.19$; 3: > 3 admissions, $M = 2.76$), $F(3, 153) = 6.58, p < .05, \eta^2 = .11$. Post-hoc comparisons indicated that sibling warmth was significantly higher when there had been only one admission to hospital in comparison to three admissions.

Table 8
Correlations of other questionnaire results with warmth domain within the sibling relationship (ASRQ)

Warmth	Mean (SD)	p	r
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.437
Total Positive Score	4.47 (1.52)	0.000	0.347
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.002	-0.245
Intrusions	1.48 (0.68)	0.002	-0.247
Hyper-arousal	1.45 (0.75)	0.004	-0.230

The relationship between the negative and positive experiences on the ECI (Szmukler, Burgess, et al., 1996) and warmth was investigated using Pearson product-moment correlation coefficients (See Table 8). There was a moderate, negative correlation between negative experiences and warmth ($r = 0.437, N = 157, p < .05$) with high levels of negative experiences resulting in less warmth within the sibling relationship. Conversely there was a moderate, positive correlation between positive experiences and warmth ($r = 0.347, N = 157, p < .05$).

The relationship between post traumatic stress symptoms (avoidance, intrusions and hyper-arousal) as measured by the IES-R (Weiss & Marmar, 1997) and warmth was

investigated using Pearson product-moment correlation coefficient. Preliminary analyses showed no violation of the assumptions of normality, linearity and homoscedasticity (related to variance). Weak negative correlations were found for each subscale and sibling warmth: avoidance ($r = 0.25, N = 157, p < .05$) intrusions ($r = 0.25, N = 157, p < .05$) and hyperarousal ($r = 0.23, N = 157, p < .05$).

Conflict

Table 9
The impact of the characteristics of early psychosis upon the self assessed conflict domain within the sibling relationship (ASRQ)

Conflict	Mean (SD)	(95%CI)	<i>p</i>	eta squared
Suicide Attempts			0.001	0.07
Yes N = 45	1.83 (0.64)	1.63-2.02		
No N = 112	1.45 (0.52)	1.36-1.55		
Persisting Psychosis			0.018	0.03
Yes N = 88	1.66 (0.61)	1.52-1.79		
No N = 69	1.44 (0.51)	1.32-1.56		
History of violence			0.001	0.33
Yes N = 15	2.41 (0.54)	2.11-2.71		
No N = 142	1.47 (0.51)	1.39-1.56		
Persisting drug use			0.005	0.04
Yes N = 42	1.77 (0.65)	1.57-1.98		
No N = 115	1.48 (0.53)	1.38-1.58		

Suicide attempts, a history of violence and persisting drug use were found to be significant factors affecting conflict within the sibling relationship. These characteristics were found to increase conflict within the relationship.

An independent-samples t-test showed a significant difference in conflict scores for participants whose brother or sister had attempted suicide ($M = 1.83$) and those who had not ($M = 1.45$). The magnitude of the differences in the means was large ($\eta^2 = 0.08$). Independent-samples t-tests also showed significant differences for participants whose brother or sister had a history of violence and persisting drug use. There was a significant difference in scores for those whose brother or sister had a history of violence ($M = 2.41$) and those who did not ($M = 1.47$). The magnitude of difference was large ($\eta^2 = 0.33$). There was also a statistically significant difference found in scores for persisting drug use ($M = 1.77$) and no drug use ($M = 1.48$, $SD = 0.53$); $t(155) = 2.85$, $p < .05$, $\eta^2 = .04$.

Table 10
Correlations of other questionnaire results with conflict domain within the sibling relationship (ASRQ)

Conflict	Mean (SD)	<i>p</i>	<i>r</i>
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	0.605
Total Positive Score	4.47 (1.52)	0.000	0.319
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	0.390
Intrusions	1.48 (0.68)	0.000	0.444
Hyperarousal	1.45 (0.75)	0.000	0.473

The relationship between the negative and positive experiences on the ECI (Szmukler, Burgess, et al., 1996) and conflict was investigated using Pearson product-moment correlation coefficients. There was a strong, positive correlation between negative experiences and conflict ($r = 0.61$, $N=157$, $p < .05$), with high levels of negative experiences resulting in more conflict within the relationship. Conversely there was a moderate, positive correlation between positive experiences and conflict ($r = 0.31$, $N = 157$, $p < .05$).

The relationship between post traumatic stress symptoms (avoidance, intrusions and hyper-arousal) as measured by the IES-R (Weiss & Marmar, 1997) and conflict was investigated using Pearson product-moment correlation coefficient. Preliminary analyses showed no violation of the assumptions of normality, linearity and homoscedasticity. Moderate, positive correlations were found between the three subscales and conflict: avoidance ($r = 0.39$, $N=157$, $p < .05$), intrusions ($r = 0.44$, $N=157$, $p < .05$) and hyper-arousal ($r = 0.47$, $N=157$, $p < .05$). High levels of avoidance, intrusive and hyper-arousal symptoms were associated with more conflict within the relationship.

Rivalry

Table 11

The impact of the characteristics of early psychosis upon the self assessed rivalry domain within the sibling relationship (ASRQ)

Rivalry	Mean (SD)	(95%CI)	p	eta squared
Suicide Attempts			0.001	0.07
Yes N = 45	0.83 (0.67)	0.63-1.04		
No N = 112	0.46 (0.60)	0.35-0.58		
Persisting Psychosis			0.028	0.03
Yes N = 88	0.67 (0.67)	0.53-0.81		
No N = 69	0.44 (0.59)	0.30-0.58		
Duration of untreated psychosis (months)			0.019	0.05
1-6 N = 42	0.41 (0.59)	0.23-0.60		
7-12 N = 61	0.75 (0.71)	0.56-0.93		
>13 N = 54	0.49 (0.57)	0.33-0.64		
History of violence			0.001	0.20
Yes N = 15	1.30 (0.66)	0.99-1.71		
No N = 142	0.48 (0.59)	0.39-0.58		
Persisting drug use			0.009	0.04
Yes N = 42	0.81 (0.73)	0.59-1.04		
No N = 115	0.48 (0.59)	0.37-0.59		
Number of admissions			0.004	0.08
0 N = 41	0.36 (0.53)	0.19-0.53		
1 N = 49	0.47 (0.58)	0.30-0.64		
2 N = 36	0.67 (0.62)	0.46-0.89		
>3 N = 31	0.87 (0.79)	0.58-1.17		

Suicide attempts, persisting psychosis, duration of untreated psychosis, a history of violence, non-compliance with treatment, persisting drug use and having more than

one hospital admission were found to be significant. These factors increased rivalry within the sibling relationship.

An independent-samples t-test showed a significant difference in rivalry scores for participants whose brother or sister had attempted suicide ($M = 0.83$) and those who had not ($M = 0.46$). The magnitude of the differences was large ($\eta^2 = .07$). A suicide attempt resulted in more rivalry within the relationship. There was also a statistically significant difference found for participants whose brother or sister had persisting psychosis ($M = 0.67$) and those who did not ($M = 0.44$, $SD = 0.59$), $t(155) = 2.22$, $p < .05$. Persisting psychosis also resulted in more rivalry within the relationship.

Independent-samples t-tests showed significant differences in rivalry scores for participants whose brother or sister had a history of violence ($M = 1.30$) and those who did not ($M = 0.48$, $SD = 0.59$), $t(155) = -5.15$, $p < .05$. The magnitude of difference was small ($\eta^2 = 0.20$). There was more rivalry when there was a history of violence. A statistically significant difference was also found for persisting drug use ($M = 0.81$) compared to no drug use ($M = 0.48$, $SD = 0.59$), $t(61.94) = 2.67$, $p < .05$, eta squared = 0.04.

A one-way between-groups analysis of variance was conducted to explore the impact of the duration of untreated psychosis on rivalry. There was a statistically significant difference between the three groups (1: 1-6months duration of untreated psychosis, $M = 0.41$; 2: 7-12 months duration of untreated psychosis, $M = 0.75$; 3: more than 13 months duration of untreated psychosis no admission, $M = 0.49$), $F(2, 155) = 4.08$, $p < .05$, $\eta^2 = .05$. Post-hoc comparisons indicated that rivalry in group one was significantly lower than for group two. Rivalry was highest when there had been a period of 7-12 months of untreated psychosis.

A one-way between-groups analysis of variance was also conducted to explore the impact on rivalry associated with the number of hospital admissions. There was a

statistically significant difference between the four groups (0: no admission, $M = 0.36$; 1: 1 admission, $M = 0.47$; 2: 2 admissions, $M = 0.67$; 3: > 3 admissions, $M = 0.87$), $F(3, 153) = 4.60$, $p < .05$, $\eta^2 = 0.08$. Post-hoc comparisons indicated that sibling rivalry after 0 to 1 admission was significantly lower than for 3 admissions. There was more rivalry in the relationship when there was 3 or more admission to hospital.

Table 12

Correlations of results of other questionnaire with rivalry domain within the sibling relationship (ASRQ)

Rivalry	Mean (SD)	p	r
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	0.486
Total Positive Score	4.47 (1.52)	0.355	-0.074
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	0.285
Intrusions	1.48 (0.68)	0.000	0.350
Hyperarousal	1.45 (0.75)	0.000	0.322

The relationship between the negative and positive experiences on the ECI (Szmukler, Burgess, et al., 1996) and rivalry was investigated using Pearson product-moment correlation coefficients. There was a moderate, positive correlation between negative experiences and rivalry ($r = 0.49$, $N = 157$, $p < .05$), with high levels of negative experiences resulting in more rivalry within the relationship.

Post traumatic stress symptoms (avoidance, intrusions and hyperarousal) as measured by the IES-R (Weiss & Marmar, 1997) and rivalry were investigated using Pearson product-moment correlation coefficient. Preliminary analyses showed no violation of the assumptions of normality, linearity and homoscedasticity. There was a weak, positive correlation between avoidance and rivalry ($r = 0.28$, $N = 157$, $p < .05$). Moderate, positive correlations were found between intrusions ($r = 0.350$, $N = 157$, $p < .05$), and hyper-arousal ($r = 0.473$, $N = 157$, $p < .05$).

Key findings for sibling relationship and the characteristics of early psychosis

The participants in this study reported that ongoing substance use and a history of violence in their ill brother or sister resulted in lower warmth, higher conflict and higher rivalry within the sibling relationship. Persisting psychotic illness also resulted in less warmth. Suicide attempts resulted in more conflict and rivalry. There was more warmth in the relationship when there had only been one admission to hospital and the lowest warmth was when there had been three admissions to hospital. There was less warmth and more conflict when the duration of untreated psychosis had been 7 to 12 months.

Participants, who reported high levels of burden, and high levels of post traumatic stress symptoms, were found to have less warmth, more conflict and more rivalry within their relationship. Conversely, those who reported high levels of positive experiences with their ill brother or sister, had more warmth, less conflict and less rivalry.

Research Question 5: Are there specific characteristics of early psychosis that are associated with lower satisfaction of quality of life for a sibling?

Independent samples t-tests, ANOVAs and Pearson correlations were conducted to examine the effect of key characteristics of early psychosis on the quality of life of the participants as measured by the WHOQOL-Bref (WHO, 1998). The characteristics examined were suicide attempts, persisting psychotic illness, duration of untreated psychosis, history of violence, compliance with treatment, persisting drug use, living with the ill brother or sister, and the number of admissions required since the onset of illness. The mean WHOQOL-Bref scores are presented together with the 95% confidence intervals and the significance levels. The guidelines for interpreting the effect size, eta squared (proposed by Cohen, 1998) are: 0.01 = small/weak effect; 0.06 = moderate effect; 0.14 = large/strong effect. Correlation analyses were also conducted with the ECI (Szmukler, Burgess, et al., 1996) and the IES-R (Weiss & Marmar, 1997). In order to determine the strength of the relationships, Cohen's (1998) guidelines are used: $r = .10$ to $.29$ or $r = -.10$ to $-.29$ small/weak; $r = .30$ to $.49$ or $r = -.30$ to $-.49$ moderate; $r = .50$ to 1.0 or $r = -.50$ to -1.0 large/strong. Only significant findings are presented. Complete findings of all analyses for this research question can be found in Appendix I. Tables 13 to 20 show the individual results for each quality of life domain as measured by the WHOQOL_BREF (Physical 13 & 14; Psychological 15 & 16; social 17 & 18; environment 19 & 20).

Physical Domain

Table 13

The impact of the characteristics of early psychosis upon the self assessed physical domain within the sibling quality of life

Physical domain	Mean (SD)	(95%CI)	<i>p</i>	eta squared
Suicide Attempts			0.025	0.03
Yes N = 45	76.11 (16.29)	71.21-81.00		
No N = 112	82.78 (16.82)	79.63-85.93		
History of violence			0.004	0.05
Yes N = 15	69.04 (19.68)	58.14-79.94		
No N = 142	82.11 (16.14)	79.43-84.79		

Sibling gender and position (See Results Research Question 1, p. 79), suicide attempts and a history of violence were found to be significant factors affecting satisfaction with the physical domain of quality of life. These factors reduced satisfaction.

An independent-samples t-test showed a significant difference in the satisfaction of the physical domain scores for participants whose brother or sister had attempted suicide ($M = 76.11$) and those whose had not ($M = 82.78$, $SD = 16.82$), $t(155) = 2.27$, $p < .05$. There was also a statistically significant difference found for having a brother or sister with a history of violence ($M = 69.04$) compared to no history ($M = 82.11$, $SD = 16.14$), $t(155) = -2.918$, $p < .05$, $\eta^2 = .05$.

Table 14

Correlations of other questionnaire results with the physical domain of quality of life (WHOQOL-Bref)

Physical	Mean (SD)	<i>p</i>	<i>r</i>
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.477
Total Positive Score	4.47 (1.52)	0.026	-0.178
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	-0.350
Intrusions	1.48 (0.68)	0.000	-0.397
Hyperarousal	1.45 (0.75)	0.000	-0.443

The relationship between the negative and positive experiences on the ECI (Szmukler, Burgess, et al., 1996) and the physical domain was investigated using Pearson product-moment correlation coefficients. There was a moderate, negative correlation between negative experiences and the physical domain ($r = -0.477$, $N = 157$, $p < .05$), with high levels of negative experiences resulting in less satisfaction with the physical domain of the participants' quality of life. Conversely there was a weak, negative correlation between positive experiences and the physical domain ($r = -0.178$, $N = 157$, $p < .05$).

The relationship between post traumatic stress symptoms (avoidance, intrusions and hyperarousal) as measured by the IES-R (Weiss & Marmar, 1997) and the physical domain was investigated using Pearson product-moment correlation coefficient. Preliminary analyses showed no violation of the assumptions of normality, linearity and homoscedasticity. Moderate, negative correlation was found between the three subscales and satisfaction with the physical domain: avoidance ($r = -0.350$, $N = 157$, $p < .05$), intrusions ($r = -0.397$, $N = 157$, $p < .05$), and hyperarousal ($r = -0.443$, $N = 157$, $p < .05$).

Psychological Domain

Table 15

The impact of the characteristics of early psychosis upon the self assessed psychological domain within the sibling quality of life

Psychological domain	Mean (SD)	(95%CI)	<i>p</i>	eta squared
Suicide Attempts			0.027	0.03
Yes N = 45	56.01 (12.79)	52.17-59.86		
No N = 112	60.56 (10.98)	58.50-62.62		
History of violence			0.030	0.02
Yes N = 15	53.05 (11.83)	46.50-59.60		
No N = 142	59.91 (11.50)	58.00-61.82		

Sibling gender and position (See Results Research Question 1, p. 87), suicide attempts and a history of violence were found to be significant factors affecting the satisfaction of participants in the psychological domain of quality of life. These factors reduced satisfaction.

An independent-samples t-test showed a significant difference in participant satisfaction in the psychological domain for those whose brother or sister had attempted suicide ($M = 56.01$) and those whose had not ($M = 60.56$, $SD=10.98$; $t(155) = 2.23$, $p < .05$). The magnitude of the difference in the means was small according to the guidelines proposed by Cohen (1988) ($\eta^2 = 0.03$). There was also a statistically significant difference found for having a brother or sister with a history of violence ($M = 53.05$) compared to no history of violence ($M = 59.91$, $SD = 11.50$), $t(155) = -2.191$, $p < .05$, $\eta^2 = .02$.

Table 16

Correlations of other questionnaire results with psychological domain of quality of life (WHO-QOL-Bref)

Psychological	Mean (SD)	<i>p</i>	<i>r</i>
Experience of Caregiving Inventory			
Total Negative Score	15.21 (5.29)	0.000	-0.334
Total Positive Score	4.47 (1.52)	0.701	0.031
Impact of Events - Revised			
Avoidance	1.59 (0.77)	0.000	-0.298
Intrusions	1.48 (0.68)	0.001	-0.262
Hyperarousal	1.45 (0.75)	0.001	-0.269

The relationship between the negative and positive experiences on the ECI (Szmukler, Burgess, et al., 1996) and the psychological domain was investigated using Pearson product-moment correlation coefficients. There was a moderate, negative correlation between negative experiences and the psychological domain ($r = -0.334$, $N = 157$, $p < .05$), with high levels of negative experiences resulting in less satisfaction with the psychological domain of quality of life. Conversely there was a very weak, positive correlation between positive experiences and the psychological domain ($r = 0.031$, $N = 157$, $p < .05$).

The relationship between post traumatic stress symptoms (avoidance, intrusions and hyperarousal) as measured by the IES-R (Weiss & Marmar, 1997) and the psychological domain was investigated using Pearson product-moment correlation coefficient. Preliminary analyses showed no violation of the assumptions of normality, linearity and homoscedasticity. Weak, negative correlations were found between the three subscales and participants' satisfaction with the psychological domain: avoidance ($r = -0.298$, $N = 157$, $p < .05$), intrusions ($r = -0.262$, $N = 157$, $p < .05$), and hyperarousal ($r = -0.269$, $N = 157$, $p < .05$).

