A NARRATIVE INQUIRY INTO THE EXPERIENCES OF
ADULT CHILDREN OF PARENTS WITH
SERIOUS MENTAL ILLNESS

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ABSTRACT

Children of parents with mental illness (COPMI) are a substantial, yet until quite recently, marginalised group within society. Whilst extensive empirical research has been conducted into their risk for adverse psychosocial outcomes as well as potential for resilience, there has been relatively little focus on their personal experiences and understandings of such experiences. In recent years, national and international mental health service policies and guidelines for service provision have been developed to address the specific needs of families and children where parents have mental illness, including serious mental illnesses such as schizophrenia and bipolar disorder. These policies and related service provision guidelines have appropriately focused health professionals’ attention on the needs and importance of prevention and early intervention for COPMI.

There has not, however, been an associated focus on the needs and experiences of adult children of parents with mental illness (ACOPMI), who have remained significantly marginalised in respect to policy and mental health service provision whilst also demonstrating an increased risk for psychosocial adversity yet potential for resilience. Thus, there has been a gap in knowledge of the experiences of adult children with parents who have mental illness, and their needs have not been served adequately.

This narrative inquiry set out to extend the limited understandings of the needs and experiences of adult children of parents with serious mental illnesses (ACOPSMI) such as schizophrenia and major depression. These illnesses have been recognised through research as having potential for long-term and often adverse impacts on children. A lengthy unstructured narrative interview and member check process was conducted with nine ACOPSMI in Australia over a nine month period. The inclusion of the researcher’s experience through the use of auto-ethnography resulted in a total of ten participants in the study.
Postmodern assumptions have provided a framework for this inquiry and so in this thesis multiplicity, diversity and attending to the voices of those on the margins have been privileged. In order to identify the concerns of ACOPSMI using methods that allowed their voices and stories to be heard from multiple perspectives, a dual analytic process was developed. As per Lather’s (1997) recommendation of doing a ‘double science’, a conventional or realist interpretation of participants’ experiences was initially performed. Field texts were analysed according to van Manen’s (1990) interpretive phenomenological thematic approach. This initial analytic phase sought to develop and build upon the existing literature which had used similar approaches. In order to thicken interpretations and add a fresh dimension to conventional understandings, the postmodern or alternate story of their experiences was then illuminated through a postmodern narrative analysis. This approach employed an analytic framework developed from the work of several other postmodern and/or narrative writers.

From the initial analysis, four phenomenological themes of participants’ experiences were uncovered. Consistent with previous literature, these adult children experienced a number of difficulties in growing up with parents with serious mental illness, including assuming responsibility for their parent and family, experiencing negative emotional impacts and developing their own mental health problems, and finding it challenging to connect emotionally with their parents and others. They also, however, demonstrated considerable resilience and effective ways of coping with their experience which assisted many of them to forge productive lives and overcome negative impacts of their past.

This thesis discusses these participants’ experiences from both conventional and alternate perspectives, as well as addressing the inter-textuality of meanings that may be found between the spaces of such findings. In the light of participants’ experiences, recommendations have been developed for health professionals’ practice which seek to inform and guide them in working with adult children and families where parents have serious mental illness.
STATEMENT OF ORIGINALITY

This work has not previously been submitted for a degree or diploma in any university.

To the best of my knowledge and belief, the thesis contains no material
previously published or written by another person
except where due reference is made in the thesis itself.

..........................................................
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GLOSSARY OF TERMS AND ABBREVIATIONS

ACOPMI  Adult Children of Parents with Mental Illness. A broad term encompassing all forms of mental illness

ACOPSMI  Adult Children of Parents with Serious Mental Illness. A specific term referring to serious and often long-standing mental illnesses such as schizophrenia, bipolar disorder, and major depression.

COPMI  Children of Parents with Mental Illness. A broad term encompassing all forms of mental illness

COPSMI  Children of Parents with Serious Mental Illness. A specific term referring to serious and often long-standing mental illnesses such as schizophrenia, bipolar disorder, and major depression.

Narrative  the structure, knowledge and skills needed in order to construct and tell a story

PMI  Parental Mental Illness

Story  a re-presentative account of peoples’ experiences and actions
FORMATS AND STYLES USED IN THIS THESIS

This study is informed by postmodern theoretical assumptions and concepts, and as such, emphasises multivocity, values multiplicity and difference, and privileges alternative representations. Subsequently, I have used a variety of writing styles throughout the thesis to re-present scholarly, personal and creative aspects of this work. In the spirit of postmodern bricolage, I have constructed the thesis within an eclectic musical and poetic pastiche where each chapter is introduced with musical lyrics or a poetic excerpt which I have used to re-present various aspects of the topic and discussed in terms of the chapter content. Throughout the thesis, auto-ethnographic stories and reflexive accounts at times also interrupt scholarly writing. I have chosen two main font styles to differentiate the various genres.

Musical lyrics, poetry, reflexive accounts, and reflective writing have been written using Century Gothic 11 pt normal font, and auto-ethnographic writing is in Century Gothic 11 pt italics. All other scholarly writing is in Times New Roman 12 pt normal font.

Three ellipsis points (…) indicate that material has been omitted from direct quotes from the literature, from musical lyrics, and from interview and other field text.

*Italics* have been used to denote quotes from participants.

‘Single inverted commas’ have been used to re-present words I acknowledge as having multiple meanings or with which I have some query, or to indicate words or phrases used in non-conventional ways. They are also used to indicate the name of published and unpublished works within the text.

Hyphens ( - ) have been used with particular words and terms in recognition that this may inscribe different meanings, and in acknowledgement there is more than one way these words can be interpreted. Forward slashes ( / ) have also been used between some words to acknowledge the potential multiplicity of what is often written as singular.
CHAPTER 1
SOUND/S OF SILENCE – AN INTRODUCTION

Musical lyrics removed for online publishing due to copyright
Reflecting on the Sound/s of Silence

Art Garfunkel, Paul Simon’s musical collaborator, has described the theme of their 1964 hit song as being about peoples’ lack of ability to communicate with each other. He said he found his own meanings within the lyrics, but the words within it were shared to tell us as readers and listeners that when meaningful communication fails the only sound left is silence. Garfunkel (1964) suggested that as with most pieces of work, the interpretation of the lyrics and the ending of the song were best left to each reader or listener to define themselves. As a postmodern writer, I know you will determine your own reading/s and meaning/s within the information, stories and interpretations presented and re-presented within the following chapters, and invite you to join me on the following personal and research journey.

I have chosen this beautiful and haunting song to re-present a number of aspects of this first chapter, and to preface the work within this thesis, along with the many overlapping, sometimes competing, but always, I hope, evocative stories it contains. As a postmodern writer, I have imposed my own interpretation and altered the meaning somewhat of the title ‘Sound of silence’ by adding the /s to ‘sound’, as to me this more fully re-presents the many and diverse sounds of silence that have surrounded the issue of children and adult children of parents with serious mental illness. I believe we have been silent, and silenced, within a society that is often uneasy with notions of mental illness, and has historically not encouraged mental health consumers themselves, let alone family members such as children, to share their experiences in a forthright and open manner without fear of judgment or reprisal.

In their song, Garfunkel (1964) contended that Simon used linguistic metaphors such as the ‘neon sign’ to re-present the superficial nature of much of the communication between people, where the result was a lack of depth of understanding between them because there had never been any meaningful communication in the first place – hence Simon’s evocative poetry of ‘people talking without speaking, and hearing without listening’.

People who don’t dare to reach out and disturb the sound/s of silence by sharing their experiences and communicating about them in ways that may be meaningful to others can be seen to contribute to the maintenance of the silences, and so the ‘silence like a cancer grows’. In conducting this research, writing this thesis, and sharing my research
and personal journey along the way with many others through written publications, conference presentations, and over countless cups of coffee in a variety of settings, I have dared to intrude upon what I hope will become apparent throughout this work as the potentially malignant continuation of the sound/s of silence surrounding the experiences of adult children of parents with serious mental illness. In doing so I aim to give further voice to an issue which has been mired in often pain-ful, yet potentially hope-ful, silences.
1.1 DISTURBING THE SOUND/S OF SILENCE

Hello darkness, my old friend,
I've come to talk with you again,
Because a vision softly creeping,
Left its seeds while I was sleeping,
And the vision that was planted in my brain
Still remains
Within the sound of silence...

It’s the autumn of 2000 and I’m sitting at my desk at work one afternoon, chatting on the phone to Mary - my friend and former colleague. “By the way, how’s your mum going?” she says. “Oh, she’s fine - doing well at the moment. I talked with her case manager recently – but, you know – all she wants to talk about is how I can help mum! There’s never any mention of how I’m going, or any recognition of how having a mother with paranoid schizophrenia might have affected me. It’s always what I can do for her,” I reply.

Mary listens patiently to my complaint and then in her familiar dry manner responds with, “well Kim, maybe there’s a phd in that”.

This is not as strange a reply as it may first seem. Mary, knowing I had been contemplating starting my doctorate, had just highlighted a potential topic area. I put the phone down and thought about it. How strange. I’d been searching around for some time for a topic that was relevant to my work as a lecturer in psychiatric mental health nursing, which I could sustain a motivation for and interest in for the usual five or so years part-time, and that had not been researched in any extensive manner by anyone else. Maybe there’d been one all along, staring me literally and metaphorically ‘in the face’, yet not being seen at all. I’d never even contemplated until this moment that my own background would contain anything worthy of a doctoral research project.

With my interest piqued I started searching the literature. The more I searched the databases, the more excited I became. Maybe there was a research project in this! No-one seemed to have done much research on the topic at all – no-one to that point in time seemed to have been very interested in exploring the experiences of children or adult children of a parent with a psychotic mental illness – adult children such as me, who every day lived with a history that was unlike so many others, and yet like some others, and who had a past that not everyone could understand. It was a past that was
not really suitable for polite dinner conversations, that could not be talked about in any depth with strangers or acquaintances, and that I’d only divulged to a few select friends who worked in the mental health field and who I trusted would not judge me or automatically think me weird for having had such a ‘different’ childhood. It was a past I had largely kept silent about for fear that others would think less of me if I revealed it and because of the shame I felt about the circumstances of my upbringing. Yet it was also a past that had been instrumental in shaping my future, my very sense of ‘self’, my career choice, my relationships with family, friends and partners, and the parenting of my own child. The more I thought about this, and the more information I found about the various effects of parental mental illness on the developing child, the more I saw the potential significances of re-searching into this area. I started to realise this was a topic certainly worthy of a doctoral research project.

This thesis contains my story – along with the stories of other grown children whose parents have had a serious mental illness. The thesis also chronicles the story of the research process that resulted in the finding, interpreting, and re-telling of the experiences generously shared by the participants. We share these stories with you so that the experiences of being the adult child a parent with serious mental illness may be further illuminated, and so that others may, in the sharing of our stories, come to more fully understand and respect experiences such as ours. We also share them with the aim of increasing recognition of, and attention to, the needs of adult children and families where parents have a mental illness, so that health and other professionals working with us may be informed in their provision of effective support for families where parents have, or have had, a serious mental illness.

1.2 LOCATING THE CHOICES OF RE-PRESENTATION, METHODOLOGY AND FRAMEWORK FOR THIS THESIS

Throughout this thesis I have purposefully chosen to use experimental, or evocative, writing to re-present my personal voice alongside use of the more conventional formal scholarly voice. This is for a number of reasons. This thesis uses the methodology of narrative inquiry, which is explained simply by Clandinin and Connelly as being “stories lived and told” (2000, p.18). The method of auto-ethnography has also been used to locate my ‘self’ and experiences as the starting point of the research, as my own story as an adult child of a mother with schizophrenia cannot be separated from that of the
Chapter 1

A postmodern framework is the theoretical lens through which this method, along with the writing, methodology, and interpretive aspects of the thesis, is viewed and re-presented. This perspective emphasises local accounts and stories, attends to ‘difference’, is concerned with the multiple nature of ‘reality’, and recognises the importance of language as a medium for the social construction of what may be considered truth (Cheek, 2000). These and other postmodern assumptions have guided the conduct and writing of the study and thesis, and can be seen threaded throughout the following chapters.

Accordingly, I have purposefully ‘messed up’ the reading of the thesis by interweaving diverse writing genres within and between each other. This is done in an attempt to more fully re-present the personal experiences and research processes in their ‘messy’ form rather than as a sanitised and linear, ‘tidy’, and orderly account. The ‘messy’ text is one that recognises reality is socially constructed and that writing is a method which structures this reality. A ‘messy’ text is multi-voiced and inter-textual and recognises the various narrative devices it contains. This is a text that does not seek to impose meaning on the reader, but provides an opportunity for multiple interpretations (Denzin, 1997).

In using a messy text, the following research and personal experience stories may be seen to unfold in a manner that also acknowledges their temporal nature, as in narrative inquiry events and experiences may be seen as located over time and with a past, an apparent present, and an implied future (Clandinin & Connelly, 2000). Yet I fully acknowledge that the research thesis is always an interpretation of such experiences and...
processes, and no matter how much I aim to re-present the stories within it as ‘messy’, the final result is inevitably an incomplete and constructed re-presentation of the research undertaken.

Similarly to Camden-Pratt (2002), I have also ‘worked the hyphen’ (Fine 1994) with some words and terms throughout the thesis, in a conscious acknowledgement of the complex and inter-subjective nature of the interaction between ‘self’ and ‘other’ which I am describing and re-presenting. This can be seen to provide opportunity for a re-interpretation of words which may have previously held a slightly different meaning. Perhaps it will also provide an opportunity for re-interpretation for the reader. I have found the use of hyphens for selected words has illuminated a deeper understanding of Fine’s (1996) arguments on the co-construction of multiple ‘selves’ and ‘others’, and Camden-Pratt’s (2002) concern with language as constitutive, with multiple meanings.

There is support within the literature for a departure from more traditional academic writing, and compelling arguments have been put forward for its use. Foley (2002) has argued persuasively for the use of ‘ordinary’ writing and a ‘highly personal’ voice within academic writing. For him this represents a conscious breaking away from formal academic writing in an effort to narrate and interpret events with a style that makes knowledge more accessible. The auto-ethnographic writing used in this thesis therefore values ordinary language over scientific language, and the use of metaphor, satire and irony to engage more fully with descriptions of life (Foley, 2002). It is an idea that resonates particularly for critical and postmodern researchers such as my ‘self’, who are interested in personal, local and alternative ways of knowing (Abma, 2002), and reflects the ‘narrative turn’ taken this century, where researchers are learning how to locate themselves differently within their writing (Denzin & Lincoln, 2000).

My use of auto-ethnographic writing can be seen as a form of resistance to my ‘self’ as researcher becoming the ‘other’. The move away from the genre of distanced, objective theoretical writing leads to a turn towards the individual and creative aspects of the researcher as instrument (Burdell & Swadener, 1999). This ‘messy’ text aims to reflexively turn objective formal writing back onto the ‘other’ of subjective writing, so
that the limitations of each are surpassed (Denzin, 1997). Evocative writing of personal experiences therefore brings forth the ‘invisible’ researcher – ‘me’ - as a subjective presence and displaces the detached mask that may be assumed in formal scholarship (Kawalilak & Dudley, 2002). In foregrounding my selves in this writing, I challenge views on silent authorship and include my own voice as another re-presentative form in research (Sparkes, 2000).

The use of subjective language that evokes emotions and responses in both the reader – ‘you’ - and the writer – ‘me’ - therefore encourages us both to reflect upon the meanings of lived human experiences (Kawalilak & Dudley, 2002). In auto-ethnography, the very act of writing becomes a way of being and knowing (Foley, 2002). Personal writing also provides an opportunity to reclaim voices that may have existed on the boundaries of academic writing and research, such as the voices of adult children of parents with a serious mental illness. Auto-ethnography is not, however, writing that is meant to be read passively. It is writing that engages you as the reader and calls for you to experience feelings (Bochner & Ellis, 1996), hence my invitation at the beginning of this chapter.

Richardson (1994), a keen advocate of experimental writing, argues that in writing evocatively on personal experience, academic research becomes more accessible to a wider public audience than that of the academic world. This idea resonates well with the tenets of modern mental health nursing, my professional discipline, where Richardson’s concepts may be seen as analogous to that of seeking to empower mental health consumers and carers through equitous provision of access to current knowledge and practices in the field of mental health. It is also synchronous with my personal view that research which has included members of the community should in return be available in an accessible form back to the very members of the community that it claims to attempt to provide benefit to; in this case, other adult children of parents with a serious mental illness.
1.2.1 The relationships between mental health nursing, qualitative inquiry and this narrative inquiry

It is recognised within the field of mental health nursing that this form of nursing emphasises the purposeful use of self, values subjectivity and the development of partnership through interpersonal relationships, and includes the ability to tolerate uncertainty and ambiguity. Mental health nursing may be seen then as having particular synchronicity with the epistemological foundations of qualitative inquiry (Chambers, 1998; Cutcliffe & Goward, 2000). Although qualitative inquiry uses multiple methods and perspectives, it is a form of inquiry that has its basis in locating participants or subjects in their natural world. This involves the qualitative researcher’s use of interpretive practices and forms of interpretation that seek to understand human experiences in terms of the meanings that may be brought to them (Denzin & Lincoln, 2000). Interpretive inquiry focuses on difference, multiplicity and multivocity, and recognises there are multiple interpretations of meaning as understanding is situated and value-laden. All interpretations are therefore constructed (Gadow, 2000). From the interpretive perspective, reality only exists within the social meanings that individuals use to account for it (Jones & Borbasi, 2003).

In mental health nursing, it can be seen that mental illness challenges a person’s sense of ‘identity’, their relationship with others and the meaning of experiences and life itself, and that the individual attempts to restore a sense of order through the use of story. Much of mental health nursing then, can be viewed as involving listening to and/or telling stories. Clients bring the stories of their lives, and how they came to be as they are, and share them with us in the hope we may be able to help them make sense of it all (Casey & Long, 2002). Nursing is an oral culture and stories may resonate as research that is meaningful and relevant to nurses. It may be argued that the richness of nursing work can be found in the highly personal and emotional stories of life as lived by clients and witnessed by nurses, where the telling of these stories may also serve to make nursing practice visible (Koch, 1998). The use of story in nursing may then reflect the intersubjective nature of the nurse-patient relationship, where neither individual is separated as object or subject, but rather, exist in connection with each other (McAllister, 2001).
The sharing of the client’s story is a privilege bestowed on the nurse, and brings with it particular responsibilities. In this context, mental health nursing requires the ability to ‘be with’ others whose emotional state is often distressed. It also requires the use of personal qualities/abilities such as empathy, warmth, respect, patience, and trustworthiness. This form of nursing may be seen to resonate well with qualitative inquiry.

Cutcliffe and Goward (2000) contend that the use of qualitative research paradigms such as narrative inquiry is particularly congruent with the philosophy of mental health nursing. They highlight the variable and fluid nature of qualitative research as being analogous to the ambiguous nature of the discipline of mental health where even the distinction between the concepts of mental health and mental illness may be unclear and subject to change. Seeking to understand nurse-client relationships and the client’s interpersonal world may also be seen as focal areas for mental health nursing inquiry (Barker, 1998), in that qualitative research enables a focus on the human experience – one of the central features of the nurse/client relationship. The nurse’s use of qualities and skills in the interpersonal relationship, central to the caring process, is also a vital focus for this form of research (Burnard & Hannigan, 2000), which, it has been argued, should be grounded in seeking to understand the meanings of what it is to be human (Chambers, 1998).

In these ways, the role of the researcher in qualitative inquiry may be viewed as synchronous to that of the mental health nurse. Both are attempting to use their selves – their thoughts, feelings, understandings and experiences, to work in partnership with others so that further understandings and meanings of the lived experience may be understood and the lives of the ‘others’ in particular, enriched. I would argue further that reflexive inquiry offers an added advantage for mental health nurses as it is a form of research where the nurse researcher’s self-identities, self-experiences, the meanings they attribute to these and the actions they take as a result, are recognised for being as legitimate a focus for research as those of research participants.

For these reasons, as a mental health nurse and adult child of a mother with schizophrenia who is also exploring the experiences of other adult children of parents with a serious
mental illness; the choice of narrative inquiry as methodology and auto-ethnography as method, within a postmodern theoretical framework, may be seen to combine synchronous personal, professional and research values and concepts to form the underlying theoretical and philosophical constructs for this research and thesis.

1.3 SITUATING THE ISSUE OF CHILDREN AND ADULT CHILDREN OF PARENTS WITH MENTAL ILLNESS

“When the mother is referred to an adult psychiatric service, it is not customary to inquire whether she is actually a parent, and even when it is asked, further questions about the current whereabouts of the children, their needs, who’s caring for them, and whether anyone has taken an interest in how the children are handling the stress, are not routinely pursued…”


Over the past few decades, the process of deinstitutionalisation has seen the care of people with serious mental illnesses such as schizophrenia and bipolar disorder shift increasingly from large psychiatric institutions into the community (Select Committee on Mental Health, 2006). This marked change to mental health service provision, combined with other factors such as the reduced impact on fertility of the second generation antipsychotic medications (Leverton, 2003), has led to growing numbers of adults with serious mental illnesses living and caring for their children in the community.

By its very nature, mental illness can be understood as a familial experience. Although an individual such as a parent may experience symptoms of mental illness and receive treatment for them, due to the inter-connected nature of families this can impact on every member of the family. Children, who are often dependent on parents for their emotional, social and physical well-being, can be among the most affected by a parent’s mental illness (Kinsella, Anderson, & Anderson, 1996). The child grows and changes within the context of living with parents and other family members, and then carries the legacy of these experiences in their continuing journey into adulthood.

Yet as the above comment by a mental health professional illustrates, in Australia, as in many other countries, children of parents with mental illness (COPMI) has until very
recent times been a neglected, albeit significant, mental health issue. It was not until the National Inquiry into the Human Rights of People with Mental Illness in 1993 (commonly referred to as ‘the Burdekin report’), that the impact of parental mental illness on children came into prominence in Australia (Burdekin, Guilfoyle & Hall, 1993). Prior to this, although from the 1920s there had been a large volume of international research into the varying impacts of parental mental illness on the developing child, there was little apparent translation of this into effective service provision for families where parents had a mental illness. This may in part have been due to a prevailing focus on addressing the needs of the individual with mental illness, rather than addressing mental illness within the broader context of the family and community (Aldridge & Becker, 1999).

Accordingly, current knowledge concerning the impacts of parental mental illness on children includes recognition that many Australian adult mental health services are only just beginning to routinely inquire as to whether their clients are parents with dependent children (Australian Infant, Child, Adolescent and Family Mental Health Association [AICAFMHA], 2001), even though various Australian surveys have identified that between 29 to 35% of clients of mental health services are women with one or more dependent children (Cowling 1999; Farrell, Handley, Hanke, Hazelton, Josephs, 1999; Hearle, Plant, Jenner, Barkla, McGrath, 1999). Research into the potential effects of parental mental illness on children and adolescents has found that 25–50% of these children can experience psychosocial problems such as academic problems, peer interaction problems, school discipline problems and/or mental disorders during their childhood and/or adolescence (Billings & Moos, 1983; Worland, Weeks & Janes, 1987). These issues may continue into adulthood where up to two thirds of these children have been found to experience adverse psychosocial and/or mental disorders as adults, whilst approximately one third appear to develop into confident and competent adults (Rutter & Quinton, 1984; Werner, 1995).

Canavan and Clark (1923), in the first published account of research into COPMI, concluded that:
the psychotic, the feebleminded, and the backward children in this group are probably definitely on a level from which they will not rise, but the nervous children and those who have conduct disorders may develop into good citizens; one can never safely predict other than optimistically. The majority manage by one method or another to make at least moderate successes. From one point of view, a nation of moderate success is superior to one of too perceptible differences, though historians might not find it so interesting (p.777).

Aside from their use of the objectifying medical language and diagnostic labels common to the time, and the debatable assertion regarding the initial group of children they refer to, Canavan and Clark make some noteworthy points concerning children of parents with mental illness. Firstly, they recognise the varying levels of impact of parental mental illness across the spectrum of children involved, a continuum also recognised in later research (see for example Falkov, Mayes, & Diggins, 1998). Secondly, and more importantly, they argue that the implications of addressing the needs of such a large group of potentially vulnerable children have considerable repercussions for the overall health and functioning of the society within which they live. The social justice perspective which is evident in their final comment regarding “a nation of moderate success” (Canavan & Clark, 1923, p. 777), remains as important now, over 80 years later, as it was in the 1920s.

In January 1999, in a long overdue recognition of the needs of children and families where parents had a mental illness, Children of Parents with Mental Illness (COPMI) were formally identified as a priority group in Australia’s Mental Health and Promotion and Prevention National Action Plan. Funding was subsequently provided for a scoping study that was conducted into the current state of service response to families where parents had a mental illness (AICAFMHA, 2001). From this, the national Children of Parents with Mental Illness (COPMI) initiative commenced in 2002, which remains in progress at the time of completion of this thesis. The aim of this initiative has been to develop national principles and practice guidelines for provision of services for children and families where parents have a mental illness, focusing on effective prevention and intervention strategies.
There has, however, been little corresponding recognition of the needs of adult children whose parents have or have had a mental illness.

1.4 LOCATING THE PRESENT STUDY - OTHER SILENT AND SILENCED ADULT CHILD VOICES

And in the naked light I saw
Ten thousand people, maybe more.
People talking without speaking,
People hearing without listening,
People writing songs that voices never share
And no one dare
Disturb the sound of silence…

The national COPMI initiative in Australia re-presents a significant and very welcome advance in the issues facing children and families where parents have a mental illness. It’s likely that Canavan and Clark would be heartened to see these significant, although somewhat delayed developments, in addressing the needs of children whose parents have a mental illness. As noted, the national initiative into COPMI did not, however, consider nor focus on adult children of parents with a mental illness, who remain a marginalised group of persons affected by parental mental illness. Due to this lack of attention to large numbers of children who have grown up in Australia and elsewhere in the intervening 80 years or so since Canavan and Clark’s (1923) initial research, there remains a substantial, silent group of adult children who have received neither recognition nor support with regard to their parent’s mental illness.

This study and thesis aims to give voice to the experiences of a purposive sample of adult children of parents with a serious mental illness and 'disturb the silences' that have developed around growing up with a parent with a serious mental illness. Understanding the experiences of children who have grown up in such families not only provides a way for such silent and silenced voices to be heard and for service improvements to be made, but may deepen understanding of the family life in which mental illness occurs.

In the first instance, I will be uncovering my own experience of having a mother with serious mental illness.
1.4.1 The 10th participant – disturbing my own sounds of silence

My past is a part of who I am today, and has been integral in shaping my many and diverse ‘selves’ and ‘identities’. As I have come to understand my past more, and processed the feelings I have had about it, I have felt a need to honour and respect the selves I have made. I have also come to recognise that experience is not static but constantly moving and shifting. Even as I write this I realise I am, moment by moment, continuously re-shaping my past as well as my present.

As I am including my own story alongside those of the other participants in this study, following Kirkman (1999), who also didn’t interview her-self, I wrote my own story as if I were telling it to the other participants. In order to do this, it means that unlike some other auto-ethnographic writing I have not written it as if I were there in the past (Ellis, 2004) but have told my story much as the participants told theirs to me, as a story of my life narrated from the perspective of the present. Apart from using my own name I have used pseudonyms for others in my story, as I also did for the other participants’ accounts, in an effort to protect their privacy. Together with other auto-ethnographic excerpts in the following chapters, my overall life story has been included in the phenomenological and postmodern narrative analyses alongside the other participants’ field texts.

1.4.1.1 Growing up

There are a mass of feelings, thoughts and memories that come to mind when I think of my childhood. Mostly, these are full of sadness, anger and shame. Although I was happy and had fun at times as a child, overall I haven’t considered my childhood as being very happy. I remember mainly a sense of shame and feeling quite alone and isolated from other people, although as I’ve gotten older this has shifted somewhat.

Particularly in primary school, I didn’t have a lot of friends and spent hours in the playground with my head buried in a book whilst the other kids played. I ended up being known as the school ‘bookworm’. I loved Enid Blyton’s series of books – ‘The Famous Five’, which was my favourite, and the ‘Secret Seven’. When I was reading about their adventures I felt that for a while I could escape my life and become part of theirs. I loved the idea of their ‘jolly’ and exciting adventures and their picnics which always seemed to include lots of great food, something I felt I didn’t get very often. When I read I could
block out sound, forget being miserable or sad, be totally unaware of time, and free to enter the world of other lives and other stories. It was great. Reading about other people was incredibly comforting – and still is - and made me feel safe.

I think part of feeling lonely was because I felt very different to other kids. From the time I was about eight until I left school at eighteen I lived in children’s homes – religious welfare institutions for children who didn’t have any parents, or whose parents couldn’t or wouldn’t look after them. The kids at school called us the ‘homekids’, which was their way of labelling us as different. I hated that label. It was like a stigmata I carried with me everywhere. We were considered second class kids. The other kids either felt sorry for us, which I couldn’t stand because it reinforced I wasn’t as good as them, or they ridiculed us, which was humiliating. We even had our own school bus! I can still recall the ignominy of arriving in it every day.

I remember once, one of the kids at school asked me what I’d done wrong to be in the homes. I was so indignant! ‘What do you mean ‘what have I done wrong’? Nothing! I haven’t done anything. I was just born, that’s all!’ I said back to her. I don’t think she believed me. Obviously I must have done something, otherwise why would I be there and not at home with my parents like other kids?

A few years ago I wrote a poem (Foster, 2001) to describe some of the things I remember most about living in this particular home, which was by far the worst of the three institutions I lived in;

we had our own schoolbus
and lived in a big, dark old house
we had kerosene put in our hair every Monday to stop the nits
we ate tripe – whether we liked it or not
we always went to church on Sundays
we were second best
we were homekids

When I was born –the eldest of six children– it seems that was the first time my mother got really unwell, and apparently she left me at home in my cot one day when I was about three months old and went interstate for about nine months. Apparently one of the neighbours rang my father because she could hear me screaming in my cot the day mum left. That’s what I’ve been told by my family. Of course I don’t actually remember what happened. There are photos of my christening though, with everyone there except my mother.
Because my father, who was only 21 when I was born, was working during this time and didn’t know how to look after a small baby, I was sent to live with his mother – my Grandma, and his sister Jenny, for a while. I’ve always felt a special connection to Jenny, who was only sixteen then, because I found out later she had taken over a lot of the childcare and looked after me during that time.

My mother seemed to become unwell after each of my brothers and sisters’ births. I don’t really know a lot of the details, and that’s been one of the problems I’ve had about my past – because my family were so separated there’s a lot of our history I don’t know. I’ve had to rely on relatives to fill in some of the gaps. And I don’t know some of what happened in term of my mother’s illness, so my understandings and knowledge of it are fragmented and there are lots of details missing.

I do know my brother Adam who was born after me died at three months of age. But no-one speaks of him. If it weren’t for the bible my mother gave me as a child which had all the birthdates and names of my brothers and sisters, and the notes we found in Nan’s garage after she died, where my mother had written about Adam describing him as ‘spastic’ and ‘gone to god’, and then the one unforgettable time my father talked about him, you’d never even know he’d been born.