Social Domain

Table 17

The impact of the characteristics of early psychosis upon the self assessed social domain within the sibling quality of life

Social domain	Mean (SD)	(95%CI)	<i>p</i>	eta squared
Suicide Attempts			0.018	0.03
Yes N = 45	64.62 (17.51)	59.36-69.89		
No N = 112	72.47 (19.07)	68.89-76.64		
History of violence			0.002	0.06
Yes N = 15	56.11 (20.03)	45.01-67.20		
No N = 142	71.71 (18.24)	68.68-74.74		
Living with ill brother or sister			0.036	0.02
Yes N = 92	67.57 (19.66)	63.49-71.64		
No N = 65	73.97 (17.27)	69.69-78.25		

Sibling gender and position (See Results Research Question 1, p. 87), living with the ill brother or sister, suicide attempts, and a history of violence were found to be significant factors affecting the satisfaction of the social domain. These factors reduced satisfaction.

An independent-samples t-test showed a significant difference in social domain scores for participants whose sister or brother had attempted suicide ($M = 64.62$) and those whose had not ($M = 72.47$, $SD = 19.07$); $t(155) = 2.383$, $p < .05$. The magnitude of the difference in the means was small according to the guidelines proposed by Cohen (1988) ($\eta^2 = .03$).

There was a statistically significant difference found in scores for having a brother or sister with a history of violence ($M = 56.11$) compared to no history ($M = 71.71$, $SD = 18.24$), $t(155) = -3.121$, $p < .05$, $\eta = .06$. A statistically significant difference was also

found for living with the ill brother or sister ($M = 67.57$) and living separately ($M = 73.97$, $SD = 17.27$), $t(155) = -2.11$, $p < .05$, $\eta^2 = 0.02$.

Table 18
Correlations of other questionnaire results with social domain of quality of life (WHO-QOL-Bref)

Social	Mean (SD)	<i>p</i>	<i>r</i>
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.486
Total Positive Score	4.47 (1.52)	0.540	0.049
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	-0.372
Intrusions	1.48 (0.68)	0.000	-0.391
Hyperarousal	1.45 (0.75)	0.000	-0.423

The relationship between the negative and positive experiences on the ECI (Szmukler, Burgess, et al., 1996) and the social domain was investigated using Pearson product-moment correlation coefficients. There was a moderate, negative correlation between negative experiences and the social domain ($r = -0.486$, $N = 157$, $p < .05$), with high levels of negative experiences resulting in less satisfaction with the social domain of quality of life.

The relationship between post traumatic stress symptoms (avoidance, intrusions and hyper-arousal) as measured by the IES-R (Weiss & Marmar, 1997) and the social domain was investigated using Pearson product-moment correlation coefficient. Preliminary analyses showed no violation of the assumptions of normality, linearity and homoscedasticity. Moderate, negative correlations were found between the three subscales and the participants' satisfaction with the social domain: avoidance ($r = -0.372$, $N = 157$, $p < .05$), intrusions ($r = -0.391$, $n = 157$, $p < .05$), and hyperarousal ($r = -0.423$, $N = 157$, $p < .05$).

Environment Domain

Table 19

The impact of the characteristics of early psychosis upon the self assessed environment domain within the sibling quality of life

Environment domain	Mean (SD)	(95%CI)	<i>p</i>	eta squared
Suicide Attempts			0.015	0.03
Yes N = 45	71.11 (15.47)	66.46-75.75		
No N = 112	78.23 (16.66)	75.11-81.35		
History of violence			0.001	0.06
Yes N = 15	61.66 (15.05)	53.32-70.00		
No N = 142	77.72 (16.05)	75.06-80.39		

Sibling gender and position (See Results Research Question 1, p.87), suicide attempts and a history of violence were found to be significant factors affecting participants' satisfaction in the environment domain of quality of life.

An independent-samples t-test showed a significant difference in environment domain scores for participants whose brother or sister had attempted suicide ($M = 71.11$) and those whose had not ($M = 78.23$, $SD = 16.66$), $t(155) = 2.47$, $p < .05$. The magnitude of the difference was small according to the guidelines proposed by Cohen (1988) ($\eta^2 = 0.03$).

There was also a statistically significant difference found in scores for having a brother or sister with a history of violence ($M = 61.66$) compared to no history ($M = 77.72$, $SD = 16.05$), $t(155) = -3.706$, $p < .05$, $\eta^2 = .06$.

Table 20

Correlations of questionnaire results with environment domain of quality of life (WHO-QOL-Bref)

Environment	Mean (SD)	<i>p</i>	<i>r</i>
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.508
Total Positive Score	4.47 (1.52)	0.033	-0.170
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	-0.353
Intrusions	1.48 (0.68)	0.000	-0.406
Hyper-arousal	1.45 (0.75)	0.000	-0.416

The relationship between the negative and positive experiences on the ECI (Szmukler, Burgess, et al., 1996) and the environment domain was investigated using Pearson product-moment correlation coefficients. There was a strong, negative correlation between negative experiences and the environment domain ($r = -0.508$, $N=157$, $p < .05$), with high levels of negative experiences resulting in less satisfaction with the environment domain of quality of life.

The relationship between post traumatic stress symptoms (avoidance, intrusions and hyperarousal) as measured by the IES-R (Weiss & Marmar, 1997) and the environment domain was investigated using Pearson product-moment correlation coefficient. Preliminary analyses showed no violation of the assumptions of normality, linearity and homoscedasticity. A moderate, negative correlation was found for all three subscales and the environment domain: avoidance ($r = -0.353$, $N=157$, $p < .05$), intrusions ($r = -0.406$, $N=157$, $p < .05$), and hyperarousal ($r = -0.416$, $N=157$, $p < .05$).

Key findings for quality of life and the characteristics of early psychosis

Suicide attempts and a history of violence impacted negatively on the satisfaction in all domains of quality of life. Participants in this study also reported that living with their ill brother or sister reduced their satisfaction with the social domain. Burden or

negative experiences significantly reduced the participants' satisfaction in all domains of quality of life. Symptoms of post traumatic stress were found to reduce the participants' satisfaction in all domains.

Summary

This chapter has presented the results for five research questions. Research Question 1 showed that gender and birth order resulted in different levels of satisfaction in the domains of quality of life, different levels of burden and post traumatic stress symptoms. Specifically, younger sisters reported being least satisfied with their quality of life, reported higher levels of burden and post traumatic stress symptoms. Research Question 2 found that there was no significant difference between the sibling relationship and normative data. Research Question 3 found that there was no significant difference between the satisfaction of quality of life of respondents and normative data of Australian young people the same age. Research Question 4 found that a less warm sibling relationship was associated with a young person having more than 6 months of untreated psychosis, requiring more than one hospital admission, having ongoing psychotic symptoms, continuing to use substances, attempting suicide and having a history of violence. High levels of burden and post traumatic stress symptoms also resulted in a less warm sibling relationship. Finally, Research Question 5 showed that if the sibling was living with the young person experiencing early psychosis, and if they had attempted suicide or had a history of violence, then siblings reported a lower satisfaction in quality of life. High levels of burden and post traumatic stress symptoms were also associated with less satisfaction in quality of life.

Chapter Five: Discussion

This chapter presents a discussion of the findings with reference to selected literature. The five research questions are answered and discussed.

Research question 1: Does the gender and birth order of a sibling with a brother or sister experiencing early psychosis, result in: different levels of knowledge of psychosis; different levels of warmth, conflict and rivalry within the relationship; a different quality of life; different levels of burden and post traumatic stress symptoms?

Knowledge of psychosis

The results indicate that participants' gender and birth order did not result in different levels of knowledge of psychosis. The results indicate that overall the participants had a strong knowledge of psychosis with 71% of answers correct in the multiple choice questionnaire. Sin, Moone and Harris (2008) identified that sibling's need information about the illness, its prognosis and treatment. This study supports this finding and shows that these participants had independently obtained knowledge about psychosis. Many respondents reported obtaining this information from the internet. Older sisters showed the most knowledge with 75% of answers correct and younger brothers showed the least knowledge with 67% of answers correct. The differences between sibling groups were not found to be significant.

The sibling relationship

A statistical significant difference was not found between gender and birth order, and levels of warmth, conflict and rivalry within the sibling relationship. Observable differences however were evident. As family systems theory contests, family members

are part of an interdependent, dynamic system whereby the behaviour of each individual impacts upon the other (Kreppner & Lerner, 1989; Minuchin, 1988). It is therefore not surprising that a diagnosis of early psychosis in a family member would impact upon the sibling relationship. Further, research has established that these relationships play a critical and formative role in human development (Bandura, 1989; Bowlby, 1969). When one individual becomes ill and is not able to perform the developmental tasks expected of late adolescence and early adulthood, the dynamics of the sibling relationship change. Further support for this finding may be found in attachment theory, as consistent sibling relationships assist adolescents in feeling supported in being a normal teen (Sears & Shepherd, 2004).

The results of this study showed that younger sisters scored the highest levels of warmth, greater than one standard deviation more than the other sibling groups. As the onset of early psychosis occurs during a younger sisters formative years, they may continue to receive companionship, intimacy, and affection from an ill brother or sister as the social provision theory by Weiss contends (1974). Therefore the reciprocal nature of the sibling relationship for younger sisters may remain, even when their older brother or sister is experiencing early psychosis.

This finding supports the work of Kim, McHale, Osgood and Crouter (2006), who implemented a longitudinal study to establish sibling warmth from childhood to adolescence in 200 healthy American families. These authors also found that sibling warmth was highest for sisters. They contended that females have higher emotional awareness, and express themselves more openly than males and this could be a reason as to why they reported higher levels of warmth.

Further reasons for this finding may be explained by the work of McHale and Crouter (2007) who interviewed 191 maritally intact American families in order to understand how older siblings influence their younger siblings in normal populations. The researchers found that older siblings were powerful socialising agents who provide

opportunities for their younger siblings to develop peer competence, leisure and sporting interests. Crouter, Whiteman, McHale and Osgood (2007) examined gender attitudes in 402 healthy adolescent siblings in another American study. They also found that younger siblings looked up to, and modelled their older siblings' attitudes, interests and behaviour when developing a gender identity. A further study that supports the finding that younger siblings show great warmth towards their older sibling is by Feinberg, Neiderhiser and Simmens (2000) who found that normal adolescent siblings placed greater importance on comparisons with each other rather than with peers of the same age.

The second major finding for this question was that younger brothers had the lowest levels of warmth. They also had the lowest levels of rivalry. This finding is consistent with the work of Dunn, Slomkowski and Bardsall (1994) who implemented semi-structured interviews with 39 healthy sibling dyads and found that during adolescence, boys report less warmth than girls. The loss of warmth was attributed to the establishment of a male peer group outside the family. Stocker, Lanthier and Furman (1997) believed that differences in warmth, conflict and rivalry were associated with the amount of contact between siblings and also the sibling's mental health. It is proposed that younger brothers may also experience grief as a result of their older brother or sister's illness. Further research is required to test this proposition but if it were so, this would be consistent with the study by Lively, Friedrich and Buckwalter (1994) who found that grief was a major theme for 30 siblings in long term psychotic illness.

Sin, Moone and Harris (2008), in their small qualitative study with 10 siblings whose brother or sister had early psychosis, found that older siblings were concerned about their younger siblings. The current study indicates that younger siblings should be the subject of further research.

Quality of Life

Older brothers in this study reported the most satisfaction in all domains of quality of life. Younger sisters reported the least satisfaction in all domains. Older brothers were found to be statistically more satisfied with the psychological domain of quality of life than both older and younger sisters. This may again be explained in light of theories of gender relationships and link closely with the quality of the sibling relationship.

The finding is consistent with the studies by Gass, Jenkins and Dunn (2007), Olivia and Arranz (2005) and Branje, Van Lieshout, Van Aken and Haselager (2004) whose research with large samples established the protective effects of sibling support in normal samples. When a young person is experiencing an early psychosis, they may be unable to provide the support that the sibling experienced prior to the onset of illness. This may result in increased distress when dealing with stressful life events, less comfort and security, less effective psychological adjustment and well being, and a decrease in self esteem, as was found in the aforementioned studies.

In regard to older sisters specifically, they reported the highest levels of conflict within their relationship and were also significantly less satisfied with their psychological quality of life than brothers. This finding supports the work of Ponzetti and James (1997) who implemented a quantitative study with 251 healthy siblings to establish the association of loneliness with the quality of the sibling relationship. The authors found that the more conflict in the sibling relationship, the more loneliness experienced by the individual. The female participants in the current study may also experience difficulty in witnessing their parent's sadness and helplessness, as was found by Sin, Moone and Harris (2008). This would also impact upon their quality of life.

The current study found that birth order, specifically for younger females, related to lower satisfaction in the participants' psychological quality of life. This supports the work of Dyergrö and Dyergrö (2005). Although this particular study sits outside the

sibling development literature, and the long term psychosis literature, its findings are consistent with the current study. The researchers implemented a mixed method study to explore the needs of siblings after losing a brother or sister to suicide. Data were collected from 70 siblings with an age range of 17 years to 29 years. The findings showed that older siblings whose brother or sister had died by suicide were less affected by symptoms of depression and anxiety due to their age (often living out of home), marital status and external social support. This can also protect older siblings of young people with early psychosis as they may be able to avoid exposure to their parents despair and the characteristics of early psychosis such as hospital admissions, non-compliance with treatment, and/or persisting symptoms.

Older brothers reported over 10 points more satisfaction with the social domain than both younger brothers and sisters. The majority of younger siblings in this study lived at home. Consequently they were exposed to more negative experiences associated with early psychosis and the characteristics of the illness. It is therefore not surprising that younger siblings living at home negatively appraised the social domain, as well as the physical and environmental domains of their quality of life. This may be interpreted as them not being open to sharing their experiences with others due to shame, embarrassment and stigma as was found by Barak and Solomon (2005). Younger siblings living at home spend less time with their peer group than older siblings therefore receiving less external support. These findings are consistent with the work of Dyergröv and Dyregrov (2005) and also with Titelman and Psyck (1991), who found that siblings of those with long term psychotic illness felt they should restrict themselves from enjoying a social life.

Burden

Older brothers reported significantly lower levels of burden than younger sisters in this study. This result is in agreement with the study by Barak and Solomon (2005) who

found that sisters in long term psychosis reported greater burden than brothers. Sisters are more prone than brothers to serve as sources of comfort and support for parents and their ill brother or sister which increases their experience of burden (Barak & Solomon, 2005). The finding is also consistent with the work by Horowitz (1993) who reported that sisters of those with long term psychosis provide care giving in terms of household tasks, shopping, support in crisis, lending money, transportation, gifts and emotional support.

In the current study younger sisters reported the highest overall burden from stigma, problems with services, the effects on family, providing back up services, feeling depended upon by their ill brother or sister, and grief (See Appendix I, page 187). Greenberg, Kim and Greenley (1997) found that older siblings reported lower levels of burden than younger siblings. The finding is again consistent with the research by Dyergröv and Dyregrov (2005), who reported that younger siblings had intimate knowledge about their brother or sister. It also concurs with the work of Barak and Solomon (2005) who found that single siblings, who lived in the family home with their ill brother and sister, undertook greater responsibility over the course of time thus resulting in higher levels of burden. Single siblings living at home were most likely younger siblings.

Stigma has been identified in the literature as a significant burden. Greenberg, Kim and Greenley (1997) found that younger siblings felt more stigma than older siblings. A fear of acquiring the illness which was related to stigma was found in early studies with siblings in long term psychosis (Rowe, 1992; Titelman & Psyck, 1991). The current study supports these findings.

Lively, Friedrich and Buckwalter (1994) and Sin, Moone and Harris (2008) found that changed relationships within the family were a consistent theme for siblings. The participants in these studies reported sharing the care giving role with their parents with respect to symptom management, medication management and practical support. The

younger female siblings in the current study reported providing these care giver services to their ill brother or sister as well.

Post Traumatic Stress Symptoms

Older brothers reported significantly lower levels of post traumatic stress symptoms than younger sisters. Younger sisters experienced more symptoms than the other sibling groups. The finding is consistent with the study by Dyregrov and Dyregrov (2005) who found that older siblings experienced significantly less post traumatic stress than younger siblings. Younger siblings living at home experienced the most difficulties. Age, living situation and social support may protect older siblings as they avoid the behaviours and characteristics associated with early psychosis such as a long duration of untreated psychosis, hospital admission, non-compliance with treatment, persisting psychosis, suicide attempts or violence.

It has been shown in other studies that parents in early psychosis experience long term stress (Addington et al., 2003; Gleeson et al., 2008; Tennakoon et al., 2000). This research adds to this finding. For siblings, it was the younger sisters who experience the most distress. The finding is consistent with Sin, Moone and Harris (2008) whose younger participants described feeling overwhelmed by their distress which was associated with their brother or sister's illness. This study adds to the finding as it is the younger sisters who reported the highest levels of post traumatic distress. It is suggested that younger brothers may not report these symptoms readily and this should be investigated further.

It is also noted that the assessment included in the survey of this study only asked participants to reflect over the past seven days and report whether they had experienced symptoms of post traumatic distress over this time period. This has implications for those who may have witnessed a traumatic hospital admission twelve months ago as this scale only assesses acute symptoms.

Research question 2: What is the sibling relationship like in early psychosis and how does it compare to normative data?

This study sample was compared to an American study sample in order to establish whether sibling relationships in early psychosis were similar to a normal sample (Stocker, Lanthier, and Furman (1997). Stocker, Lanthier, and Furman (1997) developed the Adult Sibling Relationship Questionnaire with a sample of 382 healthy young adults to ascertain the warmth, conflict and rivalry within normal sibling relationships. Normative data was established. It is difficult to generalise to Australian samples due to cultural differences however it is a first step in understanding the sibling relationships in early psychosis.

No statistically significant difference was found between the two samples. The sibling relationship in early psychosis was not statistically different from the normal sample of siblings. However, observable differences were evident. Warmth levels were the same for both samples. Conflict and rivalry scores were lower for the participants of this study in comparison to the norms provided by Stocker, Lanthier and Furman (1997). This result supports the work of Scharf, Shulamn and Avigad-Spitz (2005) who interviewed 115 normal adolescences and young adults about the quality of their sibling relationships and found warmth to be high in emerging adulthood but conflict and rivalry to decrease. The authors proposed that this is a trend of separation and individuation similar to the process children go through separating from parents. The results of the current study suggest that siblings of young people with early psychosis begin the process of individuation from their brother or sister earlier than the normal sample.

Research question 3: What is sibling quality of life like in early psychosis and how does it compare to the Australian normative data?

This study sample was compared to another Australian study sample in order to establish whether quality of life for siblings in early psychosis was similar to a normal sample of early adults (Hawthorne, et al., 2006). Hawthorne et al (2006) established norms for age groups within the Australian population using the WHOQOL-Bref (WHO, 1998). Australian norms were only provided for those aged 20-29. This resulted in only 47 study participants being used in the statistical analysis. Therefore, those siblings aged 15 to 19 years of age have no comparison data ($n = 68$) and were therefore not used in the statistical analysis. The results therefore do not provide a complete picture of the study sample.

No statistically significant difference was found between the two samples. The sibling quality of life in early psychosis was not statistically different from the normal sample of young adults. However, observable differences were evident. The current study showed lower satisfaction in the psychological domain for both male and female participants in comparison to the Australian norm. They reported over 10 points less satisfaction than the population norm. Males in the study scored higher satisfaction in the social and environment domains than the Australian norms. Females in the study reported lower satisfaction in the social domain than the Australian norms. The satisfaction of the psychological domain of quality of life has been discussed in Research Question 1 in detail so will therefore not be discussed further here.

Research Question 4: Are there specific characteristics of early psychosis that are associated with a less warm sibling relationship?

There are specific characteristics of early psychosis that are associated with less warmth in the sibling relationship. The participants in this study reported that drug use

and a history of violence by their ill brother or sister resulted in less warmth, higher conflict and higher rivalry within the relationship. This finding is consistent with the work by Smith and Greenberg (2008) and Solomon, Cavanaugh, and Gelles (2005) who found that violence in individuals with a long term psychotic illness resulted in a poor sibling relationship. Further, Solomon et al (2005) reviewed the research on physical violence of adults with long term psychotic illness and found that siblings were the second most common target. Further research should investigate the prevalence of violence towards siblings in early psychosis.

In this study, ongoing substance use of the ill brother or sister resulted in less warmth, higher conflict and higher rivalry within the relationship. This finding provides a unique sibling perspective to the family research in early psychosis. There is no research about drug use in early psychosis and its impact on families however, a number of studies have shown that persisting substance use during treatment can result in higher rates of relapse, persisting psychotic symptoms and non-compliance with treatment (Lambert et al., 2005; Wade et al., 2004).

There was less warmth and more conflict when the duration of untreated psychosis (DUP) was between 7 to 12 months. There was more warmth within the relationship when the DUP was less than 6 months. A shorter DUP means that a sibling has not had a prolonged period of stress and anxiety watching their brother or sister's mental health deteriorate and the consequent impact upon their parents. It is hypothesised that if the duration goes on for longer than 6 months without treatment the experience can result in traumatic events occurring and diminished expectations for the future. For example, Perkins et al (2005) reviewed all quantitative studies on the relationship between DUP and outcome in early psychosis and found that an extended DUP can result in lower rates of recovery, more incidences of suicide attempts and physical violence (Perkins et al., 2005).

The current study found that there was more warmth in the relationship when there had only been one admission to hospital and the lowest warmth was when there had been three or more admissions to hospital. This finding concurs with the work of Corcoran et al (2007) who found that family members perceived hospital admissions as traumatic and multiple admissions resulted in diminished expectations for the future. As Scharf, Shulamn and Avigad-Spitz (2005) indicated, siblings may find that more than one hospital admission indicates less hope for recovery, and they may begin to separate from the relationship.

Another characteristic that was found to result in a less warm sibling relationship was persisting psychotic illness. This finding is consistent with the work of Smith and Greenberg (2008) who implemented interviews with 136 siblings in a longitudinal study of adults with schizophrenia. They used multiple regression to predict the sibling relationship quality. They too found that persisting psychotic symptoms resulted in less warmth in the relationship as measured by the Positive Affect Index (Bengtson & Schrader, 1982). The finding of the current study provides an insight into early psychosis and shows a similar result to the research by Smith and Greenberg (2008).

The current study also found that suicide attempts resulted in more conflict and rivalry. This finding is consistent with the work of Dyregrov and Dyregrov (2005) who established that siblings had unique knowledge of suicide attempts in adolescents, the triggers for these and the causes. As previously defined in Chapter 2, conflict is when one sibling does something to which the other objects (Conger & Little, 2010; Dunn, 2005; Dunn, 2007; Stocker, Lathier & Furman, 1997). It is expected that a sibling would object to their brother or sister attempting suicide. Dyregrov and Dyregrov (2005) also found that parents acknowledged neglecting the sibling experience when such an event occurred in families. Rivalry is defined as the competition for attention, affection and approval from parents between siblings (Brody, 1998; Dunn, 2007; Goetting, 1986; Scharf, Shulman & Avigad-Spitz, 2005; Stocker, Lathier & Furman). It is therefore

understandable that as parents attempt to cope with a suicide attempt in the family, the well sibling's feelings of rivalry increase. These two findings by Dyregrov and Dyregrov (2005) provide possible reasons why suicide attempts resulted in more conflict and rivalry for the current study sample.

Participants in this study who reported high levels of burden were found to have less warmth, more conflict and more rivalry within their relationship. This is the first finding on sibling burden in early psychosis and contributes to the family burden literature. The finding is consistent with the work of Barak and Solomon (2005) who asked 52 siblings of individuals with long term psychotic illness and 48 controls to complete a self report questionnaire about their sibling relationship. They found that siblings had higher levels of burden, a less warm relationship and felt more shame than the control group.

The current study also found that high levels of post traumatic stress symptoms resulted in less warmth. This finding concurs with the work of Riebchleger (1991) who found that siblings in long term psychotic disorder were not assisted in dealing with trauma and experienced "chronic, unending grief" (p.235).

A high level of satisfaction in the domains of quality of life was associated with a more warm relationship. This study finding provides evidence that it is important to support siblings and the sibling relationship during early psychosis. This finding is supported in the literature by the work of Gass, Jenkins and Dunn (2007), Milevsky and Levitt (2005) and Milevsky (2005). These authors studied the protective effects of the sibling relationship and found that it could promote quality of life by moderating stressful events, levels of distress and improve psychological health. They also found the sibling relationship could buffer psychosocial risks.

Research Question 5: Are there specific characteristics of early psychosis that are associated with lower satisfaction of quality of life for a sibling?

There are specific characteristics of early psychosis that are associated with low satisfaction of quality of life. Suicide attempts and a history of violence impacted negatively on quality of life. These events disrupted sibling activities of daily living and their energy levels (physical domain); they impacted upon self esteem, resulted in negative feelings and impacted upon cognitive functioning (psychological); they affected their personal relationships and social supports (social domain); and affected their financial resources and home environment (environmental domain) (WHO, 1998). Interestingly, the results of this study also found that suicide attempts and physical violence increased conflict within the sibling relationship. This finding links with the study by Panzetti and James (1997) in that increased conflict within the relationship is associated with increased loneliness, and affects the psychological domain of quality of life.

As previously discussed in Research Question 1, in accordance with family systems theory (Kreppner & Lerner, 1989; Munuchin, 1988), a sibling's quality of life is impacted upon by the family unit as well as the individual family members. Attachment theory contends that a consistent sibling relationship assists in normal development in the adolescent years (Sears & Shepherd, 2004). It is therefore not surprising that early psychosis affects the sibling's quality of life.

In this study, suicide attempts resulted in less satisfaction in each domain of quality of life. As the majority of participants in the current study lived at home (63%) they were exposed to the consequences of this event including their parent's distress. This impacted upon their quality of life as it did for siblings in the Norwegian study by Dyregrov and Dyregrov (2005). Dyregrov and Dyregrov (2005) also found suicide to affect the sibling's psychological quality of life in the form of post traumatic distress,

depression and anxiety. Other sibling experiences reported in the literature that are consistent with the current study's findings are grief, guilt, shame, sadness and self blame (Lively et al., 1994; Titelman & Psyck, 1991).

This study found that suicide attempts resulted in a low satisfaction with the social domain of quality of life. Siblings in early psychosis may not share their experiences with others due to a sense of shame and stigma resulting in social isolation, as was found by Barak and Solomon (2005). This would negatively impact upon their satisfaction in the social domain of quality of life. It has also been found by previous researchers that siblings often provide support to their parents rather than the other way around (Dyregrov & Dyregrov, 2005; Sin, Moone & Harris, 2008). This too may contribute to less satisfaction in the social domain.

Participants in this study reported that living with their ill brother or sister reduced their satisfaction in the social domain of quality of life. As the majority of siblings in this study still lived with their ill brother or sister, they were therefore exposed to more negative experiences from their brother or sister's early psychosis and the characteristics of the illness. Siblings living at home spent less time with their peer group, received less external support and experienced more burden, including shame and stigma. Roles that normal sibling relationships provide, such as companionship, intimacy, affection and socialisation, change when a young person experiences early psychosis (McHale and Crouter, 2007; Weiss, 1974). This impact would affect satisfaction of both the psychological and social domains of quality of life.

Physical violence was found to negatively affect the quality of life of siblings in this study. This finding is consistent with the work of Smith and Greenberg (2008) and Solomon, Cavanaugh, and Gelles (2005). It is not clear if the participants in the current study were the target of physical violence as has been previously found by Solomon et al (2005) as they were not asked about this in the survey.

Findings in this study showed that burden significantly reduced the participants' satisfaction in all domains of quality of life. This supports the work of Barak and Solomon (2005), in that siblings undertook responsibility and care giving roles resulting in higher levels of burden. Sin, Moone and Harris (2008) also found that siblings in early psychosis provided care giving services to their brother or sister in the form of symptom management, medication management and practical support. The current study finding is also consistent with the work by Greenberg, Kim and Greenley (1997) who investigated the experiences of burden in 164 siblings of adults with long term psychotic illness. They found that levels of burden and siblings' quality of life were more affected by the symptoms of the illness than the care giving responsibilities.

The findings of this study showed that symptoms of post traumatic stress had a negative effect on satisfaction in all domains of sibling quality of life. It is suggested that suicide attempts and physical violence result in higher levels of post traumatic distress. Qualitative research should be conducted to understand what siblings believe would be beneficial in assisting them recovery from their traumatic experiences to reduce the impact upon their quality of life.

Summary

Many of the findings from the current study were consistent with previous research on sibling relationships, siblings in long term psychotic illness and the previous study on siblings in early psychosis. Findings from the current study also provided new information about the experience of siblings in early psychosis. The following chapter will conclude the thesis by outlining the significance of this research, its limitations and future directions.

Chapter Six: Conclusions

This chapter provides a summary of the findings of the study. It is followed by the implications for practice and limitations of the study. The chapter concludes with recommendations for future research.

Summary of research aims, methodology and findings

The aim of this research was to obtain quantitative data on the experience of siblings who have a brother or sister with early psychosis. This research used a survey methodology to explore the experience of 157 siblings in the first 18 months of their brother or sister's treatment for early psychosis. Participants reported on their knowledge of psychosis (Knowledge About Schizophrenia Questionnaire, Ascher-Svanum, 1999), their sibling relationship (Adult Sibling Relationship Questionnaire, Stocker, Lanthier & Furman, 1997), the burden they were experiencing (The Experience of Caregiving Inventory, Szmukler, Burgess, et al., 1996), the impact of events related to their brother or sister illness (Impact of Events Scale – Revised, Weiss & Marmar, 1997), and their quality of life (WHOQOL-Bref, WHO, 1998). Statistical differences between groups were investigated using independent samples t-tests and one way analysis of variance (ANOVA). Correlation analyses were used to detect relationships between scales and variables. Pearson's product-moment co-efficient (r) was used as all data were normally distributed.

The findings showed that gender and birth order did not result in different levels of knowledge of psychosis for this sample. There was also no significant difference in levels of warmth, conflict and rivalry within the relationship, however observable differences were evident. Younger sisters had the most warmth, younger brothers had the least. Older brothers were statistically more satisfied with their quality of life than

younger sisters. Older brothers also experienced significantly lower levels of burden and post traumatic stress symptoms than younger sisters.

The sibling relationship in early psychosis had the same amount of warmth, but lower levels of conflict and rivalry when compared to normative data. The study sample reported much lower satisfaction with their psychological quality of life when compared to an Australian sample.

When the young person with a diagnosis of early psychosis had experienced a period of untreated psychosis longer than 6 months, required more than one admission to hospital, had persisting psychotic symptoms, continued to use substances, and/or had a history of physical violence, the sibling relationship was reported to be less warm. This was also the case if the sibling felt more burdened and had symptoms of post traumatic stress.

When the young person with early psychosis had attempted suicide and/or had been physically violent, siblings reported being less satisfied with all the domains of their quality of life. Living with the ill brother or sister resulted in less satisfaction in the social domain of quality of life. Siblings who felt burdened and had symptoms of post traumatic stress also were less satisfaction in all domains.

Significance of the research and implications for practice

The research presented in this thesis provides insight into the experience of siblings in early psychosis and the findings suggest a need to adapt current practice. The first proposal for practising clinicians is sibling inclusion. The results of this research invite mental health clinicians to reflect on siblings as integral to interventions with the parents and the identified client. What has become obvious during this research process is that siblings are not demanding of the service system. The study has shown however that many provide care to their ill brother or sister and they see it as part of the normal sibling

role and relationship. When a clinician meets with the parents only, they may not be obtaining the full story. When a major event occurs for the young person experiencing early psychosis such as a hospital admission, a suicide attempt, or a relapse, siblings should be invited and included in family interventions.

It also remains unclear what the impact of a supportive sibling relationship can have on the recovery of the individual experiencing early psychosis. A factor that promotes recovery from early psychosis is social and family support and the sibling relationship can provide both. Mental health clinicians are encouraged to support the health of this relationship.

The second proposal for future practice is recognising that siblings require a unique approach to engagement in order for them to be included in interventions. They currently believe that the family services offered by the early psychosis clinic are for parents only. They require an individualised approach that will de-stigmatise their association with mental health clinicians and support their inclusion in family interventions.

The findings of this research suggest that a number of specific interventions may be helpful to siblings. Firstly, siblings may benefit from collaboration with mental health clinicians who understand, respect and advocate for them. Secondly, even though this research found that siblings had a good understanding of psychosis, it is suggested that just knowing the facts about psychosis does not assist in accepting or managing it. Individualised education specifically tailored to their unique circumstances and their brother or sister's illness is required. This may reduce burden such as shame, embarrassment, and stigma and assist in the development of strategies to enhance coping. Further, it is recommended that mental health clinicians educate parents on common sibling experiences during early psychosis and provide them with strategies to support siblings, particularly younger sisters.

This research has identified characteristics of early psychosis that significantly affect the sibling experience. It is suggested that clinicians use these findings to identify siblings whose ill brother or sister is experiencing these characteristics and intervene early preventing prolonged emotional impact as was seen in the studies on siblings in long term psychotic illness. Specifically, siblings whose brother or sister has more than a 6 month duration of untreated psychosis, more than one hospital admission, ongoing psychotic symptoms and has been physically violent, can be expected to have a changed sibling relationship and low satisfaction with quality of life. This research found that younger sisters were the group most affected. It is this sibling profile that may benefit from inclusion in family interventions the most.

Limitations of the research

The main limitations of the study were that participants were self selected and therefore may represent a group of siblings with more concern and hardship. Generalisability of findings must be considered accordingly. Data were not collected regarding aspects of the family that might have provided a better insight into environmental factors that influenced the sibling relationship, such as relationship with parents, parents working status, geographical location, whether any physical illnesses or disabilities existed within the family, and whether parents were receiving professional assistance for mental health problems.

Requiring consent from the young person with early psychosis may have resulted in the omission of a specific sample of siblings. This research therefore may have been unable to gain insight into siblings who were estranged or in conflict with their ill brother or sister. Young people with early psychosis may also have withheld their consent if they were concerned about their sibling's current mental health status and coping skills. The exclusion criteria of this research resulted in the omission of siblings who had

experienced a psychotic disorder themselves or had an intellectual disability. Therefore this study was unable to gain insight into these more difficult or complex sibling relationships in early psychosis.

The challenge of this study was to gain an understanding of the population in the most efficient way. Surveys can often be limited by their measures. They are conducted in the uncontrolled settings of the real world and can be affected by those settings. Surveys gain their power from the ability to measure groups of people that form a microcosm of a large population but as Groves et al (2004) report, they rarely achieve this. This research therefore established a limited perspective due to the utilisation of standardised questionnaires and did not allow for any qualitative data to be obtained. Qualitative investigations offer the possibility of rich encounters with deep understanding of participants' experiences. An in-depth reflection on the lived experience of being a younger sister, a younger brother, an older sister and an older brother would have strengthened and enriched this study.

A further limitation of this research was the reliability of information obtained from the medical records in regard to the duration of untreated psychosis, the presence of persisting psychotic symptoms, ongoing substance use, the history of suicide attempts and physical violence. Sensitive issues for young people with early psychosis and their parents or carers are not always reported to the treating team and therefore are not documented. This research only utilised data in the medical record and therefore events and patient characteristics not reported in the medical file are not reported in the data of this research. This too may affect the reliability of the findings.