By the time I was four I’d been in the first children’s home with my younger sister Sharon, who was only about eighteen months old at the time. She and I eventually went to two other homes, and from the time I was about eight we lived permanently in these homes until we left high school. My brother Andrew also ended up in a ‘boys’ home, and my two youngest brothers and sisters, Jim and Sally, were fostered out to relatives on my father’s side and eventually adopted by them. There’s a nine year gap between Sally and I, who’s the youngest. We didn’t all meet up again until I was well into my teens. I have a photo of the five of us when we all got together one momentous day at Jim and Sally’s place. It’s the only one I have. Jim died a few years later in a car accident so I didn’t get to know him very well, and my mother and Nan spent most of our childhood referring only to Sharon, Andrew and I as if the others didn’t exist. So we became a three-child family in many ways. We’re still pretty much like that now.

When I lived at home with my parents, there are particular events and memories which have remained with me. I think mum was becoming more and more unwell, and she tried to harm herself a few times and did things like put her head in the gas oven. I knew
this because she would tell us about these attempts afterward, and it was only as an adult I’ve looked back and realised what a bizarre thing that was to do, to tell us, in excruciating detail, what she’d done. I remember finding her one day after she’d tried to harm herself. In fact, it feels like it’s etched into my brain. I was about seven or so at the time, and had been sitting in the lounge with Sharon and Dad one day and he said ‘Kim, go and find your mother will you?’ as we hadn’t seen her for a while. As an adult, I’ve since wondered whether he guessed something was wrong but didn’t want to find out himself. Anyway, I eventually went to the bathroom, opened the door, and found her. She was leaning on the sink with her head hanging down, arms dangling, with blood running down them.

She’d cut her wrists with a razor blade. I was so shocked. I don’t know if I can really explain the feeling of horror I had. It was just like everything went into slow motion and time stopped for a while. I suppose I must have called for dad, and the next thing I remember is him taking her to the hospital and Sharon and I being sent over the road to Mrs Denton’s place, one of the neighbours. It was dinnertime and she gave us peanut butter and vegemite sandwiches. I couldn’t eat them, which was unusual for me because I loved my food. I just remember feeling sick.

If I were to describe how I felt about my mother as a child, I think the overwhelming feeling was fear. She seemed very powerful and I grew up being quite frightened of her, although that has changed now as an adult. I remember her as being cold, aloof, harsh and stern. She could be very cutting and scathing about what she said, and she still is even now, although it’s much less frequent. As a child I don’t recall her ever saying anything good about me, or Sharon and Andrew. It was always about what we’d done wrong. I remember standing in front of her one day – which I seemed to do a lot – and looking up at her while she declared ‘Kim, you’re only average in looks and brains, and you’re going to have to work hard to do well’. I carried that message around in my head for years. I think it’s part of what’s driven me to achieve. But I didn’t have very good self-esteem as a child and even now it’s a battle sometimes to maintain a strong sense of self-worth. I still struggle with feelings of shame whenever I make a mistake or don’t perform the way I think I’m expected to – or expect of myself.

For years Mum was a formidable figure to me and I hated getting into trouble from her, so I tried hard to be as good as possible. And I think that, looking back, as well as having psychosis she probably had also had some kind of obsessive-compulsive disorder – she
was quite preoccupied with germs and things being dirty, and always seemed to be cleaning and telling us off for getting ourselves, our clothes, or the house, dirty. I remember one time when I was about five where I’d gone to a birthday party and my ‘good’ pink and white party dress had got chocolate on it. I hid it right down the back of the wardrobe hoping she wouldn’t find it because I knew I’d be in a lot of trouble if she did. Of course she did eventually find it and I still recall the force of her anger as she stood in front of me with the dress, saying “Look at it. Look at these marks! They’ll never come out. You’re a naughty girl Kim”. My sense of guilt and shame were huge. I told her I’d be good and promised not to get the dress dirty again. Then it was as if everything went grey around the edge of my vision, and I fainted. Apparently I did that more than once, my mother told me later, although I only remember this one time.

I can remember coming around after fainting, and lying on the couch with a blanket over me and having a really sore chin, because apparently I went stiff as a board and fell straight on it when I fainted. My mother asked me whether I was awake now, and told me the doctor said I did this just to get attention. She was still annoyed, but at least she’d stopped yelling and was looking after me and letting me lie on the couch for a while, so I did feel better.

Even when we went to live in the ‘homes’ we still saw mum quite a lot, and visited her on weekends, but when she and dad separated he lived interstate and overseas for quite a while, so we only saw him very occasionally over the years. I remember he wrote a letter when I was about 12 (addressed to me because I was the eldest), explaining that he had to go away otherwise he might do what his father had done. I had to ask Nan what that was. Apparently my grandfather killed himself when dad was in his late teens. It seemed at the time he was asking my forgiveness for being an absent father, and I felt sorry for him. Now I think how emotionally demanding that was – to ask a daughter to sacrifice the love and care of her father because he couldn’t or wouldn’t deal with whatever was troubling him. Later on as adults he told us he’d become an alcoholic, and had been treated for depression. He’s also had a period of drug-induced psychosis from smoking marijuana.

I think that’s part of why I grew into such a serious and solemn child who felt so responsible for everything. I felt as if most people around me – particularly my parents - had difficulty coping with life and expected me to look after myself as well as my brothers and sisters. So I was, and still am, quite a serious person who often automatically
assumes responsibility even when perhaps it’s not mine to take on. One thing that’s always stayed in my mind about this is the photo of Sharon and I standing together in the backyard of Nan’s house when I was about 15 and she was 12. Nan told me a friend of hers picked it up one day and pointed to me and asked ‘is that the mother?’ When she told me I was torn between outrage and amusement! Did I really look old enough to be my sister’s mother? Unbelievable! Looking at it now I can see what a serious, and yes I suppose, grown up face I presented.

After I finished school, left the home, and went nursing, I continued to see my mother on occasions, often at Nan’s, with whom we kept in a lot of contact. Mum became more and more rejecting of our attempts to contact her, and often for example returned letters we had written to her unopened. When I eventually went into mental health nursing, I thought it was quite ironic to find myself in the position of knowing all about the theoretical basis of mental illness, and yet being unable to do much about my own mother’s. She deteriorated quite a lot over those years, and became increasingly paranoid and occasionally made verbal threats to family or acquaintances. One time I heard she’d threatened someone with a knife.

She often rang relatives and would rant for hours about all sorts of issues. She eventually ended up living on the streets, riding on trains all over the state for quite some years, becoming a well-known identity. One day I was at one of the main train stations in the city and saw her standing further down the station, carrying the bag she lugged around everywhere and wearing the same sort of headscarf and clothes I’d seen her in for years. I’m embarrassed to say my response was to try and melt into the crowd and hope she didn’t see me. I didn’t want to have to face meeting her, or experience her hostility or rejection.

During this time, I tried to support Nan, who was trying to help mum. I think Nan was sometimes quite frightened of mum, and what she thought she might do to her. She tried hard to get her some treatment, and I tried to help by finding out what could be done. I also eventually gathered the courage to seek out counselling. Each of the two counsellors I went to, in different periods of time, were really helpful in supporting me to process some of the buried issues that had surfaced, as well as long- suppressed feelings of sadness, anger and shame. These had silently built up over the years and were affecting my sense of self and my close relationships.
Eventually, and very fortunately, after many years of untreated and severe psychosis, mum was involuntarily admitted to hospital. Although she was extremely angry and hostile during this time, it was a very important turning point for her, and for us, and the treatment she received helped reduce her symptoms a great deal. She now lives independently and is content and settled. The acute symptoms of her illness have subsided and although she sometimes has mild relapses, her quality of life is immeasurably better than it has been for most of her life.

The thing is though - she refuses to talk about much of our past or our childhood in the homes. And she still doesn’t acknowledge her mental illness or show any awareness of the possible impacts it may have had on the rest of us.

1.5 ORGANISATION OF THIS THESIS

As it is the framework for this study, postmodern notions have informed the way the thesis has been composed and presented. Each chapter is prefaced with eclectic poetic and musical excerpts that illuminate aspects of the chapter as well as those relating to adult children of parents with serious mental illness and/or the research journey. The combination of these nine aesthetic pieces throughout the thesis can be seen to provide one particular narrative construction of the topic and research process which adds to the layering of accounts throughout.

The literature review, spread over two chapters in Chapter 2 and 3, aims to provide a detailed and comprehensive background to what is understood of the impacts of parental mental illness, and what is known of the experiences of children and adult children whose parents have had mental illness.

Chapter 4 discusses the methodological and epistemological foundations of the study, including those of narrative inquiry, postmodernism, and interpretive phenomenology. In Chapter 5, these assumptions are applied to description of the study methods, which include auto-ethnography and unstructured interactive interviews and a dual analysis of the resulting field text. The first analytic phase is a realist interpretation, using
phenomenological thematic analysis, followed by a postmodern narrative analysis and interpretation.

Chapter 6, the first findings chapter, explains the phenomenological themes and sub-themes derived from the experiences of the participants. In Chapter 7, the same field text is then de-constructed and analysed through a postmodern narrative lens, and a number of lessons are illuminated from this alternate interpretive lens.

Chapter 8 discusses both sets of findings, the inter-textuality between the meanings that were uncovered, and the implications these may have for health professionals’ practice. In the final chapter, Chapter 9, the conclusions and recommendations from the findings and arguments developed throughout the study, are presented.
CHAPTER 2
SHINE ON YOU CRAZY DIAMOND –
REVIEW OF THE LITERATURE ON CHILDREN OF
PARENTS WITH MENTAL ILLNESS

Musical lyrics removed for online publishing due to copyright
Reflecting on the ‘Crazy Diamond’

‘Shine on you crazy diamond’ was written by band members as a tribute to Syd Barrett, former founding member of the rock band Pink Floyd who left the band in the late 1960s due to his declining mental health associated with his use of psychedelic drugs such as LSD.

I have chosen these particular lyrics to re-present a number of issues relating to the literature on children of parents with mental illness. For one, they are an evocative description of the erosion of hope and fulfilment that has been associated with the development of serious mental illness such as psychosis. Yet the words ‘you seer of visions, you painter, you piper’ also hint at the brilliance, creativity and potential of many people who have experienced mental illness. The metaphor of the diamond can be seen as alluding to the multiple facets of mental illness as well as to the diversity of impacts and experiences of children whose parents have mental illness.

Children whose parents have mental illness may experience a number of issues and respond in a variety of ways to the potential effects of their parent’s illness. Born into apparent adversity, like the hardy diamond many have gone on to forge fulfilling lives, whilst others have struggled to overcome their pasts, and some may have become ‘martyred’ to their parents’ ill health. And so remembering the young, who are full of potential yet need support and guidance, is a strong thread of discourse in the following review.
2.1 INTRODUCTION

Beginning in the 1920s, there has been an immense body of research investigating the diverse impacts of parental mental illness, initially on children, and later, to a much lesser extent, on adult children. This has been constructed and investigated through a variety of theoretical and methodological lens, with a hegemonic emphasis on the problem-based paradigm which continues to emphasise risks and pathological outcomes for COPMI. The further development of the construct of resilience and strengths has led to current understandings which seek to balance risk with resilience. The resulting dialectic though, can be viewed as limited in terms of developing comprehensive understandings, as there has been little work from a postmodern or critical lens.

So that their experiences may be understood within the broader social, cultural, medical and historical contexts they have existed in, this review aims to discuss and critique the literature on both children and adult children whose parents have had a mental illness. Given the scope and extent of literature relating to children of parents with mental illness (COPMI), most of which is based on observable data, the review spans two chapters. This first chapter explores issues relating to children and the following chapter focuses on literature on adult children.

In order to ascertain the breadth and depth of research into this topic, the literature was searched widely. The search strategy is provided in Appendix A. The following review has then sought to emphasise major studies and recent developments, highlighting Australian research where appropriate. The review has been organised around four groups of constructs identified within the literature. These are attachment and developmental needs; deficits and risks; strengths and protection; and subjective experiences.
2.1.1 The temporal development of research into children of parents with mental illness

As noted, much of the literature on children of parents with mental illness has been epidemiological and empirical in nature, researched primarily from the hegemonic perspective of psychiatry, and to a lesser extent, that of psychology. The initial wave of medical research, beginning in the 1920s, problematised and pathologised parental mental illness and the language used in these studies can be seen to reflect the objectifying nature of the deficit/risk construct. Initial research findings focused on the various deleterious effects parental mental illness exerted on the child. These effects were found to have arisen from either genetic risk, and/or environmental/psychosocial stress. The second wave of research, arising out of the initial research findings in the 1970s, revealed a new construct which focused on factors identifying and facilitating resilience in the child whose parent had a mental illness. A serendipitous discovery of positive outcomes for some COPMI prompted further investigation into the specific competencies, coping skills, and overall protective factors exhibited and/or experienced by these children. Since the late 1980s, a third wave of research has developed which includes a significant input from other health professions, in particular that of nursing, psychology and social work. This work has focused on COPMIs’ subjective experiences of parental mental illness, and the coping mechanisms they have used to manage their experiences.

In the following review, the dominant constructs in the literature on children of parents with mental illness, as well as aspects of the issues that have been absent or marginalised, are illuminated. Thus, in the process of interpreting these constructs in the literature, gaps and overlooked issues in the present body of knowledge on adult children of parents with serious mental illness (ACOPSMI) begin to be revealed. To provide context for the later discussion, the review begins with a brief overview of parental mental illness.
2.2 THE CONTEXT OF PARENTAL MENTAL ILLNESS (PMI)

Psychotic disorders are a specific group within the broader term ‘mental illness’ and are included in the category ‘severe’ or ‘serious’ mental illness which incorporates schizophrenia, bipolar disorder, schizo-affective disorder, and major depression with or without psychotic features. In reviewing the literature on the impact of parental mental illness on their children, research can be grouped into three broad areas. The first has addressed the broader spectrum of parental mental disorders and is inclusive of all diagnostic groups. There has also been a research focus specifically on parental mood disorders, primarily depression. In addition, the effects of parental schizophrenia and other psychotic disorders have been separately explored. Due to the prevalence of research and literature which addresses a spectrum of parental mental illness inclusive of psychosis, as well as literature which focuses on mood disorders that often also include psychosis, the following review includes literature addressing all these areas, highlighting research that specifically addresses parental psychosis and severe affective mental illness.

2.2.1 Mental Illness

Prevalence studies from across the world indicate that in a twelve month period, between 4.3 – 26.4% of the world’s populations have a mental disorder, with an average range of 9.1% - 16.9% (The WHO World Mental Health Survey Consortium, 2004). In Australia, between one in four or five, or 20 - 25% of Australians, experience some form of mental illness during their lifetime (McDermott & Carter, 1995; SANE Australia, 1998). This indicates that in this country the prevalence of mental illness is relatively high compared to some other countries. Around three percent of the population develop a serious mental illness such as schizophrenia or bipolar affective disorder during their lifetime (SANE Australia, 1998), and approximately equal numbers of men and women experience the illness of schizophrenia (Bennett & Fossey, 2001), although women are more likely than men to experience affective disorders such as depression (Harvey, Meadows, & Singh, 2001).
It has been reported that women with mental illness are more often parents than males with mental illness, being up to twice as likely to report having children as men, and also being more likely than men to have custody of their children (Caton, Cournos, & Dominguez, 1999; Hearle, Plant, Jenner, Barkla, & McGrath, 1999). This may account in part for the amount of empirical research that has focused exclusively on the mother with regard to the impact of parental mental illness on the child (e.g. Anderson & Hammen, 1993; Beisser, Glasser, & Grant, 1967; Cannon et al., 1994; Grunebaum, Cohler, Kauffman, & Gallant, 1978; Higgins et al., 1997; Klimes-Dougan & Bolger, 1998; Parnas et al., 1993; Scherer, Melloh, Buyck, Anderson, & Foster, 1996; Schulsinger, 1976).

2.2.2 The extent of the issue: Parents with mental illness and their children

Worldwide, it has been difficult to identify the incidence of COPMI (AICAFMHA, 2001; Lancaster, 1993; Meadus & Johnson, 2000), although this is a surprising omission given the plethora of empirical research into this topic. In Australia, data on the number of adult psychiatric clients who are parents have not been regularly collected by most service providers although this has improved in recent years. The lack of systematic collection of data may in part be due to the individual rather than family focus that many mental health services have traditionally taken.

There have been, however, a number of estimates made of the percentage of parents with mental illness in Australia. These have ranged between 29 – 35%, based on specific clinical cohorts of clients with mental health problems (Farrell, Handley, Hanke, Hazelton, & Josephs, 1999; Hearle et al., 1999; Jablensky et al., 1999 & 2000). A recent estimation, inclusive of both Australian Bureau of Statistics data as well as actual service usage data, found that between 21.73 – 23.52% of children living in Australia had at least one parent with a mental illness, which equated to over a million children. Furthermore, between 4 and 12% of Australian children (44,705-125,516) were estimated to live in two parent families where one parent had a serious mental health problem such as schizophrenia (Maybery, Reupert, Patrick, Goodyear, Crase, 2005b). These figures affirm that significant numbers of children may potentially be affected by their parents’ serious mental illness.
The following section moves on to explore the construct of attachment and developmental needs, and discusses issues relating to attachment for children whose parents have mental illness, as the lack of secure attachment can be an important predictor for psychosocial problems.

2.3 ATTACHMENT AND DEVELOPMENTAL NEEDS

A prominent term in developmental theory literature in relation to the effects of parental mental illness on the child is ‘need’. Children are considered to have central needs that must be met in order to ensure their development into mentally and socially healthy adults. These include the experiences of physical and emotional sustenance, love and secure attachment, a sense of security, protection, stimulation, an effective learning environment, and the opportunity for socialisation (Bowlby, 1979; Kowalenko, Barnett, Fowler, & Matthey, 1999; Rutter, 1972). The child’s early developmental achievements are generally considered to lay the foundation for later ones. Any delays or disruption to this development, particularly to attachment, are viewed as resulting in possibly long-term consequences including remnants of unresolved issues that negatively impact on the child throughout their future (Marsh, 1996). Attachment theory is also interested in explaining the causative nature of ‘normal’ as well as ‘abnormal’ development (Schore, 2002).

One perspective evident in the literature is that development may be difficult to predict over time. There has been some evidence to support the concept that human beings can demonstrate remarkable plasticity in development, and have the potential for temporal change, even through to late in life (Grunebaum & Cohler, 1982; Papalia, Olds, & Feldman, 2001). This is an important issue as the construct of attachment and developmental needs also includes the notion that the child has the capacity to overcome potential adversity such as parental mental illness through later corrective experiences (Sroufe, Carlson, Levy, & Egeland, 1999). This notion is explored further in the following chapter.
There has been a wide array of theoretical explanations for how children develop over time (see for example, Bandura, Erikson, Gessell, Piaget, Vygotsky). No single theory, however, fully explains this development, nor is universally accepted. More recently, in keeping with postmodern tenets, there has been a trend away from the ‘grand’ development theories such as those of Freud’s psychosexual theory, towards more localised theories explaining specific facets of development (Papalia et al., 2001). In particular, it is the relationship and attachment between caregiver and child that has been seen as significant to the child’s subsequent emotional and physical development (AICAFMHA, 2001).

2.3.1 Caregiver/child attachment and need

Attachment between the caregiver and child is viewed as the fundamental start to human life and is the reciprocal long-term emotional bond between the child and a caregiver, most often the mother (Klein, 1990; Papalia et al., 2001). Various patterns of attachment have been described, with the most common and desirable being secure attachment. Further classifications include anxious or insecure attachment that can be either avoidant or ambivalent. There has also been the identification of the more recent category of disorganised-disoriented and traumatic attachment, which has been related primarily to the experience of chronic child maltreatment (Papalia et al., 2001; Schore, 2002; Streeck-Fischer & van der Kolk, 2000; Waters, Hamilton & Weinfield, 2000a).

Attachment theory maintains that the vital task of the first year of the child’s life is the formation of a secure attachment or bond of emotional closeness between the baby and primary caregiver, usually the mother (Schore, 2002). The secure baby is one who is confident in the caregiver’s availability and responsiveness, and uses them as a safe base from which to explore their environment and develop (Papalia et al., 2001; Waters et al., 2000a). Through repeated experiences with the caregiver, the child is considered to have formed internal working models that are constant cognitive representations of the ‘self’ and ‘others’ in relationships (Bowlby, 1971). Attachment theorists have argued that the interpersonal relationship between parent and child forms the basis throughout life from which the child’s social interactions, regulation of emotion, and ability to cope and
attend, particularly during times of stress, are shaped (Feeney & Noller, 1996; Weede Alexander, Quas, & Goodman, 2002). Attachment may subsequently be viewed as a relationship construct (Green & Goldwyn, 2002). The child’s attachment style is considered to continue to develop during childhood and adolescence in relation to subsequent attachment-related experiences (Bowlby, 1971).

Ainsworth, who worked closely with Bowlby, developed an assessment tool to measure children’s varying styles of attachment (Ainsworth, Blehar, Waters, & Wall, 1978). The Strange Situation tool was designed to create mild but increasing stress for the child in the form of brief separations and reunions with the primary caregiver so that any changes in the child’s behavior toward them could be observed. This assessment technique, and an abbreviated version, have been widely used in subsequent studies and are considered reliable tools, although some criticism has been leveled at researchers relying on the tool at the expense of considering the child’s behaviour in ‘naturally’ occurring situations (D’Angelo, 1986; Feeney & Noller, 1996). From their research, Ainsworth et al. (1978) describe three of the now commonly recognised attachment styles, including secure attachment. Children who are less likely to cry in response to caregiver separation, fail to greet, or ignore the caregiver on reunion were seen to characterise avoidant attachment or insecure-avoidant behavior. Ambivalent or insecure-resistant behavior on the other hand, was seen with the child who cried on separation yet continued to cry on the caregiver’s return, and was not easily comforted (Ainsworth et al., 1978; Waters et al., 2000a).

A fourth attachment classification of disorganised type was also developed to describe the observation of unusual and bizarre attachment behaviours in some children. Disorganised attachment was seen in the child’s contradictory behaviours and disintegration of emotions in the face of distress, and considered to have developed due to dysfunction in the child’s internal working models or schemas where they did not anticipate support or responsiveness from a caregiver (Green & Goldwyn, 2002; Weede Alexander et al., 2002). This type of attachment has been strongly associated with the presence of parental major depression or bipolar disorder, alcohol and other substance misuse, and child maltreatment (Fonagy, 2001), and is considered a strong risk factor for
later cognitive and social difficulties and mental disorders in the child (Green & Goldwyn, 2002).

Earlier researchers such as Bowlby (1971, 1979), maintained that the failure of secure attachment occurring would result in consistent difficulties in interpersonal relationships throughout life. It has subsequently also been argued, however, that children vary substantially in the extent to which early attachment experiences affect them in later life (Thompson, 2000), and research has found that attachment style may change in light of later experiences (Hall, 1996; Waters et al., 2000a).

### 2.3.2 Attachment and parental mental illness

“For a child, the impact of parental mental illness may range from short-term traumatisation, through to domination of the child’s early life experience.”

(Clausen & Huffine, 1979, p.183).

As Clausen & Huffine (1979) explain, there is a wide range of potential effects of parental mental illness on the child. Some writers have argued that the child’s development is significantly impacted upon by parental disturbance, and that mental illness in the mother in particular leads to significant deficits in her ability to respond to her child (Clausen & Huffine, 1979; Klein, 1990). As the most influential writer on child development from 1951 to 1969, Bowlby for example maintained that persons with any kind of mental disorder always showed impairment in their capacity to emotionally bond with their children (Bowlby, 1979; Rutter, 1972).

Research findings have indicated that children of mothers with mental illness are generally more likely to show anxious or avoidant attachments in the first two years, however this was not absolute and these attachments could change to being secure ones if there was opportunity for the child and mother to develop an improved relationship later on (Ainsworth et al., 1978). D’Angelo (1986) for instance, found that the infants of mothers with depression and schizophrenia both experienced more anxious attachments than did those of unaffected mothers. Cunningham et al. (2004), however, found levels of insecure attachment in children of mothers with mental illness were comparative with
other mother-child groups. In a key study of attachment patterns in 55 two and three year old children of mothers with bipolar and unipolar depression compared with 43 children of mothers with mild depression and those with no depression, Radke-Yarrow, Cummings, Kuczynski, and Chapman (1985) reported similar findings. Mothers were given the Schedule for Affective Disorders and Schizophrenia (SADS) which identified disorders according to diagnostic criteria. They were also rated on severity of their illness using the Global Assessment Scale (GAS). A modified version of Ainsworth and Wittig’s (1969) Strange Situation was used to assess quality of attachments in each group. Insecure attachments were more common among children of mothers with unipolar and especially bipolar depression (55% of cases) than with children of mothers with minor or no depression (25-30% of cases). Although this study found higher rates of insecure attachment in children of parents with more severe mental illness, there were also a number of children who had secure attachments and so the mother's mental illness in itself was not completely deterministic of disordered attachment in the child. Other factors such as the presence of an alternate attachment figure such as the father and social supports available to the mother were also influential. These findings may be limited, however, by the relatively small sample size.

Later studies have not necessarily supported the findings of Radke-Yarrow et al. (1985), that is, that children of mothers with bipolar depression were more likely to be insecurely attached. In a prospective case group study over 12 months, Hipwell, Goossens, Melhuish and Kumar (2000) found that mothers’ severe mood and bipolar disorders were not associated with insecure attachments in their children, and their findings did not support that children of mothers with bipolar disorder were more likely to be insecurely attached than children of mothers with unipolar depression. Again, however, whilst informative, these findings may be limited by the small sample size and particular characteristics of the sample groups.

The impact of child maltreatment on attachment in children of parents with mental illness has also been the subject of investigation. If the child is abused by their caregiver(s), attachment is also likely to be impaired. This has the potential for the child developing continuing problems with relationships, poor self-esteem, and impairment of personality.
development (Buist, 1998), with the risk of emotional difficulties being identified as particularly evident in the child’s interpersonal relationships (Klein, 1990). Traumatic attachments which may occur with all forms of chronic child maltreatment (including neglect, and emotional, physical and sexual abuse) have been associated with the later development of post-traumatic stress disorder (Schore, 2002; Streeck-Fischer & van der Kolk, 2000). Separation of the child from the mother/caregiver has also been associated with impaired attachment. Clearly, attachment cannot form when child and caregiver are separated, and there is a risk that children of mentally ill parents may be separated from the mother through hospitalisation (Hall, 1996; Rutter, 1972). Repeated separations and loss of the caregiver relationship have been found to be harmful, contributing to the child’s later difficulty in developing healthy relationships with others (Rutter, 1972).

The impact of a parent’s mental illness on the child varies, however, depending on a number of mediating factors such as the child’s age, severity of illness, length that it lasts, and whether alternate support is available (Cowling, 1999; Farrell et al., 1999). The parent’s illness is by no means the only, or even necessarily the most influential, factor in the child’s subsequent development. It may also be that there are many caregivers who have close attachments to their children who have not been involved in the studies cited in the literature (Mowbray, Oyserman, Zemencuk, & Ross, 1995). Furthermore, the deterministic nature of much of the earlier work on attachment and developmental theory has made way for later moderation in view of additional research into adult children’s development, and discussion will return to this again in the following chapter on adult children of parents with mental illness. Using a postmodern lens, this discussion moves now to review the risks and potential for problematic outcomes for COPMI that have been identified through research.

2.4 DEFICITS AND RISKS FOR CHILDREN OF PARENTS WITH MENTAL ILLNESS

The dominant construct in much of the literature and research on the effects of parental mental illness on children has focused on problems and pathology. Objectifying language and labels such as ‘offspring’, ‘schizophrenic’, ‘psychiatric patients’, ‘psychopathology’,
‘externalising’ and ‘internalising’ disorder have been frequently used, even to the present day. These terms can be seen to reflect the dominance and hegemony of psychiatry. They reinforce the marginalised situation and obscure the importance of appreciating that parents with mental illness and their children are both the subject and object of resulting research.

2.4.1 The dialectics of vulnerability, risk and protection

Over the past twenty years, ‘risk’ has been a favoured term in research, particularly in an age where insurance, litigation, consumer activism, and efficiency have been increasingly prioritised. However, being preoccupied with risk can mean that resilience, vulnerability and protective factors are not given equal attention. ‘Risk’ may be defined as antecedent or preceding individual or environmental factors/hazards that increase a child’s vulnerability to experiencing negative developmental outcomes. A risk factor may therefore be that of parental mental illness (Beardslee, Bemporad, Keller, & Klerman, 1983; Kostelny & Garbarino, 1994). Protective factors on the other hand, are seen as those that positively mediate the effects of risk, decreasing the likelihood of negative outcome.

Researchers have conceptualised the notions of risk and protection in terms of parental mental illness in a variety of ways. It is important to note, however, that both these groups of factors may exert influences that are independent of each other (Garmezy, 1987; Rutter, 1988). Furthermore, Rutter (1988) argued that whether a particular factor functioned as either risk or protective was not simply determined by the factor itself, but the circumstances in which the factor interrelated with other factors.

An analysis of the interrelationship between the two groups of factors considered as being potentially risk and/or protective suggests that rather than existing as opposites, they can be viewed as being in a dialectical relationship where the two are inter-related. From this framework the factors discussed throughout this section in terms of risk or protection of the child from stress such as parental mental illness have been grouped into four general areas: individual, family, parental, and social and environmental. Within these categories,
individual includes genetic, temperament, age, gender, intelligence, coping strategies, and other personal characteristics. Family factors include family functioning, and family environment. Parental includes parental functioning and mental illness, and parenting. Social and environmental factors include presence of social support, economic, school, community, and other external psychosocial influences. As will be seen in the following discussion on risk, and then later discussion on protection, each of these factors may be considered both protective and risk in a dynamic dialectic, dependent on context, interaction with other factors, and relative strengths and influences. Table 2.1 summarises the risk/protective factors for COPMI that have been identified in the literature.

Table 2.1: Risk/protective factors for COPMI

<table>
<thead>
<tr>
<th>Individual</th>
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<tbody>
<tr>
<td>• Genetic predisposition for developing mental disorder: one parent 10-16 %, both parents 40%</td>
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<tr>
<td>• Temperament: ‘easy’ = less risk, ‘difficult’ = higher risk</td>
<td></td>
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<tr>
<td>• Age: younger = higher risk (6 mths – 4 yrs = highest risk)</td>
<td></td>
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<tr>
<td>• Gender: male = at higher risk than female</td>
<td></td>
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<tr>
<td>• Self-esteem: lower = higher risk</td>
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<tr>
<td>• Intelligence: lower = higher risk</td>
<td></td>
</tr>
<tr>
<td>• Birth defects and physical illness = higher risk</td>
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<tr>
<td>• Learning disabilities = higher risk</td>
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<thead>
<tr>
<th>Social and Environmental</th>
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<tbody>
<tr>
<td>• Poverty, poor housing, lack of transport = higher risk</td>
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<tr>
<td>• Poor educational history = higher risk</td>
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<tr>
<td>• Social isolation and lack of support = higher risk</td>
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<tr>
<td>• Parental unemployment = higher risk</td>
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<tr>
<th>Family</th>
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<tbody>
<tr>
<td>• Marital conflict = higher risk</td>
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<tr>
<td>• Chronic family stress = higher risk</td>
<td></td>
</tr>
<tr>
<td>• Difficulty with communication = higher risk</td>
<td></td>
</tr>
<tr>
<td>• Family functioning: lower = higher risk</td>
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</table>

<table>
<thead>
<tr>
<th>Parental</th>
<th></th>
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<tbody>
<tr>
<td>• Psychosis = higher risk of child folie a deux, language delays, relationship difficulties, sleeping and eating problems</td>
<td></td>
</tr>
<tr>
<td>• Hostility, conflict and violence = higher risk</td>
<td></td>
</tr>
<tr>
<td>• Abusive behaviours = higher risk of infanticide and homicide</td>
<td></td>
</tr>
<tr>
<td>• Incapacitation/role reversal = higher risk of child parentification</td>
<td></td>
</tr>
<tr>
<td>• Warm parent/child relationship = lower risk</td>
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</tbody>
</table>
2.4.2 Individual characteristics and risk

The risks for children of parents with psychosis may begin from conception, as children of mothers with psychotic mental illness have been found to have a higher than expected risk of fetal death or stillbirth which has been attributed to a combination of antenatal, obstetric and genetic factors. These include maternal misuse of substances, lower attendance at antenatal care, unrecognised maternal medical conditions, and complications in pregnancy, labour and delivery (Jablensky, Morgan, Zubrick, Bower, Yellachich, 2005; Webb, Abel, Pickles, Appleby, 2005). Large scale population studies are needed, however, in order to understand the risks more fully (Webb et al., 2005).