Future research and directions

This research has complemented the literature on siblings in long term psychotic illness and it has added to the one previous study conducted into the sibling experience of early psychosis. This study provides a number of directions for future research.

It is recommended that qualitative studies are conducted with a broad sample of siblings in order to gain a rich and deep understanding of the experience. Such investigations could include: how younger and older brothers and sisters believe early psychosis affects their sibling relationship and quality of life; what is the burden on younger sisters in early psychosis; do siblings in early psychosis experience loneliness, shame and grief and how do they manage these feelings in their daily life.

It is recommended that future research investigate the qualitative impact of having a brother or sister with early psychosis who attempts suicide or is physically violent. The prevalence of physical violence towards siblings in early psychosis should also be established.

A further proposed study concerns parental attitudes towards healthy children when one experiences an early psychosis.

Future research could also gain an understanding of the warmth, conflict and rivalry within the sibling relationship of normal Australian adolescents and emerging adults. Research should also be conducted to ascertain the Australian population norms for the domains of adolescent quality of life.

Finally, qualitative research should be conducted with siblings to ascertain what they believe would help them cope more effectively with having a brother or sister experiencing early psychosis. Early psychosis services could then begin to offer the appropriate interventions and support.

In concluding this thesis, the findings discovered from this research contribute to the early psychosis literature and invites health professionals to pay attention to all members of the family when the onset of an early psychosis occurs, not only the parents and the young person experiencing the illness. The findings will assist clinicians in understanding, identifying and addressing the important needs of siblings.

APPENDICES

Appendix A: Information Sheet and consent forms for Siblings.



INFORMATION SHEET AND CONSENT FORM FOR SIBLINGS

We would like to ask you about being involved in a research project.

This project is being organised by Ms Siann Bowman, an Occupational Therapist at EPPIC, as part of a Masters of Applied Science Degree at Latrobe University. It is being funded by ORYGEN Youth Health and the Anita Morawetz Family Therapy Scholarship, University of Melbourne.

This project is being supervised by Dr Elspeth Macdonald and Dr Linsey Howie who are Occupational Therapists and lecturers at Latrobe University.

What is this research about?

This research aims to understand the experience of siblings when their brother or sister is experiencing an early psychosis. This will be investigated by requesting approximately 100 siblings to complete a self report questionnaire that will take 40 minutes to complete. The questionnaire will ask you to provide information regarding the following:

- demographical information
- your knowledge and opinion of psychosis
- your relationship with your ill brother or sister
- your experience of care giving
- your quality of life
- stress regarding a specific life event associated your brother or sister's illness

Why this research is important?

There has never been any previous research into the experience of siblings whose brother or sister is experiencing early psychosis. It is important to establish this experience in order to offer appropriate support to siblings if they so require it.

You will receive \$20 for your time in being involved in this research.

What would you need to do if you agree to be involved in this project?

If you agree to be in this research you will need to complete a questionnaire. You can do this by either attending EPPIC, for which you will receive a taxi voucher so you don't need to drive or take public transport. A researcher will be available to answer any questions you may have about the questionnaire, and they will be available after completion to discuss any issues that may have arisen from the questionnaire.

You may also complete the questionnaire at home. A researcher will come to your house and deliver the questionnaire for completion. She will be available to answer any questions you may have. The researcher will then return 3 to 5 days later to collect the questionnaire.

Whichever option you chose, **we will provide you with a follow up phone call** between 7 to 10 days after survey completion. This is to provide you with the opportunity to ask questions and discuss any issues that may have arisen for you.

Why do I need a follow up phone conversation with the researcher?

Sometimes families of a young person with an early psychosis are exposed to traumatic incidents, such as hospital admissions, physical violence, drug use and a change in the personality of their family member that is sudden and lasting. The questionnaire may raise sensitive issues for you. It may trigger a memory or an event or a feeling. It is important for use to be able to talk to you after the completion of the questionnaire and to ensure that we offer you the support you require. We call it debriefing.

Debriefing is not therapy but helps people to develop a psychological framework through which they will be able to understand their reactions and recovery in relation to trauma. The goals of debriefing are to reduce the impact of an event and to accelerate the normal recovery of a normal people who may be suffering painful reactions to abnormal events.

A critical incident refers to any situation which causes the individual to experience unusually strong emotional reactions which may affect them. A critical incident is said to have occurred when strong emotional or physical reactions are experienced which have the potential to interfere with an individual's ability to function either at the time of the incident or later.

Reactions to a critical incident may include moderate to high levels of anxiety as well as a sense of despair and detachment. Other reactions may occur such as anger, depression, sleep disturbance, and poor concentration. Physical discomfort in the form of headaches, tension, nausea and indigestion can also occur.

The researcher will call you and conduct a debrief over the telephone. Debriefing is not an investigation or procedure and it is not an analysis of performance. It is a seven stage model that utilises steps of how to process information or trauma.

Debriefing will

- reduce stress symptoms
- normalise feelings
- help put the jigsaw together
- help individuals better understand their reactions
- understand triggers from previous incidents
- assist the individual understand their feelings
- provide education and arrange further follow up if required.

Other strategies to reduce adverse impact on you include:

* Where possible we would like to encourage you to complete the questionnaire at EPPIC so we can support you. At the completion of the questionnaire you will be offered the opportunity to discuss the experience of the questionnaire and any issues that have arisen.

*If you become distressed during or after the questionnaire completion and you would like the opportunity to discuss issues further, please let the researcher know (please ring if you are completing it at home). She will provide you with debriefing at this time. You will be offered individual sessions with the EPPIC Family Therapist or a PACE clinician.

*If you feel that you are experiencing adverse effects from completing the questionnaire, stop doing the questionnaire. Please contact the researcher for support and debriefing.

*If you think you have an emerging psychosis, depression, suicidal thoughts, you can be referred to the Youth Access Team for assistance and referral to appropriate services – PACE, EPPIC, Private Psychiatrist or General Practitioner.

If you express preference to the questionnaire being delivered to your home, the researcher will remind you that the questionnaire may bring up strong emotional reactions and you should contact the researcher if that happens.

If any concerns arise for you whilst completing the questionnaire, it is important you ring us or tell us. We would like to support you through this research project.

The following programs of ORYGEN Youth Health can be offered to participants in this study:

PACE – a clinic for young people 14-30 years who have concerns about their thoughts, feelings or behaviours and may be at risk of psychosis. People who come to PACE usually describe a recent change in their thoughts or feelings that worry them. They may feel depressed, sad, or out of touch and unable to relate to their family. They can also describe having more difficulty than usual coping with work or school; feeling tired, lacking energy, paranoid or worried about other people and their actions; noticing a change in the way things look or sound.

PACE aims to reduce these issues and stop them from getting worse. The PACE clinic offers a free confidential counselling and support service. It can assist in referring to other services if more appropriate.

EPPIC Family Programs – Family and friends are very important to the well-being of young people and they can be affected by the young person's difficulties. They need to learn techniques to help themselves cope with their own reactions. Family programs are for parents, partners, children, siblings, extended family, close friends, and anyone who carried a care giving function for the person with an early psychosis.

Family programs provide: individual sessions with a family worker to discuss issues that concern you and your ill family member; information to help you

further understand mental illness; a support group where families can share experienced, learn from and support each other; and a family resource room

The EPPIC family worker is available for you to call or meet with Monday to Friday 9am-5pm.

The Youth Access Team (YAT) – YAT is a 24 hour, seven day a week service, which provides crisis mental health intervention to young people. YAT performs a number of roles which include:

Triage – the first point of call for individuals wishing to refer someone to ORYGEN Youth Health

The acute team - provides community treatment; crisis intervention; phone support and home visits.

YAT clinicians include consultant psychiatrists, occupational therapists, clinical psychologists, psychiatric nurses and social workers. If you would like to contact this team, please ring 1800888320.

We will keep your information confidential

Your information will be stored under a code number. We will not use your name. We guarantee that we will keep your information confidential and safely stored. Your brother/sisters details will also remain confidential. Only researchers in the study will be able to access your information. Your name will not be used at any stage during the study and will not be used when the results of the study are written in the thesis and published. All traces of your participation will be destroyed 20 years after the study.

Your consent must be voluntary

It is important that you understand that your participation in this study must be voluntary.

Your decision to take part, or not to take part, or to withdraw, is entirely independent to your ill brother or sister's access to and the quality of the treatment they receive. **It is important that you understand that your willingness to participate has nothing to do with your brother or sisters relationship with their case manager and doctor or their treatment.**

You can ask for any further information you want

If you would like more information about the study do not hesitate to ask one of the researchers or your case manager. People you can ask are Siann Bowman on (03) 93422800, or Drs Elspeth Macdonald or Linsey Howie on (03) 94795733. Additionally you may contact the Latrobe University Human Ethics Committee on (03) 94791794 or the Secretary of the Behavioural and Psychiatric Research and Ethics Committee on (03) 93451681.

Thank you for your assistance,

Ms Siann Bowman
Dr Elspeth Macdonald,
Dr Linsey Howie.



CONSENT FORM FOR SIBLINGS

RESEARCHER:

I, CERTIFY THAT I have fully explained the aims, risks, and procedures of the research to the Sibling named herein (or to the lawful guardian of such sibling) and have handed to the Sibling (or Guardian) a copy of this Consent together with a SIBLING INFORMATION SHEET.

SIGNEDDATE:.....

SIBLING CONSENT:

The purpose of the above project has been fully explained to me and I have read the attached INFORMATION SHEET. I understand the aims and the procedures of the study and any risks to myself which are involved and I request to participate on the condition that I can withdraw my consent at any time.

I, DO / DO NOT (cross out whichever does not apply)

Wish to participate in this research

SIGNED DATE

CONSENT OF PRIMARY CARER

Required for participants less than 18 years of age.

The purpose of this project has been fully explained to me and I have read the attached SIBLING INFORMATION SHEET. I understand the aims and procedures of the study and any risks to those involved and I REQUEST my son/daughter participate on the condition I can withdraw my consent at any time.

SIGNED DATE

WITNESS OF SUBJECTS SIGNATURE

I,, of

Confirm that the aims and procedures of the study and any risks to the Sibling has been adequately explained to the Sibling whose signature I witness. In my opinion he/she appears to understand and wishes to participate.

SIGNED DATE.....

CONSENT for re-contact via telephone after completion of the survey.

NAME OF SIBLING:

I, agree for the researchers to contact me again for a follow up telephone interview after completion of the questionnaire.

Signature: Date:

NAME OF WITNESS

Signature: Date:

RESEARCHER:

Signature: Date:

Appendix B: The Survey for Participants

APPENDIX B

The Survey

ORYGEN Youth Health

35 Poplar Road, Parkville

Telephone: 9342 2800

Facsimile: (03) 9387 3003

Dear Participant,

Thank you for agreeing to participate in our study titled: Brothers and Sisters in Early Psychosis.

This research aims to understand the experience of brothers and sisters of young people experiencing early psychosis and requires you to complete a self-report questionnaire that will take approximately 40-60 minutes of your time. Please complete all sections of the questionnaire.

This research is important because very little previous work has been done to understand this. In order to offer appropriate support to brothers and sisters during early psychosis, we need to first understand their experience.

As a token of appreciation for participating in this research, you will receive \$20 for your time.

The attached questionnaire will ask you to provide the following information:

- personal information
- your knowledge and view of psychosis
- the relationship with your brother or sister experiencing early psychosis
- your experience of care giving to your unwell brother/sister
- the stress associated with your brother/sister's illness
- your quality of life

Please contact Siann Bowman on 9342 2800 or siannbowman@mh.org.au, if you have any particular questions regarding the questionnaire itself. Again, thank you for your participation.

Sincerely,

Siann Bowman

SECTION 1 – Personal Information

1

This questionnaire asks about your relationship with your brother or sister who has experienced an early psychosis. We begin by asking you some general questions about your brother or sister and yourself. Please circle or fill in the correct response.

1. Your age: _____(yrs)_____(mths) Date of Birth: ____/____/____

2. Your brother/sister's age _____(yrs)_____(mths) Date of Birth: ____/____/____

3. Your gender: Male Female

4. Your brother/sister's gender Male Female

5. Your birth order:
Firstborn
Secondborn
Thirdborn
Fourthborn
Laterborn

6. Your brother/sister's birth order:
Firstborn
Secondborn
Thirdborn
Fourthborn
Laterborn

7. Total number of children in the family: (please circle)
2 3 4 5 6 7

8. Now we would like some information about your other brother and sisters, not including your brother/sister who attends EPPIC. Please fill in this chart:

	Age	Gender	Relationship (biological, step, twin)
Sibling 1	_____	_____	_____
Sibling 2	_____	_____	_____
Sibling 3	_____	_____	_____
Sibling 4	_____	_____	_____
Sibling 5	_____	_____	_____

10. Your brother/sister's marital status:

Single

Married

Defacto

Divorced

Widowed

12. Your brother/sister's highest education:	Secondary
	Tertiary degree
	TAFE

14. Is your brother/sister employed? Yes No

15. Are your parents separated or divorced? Yes No

17. Where do you live? _____ (suburb)

18. Do you live with your parents? Yes No

19. (a) Does your brother/sister live with you? Yes No

If you answered No to question 19.(a), please answer the following questions.If you answered Yes, please go to question 26.

19. (b) If No, how many years has it been since you lived with your brother/sister? YES

19. (c) Did you move away because of your brother/sister's illness? Yes No

20 Where does your brother/sister live? _____ (suburb)

Please tick the appropriate response:

Please tick the appropriate response:		Hardly at all	A Little	Somewhat	Very Much
21.	How often do you see your brother/sister?				
22.	How often does your brother/sister phone you?				

Please tick the appropriate response:

Hardly at all	A Little	Somewhat	Very Much

23. How often do you phone your brother/sister?

24. How often do you and your brother/sister see each other?

25. What is your relationship to your brother/sister? (circle)

Biological Twin Step Half Other

26. Has your brother/sister ever been admitted to hospital for his or her illness?

Yes No

27. (a) Is your brother/sister currently in hospital?

Yes No

If Yes, please answer the following 27.(b):

27. (b) How long has your brother/sister been in hospital?

28. Have you visited your brother/sister in hospital?

Yes No

29. Have you attended EPPIC Family and Friends Sessions?

Yes No

30. Have you attended EPPIC with your family for sessions?

Yes No

31. Have you ever sought support from a professional to help you manage your brother/sister's illness?

Yes No

If Yes, please tick the appropriate answer:

- _____ School Counsellor
 _____ Pastor
 _____ Self-help Organisation
 _____ Psychologist
 _____ Psychiatrist
 _____ Public Mental Health Service
 Other: _____

Section 2: Quality of Care Provided to your Brother/Sister

2

1. (a) Did you know where to get help for your brother/sister before you met the Youth Access Team (YAT) Yes No Unsure

If Yes, where did you find the information?

1. (b) _____ Advertising
 _____ Word of mouth (friends/family)
 _____ School Counsellor
 _____ General Practitioner
 _____ TV/radio
 _____ Newspaper/magazine/books
 _____ Work
 Other _____

2. For how long before your brother/sister came to EPPIC do you think they were unwell? _____ (yrs) _____ (mths)

3. Have you been happy with your brother/sister's treatment since coming to EPPIC? Yes No Unsure

Please comment on aspects you have been happy with and aspects you have not:

Happy with _____

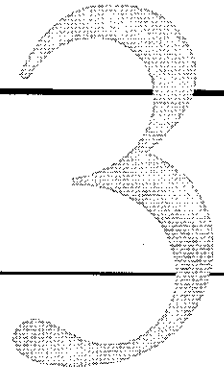
Not happy with _____

4. Have you had contact with the treating team? Yes No

5. Has this contact been as frequent as you would like? Yes No

6. How would you rate your brother/sister's current care? _____ Excellent
 _____ Very Good
 _____ Acceptable
 _____ Poor

Section 3: Your knowledge of Psychosis



Please circle the response most correct for you

1. The chance of experiencing a psychosis is:
 - (a) 3 out of every million people.
 - (b) 3 out of every 100 people.
 - (c) 3 out of every 10 people.
 - (d) 3 out of every 1000 people.

2. People with psychosis may behave in ways that seem strange to others.
Why could this be?
 - (a) They like scaring people.
 - (b) They are scared and confused.
 - (c) They take too many drugs.
 - (d) They are brain damaged.

3. Which areas of a person's life does psychosis affect?
 - (a) Thinking.
 - (b) Feeling.
 - (c) Behaving.
 - (d) None of the above.
 - (e) All of the above.

4. A delusion is:
 - (a) Seeing things that are not really there.
 - (b) Not a symptom of psychosis.
 - (c) A feeling of sadness.
 - (d) A belief that seems very real even though it is totally false and not shared by other people.

5. A visual hallucination is:
 - (a) Not a symptom of psychosis.
 - (b) Seeing things that are not really there.
 - (c) A type of delusion.
 - (d) A symptom that psychiatry cannot treat.

6. The cause of psychosis is:
 - (a) Unclear, but thought to be the same for every person.
 - (b) Unclear, but thought to be different for every person.
 - (c) Clear, and the same for every person.
 - (d) Clear, and different for every person.

7. What does the family of the person who has psychosis need most? Choose one:
- (a) Education and support.
 - (b) Courses in psychological medicine and care.
 - (c) Nothing – the person who has psychosis needs the most help.
 - (d) Regular relief from caring for the person who has psychosis.
8. Psychosis is:
- (a) Like having multiple personalities.
 - (b) A mental illness that causes people to become confused and have difficulty deciding what is real.
 - (c) Likely to be caused by using LSD or marijuana.
 - (d) A contagious disease.
 - (e) All of the above
9. Which of the following makes psychosis worse?
- (a) Stress with family members.
 - (b) Having nothing to do with one's free time.
 - (c) Taking street drugs.
 - (d) Drinking alcohol.
 - (e) All of the above
10. Common side effects of antipsychotic drugs are:
- (a) Drowsiness.
 - (b) Weight gain.
 - (c) Restless legs or shakiness.
 - (d) All of the above.
 - (e) None of the above.
11. Ways of coping with and reducing side effects include:
- (a) Waiting awhile.
 - (b) Reducing the dosage on doctor's advice.
 - (c) Changing to a medication without the annoying side effects on doctor's advice.
 - (d) All of the above.
 - (e) None of the above.
12. A person suffering from psychosis nearly always has:
- (a) Difficulty deciding what is real and what is not real.
 - (b) An abnormal heart beat.
 - (c) A fear of heights.
 - (d) A tendency to behave violently.
 - (e) Two or more personalities.

13. A person suffering from psychosis:

- (a) Sees things that others do not see.
- (b) Hears voices when there is nobody around.
- (c) Believes that thoughts are being put into his/her mind by other people.
- (d) Believes that he/she is someone very important (like Jesus, Virgin Mary, Allah).
- (e) All of the above

14. A person with psychosis who is under pressure should:

- (a) Take an extra dose of medication (without consulting the doctor).
- (b) Spend several days in bed and rest.
- (c) Discuss his/her difficulties with a doctor or therapist.
- (d) Ignore it because time will heal all problems.

15. Which is the most important treatment of psychosis?

- (a) Electro-shock treatment and medication.
- (b) Medication, counselling and practical assistance.
- (c) Occupational therapy and Physiotherapy.
- (d) Recreational therapy and Electro-shock treatment.

16. Antipsychotic medications do not cure psychosis, but they do:

- (a) Damage the brain.
- (b) Result in addiction to the drug.
- (c) Take all your problems away.
- (d) Help control the symptoms of the illness.

17. A significant proportion of those who have psychosis (choose one):

- (a) End up in prison.
- (b) Relapse and need to be kept in hospital for life.
- (c) Recover and lead normal lives.
- (d) Develop drug addictions.

18. Which symptoms of psychosis tend not to be improved by antipsychotics?

- (a) Feeling bored.
- (b) Hallucinations.
- (c) Delusions.
- (d) Problems in thinking.

19. Antipsychotic medication is not (choose one):

- (a) Addictive.
- (b) Good at helping distressing thoughts become less important.
- (c) Good at reducing the chance of becoming psychotic again.
- (d) Helping you take control of your psychosis.

20. People who experience psychosis usually (choose one):

- (a) Have a shorter life expectancy.
- (b) Suffer considerable memory loss.
- (c) Require care for the rest of their lives.
- (d) Lead a productive life.

21. Which one of the following is most commonly thought to cause a vulnerability to psychosis?

- (a) Bad parenting.
- (b) Bad experiences at birth.
- (c) Genetic mutation.
- (d) Having a close relative with psychosis.

22. Electro-shock therapy (ECT) is rarely used in the treatment of psychosis, but when it is used, it is:

- (a) Very painful.
- (b) Painless and safe.
- (c) Very time-consuming and much slower to help than medicines.
- (d) Quite unsafe.

23. What are commonly the three phases of psychosis?

- (a) Prodrome, acute, recovery.
- (b) Prodrome, acute, chronic.
- (c) Prodrome, acute, prison.
- (d) Prodrome, acute, suicide.

24. If a person who has been diagnosed with psychosis continues to take medicines as prescribed by the doctor, he or she:

- (a) Is likely to have more severe symptoms during relapse (recurrence of the illness).
- (b) Does not change at all the chances of being rehospitallised for schizophrenia.
- (c) Is more likely to be rehospitallised because of medicine's side effects.
- (d) Double the chances of staying out of the hospital (of not having a relapse).

25. Who can experience a psychosis:

- (a) Anyone.
- (b) Men only.
- (c) People with personality disorders.
- (d) People with schizophrenia only.

SECTION 4: THE RELATIONSHIP WITH YOUR BROTHER OR SISTER

Each question asks you to rate how much different behaviours and feelings occur in your relationship. Try and answer each one as quickly and accurately as you can. Try and answer the questions as your relationship is now, not how it was in the past, or how you think it might be in the future.

Please 6 circle the most appropriate response:

	HARDLY AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	EXTREMELY
1) How much do you and this sibling have in common?	0	1	2	3	4
2) How much do you talk to this sibling about things that are important to you?	0	1	2	3	4
3) How much does this sibling talk to you about things that are important to him or her?	0	1	2	3	4
4) How much do you and this sibling argue with each other?	0	1	2	3	4
5) How much does this sibling think of you as a good friend?	0	1	2	3	4
6) How much do you think of this sibling as a good friend?	0	1	2	3	4
7) How much do you irritate this sibling?	0	1	2	3	4
8) How much does this sibling irritate you?	0	1	2	3	4

HARDLY AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	EXTREMELY
---------------	--------------	----------	-------------	-----------

9) How much does this sibling admire you? 0 1 2 3 4

10) How much do you admire this sibling? 0 1 2 3 4

11) Do you think your mother favours you or this sibling more? (circle)

a) I usually get more support

b) I sometimes get more support

c) We are supported equally

d) This sibling sometimes gets more support

e) This sibling usually gets more support

12) Does this sibling think your mother favours him/her or you more?

a) I usually get more support

b) I sometimes get more support

c) We are supported equally

d) This sibling sometimes gets more support

e) This sibling usually gets more support

13) How much does this sibling try to cheer you up when you are feeling down? 0 1 2 3 4

14) How much do you try to cheer this sibling up when he or she is feeling down? 0 1 2 3 4

15) How competitive are you with this sibling? 0 1 2 3 4

16) How competitive is this sibling with you? 0 1 2 3 4

17) How much does this sibling go to you for help with non-personal problems? 0 1 2 3 4

18) How much do you go to this sibling for help with non-personal problems? 0 1 2 3 4

19) How much do you dominate this sibling? 0 1 2 3 4

20) How much does this sibling dominate you? 0 1 2 3 4

HARDLY AT ALL

A LITTLE BIT

SOMEWHAT

QUITE A BIT

EXTREMELY

21) How much does this sibling accept your personality?

0 1 2 3 4

22) How much do you accept this sibling's personality?

23) Do you think your father favours you or this sibling more?

a) I usually get more support

b) I sometimes get more support

c) We are supported equally

d) This sibling sometimes gets more support

e) This sibling usually gets more support

24) Does this sibling think your father favours him/her or you more?

a) I usually get more support

b) I sometimes get more support

c) We are supported equally

d) This sibling sometimes gets more support

e) This sibling usually gets more support

25) How much does this sibling know about you?

0 1 2 3 4

26) How much do you know about this sibling?

0 1 2 3 4

27) How much do you and this sibling have similar personalities?

0 1 2 3 4

28) How much do you discuss your feelings or personal issues with this sibling?

0 1 2 3 4

29) How much does this sibling discuss his or her feelings or personal issues with you?

0 1 2 3 4

HARDLY AT ALL

A LITTLE BIT

BOTH

QUITE A BIT

EXTREMELY

30) How often does this sibling criticise you?

0

1

2

3

4

31) How often do you criticise this sibling?

0

1

2

3

4

32) How close do you feel to this sibling?

0

1

2

3

4

33) How close does this sibling feel to you?

0

1

2

3

4

34) How often does this sibling do things to make you mad?

0

1

2

3

4

35) How often do you do things to make this sibling mad?

0

1

2

3

4

36) How much do you think that this sibling has accomplished a great deal in life?

0

1

2

3

4

37) How much does this sibling think that you have accomplished a great deal in life?

0

1

2

3

4

38) Does this sibling think your mother supports him/her or you more?

a) I usually get more support

b) I sometimes get more support

c) We are supported equally

d) This sibling sometimes gets more support

e) This sibling usually gets more support

39) Do you think your mother supports you or this sibling more?

a) I usually get more support

b) I sometimes get more support

c) We are supported equally

d) This sibling sometimes gets more support

e) This sibling usually gets more support

	HARDLY AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	EXTREMELY
40) How much can you count on this sibling to be supportive when you are feeling stressed?	0	1	2	3	4
41) How much can this sibling count on you to be supportive when he or she is feeling stressed?	0	1	2	3	4
42) How much does this sibling feel jealous of you?	0	1	2	3	4
43) How much do you feel jealous of this sibling?	0	1	2	3	4
44) How much do you give this sibling practical advice? (e.g., household or car advice)	0	1	2	3	4
45) How much does this sibling give you practical advice?	0	1	2	3	4
46) How much is this sibling bossy with you?	0	1	2	3	4
47) How much are you bossy with this sibling?	0	1	2	3	4
48) How much do you accept this sibling's lifestyle?	0	1	2	3	4
49) How much does this sibling accept your lifestyle?	0	1	2	3	4

50) Does this sibling think your father supports him/her or you more?

- a) I usually get more support
- b) I sometimes get more support
- c) We are supported equally
- d) This sibling sometimes gets more support
- e) This sibling usually gets more support

51) Do you think your father supports you or this sibling more?

- a) I usually get more support
- b) I sometimes get more support
- c) We are supported equally
- d) This sibling sometimes gets more support
- e) This sibling usually gets more support

	HARDLY AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	EXTREMELY
52) How much do you know about this sibling's relationships?	0	1	2	3	4
53) How much does this sibling know about your relationships?	0	1	2	3	4
54) How much do you and this sibling think alike?	0	1	2	3	4
55) How much do you really understand this sibling?	0	1	2	3	4
56) How much does this sibling really understand you?	0	1	2	3	4
57) How much does this sibling disagree with you about things?	0	1	2	3	4
58) How much do you disagree with this sibling about things?	0	1	2	3	4
59) How much do you let this sibling know you care about him or her?	0	1	2	3	4
60) How much does this sibling let you know he or she cares about you?	0	1	2	3	4
61) How much does this sibling put you down?	0	1	2	3	4
62) How much do you put this sibling down?	0	1	2	3	4
63) How much do you feel proud of this sibling?	0	1	2	3	4
64) How much does this sibling feel proud of you?	0	1	2	3	4
65) Does this sibling think your mother is closer to him/her or you?	a) Our mother is usually closer o me b) Our mother is sometimes closer to me c) Our mother is equally close to both of us d) Our mother is sometimes closer to this sibling e) Our mother is usually closer to this sibling				
66) Do you think your mother is closer to you or this sibling?	a) Our mother is usually closer o me b) Our mother is sometimes closer to me c) Our mother is equally close to both of us d) Our mother is sometimes closer to this sibling e) Our mother is usually closer to this sibling				

	HARDLY AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	EXTREMELY
67) How much do you discuss important personal decisions with this sibling?	0	1	2	3	4
68) How much does this sibling discuss important personal decisions with you?	0	1	2	3	4
69) How much does this sibling try to perform better than you?	0	1	2	3	4
70) How much do you try to perform better than this sibling?	0	1	2	3	4
71) How likely is it you would go to this sibling if you needed financial assistance?	0	1	2	3	4
72) How likely is it this sibling would go to you if he or she needed financial assistance?	0	1	2	3	4
73) How much does this sibling act in superior ways to you?	0	1	2	3	4
74) How much do you act in superior ways to this sibling?	0	1	2	3	4
75) How much do you accept this sibling's ideas?	0	1	2	3	4
76) How much does this sibling accept your ideas?	0	1	2	3	4
77) Does this sibling think your father is closer to him/her or you?					
a) Our father is usually closer to me					
b) Our father is sometimes closer to me					
c) Our father is equally close to both of us					
d) Our father is sometimes closer to this sibling					
e) Our father is usually closer to this sibling					
78) Do you think your father is closer to you or this sibling?					
a) Our father is usually closer to me					
b) Our father is sometimes closer to me					
c) Our father is equally close to both of us					
d) Our father is sometimes closer to this sibling					
e) Our father is usually closer to this sibling					

79) How much do you know about this sibling's ideas?

HARDLY AT ALL

A LITTLE BIT

SOMEWHAT

QUITE A BIT

EXTREMELY

0

1

2

3

4

80) How much does this sibling know about your ideas?

0

1

2

3

4

81) How much do you and this sibling lead similar lifestyles?

0

1

2

3

4

Section 5: Your Experience of Care Giving



The following questions contain a number of statements that commonly apply to people who care for relatives or friends with a serious mental illness.

We would like you to read each one and decide how often it has applied to you over the past one month.

It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. Please circle the most appropriate response.

During the past month how often have you thought about:

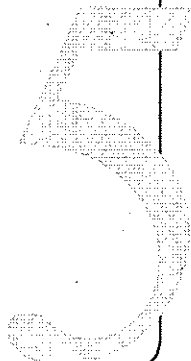
	NEVER	Rarely	SomeTIMES	OFTEN	NEarly
1. Your covering up her illness	0	1	2	3	4
2. Feeling unable to tell anyone of the illness	0	1	2	3	4
3. Her difficulty looking after money	0	1	2	3	4
4. Having to support her	0	1	2	3	4
5. What sort of life she might have had	0	1	2	3	4
6. Her risk of committing suicide	0	1	2	3	4
7. I have learnt more about myself	0	1	2	3	4
8. I have contributed to others' understanding of the illness.	0	1	2	3	4
9. Being unable to do the things you want to do	0	1	2	3	4
10. How health professionals do not take you seriously	0	1	2	3	4
11. Her dependence on you	0	1	2	3	4
12. Helping her to fill in the day	0	1	2	3	4
13. I have contributed to her wellbeing	0	1	2	3	4

	NEVER 0	Rarely 1	SomeTIMES 2	OFTEN 3	NEarly 4
14. That she makes a valuable contribution the household.					
15. The effect on your finances if she becomes more seriously ill	0	1	2	3	4
16. Dealing with psychiatrists	0	1	2	3	4
17. Her always being at the back of your mind	0	1	2	3	4
18. Whether you have done something to make her ill	0	1	2	3	4
19. That she has shown strengths in coping with her illness	0	1	2	3	4
20. I have become more confident in dealing with others	0	1	2	3	4
21. How family members do not understand your situation	0	1	2	3	4
22. That she is good company	0	1	2	3	4
23. I have become more understanding of others with problems	0	1	2	3	4
24. How she thinks a lot about death	0	1	2	3	4
25. Her lost opportunities	0	1	2	3	4
26. How to deal with mental health professionals	0	1	2	3	4
27. Feeling unable to have visitors at home	0	1	2	3	4
28. How she gets on with other family members	0	1	2	3	4
29. Backing her up when she runs out of money	0	1	2	3	4
30. How family members do not understand the illness	0	1	2	3	4
31. How she deliberately attempts to harm herself	0	1	2	3	4
32. I have become closer to some of my family	0	1	2	3	4

	NEVER	Rarely	SomeTIMES	OFTEN	NEarly
33. I have become closer to friends	0	1	2	3	4
34. I share some of her interests	0	1	2	3	4
35. I feel useful in my relationship with her	0	1	2	3	4
36. How health professionals do not understand your situation	0	1	2	3	4
37. Whether she will ever get well	0	1	2	3	4
38. Feeling the stigma of having a mentally ill relative	0	1	2	3	4
39. How to explain her illness to others	0	1	2	3	4
40. Others leaving home because of the effect of the illness	0	1	2	3	4
41. Setting her up in accommodation	0	1	2	3	4
42. How to make complaints about her care	0	1	2	3	4
43. I have met helpful people	0	1	2	3	4
44. I have discovered strengths in myself	0	1	2	3	4
45. Feeling unable to leave her home alone	0	1	2	3	4
46. The effect of the illness on children in the family	0	1	2	3	4
47. The illness causing a family breakup	0	1	2	3	4
48. Her keeping bad company	0	1	2	3	4
49. How her illness effects special family events	0	1	2	3	4
50. Finding out how hospitals or mental health services work	0	1	2	3	4
51. Doctors knowledge of the services available to families	0	1	2	3	4
52. The difficulty getting information about her illness	0	1	2	3	4

During the past month how often have you thought about her being:

	NEVER	Rarely	SomeTIMES	OFTEN	NEarly
53. Moody	0	1	2	3	4
54. Unpredictable	0	1	2	3	4
55. Withdrawn	0	1	2	3	4
56. Uncommunicative	0	1	2	3	4
57. Not interested	0	1	2	3	4
58. Slow at doing things	0	1	2	3	4
59. Unreliable about doing things	0	1	2	3	4
60. Indecisive	0	1	2	3	4
61. Irritable	0	1	2	3	4
62. Inconsiderate	0	1	2	3	4
63. Behaving in a reckless way	0	1	2	3	4
64. Suspicious	0	1	2	3	4
65. Embarrassing in appearance	0	1	2	3	4
66. Behaving in a strange way	0	1	2	3	4



Section 6: The Stress Associated with your Brother or Sister's illness

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you.

DURING THE PAST SEVEN DAYS with respect to YOUR BROTHER OR SISTERS illness or treatment, how much were you distressed or bothered by these difficulties.

Please circle the appropriate response:

	Not at all	A little bit	moderately	quite a bit	extremely
1. Any reminder brought back feelings about it:	0	1	2	3	4
2. Other things kept making me think about it:	0	1	2	3	4
3. I felt irritable and angry	0	1	2	3	4
4. I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
5. I thought about it when I didn't mean to	0	1	2	3	4
6. I felt as if it hadn't happened or wasn't real	0	1	2	3	4
7. I stayed away from reminders about it	0	1	2	3	4
8. Pictures about it popped into my mind	0	1	2	3	4
9. Pictures about it popped into my mind	0	1	2	3	4
10. I was jumpy and easily startled	0	1	2	3	4
11. I tried not to think about it	0	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	2	3	4
13. My feelings about it were kind of numb	0	1	2	3	4
14. I found myself acting or feeling as though I was back at that time	0	1	2	3	4

	Not at all	A little bit	moderately	quite a bit	extremely
15. I had trouble falling asleep	0	1	2	3	4
16. I had waves of strong feelings about it	0	1	2	3	4
17. I tried to remove it from my memory	0	1	2	3	4
18. I had trouble concentrating	0	1	2	3	4
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing nausea, or a pounding heart	0	1	2	3	4
20. I had dreams about it	0	1	2	3	4
21. I felt watchful or on-guard	0	1	2	3	4
22. I tried not to talk about it	0	1	2	3	4

SECTION 7: YOUR QUALITY OF LIFE

These questions ask you about your quality of life, health and other areas of your life. Please answer all the questions. If you are unsure about which response to give, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. Please read each question, assess your feelings, and circle the answer that is the best for you.