There has also been extensive recognition through research findings that children of parents with a mental illness in general have a greater risk than children of mentally well parents of developing a mental disorder (Beardslee, Bemporad, Keller & Klerman, 1983; Cantwell & Baker, 1984; Landau, Harth, Othnay, Sharhertz, 1972; Rutter & Quinton, 1984). For instance, the child has a 10 – 16% chance of developing schizophrenia or another psychotic disorder (Cowling, McGorry, & Hay, 1995; Farrell et al., 1999; Gottesman, 1991; Grunebaum & Cohler, 1982; Sameroff, Barocas & Seifer, 1984; Worland, Weeks & Janes, 1987). If both parents have a psychosis, the risk rises to around 40% (Grunebaum & Cohler, 1982). Beardslee et al. (1983), in a review of the literature, also reported high rates of impairment in children of parents with an affective disorder.

Gottesman (1991) acknowledges that whilst the genetic transmission of schizophrenia, for example, is essential as a predisposition or diathesis towards the illness, it is not sufficient on its own to fully account for its development in vulnerable individuals. Genetic inheritance of the illness is circumstantial, and based on clinical population genetics where family, twin and adoption studies provide some indication of risk.

Indications of risk in childhood for COPMI who go on to develop schizophrenia-related psychoses include verbal memory, gross motor, and attention deficits, which may also be indicative of the genetic vulnerability to schizophrenia (Erlenmeyer-Kimling et al., 2000). Nevertheless, although genetic influences on the transmission of psychiatric disorder have been found to be significant, this influence varies considerably according to the type
of mental disorder and awareness that there are multi-factorial causes, with environmental factors playing a significant role (Rutter, 1999).

In terms of the child themselves, characteristics such as age at time of parental illness, gender, temperament, self-esteem, lower level of intelligence, birth defects, medical illness, and learning disabilities have been found to exert an influence (Brooks, 1994; LaRoche, 1989; Rutter, 1988). The age between 6 months to 4 years has been found to be most vulnerable period for stressful events, and in general, the younger the age the greater the impact of parental mental illness (Anthony, 1969; Landau et al., 1972; Marsh, 1996; Rutter, 1988). In terms of gender and stress, boys have been found to be more vulnerable to developing adverse responses than girls (Rutter, 1988; Rutter & Quinton, 1984). Self-esteem has also been a key component in determining risk (Marsh, 1996). Children with low self-esteem have been found to use counter-productive coping behaviours such as denying, bullying or giving up which are used to escape from challenging situations rather than adapting to them (Brooks, 1994).

2.4.3 Environmental influences and risk

With regard to environmental risk factors, it has been found that socioeconomic issues such as poverty and its sequelae of poor housing and lack of transport, as well as a poor educational history including the child’s maladjustment at school, along with social isolation and lack of support from other adults, are influential in terms of the child’s response to parental mental illness (Devlin, 1995). Indeed, it has been argued that the effects of socioeconomic deprivation and parental unemployment due to the presence of mental illness may be more damaging to the child than the parental mental illness itself (Billings & Moos, 1983; Rutter & Quinton, 1984). Environmental risks can also include those related to family characteristics and parental functioning.

2.4.4 Family characteristics and risk

The literature on family factors has noted an association between risk and marital conflict, high levels of chronic family stress, difficulty with communication, discordant
family environment, and overall reduction in effective family functioning (Inoff-Germain, Nottleman, Radke-Yarrow, 1997; Kaslow, Gray Deering & Racusin, 1994; LaRoche, 1989; Rutter & Quinton, 1984; Rutter, 1993). Rutter (1993) argued though, that it might be the differential impact of all these factors that was more important in terms of specific risk for the child than the overall risk of the factor. If the child was able, for example, to distance him or herself from family discord, this factor may not exert a particularly negative influence.

### 2.4.5 Parental functioning, mental illness and risk

There have been a number of studies examining the specific impact of parental psychosis on the child. Earlier studies found that delusional and hallucinatory perceptions of women with schizophrenia often focused on their relationship with family members including children, and that the child may become the object of parental psychotic behavior and/or take on the content of parental delusional states as in ‘folie a deux’¹ (Anthony, 1969; Bleuler, 1974; Rutter, 1966). Parental psychosis has also been linked with delays in the child’s language development, in difficulties with interpersonal relationships with peers and siblings, and in a higher incidence of sleeping and eating problems than control groups (Landau et al., 1972). Even so, the child’s age at the time, the duration of exposure to the psychotic behavior, and the presence of other surrogate caregivers can influence the impact of the parental psychosis on individual children (Anthony, 1969).

Parents’ most recent overall level of functioning has also been associated with the risk of children’s behavioral problems, (Inoff-Germain et al., 1997), and parental hostility, irritability and/or aggression toward the child can be more important in terms of risk than the affective or psychotic disorder itself (Rutter & Quinton, 1984). In particular, the presence of violence, conflict or hostility from fathers with mental illness may be particularly harmful to their sons (Gopfert, Webster & Seeman, 1996), and children of depressed parents with ‘anger attacks’, a sub-type of depression, have been found to have even higher rates of delinquency, aggression and lower levels of social and academic

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¹ Folie a deux is a term used to describe the situation where another person also believes the false belief of the person who is delusional.
competencies compared to those of depressed parents without ‘anger attacks’ (Alpert et al., 2003).

Whilst it has also been recognised there is a relationship between parental mental disorder and child maltreatment or abuse, there is inadequate data to define clearly the causative link (Tomison, 1996). There are, however, a number of documented issues with respect to negative and sometimes abusive parenting practices including violence, infanticide and homicide by persons who have a mental illness - particularly those which are chronic and/or psychotic (Anthony, 1986; Buist, 1998; Clausen & Huffine, 1979; Devlin & O’Brien, 1999; Falkov, Mayes, & Diggins, 1998; Jacobsen & Miller, 1998). Anthony (1986) for example, detailed a number of case situations where parents who were psychotic perpetrated ‘terrorising attacks’ on their children. In his words, these episodes were linked with ‘manic rage’, ‘paranoid fury’, and ‘schizoaffective excitement’. These included incidents of attempts to kill the child, use of physical abuse, and violence and verbal threats. Ulzen and Carpentier (1997) reported similar behaviours by parents who were delusional.

In terms of specific parental disorder, depression has been found to be uniquely associated with physical abuse, where depressed parents were almost three and a half times more likely to instigate physical abuse than non-depressed parents (Chaffin, Kelleher, & Hollenberg, 1996). Furthermore, the incapacitation of the parent through mental illness/substance abuse may lead to role reversal whereby the child assumes adult functioning, ‘parentification’ - which has also been considered a form of maltreatment. In addition, neglect of the child, whilst often unintended, can be evident when parents are unwell and when insufficient supervision and lack of emotional availability may increase the risk of danger (Clausen & Huffine, 1979; Devlin & O’Brien, 1999; Falkov, Mayes, & Diggins, 1998).

Not all parents with mental illness, however, are ineffective, inconsistent or abusive in their parenting. As previously stated, no causal connection has been found between harmful or uniform parenting practices and parental mental illness (Devlin & O’Brien, 1999; Jacobsen & Miller, 1998; Silverman, 1989). Many mentally ill parents are
competent and caring parents with warm relationships with their children, although this is variable (Inoff-Germain et al., 1997; Nicholson, Sweeney & Geller, 1998). Indeed, it has been recognised there may even be a reciprocal effect where problems experienced by the child can negatively impact on the parent’s mental health, and that parenting itself may not have a positive impact on the course of the parent’s illness (Caton et al., 1999; Devlin & O’Brien, 1999; Nicholson et al., 1998; Rutter & Quinton, 1984).

2.5 PROCESS BY WHICH PARENTAL MENTAL ILLNESS AFFECTS CHILDREN

A number of studies have found that in respect to the development of psychosocial impairment and/or mental disorders in children of the mentally ill, the main risk has actually been from psychosocial disturbance in the family and/or an unsettled living situation, than from the parental mental illness itself (Cantwell & Baker, 1984; El-Guebaly, & Offord, 1980; Kraemer Tebes, Kaufman, Adnopoz, & Racusin, 2001; Rutter & Quinton, 1984; Sameroff, Barocas & Seifer, 1984). As Hindle (1998) has recognised, a linear model of causation oversimplifies the complexity of the situation. The mental health problems of one person do not, as such, cause disturbance in their children.

It has also been argued that it is difficult to separate the direct effects of parental mental illness, including suicidal tendencies and homicidal delusion, from the indirect effects of marital disharmony, separation due to hospitalisation, unemployment, impaired parenting, disrupted parent-child bond, and social disadvantage, as they may be synergistic (Anthony, 1986; Cowling et al., 1995; Dunn, 1993; Hall, 1996; Klein, 1990; Sameroff, Barocas & Seifer, 1984).

A pivotal study by Rutter and Quinton in 1984 was to be the seminal work in identifying the process by which a parent’s mental illness might lead to disorder in the child. It laid the groundwork for many subsequent investigations. Their four-year prospective study was conducted with a representative sample of 137 English-speaking families of newly referred clients where the children at home were aged less than 15 years. Yearly teacher questionnaires (the Rutter ‘B’ scale) were obtained for all the school age children, with the use of classroom controls matched for age and gender. Standardised interviews were
also undertaken yearly with the parents/clients and their spouses. A comparison control group consisted of a cross-sectional representative general population sample of families with 10 year old children who lived in the same geographical areas. The study had very low failure rates in the data collection phases. Nevertheless, the use of teacher and parent reports may have meant that parental, and even teacher perceptions, were mediated by self-perceptions.

The most common parental psychiatric diagnosis found in Rutter and Quinton’s (1984) study was depression (47%), and personality disorder (56% of male clients, and 24% of female clients) followed by phobic anxiety (15%). Schizophrenia and manic-depressive psychosis accounted for 10% and 5% of the diagnoses respectively. The spouses of the clients also showed a higher rate of psychiatric disorder than that of the general population. The husbands of female clients had a high rate of personality disorder (22%). In contrast, the wives of male clients showed a higher rate of affective disorder (Rutter & Quinton, 1984).

The major findings of Rutter and Quinton’s (1984) influential work were an increased rate of emotional and behavioral disturbances and significantly greater risk of developing a mental illness during childhood for COPMI, and a high level of marital discord between parents. Just as significantly, however, they found that approximately one third of the children did not suffer any form of disturbance, and that the major risk for COPMI was not from the parent’s mental illness, but from associated psychosocial disturbances such as marital discord and disturbed family relationships.

**2.6 OUTCOMES FOR THE CHILD WHO EXPERIENCE****

**PARENTAL MENTAL ILLNESS**

As noted above, children and adolescents of parents with mental illness may develop a number of psychosocial problems and/or disorders. It has been estimated that approximately 25%-50% of COPMI will experience some kind of mental health problem throughout their life, compared to 10%-20% of the general population (Worland, Weeks & Janes, 1987), revealing that COPMI are more likely to suffer mental health problems than other children (Cantwell & Baker, 1984; Rutter & Quinton, 1984). In their study,
Rutter and Quinton (1984) identified three levels of risk for children, where one third experienced psychiatric disturbances, a third had transient psychosocial problems, and a third demonstrated no disturbances. More recently, with a racially diverse sample Mowbray et al. (2004) identified five clusters of psychosocial outcomes for adolescent children of mothers with a range of serious mental illnesses including schizophrenia, bipolar disorder, schizoaffective disorder, and depression. The largest cluster of children (30%) appeared socially and academically competent with no psychosocial problems. A further 22% were ‘average’ in functioning but were adult-oriented. Mental health problems were evidenced in 15% of the children and 27% had possible behavioural disturbances. Only 4.8% of children were socially isolated. In this study then, over half the children were functioning reasonably well across a range of social, behavioural, academic and mental health domains although their mothers were in treatment, which may have increased their functioning, and there was no normative control group with which to compare the sample group of children. Falkov, Mayes, and Diggins (1998) has also identified five groups of risk for COPMI, which ranged from being ‘well’, through to ‘resilient but needing support’, ‘vulnerable and needing services’, ‘vulnerable and needing services and protection’, and lastly, ‘children who have been killed’. Importantly, this model recognised that a child may move along the spectrum depending on the impact of individual, parental and support factors.

Research has also consistently revealed little correlation between the type of parental mental illness, and the type of disorder the child may develop (Cantwell & Baker, 1984; Rutter & Quinton, 1984). In particular, parental psychotic disorders are not a homogenous group, and the effects of the major psychotic illnesses are believed to differ in their impact on children (Grunebaum & Cohler, 1982). It should be noted, however, that many of the following studies, whilst illuminating, have been conducted with clinical samples which may not represent the diversity or severity of parental mental illness in the broader community.
A number of large-scale follow-up and/or prospective longitudinal studies\(^2\), which are particularly helpful in tracking changes over time, have focused on the children of parents with schizophrenia. Findings include that children of these parents may develop a variety of psychiatric diagnoses, and that these tend to be the more serious and persistent mental disorders. They include schizophrenia (particularly paranoid), schizo-affective disorders, schizophreniform psychosis, schizotypal, paranoid and schizoid personality disorders, major depression, substance abuse and dependence, post-traumatic stress disorder, phobias, non-psychotic mood disorder and atypical psychosis (Anthony, 1986; Higgins et al., 1997; Parnas et al., 1993; Rutter & Quinton, 1984). Schizophrenia-spectrum disorders and anxiety disorders have also been found to be more prevalent for adolescent children of parents with schizophrenia than those of parents with non-schizophrenic disorders or no mental disorder (Hans, Auerbach, Styr, & Marcus, 2004).

Studies examining the impact of parental affective disorders have found these children may experience similar disorders to those of children whose parents have schizophrenia, although Kauffman, Grunebaum, Cohler and Gamer (1979) found that children of depressed mothers appeared to suffer more decline in intellectual performance than children of mothers with schizophrenia. Kauffman et al. hypothesized that the impact of maternal apathy and lethargy due to depression was more negatively influential than the cognitive disturbance of schizophrenia. Similarly, Grunebaum and Cohler (1982) found that children of mothers with depression were more vulnerable on measures of intellectual functioning and attention compared with children whose mothers had schizophrenia. Increased rates of mental disorders have also been found in children of parents with bipolar disorder (Duffy, Alda, Kutcher, Fusee, & Grof, 1998; Hillegers et al., 2005). Billings and Moos (1983) found that children of depressed parents exhibited depression and anxiety, whilst Rosenbaum et al. (2000) found that children of parents with major depression and panic disorder were more likely to exhibit behavioural inhibition, considered a precursor to anxiety disorders.

\(^2\) However, as the diagnostic criteria/nomenclature used to identify mental disorders in these studies has changed over time, there is some difficulty in accurate comparison of diagnoses from more recent studies (1990s & 2000s) to earlier ones, e.g. 1970s.
One of the few follow-up studies investigating the comparative effects of both paternal and maternal major depression on their adolescent and young adult children (Klein, Lewinsohn, Rohde, Seeley, & Olino, 2005) found that maternal major depression was significantly associated with the child developing major depression, whilst paternal major depression was also significantly associated, although only among children whose depressive episodes were of moderate or greater severity. The study confirmed previous findings of an increased risk of major depression for children of parents with major depression.