1. How would you rate your quality of life?

- a) Very poor
- b) Poor
- c) Neither poor nor good
- d) Good
- e) Very good

2. How satisfied are you with your health?

- a) Very dissatisfied
- b) dissatisfied
- c) Neither satisfied or dissatisfied
- d) Satisfied
- e) Very satisfied

The following questions ask about how much you have experienced certain things in the last two weeks.

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

- a) An extreme amount
- b) Very much
- c) A moderate amount
- d) A little
- e) Not at all

4. How much do you need any medical treatment to function in your daily life?

- a) An extreme amount
- b) Very much
- c) A moderate amount
- d) A little
- e) Not at all

5. How much do you enjoy life?

- a) Not at all
- b) A little
- c) A moderate amount
- d) Very much
- e) An extreme amount

6. To what extent do you feel your life to be meaningful?

- a) Not at all
- b) A little
- c) A moderate amount
- d) Very much
- e) An extreme amount

7. How well are you able to concerntrate?

- a) Not at all
- b) A little
- c) A moderate amount
- d) Very much
- e) Extremely

8. How safe do you feel in your daily life?

- a) Not at all
- b) A little
- c) A moderate amount
- d) Very much
- e) Extremely

9. How healthy is your physical environment?

- a) Not at all
- b) A little
- c) A moderate amount
- d) Very much
- e) Extremely

The following questions ask you how completely you experience or were able to do certain things in the last two weeks.

10. Do you have enough energy for everyday life?

- | | | |
|-------------------------------------|-------------------------------------|-------------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> A Little | <input type="checkbox"/> Moderately |
| <input type="checkbox"/> Mostly | <input type="checkbox"/> Completely | |

11. Are you able to accept your bodily appearance?

- | | | |
|-------------------------------------|-------------------------------------|-------------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> A Little | <input type="checkbox"/> Moderately |
| <input type="checkbox"/> Mostly | <input type="checkbox"/> Completely | |

12. Have you enough money to meet your needs?

- | | | |
|-------------------------------------|-------------------------------------|-------------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> A Little | <input type="checkbox"/> Moderately |
| <input type="checkbox"/> Mostly | <input type="checkbox"/> Completely | |

13. How available to you is the information that you need in your day-to-day life?

- | | | |
|-------------------------------------|-------------------------------------|-------------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> A Little | <input type="checkbox"/> Moderately |
| <input type="checkbox"/> Mostly | <input type="checkbox"/> Completely | |

14. To what extent do you have the opportunity for leisure activities?

- | | | |
|-------------------------------------|-------------------------------------|-------------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> A Little | <input type="checkbox"/> Moderately |
| <input type="checkbox"/> Mostly | <input type="checkbox"/> Completely | |

15. How well are you able to get around?

- | | | | | |
|------------------------------------|-------------------------------|----------------------------------|-------------------------------|------------------------------------|
| <input type="checkbox"/> Very poor | <input type="checkbox"/> Poor | <input type="checkbox"/> Neither | <input type="checkbox"/> Good | <input type="checkbox"/> Very Good |
|------------------------------------|-------------------------------|----------------------------------|-------------------------------|------------------------------------|

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

16. How satisfied are you with your sleep?

- | | | | | |
|--|---------------------------------------|----------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Dissatisfied | <input type="checkbox"/> Neither | <input type="checkbox"/> Satisfied | <input type="checkbox"/> Very Satisfied |
|--|---------------------------------------|----------------------------------|------------------------------------|---|

17. How satisfied are you with your ability to perform your daily living activities?

- | | | | | |
|--|---------------------------------------|----------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Dissatisfied | <input type="checkbox"/> Neither | <input type="checkbox"/> Satisfied | <input type="checkbox"/> Very Satisfied |
|--|---------------------------------------|----------------------------------|------------------------------------|---|

18. How satisfied are you with your capacity for work?

- | | | | | |
|--|---------------------------------------|----------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Dissatisfied | <input type="checkbox"/> Neither | <input type="checkbox"/> Satisfied | <input type="checkbox"/> Very Satisfied |
|--|---------------------------------------|----------------------------------|------------------------------------|---|

19. How satisfied are you with yourself?

- | | | | | |
|--|---------------------------------------|----------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Dissatisfied | <input type="checkbox"/> Neither | <input type="checkbox"/> Satisfied | <input type="checkbox"/> Very Satisfied |
|--|---------------------------------------|----------------------------------|------------------------------------|---|

20. How satisfied are you with your personal relationships?

- | | | | | |
|--|---------------------------------------|----------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Dissatisfied | <input type="checkbox"/> Neither | <input type="checkbox"/> Satisfied | <input type="checkbox"/> Very Satisfied |
|--|---------------------------------------|----------------------------------|------------------------------------|---|

21. How satisfied are you with your sex life?

- | | | | | |
|--|---------------------------------------|----------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Dissatisfied | <input type="checkbox"/> Neither | <input type="checkbox"/> Satisfied | <input type="checkbox"/> Very Satisfied |
|--|---------------------------------------|----------------------------------|------------------------------------|---|

22. How satisfied are you with the support you get from your friends?

☐ Very dissatisfied ☐ Dissatisfied ☐ Neither ☐ Satisfied ☐ Very Satisfied

23. How satisfied are you with the conditions of your living place?

☐ Very dissatisfied ☐ Dissatisfied ☐ Neither ☐ Satisfied ☐ Very Satisfied

24. How satisfied are you with your access to health services?

☐ Very dissatisfied ☐ Dissatisfied ☐ Neither ☐ Satisfied ☐ Very Satisfied

25. How satisfied are you with your transport?

☐ Very dissatisfied ☐ Dissatisfied ☐ Neither ☐ Satisfied ☐ Very Satisfied

The following question refers to how often you have felt or experienced certain things in the last two weeks.

26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

☐ Never ☐ Seldom ☐ Quite often ☐ Very often ☐ Always

We would like to take this opportunity to thank you for taking the time to complete this questionnaire. The results will contribute to our understanding of brothers and sisters of young people experiencing early psychosis.

ANSWER SHEET FOR EXAMINER :

FOR KNOWLEDGE QUESTIONNAIRE – REVISED (KQ-R)

- (1) A **B** C D
- (2) **A** B **C** **D** E
- (3) **A** B C D
- (4) **A** B C D
- (5) A B **C** D
- (6) A **B** C D
- (7) A **B** **C** D **E** F
- (8) A B C **D**
- (9) A **B** C D
- (10) **A** **B** C D **E** F
- (11) **A** **B** C **D** E **F** G H
- (12) A **B** C D
- (13) A B **C** D
- (14) **A** B C D
- (15) **A** B C D
- (16) A B **C** D
- (17) A **B** C D
- (18) A B C **D**
- (19) **A** B C D E
- (20) **A** B C D
- (21) A B C **D**

Appendix C: The Cronbach Alpha Coefficients

The Cronbach alpha coefficients

Table 1

Cronbach Alpha Coefficient for Adult Sibling Relationship Questionnaire

Sibling Relationship factors	Study Sample (1997) α	Stocker et al., α
Warmth	0.98	0.97
Acceptance	0.93	0.88
Admiration	0.94	0.83
Affection	0.94	0.92
Emotional Support	0.94	0.90
Intimacy	0.95	0.92
Instrumental Support	0.82	0.76
Knowledge	0.90	0.88
Similarity	0.90	0.83
Conflict	0.92	0.93
Antagonism	0.88	0.90
Competition	0.72	0.85
Dominance	0.79	0.74
Quarrelling	0.87	0.86
Rivalry	0.91	0.88
Maternal Rivalry	0.92	0.85
Paternal Rivalry	0.95	0.89

Table 2

Cronbach alpha coefficient for the Experience of Caregiving Inventory

Experience of caregiving scales	Study Sample	Szmukler et al., (1996)
	α	α
Difficult behaviours	0.91	0.91
Negative symptoms	0.91	0.89
Stigma	0.87	0.82
Problems with services	0.88	0.90
Effects on family	0.82	0.82
Need to back up	0.72	0.76
Dependency	0.80	0.74
Loss	0.85	0.79
Positive personal experiences	0.88	0.86
Good aspects of the relationship	0.83	0.82

Table 3

Cronbach alpha coefficient for the Impact of Events Scale-Revised

Impact of events-revised	Study Sample	Weiss & Marmar (1997)
subscales	α	α
Intrusions	0.93	0.87 - 0.92
Avoidance	0.94	0.84 - 0.86
Hyperarousal	0.91	0.79 - 0.90
Overall	0.97	0.96

Table 4

Cronbach alpha coefficient for the WHOQOL-Bref

Domains	Study Sample	WHO (1998)
	α	α
Physical domain	0.70	0.68-0.74
Psychological domain	0.79	0.79-0.80
Social domain	0.79	0.68-0.70
Environment domain	0.79	0.84-0.87

Appendix D: The Young Persons Medical File Review Form

Young Persons Medical file Review Form

Assigned number:-

Age :-

Gender:-

Position in the family:-

Living situation:-

Work situation:-

Education level acquired:-

Diagnosis:-

Treatment first received:-

Estimated duration of untreated psychosis:-

Number of hospitalisations:-

Medication:-

Compliant with treatment:-

Suicide attempts (if yes, state number of incidents):-

History of violence (if yes, state details):-

Current drug use: -

Persisting psychosis: -

Appendix E: Ethical Approval Certificates

17th April 2003

Siann Bowman
ORYGEN Youth Health
Locked Bag 10
PARKVILLE, VIC. 3052

Behavioural and
Psychiatric Research
and Ethics Committee

c/- Sunshine Hospital
176-190 Furlong Road
St Albans Vic 3021
Tel 61 3 8345 1681
Fax 61 3 9364 3792

Dear Siann,

RE: *"Siblings in Early Psychosis"*

Protocol Reference: E/03/008

Thank you for the amendments as requested by the Ethics Committee following the meeting on 28th February 2003.

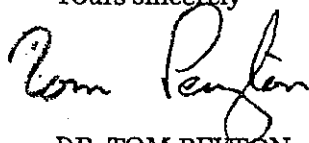
This protocol was reviewed and approved by the Research Committee on 07.03.03. The Ethics Committee reviewed and approved this protocol at the meeting on 28.02.03.

Enclosed please find a copy of the signed contract, approving this protocol.

This completes the requirements for Ethics and Research approval.

On behalf of the Committee may I wish you the very best in your research and we look forward to hearing your results.

Yours sincerely



DR. TOM PEYTON

Chairman

Behavioural & Psychiatric Ethics Committee



MELBOURNE HEALTH

North Western Mental Health is
a part of Melbourne Health Service

www.mh.org.au
ABN 73 802 706 972

**NORTH WESTERN MENTAL HEALTH
BEHAVIOURAL & PSYCHIATRIC RESEARCH & ETHICS COMMITTEE**

**CONTRACT WITH RESEARCHERS FOR RESEARCH & ETHICS APPROVAL
OF RESEARCH PROJECT**

Behavioural and
Psychiatric Research
and Ethics Committee

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Protocol Ref.: E/13/08

Behavioural and Psychiatric Research and Ethics Committee X

I, SIANN BOWMAN acknowledge that I have the approval of the Behavioural and Psychiatric Research and Ethics Committee for the protocol

titled SIBLINGS IN EARLY PSYCHOSIS



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ABN 73 802 706 972

I agree to observe the following conditions:-

1. To comply with the conditions as outlined in the final and Committee approved copy of the research protocol.
2. I agree that any variation to the approved Protocol, Plain Language Statement or Title will be presented to the Behavioural and Psychiatric Research and Ethics Committee for approval. Modifications cannot proceed until such approval is obtained in writing.
3. To provide progress reports by the 31st October each year or upon request by the Behavioural and Psychiatric Research and Ethics Committee. Failure to do so will lead to withdrawal of approval of the research protocol and re-application to the appropriate Committee must occur before recommencing.
4. To provide a report and a copy of the published material at the end of the project.
5. To maintain that the confidentiality and anonymity of all research subjects at all times.
6. To protect the integrity and confidentiality of patient records and to ensure that records will be preserved as set out in the research protocol and in accordance with the appropriate record storage guidelines.
7. To provide all research study participants with a copy of the "Notice to all taking part in a research project" (given out to the researcher), a signed copy of the consent form and a copy of the plain language statement.

Signed: [Signature] (Researcher) Dated: 14/4/03

Signed: [Signature] (Supervisor) Dated: 14/4/03

Date of Final Approval Given by Research Committee: 7/2/03

Date of Final Approval Given by Ethics Committee: 17/4/03

Signed (Ethics Committee Representative): [Signature]

**PLEASE NOTE: FAILURE TO COMPLY WITH THIS CONTRACT WILL RESULT IN
WITHDRAWAL OF ETHICS COMMITTEE APPROVAL TO CONTINUE THE PROJECT**

MEMORANDUM

To: Ms Siann Bowman, School of Occupational Therapy
Dr Lindsey Howie, School of Occupational Therapy

From: Secretary, La Trobe University Human Ethics Committee

Subject: Review of Human Ethics Committee Application No. 03-104:

La Trobe University ethics non-compliance for the project
Siblings in early psychosis

Date: 22 August 2006

Thank you for providing a detailed submission dated 3 July 2006 to the La Trobe University Human Ethics Committee (HEC) explaining the circumstances why data was collected for the above project without La Trobe University human ethics approval and seeking permission to now use that data towards Ms Bowman's thesis. The HEC wishes to acknowledge your forthrightness and accepting responsibility for these unfortunate circumstances.

It must be emphasized that the collection of data without La Trobe University ethics approval is a serious matter and Section 1.1.4 of the University's *Guidelines for the Conduct of Research* clearly states that research cannot proceed without such approval. Researchers have an obligation to themselves, the University and the community to ensure that all aspects of the research process are conducted with the highest professional standards. A cornerstone of responsible research conduct is ensuring compliance with a system that sets out the national standards of ethical research involving human participants. It is a system that serves to protect the rights of legitimate research as well as the rights of human participants.

At its meeting of 7 August 2006, the Committee discussed whether the data could now be published as part of the student's thesis. The Committee considered the following factors in its determination:

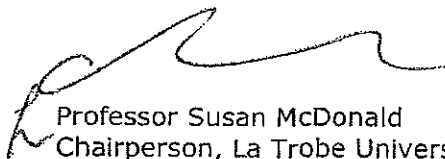
1. The project received ethics approval from a properly constituted NHMRC Human Research Ethics Committee;
2. The collection of data was completed in a way that did not give rise to ethical issues;
3. Supervisory changes and administrative errors resulted in the oversight of ensuring that La Trobe ethics approval had been received for the project before data collection commenced. However, it must be made clear that it is the responsibility of the supervisor and student to ensure that institutional ethics approval is obtained before data collection can commence.

The La Trobe HEC does not grant retrospective ethics approval and therefore no protection against claims of negligence made against the researchers would be covered by the University.

The HEC determined that as initial ethics approval was granted by the Behavioral and Psychiatric Ethics Committee at North Western Mental Health, the ***La Trobe HEC would approve the use of the data to be published as part of Ms Bowman's Master's thesis.***

Should you wish to discuss this matter further, you can contact me on 8458 4945 or s.mcdonald@latrobe.edu.au

Yours sincerely

A handwritten signature in black ink, appearing to be 'Susan McDonald', written in a cursive style.

Professor Susan McDonald
Chairperson, La Trobe University Human Ethics Committee

Appendix F: Information Sheet and Consent Forms for Young People attending EPPIC



INFORMATION SHEET AND CONSENT FORM FOR YOUNG PEOPLE ATTENDING EPPIC

We would like to ask you about your brother/sister(s) being involved in a research project.

This project is being organised by Ms Siann Bowman, an Occupational Therapist at EPPIC, as part of a Masters of Applied Science Degree at Latrobe University. It is being funded by ORYGEN Youth Health and the Anita Morawetz Family Therapy Scholarship, University of Melbourne.

This project is being supervised by Dr Elspeth Macdonald and Dr Linsey Howie who are Occupational Therapists and lecturers at Latrobe University.

What is this research about?

This research aims to understand the experience of siblings when their brother or sister is experiencing an early psychosis. This will be investigated by requesting approximately 100 siblings to complete a self report questionnaire that will take 40 minutes to complete. The questionnaire will ask you to provide information regarding the following:

- demographical information
- their knowledge and opinion of psychosis
- their relationship with you
- their experience of care giving to you
- their quality of life
- stress regarding a specific life event associated with your illness

Why this research is important?

There has never been any previous research into the experience of siblings whose brother or sister is experiencing early psychosis. It is important to establish this experience in order to offer appropriate support to siblings if they so require it.

You will receive \$20 for your time in being involved in this research.

What would you need to do if you provide consent for your brother or sister to be involved in this research?

If your brother or sister is involved in this research we would need to gather some information from your medical file.

We would need to gather information about:

- your age, gender, living and work situation
- your illness (such as what type of illness you have, when you first received treatment, how many times you have been sick or hospitalised and what medication you take)
- whether you use drugs, have a persisting illness, and other such characteristics specific to your experience of early psychosis

We will keep your information confidential

Your information will be stored under a code number. We will not use your name. We guarantee that we will keep your information confidential and safely stored. Your brother/sisters details will also remain confidential. Only researchers in the study will be able to access your information. Your name will not be used at any stage during the study and will not be used when the results of the study are written in the thesis and published. All traces of your participation will be destroyed 20 years after the study.

Your consent must be voluntary

It is important that you understand that your participation in this study must be voluntary.

We have asked for your consent to allow your brother or sister to be involved in this research. We do not wish to contact your brother or sister without your knowledge or permission. This is because your treatment at EPPIC is confidential and your brother or sister may not realise you are receiving assistance from this service.

Your decision to allow your brother or sister to take part, or not to take part, is entirely independent to your access to and the quality of the treatment you receive. **It is important that you understand that your willingness to participate has nothing to do with your brother or sisters relationship with their case manager and doctor or their treatment.**

You should be aware that if your brother or sister becomes distressed by the content of the questionnaire, support will be offered to them. They will also receive follow up from the researcher after the questionnaire has been completed in order to monitor any effects from the questionnaire.

You can ask for any further information you want

If you would like more information about the study do not hesitate to ask one of the researchers or your case manager. People you can ask are Siann Bowman on (03) 93422800, or Drs Elspeth Macdonald or Linsey Howie on (03) 94795733. Additionally you may contact the Latrobe University Human Ethics Committee on (03) 94791794 or the Secretary of the Behavioural and Psychiatric Research and Ethics Committee on (03) 93451681.

Thank you for your assistance,

Ms Siann Bowman
Dr Elspeth Macdonald,
Dr Linsey Howie.



CONSENT FORM FOR YOUNG PEOPLE ATTENDING EPPIC

RESEARCHER:

I, CERTIFY THAT I have fully explained the aims, risks, and procedures of the research to the individual named herein (or to the lawful guardian of such individual) and have handed to the individual or Guardian a copy of this Consent together with a INFORMATION SHEET FOR YOUNG PEOPLE ATTENDING EPPIC.

SIGNEDDATE:.....

CONSENT OF YOUNG PERSON ATTENDING EPPIC FOR BROTHER/SISTER PARTICIPATION AND MEDICAL FILE REVIEW:

The purpose of the above project has been fully explained to me and I have read the attached INFORMATION SHEET. I understand the aims and the procedures of the study and any risks to myself which are involved and I request to participate on the condition that I can withdraw my consent at any time.

I, DO / DO NOT (cross out whichever does not apply)

Wish to participate in this research

NAME:

SIGNED DATE

CONSENT OF PRIMARY CARER

Required for young people attending EPPIC who are less than 18 years of age.

The purpose of this project has been fully explained to me and I have read the attached INFORMATION SHEET. I understand the aims and procedures of the study and any risks to those involved and I REQUEST my son/daughter participate on the condition I can withdraw my consent at any time.

SIGNED DATE.....

WITNESS OF SUBJECTS SIGNATURE

I,, of

Confirm that the aims and procedures of the study and any risks to the individual have been adequately explained to the individual whose signature I witness. In my opinion he/she appears to understand and wishes to participate.

SIGNED DATE.....

Appendix G: Pilot Study Response Form

Pilot Study Response Form

1. Do you believe the survey asks appropriate questions relevant to your experience?
Please provide any comments or recommendations.

2. Can you please report any mistakes, or grammatical errors you noticed in the survey?

3. What was the hardest part of the survey and why?

4. What was the easiest part of the survey and why?

5. How can this survey be improved to further capture your experience and make filling it in easier?

Thanks so much for your input and the time you have given to improving this research.

Appendix H: The Clinician Information Sheet



CLINICIAN INFORMATION SHEET

This research aims to understand the experience of siblings in early psychosis. This will be investigated by requesting approximately 100 siblings to complete a self-report questionnaire that will take 40 minutes to complete. The questionnaire will ask siblings to provide information regarding the following:

- demographical information
- their knowledge and opinion of psychosis
- their relationship with your ill brother or sister
- their experience of care giving
- their quality of life
- stress regarding a specific life event associated with your brother or sister's illness

All siblings who participate will receive \$20 for their time involved in this research. Siblings can complete this questionnaire at EPPIC or at home. Taxi vouchers will be provided to siblings who attend EPPIC.

We are interested in approaching siblings who meet the selection criteria and are happy to contribute to this exploratory research.

Potential participants will be included if they:

- Are aged between 15 and 29 years of age
- Have a brother or sister who is a current client of EPPIC and receiving treatment for a first episode psychosis
- Verbally report no previous history of psychotic illness
- Are to give written consent
- Are able to speak and understand written English fluently.

What we would like from you

We would like you to briefly describe this study to your clients using the information provided on the Information Sheet for Young People. If a client expresses interest in their sibling participating in this study, please obtain his/her verbal permission for you to organise an appointment with you and the researcher (Ms Siann Bowman).

Please contact Ms Siann Bowman (Occupational Therapist) at EPPIC on 93422800 with any details of potential participants or if you have any further questions about this research.

Appendix I: Additional statistical analyses

Additional statistical analyses

Research question 1: Does the gender and birth order of a sibling with a brother or sister experiencing early psychosis, result in: different levels of knowledge of psychosis; different levels of warmth, conflict and rivalry within the relationship; a different quality of life; different levels of burden and post traumatic stress symptoms?

Knowledge of psychosis

Results of the KASQ. Scores are presented for sibling gender and position (older brother (OB), younger brother (YB), older sister (OS), younger sister (YS)), and for total numbers (total siblings(T)).

OB N=42 Mean (SD)	YB N=39 Mean (SD)	OS N=44 Mean (SD)	YS N=32 Mean (SD)	T N=157 Mean (SD)
17.50 (3.82)	16.86 (3.29)	18.81 (2.95)	17.67(3.93)	17.76(3.52)

* Knowledge scores range from 0-25, with higher scores indicating higher levels of knowledge.

Sibling Relationship

Results of the Adult Sibling Relationship Questionnaire (ASRQ) compared to results from the Stocker et al., 1997 are presented. Scores are presented by sibling gender and position (older brother (OB), younger brother (YB), older sister (OS), younger sister (YS), and for total numbers (total siblings(T)).

	OB	YB	OS	YS	Total	Stocker et al., 1997
	N=42 Mean (SD)	N=39 Mean (SD)	N=44 Mean (SD)	N=32 Mean (SD)	N=157 Mean (SD)	N=383 Mean (SD)
Warmth	3.37 (0.80)	3.08 (0.91)	3.29 (0.97)	4.43 (0.94)	3.29 (0.91)	3.30 (0.7)
Acceptance	3.82 (0.87)	3.46 (0.96)	3.62 (1.03)	3.83 (1.02)	3.68 (0.97)	3.70 (0.76)
Admiration	3.56 (0.94)	3.19 (1.05)	3.38 (1.06)	3.52 (1.11)	3.41 (1.04)	3.65 (0.72)
Affection	3.71 (0.96)	3.44 (0.99)	3.64 (1.12)	3.68 (1.13)	3.62 (1.04)	3.51 (0.95)
Emotional Support	3.40 (1.00)	2.97 (1.13)	3.25 (1.20)	3.53 (1.13)	3.28 (1.12)	3.22 (0.90)
Intimacy	3.10 (1.03)	2.79 (1.08)	3.19 (1.16)	3.30 (1.60)	3.09 (1.09)	3.05 (0.92)
Instrumental Support	2.34 (0.85)	2.20 (0.98)	2.51 (0.90)	2.66 (0.85)	2.42 (0.90)	2.66 (0.82)
Knowledge	3.79 (0.65)	3.54 (0.84)	3.59 (0.91)	3.73 (0.87)	3.66 (0.82)	3.35 (0.81)
Similarity	3.18 (0.89)	3.00 (0.94)	3.08 (1.07)	3.13 (1.03)	3.10 (0.98)	3.01 (0.86)
Conflict	1.39 (0.45)	1.52 (0.58)	1.70 (0.61)	1.63 (0.64)	1.56 (0.58)	2.20 (0.70)
Antagonism	1.59 (0.68)	1.73 (0.83)	1.87 (0.85)	1.79 (0.85)	1.75 (0.80)	2.11 (0.84)
Competition	1.14 (0.33)	1.13 (0.31)	1.31 (0.54)	1.21 (0.50)	1.21 (0.43)	2.19 (0.93)
Dominance	1.28 (0.43)	1.55 (0.78)	1.64 (0.70)	1.65 (0.77)	1.52 (0.69)	2.07 (0.72)
Quarrelling	1.59 (0.71)	1.72 (0.86)	2.04 (0.87)	1.93 (0.89)	1.82 (0.84)	2.45 (0.82)
Rivalry	0.53 (0.58)	0.46 (0.61)	0.59 (0.70)	0.71 (0.69)	0.57 (0.64)	0.70 (0.60)
Maternal	3.09 (0.90)	3.14 (0.76)	3.00 (0.76)	3.04 (0.84)	3.07 (0.81)	0.72 (0.59)
Paternal	3.17 (0.82)	3.22 (0.79)	2.81 (0.88)	2.89 (1.04)	3.02 (0.89)	0.66 (0.64)

Quality of Life

Results of the WHOQOL-BREF. Scores are presented for sibling gender and position (older brother (OB), younger brother (YB), older sister (OS), younger sister (YS)), and in total numbers (total siblings(T)).

	OB N=42 <i>mean (SD)</i>	YB N=39 <i>mean (SD)</i>	OS N=44 <i>mean (SD)</i>	YS N=32 <i>mean (SD)</i>	Total N=157 <i>mean (SD)</i>
Physical Domain	87.24 (13.84)	81.41 (17.24)	78.32 (17.43)	75.33 (17.31)	80.8(16.9)
Psychological Domain	63.59 (10.41)	61.53 (9.81)	57.10 (9.90)	53.77 (14.79)	59.2 (11.7)
Social Domain	77.97 (15.15)	67.52 (20.83)	69.69 (18.51)	64.06 (18.98)	70.2 (18.9)
Environment Domain	81.69 (14.97)	78.20 (16.72)	73.65 (14.78)	70.01 (18.69)	76.2 (16.6)

Experience of Care giving

Results of the Experience of Caregiving Inventory (ECI). Scores are presented for sibling gender and position (older brother (OB), younger brother (YB), older sister (OS), younger sister (YS)), and in total numbers (total siblings(T))

	OB N=42	YB N=39	OS N=44	YS N=32	Total N=157
<i>mean (SD)</i>					
Difficult behaviours	12.73 (5.76)	16.84 (8.30)	16.95 (7.56)	16.75 (7.82)	15.75 (7.53)
Negative symptoms	12.61 (6.40)	12.23 (5.91)	15.25 (6.17)	14.31 (6.80)	13.60 (6.37)
Stigma	10.07 (4.59)	11.76 (5.60)	10.97 (3.37)	12.28 (5.35)	11.19 (4.76)
Problems with services	10.02 (3.71)	10.30 (3.89)	12.22 (5.77)	12.46 (4.99)	11.21 (4.76)
Effects on family	11.54 (5.09)	12.25 (5.67)	13.04 (4.87)	14.34 (6.65)	12.71 (5.56)
Need to back up	9.16 (3.58)	9.25 (3.10)	10.88 (4.42)	11.25 (5.03)	10.09 (4.12)
Dependency	8.59 (3.60)	7.94 (3.74)	10.18 (4.64)	10.68 (4.26)	9.30 (4.19)
Loss	12.90 (6.20)	12.76 (5.17)	13.75 (4.89)	16.37 (7.19)	13.81 (5.94)
Positive experiences	13.21 (6.34)	12.69 (6.03)	16.68 (7.04)	17.56 (6.77)	14.94 (6.82)
Good aspects	14.88 (5.32)	14.38 (4.78)	15.72 (4.86)	18.06 (5.43)	15.64 (5.21)
Total negative score	87.62 (4.70)	93.30 (5.30)	103.24 (4.86)	108.4 (6.10)	97.66 (5.30)
Total positive score	28.09 (1.55)	27.07 (1.30)	32.40 (1.45)	35.6 (1.53)	30.58 (1.52)

Impact of events

Results of the Impact of Events Scale-Revised (IES-R) (Weiss & Marmar, 1997). Scores are presented for sibling gender and position (older brother (OB), younger brother (YB), older sister (OS), younger sister (YS)), and in total numbers (total siblings (T))

	OB N=42	YB N=39	OS N=44	YS N=32	T N=157
<i>mean (SD)</i>					
Avoidance	1.28 (0.39)	1.65 (0.83)	1.17 (0.91)	1.75 (0.77)	1.59 (0.77)
Intrusions	1.18 (0.32)	1.51 (0.79)	1.59 (0.78)	1.67 (0.66)	1.48 (0.68)
Hyperarousal	1.17 (0.28)	1.54 (0.90)	1.46 (0.73)	1.69 (0.90)	1.45 0.75)

Research Question 4: Are there specific characteristics of early psychosis that are associated with a less warm sibling relationship?

The impact of the characteristics of early psychosis upon the self assessed warmth within the sibling relationship (ASRQ)

Warmth	Mean (SD)	(95%CI)	p	eta squared
Dyads			0.356	0.020
Older Brother N=42	3.37 (0.80)	3.12-3.62		
Younger Brother N=39	3.08 (0.91)	2.78-3.37		
Older Sister N=44	3.29 (0.97)	2.99-3.59		
Younger Sister N=32	4.43 (0.94)	3.09-3.77		
Suicide Attempts			0.131	0.014
Yes N = 45	3.11 (1.05)	2.80-3.43		
No N = 112	3.36 (0.84)	3.20-3.51		
Divorce			0.137	-0.019
Yes N = 69	3.17 (0.99)	2.93-3.40		
No N = 88	3.38 (0.83)	3.21-3.56		
Persisting Psychosis			0.001	-0.058
Yes N = 88	3.03 (0.86)	2.84-3.21		
No N = 69	3.62 (0.87)	3.41-3.83		
Duration of untreated psychosis (months)			0.016	0.052
1-6 N = 42	3.49 (0.86)	3.22- 3.76		
7-12 N = 61	3.03 (0.93)	2.79- 3.27		
≥13 N =54	3.42 (0.86)	3.19- 3.67		
History of violence			0.001	-0.083
Yes N = 15	2.09 (0.91)	1.60-2.58		
No N = 142	3.42 (0.80)	3.29-3.56		
Compliance			0.005	0.050
Yes N = 124	3.39 (0.88)	3.24-3.55		
No N = 33	2.89 (0.92)	2.56-3.22		
Persisting drug use			0.001	-0.058
Yes N = 42	2.80 (0.94)	2.50-3.09		
No N = 115	3.47 (0.83)	3.31-3.62		
Living with ill brother or sister			0.324	0.006
Yes N = 92	3.35 (0.91)	3.16-3.54		
No N = 65	3.20 (0.90)	2.98-3.43		
Number of admissions			0.001	0.114
0 N = 41	3.37 (0.77)	3.13-3.62		
1 N = 49	3.62 (0.79)	3.39-3.85		
2 N = 36	3.19 (1.04)	2.84-3.54		
≥3 N = 31	2.76 (0.86)	2.45-3.07		

Correlations of results of other questionnaire with warmth domain within the sibling relationship (ASRQ)

Warmth	Mean (SD)	p	r
Knowledge of Psychosis Questionnaire	17.76 (3.51)	0.015	-0.194
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.437
Total Positive Score	4.47 (1.52)	0.000	0.347
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.002	-0.245
Intrusions	1.48 (0.68)	0.002	-0.247
Hyperarousal	1.45 (0.75)	0.004	-0.230
WHOQOL-Bref			
Physical domain	80.86 (16.89)	0.001	0.321
Psychological domain	59.26 (11.67)	0.001	0.300
Social domain	70.22 (18.92)	0.001	0.454
Environment domain	76.19 (16.60)	0.001	0.334

The ten subscales of The Experience of Caregiving Inventory (ECI)

	Warmth	
	r	p
Difficult behaviours	-0.63	0.001
Negative symptoms	-0.51	0.001
Stigma	-0.42	0.001
Problems with services	-0.14	0.700
Effects on family	-0.39	0.001
Need to back up	-0.19	0.120
Dependency	-0.39	0.623
Loss	-0.24	0.002
Positive personal experiences	0.72	0.371
Good aspects of relationship	0.54	0.001

The impact of the characteristics of early psychosis upon the self assessed conflict domain within the sibling relationship (ASRQ)

Conflict	Mean (SD)	(95%CI)	p	eta squared
Dyad			0.081	0.04
Older Brother	1.39 (0.45)	1.25-1.53		
Younger Brother	1.52 (0.58)	1.33-1.71		
Older Sister	1.70 (0.61)	1.51-1.89		
Younger Sister	1.63 (0.64)	1.40-1.87		
Total	1.56 (0.58)	1.47-1.65		
Suicide Attempts			0.001	0.08
Yes N = 45	1.83 (0.64)	1.63-2.02		
No N = 112	1.45 (0.52)	1.36-1.55		
Divorce			0.046	0.02
Yes N = 69	1.66 (0.60)	1.52-1.81		
No N = 88	1.48 (0.55)	1.36-1.60		
Persisting Psychosis			0.018	0.03
Yes N = 88	1.66 (0.61)	1.52-1.79		
No N = 69	1.44 (0.51)	1.32-1.56		
Duration of untreated psychosis (months)			0.14	0.02
1-6 N = 42	1.49 (0.55)	1.31-1.66		
7-12 N = 61	1.50 (0.51)	1.37-1.63		
>13 N = 54	1.69 (0.66)	1.51-1.87		
History of violence			0.001	0.33
Yes N = 15	2.41 (0.54)	2.11-2.71		
No N = 142	1.47 (0.51)	1.39-1.56		
Compliance			0.244	0.008
Yes N = 124	1.53 (0.58)	1.43-1.64		
No N = 33	1.67 (0.55)	1.47-1.86		
Persisting drug use			0.005	0.04
Yes N = 42	1.77 (0.65)	1.57-1.98		
No N = 115	1.48 (0.53)	1.38-1.58		
Living with ill brother or sister			0.296	0.007
Yes N = 92	1.52 (0.58)	1.40-1.65		
No N = 65	1.62 (0.57)	1.48-1.76		
Number of admissions			0.16	0.03
0 N = 41	1.58 (0.54)	1.40-1.75		
1 N = 49	1.50 (0.56)	1.33-1.66		
2 N = 36	1.46 (0.54)	1.28-1.64		
>3 N = 31	1.76 (0.67)	1.51-2.00		