Studies that have included both major parental psychotic mental illness and/or other mental illness have discovered similar rates and types of disorder in the children. Rutter and Quinton (1984) found higher rates of conduct disorder in boys than girls of parents with a variety of mental disorders. Anthony (1986) found varying responses to parental psychosis, where some children experienced various long-term issues such as anxiety episodes, phobias, paranoid schizophrenia, post-traumatic stress disorder and difficulties in adult personal relationships, whilst others appeared to do well both personally, academically and occupationally.

The child’s psychosocial functioning too may be adversely affected by parental mental illness. Children of parents with mental illness have been found to have higher rates of academic problems, peer interaction problems, and school discipline problems than children of non-mentally ill parents (Billings & Moos, 1983). Children’s capacity to form interpersonal relationships has also been linked with parental mental illness (Grunebaum & Cohler, 1982). In a comparison of children of unipolar depressed, bipolar, medically ill, and ‘normal’ mothers, Anderson and Hammen (1993) found that children of women with unipolar depression displayed significant problems in psychosocial functioning compared to the other groups. Depression in the mother has also been linked with impaired attention in the child, although as these researchers subsequently acknowledge, the number of participants in the studies conducted were so small as to not be generalisable (Grunebaum, Cohler, Kauffman, Gallant, 1978; Grunebaum & Cohler, 1982).
Children of mentally ill parents have additionally been found to have an increased suicide rate related to both the genetic and psychosocial stresses of their parent’s illness. They have also been found to have feelings of fear, a sense of isolation, and often significant responsibility and burden through, for example, parentification (Anthony, 1986; Drake, Racusin & Murphy, 1990; Rossow & Lauritzen, 2001). These issues will be further explored in the discussion on COPMIs’ subjective experiences.

2.7 STRENGTHS AND PROTECTION

The review of the literature discussed so far has revealed a dominant thread where problematic and negative effects for the child have been considered to result from the biopsychosocial effects of parental mental illness. Given the hegemony of problem-based medical research, it is perhaps not surprising that the initial focus of research from the psychiatric perspective was on risks rather than potential benefits or positive outcomes that may have occurred.

Indeed, it was only through an unexpected discovery of children who were functioning well that researchers developed an awareness that not all children were negatively affected by their parent’s illness, and would not necessarily go on to develop future adverse psychosocial problems (Feldman, Stiffman & Jung, 1987; Silverman, 1989). Various superlatives were coined to describe this group of children who had increasingly become of interest to researchers. These include the ‘invulnerable’ (Anthony & Koupernik, 1974; Garmezy, 1974), ‘superphrenic’ (Karlsson, 1968), or ‘superkids’ (Kauffman et al., 1979). These terms described children considered to be outstanding and who functioned even more successfully than those who had parents without mental illness, a claim that was perceived to demonstrate the plasticity and unpredictability of human development over time (Grunbaum & Cohler, 1982; Kaufman et al., 1979).

The concept of ‘exceptional’ children, whilst intriguing, was subsequently seen as misleading in that the ability of the child to avoid risk associated with parental mental illness was not necessarily permanent. A developmental progression could occur, where vulnerabilities and/or further strengths emerged in the child according to changes in life
circumstances (Feldman et al., 1987; Luthar, Cichetti, & Becker, 2000a; Rutter, 1985). As Feldman, Stiffman and Jung (1987) have commented, the use of terms such as ‘superkid’, invulnerable’ and ‘superphrenic’, whilst dramatic and attention-getting, appeared to have hindered rather than enhanced systematic research into the impact of parental mental illness as they resulted in contradictory and inconsistent criteria being applied in the research of invulnerable children. As Feldman et al. (1987) also pointed out, these labels were not immutable, and the child’s status could change over time.

Subsequent to these discoveries, over time the language used in the literature have shifted from the previously absolute concept of ‘invulnerability’, to the more relative one of ‘resilience’ (Rutter, 1985; Luthar et al., 2000a). Further to this, resilience itself has been proposed to exist in varying degrees within a spectrum of ‘successful’ outcome (Osborn, 1990).

2.7.1 Becoming resilient

Although it has not come to prominence until more recently, the concept of resilience has been present in the literature for more than thirty years. As illuminated in the previous section, the empirical literature studying the effects of parental mental illness on the child played a significant role in the emergence of childhood resilience as a theoretical construct (Luthar et al., 2000a). The psychologist Garmezy has been recognised as a pioneer in resilience research, being one of the investigators who, having studied the effects of parental mental illness, found there were children who seemed to thrive even in the face of severe stress (e.g. Garmezy, Masten, & Tellegen, 1984). This finding illustrates an important facet of resilience research generally in that it has been concerned not only with the absence of dysfunction, but also with exploring the dimension of wellness itself (Luthar et al., 2000b). This is a characteristic distinguishing it from the previously cited problem-oriented research on the effects of parental mental illness on the child. The construct of resilience heralded a change in research focus where parental mental illness began to be recognised as not necessarily deterministic of future difficulties for the child.
There have been a number of operational definitions of resilience over time. Resilience has been described as an ability to rebound from adversity and overcome difficult circumstances in one’s life (Marsh, 1996). Resilience has also been viewed in terms of two major concepts, those of competence and vulnerability. Children who were vulnerable due to risk yet achieved ‘competence’ were deemed resilient (Osborn, 1990). More recently, resilience has been viewed as a complex cultural construct that involved the dynamic interaction between individual or family maintenance of positive adaptation despite experience(s) of considerable adversity (Deveson, 2003; Luthar et al., 2000; Marmion & Joyce, 2001; Marsh et al., 1996). This definition notably includes the concept of the family as a group, rather than just the individual having the ability to demonstrate resilience.

As with the effects of parental mental illness on the child, resilience, whilst primarily discussed in the literature from a psychosocial framework of resources such as personality traits and characteristics, personal abilities, and the presence of support external to the child, has also been discussed from a biological/genetic framework. Rende and Plomin (1993) for example, argued there might be genetic contributions to resilience that served to protect some children in families where there was risk of the child developing negative outcomes such as psychopathology when parents had a mental illness.

### 2.7.2 Protective factors

Protective factors are influences that are able to modify, alter or improve an individual’s response to an external risk which may have otherwise predisposed them to a negative outcome (Rutter, 1985). In terms of parental mental illness, protective factors are the specific resources the child may have or experience that can support them in developing and maintaining resilience (Brooks, 1994). A number of protective factors have been considered to mediate the more negative effects of environmental stress including that of parental mental illness (Rutter & Quinton, 1984; Thompson & Calkins, 1996). These can be separated into internal factors within the child and external resources accessed by the child that support the development and maintenance of the construct of resilience.
There is a large body of work from psychology indicating that internal psychological factors are effective in providing protection against adversity and strengthen resilience (Beardslee & Podoresky, 1988; Dumont & Provost, 1999; Fonagy, Steele, Steele, Higgit & Target, 1994; Luthar & Zigler, 1991; McGrath, 2001; Rutter & Quinton, 1984; Seligman, 1995; Thompson & Calkins, 1996; Werner, 1995). These include higher intelligence, a belief in one’s own effectiveness (internal locus of control), ability to be autonomous, being optimistic, having a low risk or ‘easy’ temperament, using effective communication and problem-solving, having a sense of humour, involvement in social activities and commitment to relationships with others, having a special interest or hobby, having high self-esteem and positive self-concept, substantial self-understanding, and the ability to manage emotional regulation.

Related to these factors is the concept of ‘emotional intelligence’ (Goleman, 1995). Gardner (1993) has constructed this in terms of having interpersonal (between) and intrapersonal (within) intelligence, two of seven multiple forms of intelligence he identified. Furthermore, the work of Seligman (1995) has been pivotal to advances in understanding the protective influence of optimism and how it may impact on the child’s ability to be resilient, deal with adversity, and enhance his/her emotional intelligence. In his influential text on optimism in children (1995), Seligman conducted research into learned helplessness and argued that children could be psychologically ‘immunised’ against the effects of stress by developing personal mastery through the use of optimism. Seligman defined optimism as containing the fundamental feature of the way a person thinks about causes. He contended that the explanatory style a child developed to explain why positive or negative events occurred was used throughout life, unless mediated by intervention. Thus, optimistic children held explanatory styles that included the belief that negative events were temporary rather than permanent, were local rather than generalised, and externally created rather than personal. The important feature of Seligman’s argument was that children, even if temperamentally prone to pessimism, could be taught to develop cognitive thought patterns that provided resistance to becoming depressed in later life.
External protective factors for resilience include those within the family and community that may enhance the child’s resilience. These include a positive relationship with a caregiver such as the mother, positive sibling relationships and support, reading and interest in literature, use of music, and support and positive feedback from other adults (Hindle, 1998; Inoff-Germain et al., 1997; Kauffman et al., 1979; Silverman, 1989; Werner, 1995). Social support in general, however, has not necessarily been found to be consistently protective across studies (Dumont & Provost, 1999). Nevertheless, the opportunity to establish a close bond with a competent and emotionally stable person, particularly schoolteachers, has been considered an important protective factor for many resilient children. The development of affectional ties with other adults throughout development has been found to provide the child with caring and positive role models who reinforced the child’s competencies and affirmed their intrinsic worth (Anthony, 1987; Kauffman et al., 1979; Werner, 1995).

The final section of this review moves now to hearing the voices of children of parents with mental illness and what is currently understood of their experiences.

**Amazing revelations…**

Sharon and I sit quietly on the floor in the small, cluttered room of mum’s bedsit, listening to her as she goes on and on about lots of things. It feels like we’ve been sitting here for ages. She’s talking about the bible now. She holds it up in front of us, opened at a particular page. ‘Yes. Here we are. In the Book of Revelations. See? The number 6. 6 children, our family is 6.’

‘Wow’, I think. That’s pretty interesting. Who would have thought our family was in the Bible? Isn’t Revelations about the devil? I puzzle for a minute. But wasn’t the bible written a long time ago? I guess mum would know. But I thought it was written, like, ages ago, before we were born.

I look at the unmade bed, table piled with books and paper, the cork board tacked full of newspaper clippings, and then move round on the floor, trying to get more comfortable. My knees hurt from kneeling.
Mum’s loud, angry voice jolts me out of my thoughts ‘Kim! Wipe that smirk off your face!’ I sit up quickly and glance at Sharon, whose blue eyes look huge in her small face. I hate getting in trouble. She’s said that a few times now.

What’s smirking? What does she mean? If only I could work out what it is.

Is it smiling? I’m not smiling. I’m trying to look serious.

I sit up straighter and try and keep my face blank. Does she think I’m laughing at her?

She carries on, ‘See, and here we are. They’re writing about us too.’

She holds up a newspaper cartoon. I lean forward and try and see what’s on it. Have they really said that about us? I wonder how they know about us?

Who would want to write about our family?

The room’s getting darker. It’s time to go and catch the bus back to the home. Sharon and I say good-bye to mum and cross the road and walk up to the bus-stop. When we get to the other side, away from mum’s place, we look at each other and start to giggle, letting out big sighs of relief.

‘Whew, I’m glad that’s over. Do you reckon that was true – the stuff about the bible, and the cartoons?’ she says, looking up at me.

I shrug. ‘Don’t know. It was kind of strange don’t you think? Some of it was pretty weird.’

2.8 SUBJECTIVE EXPERIENCES OF CHILDREN OF PARENTS WITH MENTAL ILLNESS

‘Your mum is weird!’, and I said ‘Yes, she’s gone to the loony bin.’ I feel really guilty about that now, but I was only 13. I didn’t know what was really happening, so how could I explain it to them?”


As demonstrated clearly in the preceding review, there has been considerable attention and research directed at understanding the effects of parental psychopathology on the developing child, and the implications this may have for children’s adverse outcomes, resilience and coping. Given it has been argued by these researchers that there are significant risks for the child in terms of their psychosocial development and consequent behaviour, it is intriguing there has been comparatively little attention directed at understanding the experience from the perspective of the children themselves. It appears that one factor may be that the qualitative/’subjective’ research required to explore
children's experiences has not been seen as credible in comparison to quantitative/‘objective’ methodology. For example, Beardslee et al. (1983) did not include retrospective accounts of childhood from adults with affective disorder in their review as they considered it possible that these accounts would so influenced by the person’s clinical state as to be inaccurate. This perspective in empirical research may be seen as disempowering of the individual, reflected a paradigm that has focused on objectivity.

Arguably, from a socio-cultural model of health the knowledge accumulated from empirical research has privileged diagnosis, risk and treatment, but overlooked understanding of the human experience, protective factors, and resilience. In their review, Mordoch and Hall (2002) affirm my own analysis that the problem-focused emphasis in the empirical literature has resulted in children’s perspectives being largely ignored, although this has begun to change more recently.

Subsequently, there have been comparatively few qualitative investigations into the experiences of children and adolescents of parents with a mental illness, although in recent years interpretive studies into this area have increasingly been produced, most of which has been conducted by nurse researchers and other allied health professionals (Aldridge & Becker, 2003; Beardslee & Podorefsky, 1988; Cogan, Riddell & Mayes, 2005; Farrell et al., 1999; Fudge & Mason, 2004; Garley, Gallop, Johnston, & Pipitone 1997; Maybery, Ling, Szakacs, Reupert, 2005a; Meadus & Johnson, 2000; Polkki, Ervast, Huuponen, 2004; Riebschleger, 2004; Shih, 1995; Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004; Valiakalayil, Paulson, & Tibbo, 2004). This may reflect nurses’ and other allied health professionals’ awareness of, and concern for, the subjective experience of clients, rather than a medical focus on epidemiology, risk, protection and treatment.

Notwithstanding the relative paucity of research and respective differences in focus, a number of studies unfortunately also do not develop or even refer to each other’s work, although researchers have clearly made attempts to remedy this omission in the more recent studies. It is important to note then that the following research findings into children’s experiences do not necessarily build on each other’s findings.
The first study to explore children’s experiences of their parents’ mental illness was by Beardslee and Podorefsky in 1988. As part of a larger study investigating the impact of serious parental affective illness on children, they interviewed eighteen adolescents who had demonstrated considerable resilience, asking them about their experience, awareness and understanding of their parents’ illness and coping strategies.

Major findings of the study by Beardslee and Podorefsky (1988) included participants’ description of their experiences of parental mental illness specifically in terms of changes to their parent’s behaviour or attitude including feelings of sadness, irritability, lack of energy and excessive drinking. These adolescents also identified disruptions to their own lives as a consequence of their parent’s illness such as economic hardship, moving house, and a lack of the parent’s involvement and awareness. They described their experience in terms of feeling disillusioned, confused and helpless. Many of the participants described the loss of a role model, and the lack of availability of the parent to do usual household tasks. They reported feelings of anger and frustration about not understanding what was happening, and needing to turn to another person (such as an adult outside the family, or a sibling) when their parent was ill in order to gain comfort or to try and make sense of the experience. Participants saw these relationships as extremely important as they enabled them to separate from their parents. Many participants also assumed a caretaking role in the family, including caring for younger siblings. Subsequently, two of them were intending to pursue careers in helping professions. Beardslee and Podorefsky (1988) concluded that although these COPMI had faced adversity, they had demonstrated substantial self-understanding, a commitment to relationships, and the ability to think and act independently from their parents.

In 1995, Shih conducted a phenomenological study into the experiences of fifteen Chinese children (6 girls and 9 boys, from 9 – 18 years) in Taiwan who had parents with primarily serious mental illnesses (schizophrenia (7), bipolar disorder (4), schizoaffective disorder (2) and alcohol/substance abuse (2). Three essential themes emerged as characteristic of their experiences. These were ‘disruption of the family’, ‘experiencing the consequences’, and ‘coping with parental mental illness’. Similarly to Beardslee and Podorefsky (1988), Shih (1995) found that the children experienced a disrupted life in
terms of PMI, as well as a disruption to family life and family atmosphere. They also experienced strong emotional disturbances of helplessness and a sense of uncertainty and feeling unloved. Whilst they also took on a caretaking role within their families, they reported having at least one other significant caregiver(s) who sustained their well-being. The children coped with their experiences in a variety of ways, including separating themselves from their parent’s illness, learning to be independent, and using religious teachings.