Correlations of results of other questionnaire with conflict domain within the sibling relationship (ASRQ)

Conflict	Mean (SD)	p	r
Knowledge of Psychosis Questionnaire	17.76 (3.51)	0.025	0.179
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	0.605
Total Positive Score	4.47 (1.52)	0.000	0.319
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	0.390
Intrusions	1.48 (0.68)	0.000	0.444
Hyperarousal	1.45 (0.75)	0.000	0.473
WHOQOL-Bref			
Physical domain	80.86 (16.89)	0.001	-0.420
Psychological domain	59.26 (11.67)	0.005	-0.224
Social domain	70.22 (18.92)	0.001	-0.387
Environment domain	76.19 (16.60)	0.001	-0.511

The ten subscales of The Experience of Caregiving Inventory (ECI)

	Conflict	
	r	p
Difficult behaviours	0.626	0.001
Negative symptoms	0.418	0.001
Stigma	0.358	0.001
Problems with services	0.571	0.001
Effects on family	0.568	0.001
Need to back up	0.532	0.001
Dependency	0.457	0.001
Loss	0.335	0.001
Positive personal experiences	0.512	0.001
Good aspects of relationship	0.056	0.485

The impact of the characteristics of early psychosis upon the self assessed rivalry domain within the sibling relationship (ASRQ)

Rivalry	Mean (SD)	(95%CI)	p	eta squared
Dyads			0.440	0.01
Older Brother	0.53 (0.58)	0.35-0.71		
Younger Brother	0.46 (0.61)	0.26-0.66		
Older Sister	0.59 (0.70)	0.38-0.81		
Younger Sister	0.71 (0.69)	0.46-0.96		
Total	0.57 (0.64)	0.47-0.67		
Suicide Attempts			0.001	0.07
Yes N = 45	0.83 (0.67)	0.63-1.04		
No N = 112	0.46 (0.60)	0.35-0.58		
Divorce			0.228	0.0009
Yes N = 69	0.64 (0.70)	0.47-0.81		
No N = 88	0.51 (0.59)	0.58-0.64		
Persisting Psychosis			0.028	0.03
Yes N = 88	0.67 (0.67)	0.53-0.81		
No N = 69	0.44 (0.59)	0.30-0.58		
Duration of untreated psychosis (months)			0.019	0.05
1-6 N = 42	0.41 (0.59)	0.23-0.60		
7-12 N = 61	0.75 (0.71)	0.56-0.93		
>13 N = 54	0.49 (0.57)	0.33-0.64		
History of violence			0.001	0.20
Yes N = 15	1.30 (0.66)	0.99-1.71		
No N = 142	0.48 (0.59)	0.39-0.58		
Compliance			0.059	0.02
Yes N = 124	0.51 (0.60)	0.40-0.62		
No N = 33	0.79 (0.76)	0.52-1.06		
Persisting drug use			0.009	0.04
Yes N = 42	0.81 (0.73)	0.59-1.04		
No N = 115	0.48 (0.59)	0.37-0.59		
Living with ill brother or sister			0.129	0.01
Yes N = 92	0.50 (0.59)	0.38-0.62		
No N = 65	0.66 (0.70)	0.49-0.84		
Number of admissions			0.004	0.08
0 N = 41	0.36 (0.53)	0.19-0.53		
1 N = 49	0.47 (0.58)	0.30-0.64		
2 N = 36	0.67 (0.62)	0.46-0.89		
>3 N = 31	0.87 (0.79)	0.58-1.17		

Correlations of results of other questionnaire with rivalry domain within the sibling relationship (ASRQ)

Rivalry	Mean (SD)	p	r
Knowledge of Psychosis Questionnaire	17.76 (3.51)	0.065	0.418
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	0.486
Total Positive Score	4.47 (1.52)	0.355	-0.074
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	0.285
Intrusions	1.48 (0.68)	0.000	0.350
Hyperarousal	1.45 (0.75)	0.000	0.322
WHOQOL-Bref			
Physical domain	80.86 (16.89)	0.001	-0.324
Psychological domain	59.26 (11.67)	0.001	-0.314
Social domain	70.22 (18.92)	0.001	-0.429
Environment domain	76.19 (16.60)	0.001	-0.457

The ten subscales of The ECI

	Rivalry	
	r	p
Difficult behaviours	0.563	0.001
Negative symptoms	0.402	0.001
Stigma	0.418	0.001
Problems with services	0.211	0.008
Effects on family	0.481	0.001
Need to back up	0.283	0.001
Dependency	0.233	0.003
Loss	0.374	0.001
Positive personal experiences	0.110	0.171
Good aspects of relationship	-0.238	0.003

Research Question 5: Are there specific characteristics of early psychosis that are associated with lower satisfaction of quality of life for a sibling?

The impact of the characteristics of early psychosis upon the self assessed physical domain within the sibling quality of life

Physical domain	Mean (SD)	(95%CI)	p	eta squared
Dyads			0.014	0.07
Older Brother N=42	87.24 (13.84)	82.93-91.55		
Younger Brother N=39	81.41 (17.24)	75.81-87.00		
Older Sister N=44	78.32 (17.43)	73.02-83.62		
Younger Sister N=32	75.33 (17.31)	69.09-81.57		
Suicide Attempts			0.025	0.03
Yes N = 45	76.11 (16.29)	71.21-81.00		
No N = 112	82.78 (16.82)	79.63-85.93		
Divorce			0.777	0.05
Yes N = 69	80.43 (17.20)	76.30-84.55		
No N = 88	81.20 (16.73)	77.66-84.75		
Persisting Psychosis			0.158	0.01
Yes N = 88	79.18 (17.05)	75.56-82.79		
No N = 69	83.02 (16.55)	79.04-86.99		
Duration of untreated psychosis (mths)			0.767	0.01
1-6 N = 42	81.97 (19.15)	76.00-87.94		
7-12 N = 61	81.26 (16.87)	76.94-85.58		
>13 N = 54	79.56 (15.19)	75.41-83.70		
History of violence			0.004	0.05
Yes N = 15	69.04 (19.68)	58.14-79.94		
No N = 142	82.11 (16.14)	79.43-84.79		
Compliance			0.104	0.01
Yes N = 124	81.99 (16.64)	79.04-84.95		
No N = 33	76.67 (17.40)	70.45-82.79		
Persisting drug use			0.093	0.01
Yes N = 42	77.12 (17.33)	71.72-82.52		
No N = 115	82.23 (16.59)	79.17-85.30		
Living with ill brother or sister			0.754	0.006
Yes N = 92	80.51 (17.92)	76.79-84.22		
No N = 65	81.37 (15.43)	77.54-85.19		
Number of admissions			0.351	0.02
0 N = 41	79.35 (19.48)	73.20-85.50		
1 N = 49	83.96 (15.85)	79.41-88.51		
2 N = 36	81.34 (15.79)	76.00-86.69		
>3 N = 31	77.41 (15.90)	71.58-83.25		

Correlations of results of other questionnaire with the physical domain of quality of life (WHOQOL-Bref)

Physical	Mean (SD)	p	r
Knowledge of Psychosis Questionnaire	17.76 (3.51)	0.043	-0.162
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.477
Total Positive Score	4.47 (1.52)	0.026	-0.178
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	-0.350
Intrusions	1.48 (0.68)	0.000	-0.397
Hyperarousal	1.45 (0.75)	0.000	-0.443

The ten subscales of The Experience of Caregiving Inventory (ECI)

	Physical Domain	
	r	p
Difficult behaviours	-0.427	0.001
Negative symptoms	-0.385	0.001
Stigma	-0.276	0.001
Problems with services	-0.364	0.001
Effects on family	-0.375	0.001
Need to back up	-0.382	0.001
Dependency	-0.444	0.001
Loss	-0.352	0.001
Positive personal experiences	-0.323	0.001
Good aspects of relationship	0.006	0.943

The impact of the characteristics of early psychosis upon the self assessed psychological domain within the sibling quality of life

Psychological domain	Mean (SD)	(95%CI)	p	eta squared
Dyads			0.001	0.10
Older Brother N=42	63.59 (10.41)	60.34-66.83		
Younger Brother N=39	61.53 (9.81)	58.35-64.72		
Older Sister N=44	57.10 (9.90)	54.08-60.11		
Younger Sister N=32	53.77 (14.79)	48.44-59.10		
Suicide Attempts			0.027	0.03
Yes N = 45	56.01 (12.79)	52.17-59.86		
No N = 112	60.56 (10.98)	58.50-62.62		
Divorce			0.163	0.01
Yes N = 69	57.78 (11.09)	55.12-60.45		
No N = 88	60.41 (12.05)	57.86-62.97		
Persisting Psychosis			0.436	0.003
Yes N = 88	58.61 (11.35)	56.21-61.02		
No N = 69	60.08 (12.11)	57.17-62.99		
Duration of untreated psychosis (mths)			0.482	0.009
1-6 N = 42	61.11 (10.95)	57.69-64.52		
7-12 N = 61	58.40 (13.33)	54.98-61.81		
>13 N = 54	58.79 (10.16)	56.02-61.57		
History of violence			0.030	0.02
Yes N = 15	53.05 (11.83)	46.50-59.60		
No N = 142	59.91 (11.50)	58.00-61.82		
Compliance			0.352	0.005
Yes N = 124	59.71 (11.34)	57.69-61.72		
No N = 33	57.57 (12.90)	53.00-62.15		
Persisting drug use			0.151	0.01
Yes N = 42	57.04 (11.40)	53.49-60.59		
No N = 115	60.07 (11.77)	57.90-62.23		
Living with ill brother or sister			0.666	0.001
Yes N = 92	59.60 (12.97)	56.95-62.25		
No N = 65	58.78 (9.96)	56.31-61.25		
Number of admissions			0.141	0.03
0 N = 41	56.70 (13.65)	52.39-61.01		
1 N = 49	61.98 (10.08)	59.09-64.88		
2 N = 36	59.95 (9.92)	56.59-63.31		
>3 N = 31	57.52 (12.56)	52.91-62.13		

Correlations of results of other questionnaire results with psychological domain of quality of life (WHO-QOL-Bref)

Psychological	Mean (SD)	p	r
Knowledge of Psychosis Questionnaire	17.76 (3.51)	0.058	-0.152
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.334
Total Positive Score	4.47 (1.52)	0.701	0.031
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	-0.298
Intrusions	1.48 (0.68)	0.001	-0.262
Hyperarousal	1.45 (0.75)	0.001	-0.269

The ten subscales of The Experience of Caregiving Inventory (ECI)

	Psychological Domain	
	r	p
Difficult behaviours	-0.382	0.001
Negative symptoms	-0.367	0.001
Stigma	-0.258	0.001
Problems with services	-0.041	0.614
Effects on family	-0.288	0.001
Need to back up	-0.177	0.027
Dependency	-0.223	0.005
Loss	-0.244	0.002
Positive personal experiences	-0.099	0.216
Good aspects of relationship	0.152	0.058

The impact of the characteristics of early psychosis upon the self assessed social relationships domain within the sibling quality of life

Social relationships domain	Mean (SD)	(95%CI)	p	eta squared
Dyads			0.009	0.07
Older Brother	77.97 (15.15)	73.25-82.69		
Younger Brother	67.52 (20.83)	60.76-74.27		
Older Sister	69.69 (18.51)	64.06-75.32		
Younger Sister	64.06 (18.98)	57.21-70.90		
Suicide Attempts			0.018	0.03
Yes N = 45	64.62 (17.51)	59.36-69.89		
No N = 112	72.47 (19.07)	68.89-76.64		
Divorce			0.546	0.002
Yes N = 69	71.25 (16.82)	67.21-75.29		
No N = 88	69.41 (20.47)	65.07-73.75		
Persisting Psychosis			0.051	0.02
Yes N = 88	67.61 (18.92)	63.60-71.62		
No N = 69	73.55 (18.52)	69.10-78.00		
Duration of untreated psychosis (mths)			0.352	0.01
1-6 N = 42	73.80 (16.10)	68.79-78.82		
7-12 N = 61	68.57 (21.37)	63.10-74.05		
>13 N = 54	69.29 (17.94)	64.39-74.18		
History of violence			0.002	0.06
Yes N = 15	56.11 (20.03)	45.01-67.20		
No N = 142	71.71 (18.24)	68.68-74.74		
Compliance			0.194	0.01
Yes N = 124	71.23 (18.5)	67.94-74.53		
No N = 33	66.41 (20.1)	59.27-73.55		
Persisting drug use			0.069	0.02
Yes N = 42	65.67 (19.58)	59.57-71.77		
No N = 115	71.88 (18.48)	68.46-75.29		
Living with ill brother or sister			0.036	0.02
Yes N = 92	67.57 (19.66)	63.49-71.64		
No N = 65	73.97 (17.27)	69.69-78.25		
Number of admissions			0.183	0.03
0 N = 41	69.91 (20.23)	63.53-76.30		
1 N = 49	74.65 (17.17)	69.72-79.59		
2 N = 36	68.51 (18.37)	62.30-74.73		
>3 N = 31	65.59 (19.80)	58.32-72.85		

Correlations of results of other questionnaire results with social domain of quality of life (WHO-QOL-Bref)

Social	Mean (SD)	p	r
Knowledge of Psychosis Questionnaire	17.76 (3.51)	0.049	-0.158
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.486
Total Positive Score	4.47 (1.52)	0.540	0.049
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	-0.372
Intrusions	1.48 (0.68)	0.000	-0.391
Hyperarousal	1.45 (0.75)	0.000	-0.423

The ten subscales of The Experience of Caregiving Inventory (ECI)

	Social Domain	
	r	p
Difficult behaviours	-0.512	0.001
Negative symptoms	-0.397	0.001
Stigma	-0.456	0.001
Problems with services	-0.193	0.016
Effects on family	-0.439	0.001
Need to back up	-0.298	0.001
Dependency	-0.323	0.001
Loss	-0.347	0.002
Positive personal experiences	-0.125	0.118
Good aspects of relationship	0.209	0.008

The impact of the characteristics of early psychosis upon the self assessed environment domain within the sibling quality of life

Environment domain	Mean (SD)	(95%CI)	p	eta squared
Dyads			0.013	0.07
Older Brother N=42	81.69 (14.97)	77.00-86.36		
Younger Brother N=39	78.20 (16.72)	72.78-83.62		
Older Sister N=44	73.65 (14.78)	69.15-78.14		
Younger Sister N=32	70.01 (18.69)	63.27-76.76		
Suicide Attempts			0.015	0.03
Yes N = 45	71.11 (15.47)	66.46-75.75		
No N = 112	78.23 (16.66)	75.11-81.35		
Divorce			0.312	0.006
Yes N = 69	74.68 (17.53)	70.47-78.89		
No N = 88	77.37 (15.83)	74.02-80.73		
Persisting Psychosis			0.076	0.02
Yes N = 88	74.11 (15.66)	70.79-77.43		
No N = 69	78.84 (17.48)	74.64-83.04		
Duration of untreated psychosis (months)			0.878	0.001
1-6 N = 42	76.93 (17.6)	71.43-82.44		
7-12 N = 61	76.48 (17.3)	72.05-80.44		
>13 N = 54	75.28 (15.1)	71.16-79.42		
History of violence			0.001	0.06
Yes N = 15	61.66 (15.05)	53.32-70.00		
No N = 142	77.72 (16.05)	75.06-80.39		
Compliance			0.100	0.01
Yes N = 124	77.31 (16.61)	74.36-80.27		
No N = 33	71.96 (16.09)	66.26-77.67		
Persisting drug use			0.083	0.02
Yes N = 42	72.39 (17.04)	67.08-77.70		
No N = 115	77.58 (16.29)	74.57-80.59		
Living with ill brother or sister			0.719	0.0008
Yes N = 92	76.59 (17.4)	72.98-80.20		
No N = 65	75.62 (15.4)	71.79-79.45		
Number of admissions			0.371	0.02
0 N = 41	76.90 (15.68)	71.95-81.85		
1 N = 49	78.76 (18.05)	73.57-83.94		
2 N = 36	75.34 (14.09)	70.57-80.11		
>3 N = 31	72.17 (17.97)	65.58-78.77		

Correlations of results of other questionnaire results with environment domain of quality of life (WHO-QOL-Bref)

Environment	Mean (SD)	p	r
Knowledge of Psychosis Questionnaire	17.76 (3.51)	0.043	-0.162
Experience of Caregiving Inventory:			
Total Negative Score	15.21 (5.29)	0.000	-0.508
Total Positive Score	4.47 (1.52)	0.033	-0.170
Impact of Events – Revised			
Avoidance	1.59 (0.77)	0.000	-0.353
Intrusions	1.48 (0.68)	0.000	-0.406
Hyperarousal	1.45 (0.75)	0.000	-0.416

The ten subscales of The Experience of Caregiving Inventory (ECI)

	Environment Domain	
	r	p
Difficult behaviours	-0.458	0.001
Negative symptoms	-0.393	0.001
Stigma	-0.333	0.001
Problems with services	-0.387	0.001
Effects on family	-0.447	0.001
Need to back up	-0.382	0.001
Dependency	-0.437	0.001
Loss	-0.361	0.001
Positive personal experiences	-0.337	0.001
Good aspects of relationship	0.033	0.680

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