In 1997, Garley et al. investigated the experiences of six adolescents, two of whom had mothers who had depression, and four whose fathers had depression (1) or manic depression (3). Being one of the few published studies into COPMI experiences, some of the following studies have also compared their findings with these. Four major themes emerged from the study: ‘Understanding the illness’, ‘Recognising the signs’, ‘Impact of hospitalisation’, and ‘Managing the illness’. Participants saw their parent’s illness as having negatively affected both their academic performance at school, and their behaviour. They were concerned about their own genetic risk of developing the illness. There were varying understandings of the causality of a mood disorder, and it was also apparent that these children craved information about their parent’s illness. The most important issue in ‘Understanding the illness’ was that the participants feared their parents would separate, and similarly to Rutter and Quinton (1984), Garley et al. (1997) questioned whether it was marital separation and family breakdown or the parental mental illness that exerted the greatest impact on children.

‘Recognising the signs’ was a theme that referred to the child’s ability to know when the parent was becoming ill, and feeling reassured that any subsequent negative behaviour was a reflection of the illness, rather than being personally focused on the child. Unlike some other studies, these participants, due to feelings of relief, generally felt the impact of hospitalisation was positive as either they or their parent were being cared for (Garley et al., 1997).

‘Managing the illness’ included participants’ sense that friends were an important source of support, that denial was a common defense mechanism to manage their discomfort
about their parent’s illness, and that support groups were a safe place to share common problems and experiences. These adolescents used diversionary activities such as watching television, reading and playing sport as additional methods that helped them to cope. Many participants felt burdened by the parental illness, and experienced role reversal with an increased level of responsibility (parentification), which was resented at times. They did understand, however, the chronic and often intractable nature of the parent’s mood disorder, recognising it could be managed rather than cured (Garley et al., 1997).

In one of the first published Australian studies on COPMIs’ subjective experiences, and in a development of Garley et al’s (1997) work, Farrell et al. (1999) identified seven themes of the experiences of four adolescent girls. Four themes were the same as Garley et al’s. In addition, three new themes were found; ‘Ripple effect of mental illness on the whole family’, ‘Stigma and isolation’, and ‘Support services required’. These adolescents recognised that their parent’s mental illness affected all members of the family, which affected the family structure and alliances between family members. A sense of isolation, both within and outside the family, was also experienced. The adolescents identified the need for further support from both school and teachers, as well as from family members, and outside agencies who could supply support groups and counselling for them.

In 2000, Meadus and Johnson (2000) identified three phenomenological themes in relation to three female adolescents’ experience of living with a parent with mood disorder. These were ‘Unavailability of the ill parent’, ‘Lack of knowledge and understanding’, and ‘Coming to terms’. Supporting the findings of previous research, these adolescents also struggled to cope with their parent’s illness, felt frustration and uncertainty due to lack of knowledge about their parent’s illness, experienced great disruption to family life, and felt a strong sense of responsibility in taking on the roles their parents were unable to fulfill.

More recently, there has been a growing emphasis on exploration into children’s experiences of parental mental illness, sometimes as a result of researchers’ recognition of unanticipated areas of need arising from larger studies. As the findings from the
previously cited subjective experience studies also indicated, carer burden and
parentification emerged as concerns for children and adolescents in families where
parents have a mental illness, and become a further focus for investigation. Riebschleger
(2004) for instance, reported four main themes from the experiences of twenty two
adolescents whose parents had primarily been diagnosed with bipolar disorder and major
depression (16), and schizophrenia (4). These were ‘good days’, where parents were
doing well and children felt happy and interacted positively with them, and ‘bad days’,
where parents were not doing so well and were less attentive, irritable and angry. At these
times children felt sad, worried, confused or angry, and tried to ignore, avoid or reduce
the family stress, sometimes increasing their caregiving behaviours. The third theme of
‘views of psychiatric disability’ included parents’ symptoms being perceived by the
children as resulting in less attention from them, and their fear that when parents’
symptoms worsened they would be hospitalised and/or become suicidal, and/or the child
would be moved to another home/setting. Most of the children reported never having
been told of their parent’s illness until they entered a prevention program.

The fourth theme, ‘perceptions of psychiatric rehabilitation’, included their limited
knowledge of parents’ treatments and very limited understanding of reasons for parents’
hospitalisation. The children also reported that their parents’ mental illness was only one
of a number of concerns for them, and similarly to Garley et al. (1997), they were often
more concerned with associated psychosocial issues such as parental divorce and poverty,
being teased by school peers, and having to move house frequently. Some children also
blamed themselves for their parent’s illness and were concerned about inheriting it.

Findings from other recent studies, although they do not always refer to the previous
work, can be seen to support many of the previous findings. Stallard et al. (2004) for
example, reported that in their study with twenty six children (10 girls and 16 boys
between 6 -17 years of 24 parents with a range of mental illnesses including mood
disorders (15) and psychoses (6), were concerned about their parents, had little
understanding of their parent’s illness, and the majority wanted more information about
the illness.
In a rare comparative study with ‘non-affected’ children, Cogan, Riddell and Mayes (2005) found that 20 adolescent COPMI understood their parents’ mental illness in a variety of ways. The six major themes included ‘alternative choice of language’ (e.g. using terms such as ‘bad days’, ‘problems’, ‘sadness’, ‘sick’ or ‘stress’ to describe their parent’s problem), and ‘distinction from physical health problems’, where the children drew comparisons with physical health problems to illustrate their understandings of mental health problems. The third theme was ‘source of understandings’ which referred to their understandings of their parent’s illness as being primarily grounded in their experiences of living with them. Similarly to Riebschleger’s (2004) findings (although her study was not referred to), some children referred to there being ‘good days and bad days’ at home. Findings also included that these children, in contrast to those in Garley et al’s (1997) study, did worry about their parents when hospitalised and felt scared and unsafe. Cogan et al. (2005) concluded that these children were less likely to hold stigmatising views of people with mental illness due to their personal experiences.

Recent Australian studies have also sought the opinions of COPMI with regard to their experiences, needs and coping mechanisms. Major findings from a study by Fudge and Mason (2004) with twenty six COPMI between 7-20 years included increased care-giving responsibilities, lack of practical and emotional support for the family, communication difficulties between families and with service providers, and the need for education and stigma reduction for mental illness. Similarly to other qualitative studies and the empirical research, the presence of supportive adults and peers, ‘time out’, having activities, being given information, and having someone to talk to were found to be helpful in coping when the parent was unwell (Fudge & Mason, 2004). In a further study with twelve children between 6-16 years whose parents (12) had a variety of mental disorders including mood disorders (5), and a psychotic disorder (1), Maybery et al. (2005a) identified major themes such as ‘major episodes’ (including hospitalisation), ‘importance of siblings and friendships’, ‘coping strategies’, and ‘extra roles assumed when parents unwell’. The negative impact of medications on parents’ physical and emotional availability was a common issue, and of note, the children found sibling relationships to be particularly positive and helpful supports.
The experiences of COPMI who care for and provide assistance to their ill parents has also been the focus of research, although children have often been overlooked in terms of family experiences of burden and work has been limited in this area. In a key study with forty young carers (27 girls and 13 boys ranging from 10 to 19 years) whose parents had severe mental illness (primarily affective disorders), Aldridge and Becker (2003) reported a number of significant findings. Similarly to previous research, some children had experienced stigma and discrimination related to their parents’ mental illness from schoolmates, friends and others in the community. Although 16 of the 40 children described negative caring experiences with their parents, half of the young carers described positive experiences, and more than half described having strong relationships with their ill parents. In contrast to some of the previous findings, there was no evidence of physical abuse of these children and only 4 children described their caring responsibilities in terms of parentification and role reversal. Notably, Aldridge and Becker (2003) concluded that rather than being totally negative experiences, COPMI’s caring relationships with ill parents could facilitate secure attachments with them and help to allay concerns about the mental illness, and their role adaptations suggested a mixture of positive as well as negative experiences.

In contrast, findings from a study of 13 adolescent children whose parents had schizophrenia (Valiakalayil, Paulson & Tibbo, 2004), included that these adolescents did experience subjective burden through having lack of information about their parent’s illness, found it difficult to deal with their parent’s symptoms (including delusions and hallucinations), and were concerned about their parent’s welfare. Those adolescents living with their ill parents also reported objective burden in terms of role changes from taking on additional, more ‘parental’, responsibilities in managing the household. Some adolescents reported feeling ‘unconnected’ to their ill parent, and embarrassed and concerned about their parent’s behaviour when they were psychotic. Although they coped with their experiences through praying, journalling, reflecting quietly, talking with siblings, friends or other family members, these adolescents reported these were not adequate in alleviating their concerns and they would have found further information on the illness and additional support helpful. Nevertheless, many of them also reported positive aspects to their relationships with parents, including feeling closer to them and
having learnt important lessons through understanding and accepting the impacts of their parent’s illness. Valiakalayil et al. acknowledged that follow-up studies investigating children’s burden would be important as they grew into adulthood. See Table 2 for a summary of the studies on COPMIs’ subjective experiences, including criticisms and limitations.

In summary, the findings from these qualitative investigations and reports, apart from the studies by Shih (1995) and Valiakalayil et al. (2004), were primarily conducted with adolescent children of parents with affective disorders. They highlight a number of issues for COPMI. The lack of understanding of the illness and its effects on the parent’s behaviour can lead to confusion, misunderstanding, and a sense of powerlessness and lack of control over their lives. The child’s increased responsibility and assumption of caring roles for the parent and family may also result in both subjective and objective burden, although this is not inevitable and they may also experience benefits from these experiences. The ambivalence of feeling anger and fear toward the parent, coupled with love and loyalty, can result in an invidious position for some children where they may compromise their emotional development in order to protect their parent. All these issues can, however, contribute to the child’s and family’s social isolation, which may be further compounded by stigma and ignorance from other family members, peers, and acquaintances. This isolation may be exacerbated by a lack of access to mental health services and information and support from health professionals.

2.9 CONCLUSION

In conclusion, this review of the literature has revealed a number of constructs which in the first instance focused on attachment and developmental needs and the potential deficits and risks for children in relation to parental mental illness. Strengths and protection from these problems has also been explored, and finally, the developing body of research into the subjective experiences of children of parents with mental illness has been discussed and critiqued. The following chapter continues and develops this discussion through exploration of the more limited literature on adult children of parents with mental illness.
Table 2.2: Summary of COPMI subjective experience studies

<table>
<thead>
<tr>
<th>Author/s</th>
<th>Methods</th>
<th>Findings</th>
<th>Criticisms and/or limitations</th>
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<tbody>
<tr>
<td>Beardslee &amp; Podorefsky (1988)</td>
<td>Part of larger study Structured interviews</td>
<td>Experiencing changes to parent’s behaviour</td>
<td>Lack of explanation of methodological processes</td>
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<td></td>
<td>Content analysis</td>
<td>Disruptions to own lives</td>
<td>Limited content analysis approach to data constricted scope and depth of experiential information</td>
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<tr>
<td></td>
<td></td>
<td>Feeling disillusioned, confused, helpless, angry, frustrated</td>
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<td>Not understanding what’s happened</td>
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<td>Loss of a parental role model</td>
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<td>Needing to turn to others</td>
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<td></td>
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<td>Assuming a caretaking role</td>
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<td></td>
<td>In depth interviews</td>
<td>Disruption of the family</td>
<td>Has not contributed to development of wider understandings</td>
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<tr>
<td></td>
<td>Analysed using Colaizzi, van Manen and Giorgi methods</td>
<td>Experiencing the consequences</td>
<td></td>
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<td></td>
<td></td>
<td>Coping with parental mental illness</td>
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<tr>
<td>Garley, Gallop, Johnston, Pipitone (1997)</td>
<td>Exploratory descriptive pilot study</td>
<td>4 major themes:</td>
<td>Participants had parents with mood disorder only</td>
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<tr>
<td></td>
<td>Semi-structured focus groups using ethnographic approach</td>
<td>Understanding the illness</td>
<td></td>
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<td></td>
<td>4 x one week intervals</td>
<td>Recognising the signs</td>
<td></td>
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<td></td>
<td>Coding for themes</td>
<td>Impact of hospitalisation</td>
<td></td>
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<td></td>
<td></td>
<td>Managing the illness</td>
<td></td>
</tr>
<tr>
<td>Farrell, Hankey, Hazleton, Johnson &amp; Josephs (1999)</td>
<td>Stage 2 of larger study</td>
<td>7 themes (3 new*):</td>
<td></td>
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<tr>
<td></td>
<td>Focus groups and individual interviews</td>
<td>Struggle to understand mental illness</td>
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<tr>
<td></td>
<td>Modified, extended version of Garley et al’s themes</td>
<td>Managing the illness</td>
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<td></td>
<td></td>
<td>Recognising the signs</td>
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<tr>
<td></td>
<td></td>
<td>Impact of hospitalisation and separation from parent</td>
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<td></td>
<td></td>
<td>*Ripple effect of mental illness on whole family</td>
<td></td>
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<td></td>
<td></td>
<td>*Stigma and isolation</td>
<td></td>
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<td></td>
<td></td>
<td>*Support services required</td>
<td></td>
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<tr>
<td>Reference</td>
<td>Methodology</td>
<td>Themes/Findings</td>
<td>Sample Notes</td>
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<tr>
<td>Meadus &amp; Johnson (2000)</td>
<td>Phenomenological study 2 unstructured interviews Analysed used Giorgi method</td>
<td>3 essential themes: Unavailability of the ill parent Lack of knowledge and understanding Coming to terms</td>
<td>3 female adolescent participants with parents with mood disorder only Does not refer to Garley et al’s study</td>
</tr>
<tr>
<td>Riebschleger (2004)</td>
<td>Secondary analysis from earlier study Individual interviews or focus groups Analysed using Strauss and Corbin’s open, axial and selective coding system</td>
<td>4 main themes: ‘Good days’ ‘Bad days’ Views of psychiatric disability Perceptions of psychiatric rehabilitation</td>
<td></td>
</tr>
<tr>
<td>Stallard, Norman, Huline-Dickens, Salter, &amp; Cribb (2004)</td>
<td>Part of a larger study with parents with mental illness Children given semi-structured interviews &amp; Strengths and Difficulties questionnaire &amp; Birleson Depression Inventory</td>
<td>Issues and themes from interviews: Understanding of the parent’s illness Children’s wishes and worries Emotional and behavioural problems Effect upon parent-child relationship Sibling relationships and peer friendships</td>
<td>Some confusion with use of terms to describe themes Lack of explicit sampling strategy</td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Findings</td>
<td>Issues and Themes</td>
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<td>-------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
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<tr>
<td>Fudge &amp; Mason (2004)</td>
<td>One phase of national consultation process with COPMI</td>
<td>Some issues and themes for various questions:</td>
<td>Some demographic information not recorded</td>
</tr>
<tr>
<td></td>
<td>Structured focus groups and peer interviews</td>
<td>Increased care-giving responsibilities</td>
<td>Some inconsistency in data collection between focus groups</td>
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<tr>
<td></td>
<td>Thematic analysis</td>
<td>Communication problems within families</td>
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<td></td>
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<td>Need for extra help for family</td>
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<td>Coping methods</td>
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<td>Lack of support services and facilities</td>
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<td></td>
<td>Need for universal education and stigma reduction</td>
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<tr>
<td>Maybery, Ling, Szakacs &amp; Reupert (2005a)</td>
<td>Qualitative part of mixed methods study with parents and children</td>
<td>5 themes:</td>
<td>Some demographic information not recorded</td>
</tr>
<tr>
<td></td>
<td>Aimed to replicate Fudge and Mason’s findings</td>
<td>Major episodes (e.g. parent’s hospitalisation)</td>
<td></td>
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<tr>
<td></td>
<td>Structured focus groups and brief questionnaire</td>
<td>Importance of siblings</td>
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<td></td>
<td>Content analysis for themes</td>
<td>Coping strategies employed by COPMI</td>
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<td></td>
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<td>Importance of friendships</td>
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<td>Extra roles assumed when parent unwell</td>
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<tr>
<td>Aldridge &amp; Becker (2003)</td>
<td>Two-phase in-depth semi-structured interviews</td>
<td>Main headings:</td>
<td>Focused specifically on young carers of parents with primarily affective disorders</td>
</tr>
<tr>
<td></td>
<td>Analysis not specified</td>
<td>Factors mediating the onset of care by children</td>
<td>Lack of explanation regarding analytical processes and type of findings</td>
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<td></td>
<td>Type of findings not specified</td>
<td>Factors influencing children’s experiences of living with and caring for parents with mental illness</td>
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<td></td>
<td>(e.g. whether themes, issues)</td>
<td>The nature of parent-child relationships</td>
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<td></td>
<td></td>
<td>The effects of caring on children and their needs</td>
<td></td>
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<tr>
<td>Valiakalayil, Paulson &amp; Tibbo (2004)</td>
<td>Pilot study. Part of larger study on schizophrenia</td>
<td>6 themes:</td>
<td>Adolescent children of parents with schizophrenia only</td>
</tr>
<tr>
<td></td>
<td>Semi-structured interviews</td>
<td>Attribution</td>
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<td>Coding for themes</td>
<td>Dealing with symptoms</td>
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<td>Changing roles</td>
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<td>Personal feelings</td>
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<td>Coping strategies</td>
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<td>Positive aspects of the relationship</td>
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CHAPTER 3
LIKE CANDLES IN THE WIND: REVIEW OF THE LITERATURE ON ADULT CHILDREN OF PARENTS WITH MENTAL ILLNESS

Musical lyrics removed for online publishing due to copyright
Reflecting on Candles in the Wind

Elton John and Bernie Taupin’s famous song, written about the Hollywood-created persona of ‘Marilyn Monroe’, may be read as a mournful remembrance of a woman often considered by others to have a tenuous grip on her sense of ‘self’ and ‘identity’, as indicated by the song’s title phrase “it seems to me you lived your life like a candle in the wind, never knowing who to cling to when the rain set in”. This perception by others that ‘Marilyn’ may have struggled with her sense of ‘self’ and place in the world could in part have been based on her attempted suicides and abuse of drugs, which led to her eventual apparent suicide.

Yet what was not so commonly known was that ‘Marilyn’, whose ‘real’ name was Norma Jean Baker, was also the adult child of a mother with schizophrenia, and her experiences in childhood appear to have had an extensive impact on her sense of ‘self’ and relationships with others. Steinem (1992) recounts that as a child Norma Jean lived in an orphanage and then a series of foster homes, also experiencing sexual abuse, after her mother Gladys was institutionalised for her mental illness when Norma Jean was five. Norma Jean is later reported to have said about this time in her life:

> but when a little girl feels lost and lonely and that nobody wants her, it’s something she never can forget as long as she lives. (Steinem, 1992, p. 37).

The ambiguities and contradictions in these lyrics are synchronous with some of the notions surrounding the experiences of growing up with a parent with a serious mental illness which I will be addressing further in this thesis. The metaphor of the candle wavering in the wind can be seen as alluding to the unstable re-presentation of Norma Jean as ‘victim’ by the media. Yet her ‘sex symbol’ persona does not do justice to the complexity of who she may have been as a person. As the following discussion also suggests, the experiences of adult children whose parents have a serious mental illness are neither predictable nor one-dimensional, and children who develop out of such environments can mature in a variety of ways.
3.1 INTRODUCTION

In a continuation of the aims of Chapter 2, and in a further development of the constructs identified in the previous chapter, the following review uses similar constructs within which to discuss the literature on adult children of parents with mental illness. These are Adult Attachment, Deficits and Risks, Strengths and Protection, and Subjective Experiences. The literature was searched as part of the same strategy used in Chapter 2, contained in Appendix A. As can be seen from the following discussion, there has been far less attention paid to research on the area of adult children of parents with mental illness and much of the work that has been conducted does not build upon previous studies. The understandings of adult children of mental illness to date are therefore far more limited than those of children of parents with mental illness.

3.2 ADULT ATTACHMENT

As previously outlined in Chapter 2, the work on attachment theory has generally supported Bowlby’s contention that the nature of attachment relationships continues across the lifespan, affecting the person into adulthood (Feeney & Noller, 1996; Rutter, 1985). Specifically, attachment style is considered to reflect the adult’s understandings of self and others. This includes their level of self-esteem and self-worth, ability to trust others in close relationships, and motivation to achieve and reach performance goals (Elliot & Reis, 2003; Luke, Maio, Carnelley, 2004). Attachment has also been linked with adult children’s willingness to provide caregiving for aging parents. Caregiving is considered complementary to attachment behaviour in that it operates to protect the attachment figure (Bowlby, 1979). A stronger more secure attachment with the parent has been found to relate to lower subjective burden when caregiving is provided in adulthood, whilst a strong sense of obligation has related to a greater sense of burden, although caregiving can be seen as determined by multiple motives rather than just attachment and/or obligation alone (Cicirelli, 1993).

Longitudinal studies on attachment development in young adults who have experienced negative or stressful life events including parental mental illness and/or substance abuse,
as well as physical or sexual child abuse, parental divorce, and poverty, have found that whilst attachment states can be stable across long portions of a person’s life they are also open to revision in terms of subsequent experiences. Waters, Merrick, Treboux, Crowell, and Albersheim (2000b) and Weinfield, Sroufe, and Egeland (2000) found that whilst childhood secure attachment styles could be significantly related to continuation of secure attachment as young adults, this was not the case for a number of participants who transitioned to insecure attachments after experiencing chaotic life experiences such as parental mental illness. Weinfield et al. (2000) subsequently suggested that these ‘difficult’ life experiences would affect children despite the presence of resilience, although it was possible they might transition later to more secure attachments if they were able to explore the meanings of their negative experiences.

In terms of attachment, the loss of a parent before the age of 5 years, either symbolically through mental illness or actually through death or hospitalisation, has also been linked to an increased risk of adult mental disorder such as depression (Rutter, 1985). Lack of effective parenting, and/or institutionalisation of COPMI have been associated with psychosocial problems in adulthood (Rutter & Quinton, 1984). Adult attachment styles are not necessarily completely determined by caregiving received in childhood, however, (Feeney & Noller, 1996) and children who have been institutionalised or experienced ineffective parenting have not necessarily gone on to experience negative outcomes. The influence of protective factors such as good experiences with social relationships at school, scholastic and other successes, and finding a supportive marital partner in adulthood, have been particularly evident in research as ameliorating the potentially negative aspects of parental mental illness (Rutter & Quinton, 1984).

The following section moves now to outline what is known of the deficit/risk outcomes for adult children who have had parents with mental illness.

3.3. DEFICITS AND RISKS

Compared with the plethora of literature investigating outcomes for COPMI, there has comparatively been far less focus on outcomes for ACOPMI. What is known about adult
children’s psychosocial outcomes has been derived mainly from longitudinal and follow-up studies on COPMI, which have been primarily epidemiological in focus.

Several follow-up studies in various countries have sought to identify the cumulative incidence of schizophrenia in adult children of parents (primarily mothers) with psychotic disorders. This has been found to range from 6.7% - 16.2%, which, in comparison to the previously cited incidence rates in Chapter 2, are considerably higher than those of the general population. The overall incidence of psychotic disorders has also been found to be higher for these ACOPSMI than adults in control groups (Erlenmeyer-Kimling, Adamo, Rock, Roberts, Bassett, 1997; Niemi, Suvisaari, Haukka, Wede, & Lonnvqvist, 2004; Parnas et al., 1993). A higher incidence (7%) of having any type of psychotic disorder has also been found for adult children of mothers with schizophrenia (Schubert & McNeil, 2003). Variations in incidence rates across studies have been attributed in part to differences in sample size and case selection methods. These results also support those in Chapter 2, which indicated a higher risk of a range of mental disorders across the lifespan for children whose parents have psychosis.

Longitudinal prospective and retrospective studies investigating the risk of disorders in adult children whose parents have depression indicate there is also some increase in risk, although this seems to be more inconsistent. Maki et al. (2004) found that children of mothers with depression had 0.9% cumulative incidence of schizophrenia, which was similar to that found by Gottesman (1991), but that a depressed mood in the mother was not necessarily connected to risk of schizophrenia in the adult child. Schubert and McNeil (2003) found that adult children of mothers with affective disorders had an increased risk of developing depressive disorders, whilst Peisah, Brodaty, Lubscombe, and Anstey (2004), in a 25 year follow-up study of children of parents with depression, found they had higher rates of anxiety and substance use disorders but most adult children demonstrated considerable resilience in that overall morbidity and quality of intimate relationships were similar to those of controls.

In a ten-year follow up study, Weissman et al. (1997) also found a greater risk of alcohol dependence, major depression and anxiety disorders in adult children of depressed
parents. In a 20 year follow-up study, Pilowsky, Wickramaratne, Nomura & Weissman (2006) found that parental depression was associated with family discord and was a consistent risk factor for major depression and anxiety disorders in adult children. An increased risk of disorder may also extend through the generations as Weissman et al. (2005) found, in a continuation of their longitudinal study over three generations, that a very high percentage (59.2%) of grandchildren with two generations of parental major depression had a psychiatric disorder in adolescence.

In comparison to adult children of parents with alcohol dependence, adult children of parents with mental illness and alcohol dependence, and adult children with no parental disturbances, female (but not male) adult children of parents with mental illness have also been found to have statistically significant higher levels of depression, anxiety, somatisation, and drinking frequency and quantity (Neff, 1994). Similarly, Williams and Corrigan (1992) found that adult children of parents with mental illness demonstrated greater anxiety and depression than adult children of parents with alcohol dependence, although both groups reported lower self-esteem and greater dysphoria and social anxiety than adult children with no parental disturbances. Nevertheless, as the following discussion reveals, this has not been the case for all adult children. In the following section, literature addressing resilience and protection for adult children of parents with mental illness is reviewed. There is evidence that adult children of parents with mental illness have also demonstrated considerable strengths in the face of potential adversity.

3.4 STRENGTHS AND PROTECTION

Longitudinal research on resilience has been very influential in identifying multiple protective factors for adults experiencing adversity, although most of this has not been conducted with adult children of parents with mental illness. An exception is the seminal prospective longitudinal study led by Werner (1995), conducted over more than three decades (from 1955) with an original cohort of 698 children in Kaui, Hawaii. Werner and her team explored protective factors for the group. Some thirty percent of these children were considered ‘high risk’ due to factors such as parental mental illness and poverty. It is significant that their findings support previous research in that parental mental illness and other risks were found not or necessarily determine future problems; as one third of
the children in the study went on to develop into competent and confident adults. Although Werner and Smith (1992) report that by the time the ‘high-risk’ children were followed into their early thirties, 38% had developed serious coping problems including mental health problems, there remained a group of resilient adults (one third of the high-risk group, 10% of the cohort), who functioned very well.

A further significant finding (Werner, 1995; Werner & Smith, 1992), which develops the findings from discussion of the previous construct of adult attachment, affirmed that even the children considered ‘high-risk’ who experienced difficulties during adolescence could rebound in adulthood. Most of the high-risk young people with coping problems in this study had recovered to a large extent by their early thirties. Important protective factors assisting them to overcome their difficulties included a higher level of intelligence, supportive friends, personal competence, and determination. Critical turning points they identified included the birth of their first child, seeking further education, joining the armed forces, beginning long-term relationships, and active religious faith and church involvement. Rutter (1993) has reinforced that these turning points in individual lives can enable them to change course to a more positive trajectory, due to the benefits and resilience that such experiences may bring. Furthermore, it is the cognitive perceptual variance between individuals, where each views the same situation differently, that also plays a role in the development of resilience.

The phone call

I’m at work in my office, typing away on the computer, deep in thought. My mobile rings. I wonder who it could be. I don’t usually get a lot of calls on it.
‘Hello. Kim Foster’.
‘Is that you Kim?’
Oh no. It’s mum. What’s she doing ringing me at work on my mobile? She never rings me at work. Actually, she never rings my mobile. How’d she get the number?
‘How are you?’
‘Fine Mum. How are you?’
‘Good. I’m good. Sorry to ring you at work. Auntie Joan gave me your number. I’ve been trying to get hold of you.’
Ah, hah. Mystery solved. Thanks Auntie Joan.
‘oh, right’
‘Have you spoken to Sharon and Andrew lately?’
‘um…yes, I spoke to Sharon not too long ago. She’s fine. Busy with work’. 

Chapter 3

69
What’s this about?
I suppose I know really. I’m the only one speaking to her at the moment. Actually, I’m also the only one she’s speaking to. After Gran died and Sharon had that huge argument with her at the hospital, they haven’t spoken since. And then Andrew got sick of her constant calls and hung up on her, so I’m the only one left. It’s been months. Sharon says they’re relying on me to keep up the good work. I’m starting to feel like the lone ranger.

‘They never ring me you know. I haven’t heard from them in months.’
Tricky. What do I say? Has she really forgotten about the arguments?
‘Uhh, well, I suppose…’
‘I don’t know why’. Her tone’s getting shorter and more clipped. There’s that familiar edge to it. Not a good sign. And it reminds me of being a kid again.

I take a breath, slowly let it out. ‘Well mum, maybe it’s got to do with our childhood.’
I hold my breath, and wait.
I’ve never said that before. I, all of us, don’t talk with her about being in the homes, or her having a mental illness for most of our lives. It’s like life magically started when we were all grown up.
‘So what? What about it?!’ Her voice heats up.
‘I remember to let the breath out.
Silence.
Faster. Louder now. Sharp. ‘Well you’re not the only one with problems Kim. My childhood was bad too. Just get over it’.
Get over it? That’s the best you can say after all this time? What does she mean her childhood was bad?

‘maybe it’s also to do with your mental illness’
Louder now. Harsh and clipped. Just like I remember. ‘I do NOT have a mental illness’
‘well, you do mum…’
Voice rising. ‘I do NOT. I don’t. I DON’T have a MENTAL ILLNESS…’
Keeps going. Starts to shout. ‘I DO NOT…’
I keep talking. ‘…actually you do mum. You do have a mental illness, and…’
Yelling now. ‘I DO NOT! How dare you?’
BANG
Silence.

I lean back in my chair. My hands are shaking. I can feel my heart thundering, nearly leaping out of my chest. What have I done?
I feel angry. And anxious, glad, guilty. All at once. Finally to be able to say it, to unmask the spectre that’s lurked around every family gathering and conversation.

But it wasn’t kind. I shouldn’t have kept going. I should have been more understanding. Yet the small voice keep murmuring – ‘…it’s your life too. You have a right to your past. You can’t always sacrifice it for her…’

She doesn’t ring for six months.
Sharon and Andrew are amused. Another one bites the dust.
3.5 SUBJECTIVE EXPERIENCES OF BEING THE ADULT CHILD OF A PARENT WITH MENTAL ILLNESS

The following eight studies, (three of which are unpublished) conducted over more than a ten year period, re-present the current state of knowledge concerning the subjective experiences of adult children of parents with mental illnesses including psychosis. Addressing varying facets of adult child experience and using a range of methodological approaches, these studies continue to build a picture of what it can be like to grow up with parents with mental illness. Some of the following findings share similarities with those of the COPMI experiences in Chapter 2, whilst others reveal new facets of such experiences.

In the first published study to focus specifically on parental psychosis, Dunn (1993) explored the experiences of nine adult children (4 men and 5 women) ranging from 21 - 41 years whose mothers had psychotic mental illness. The parental psychoses included schizophrenia (4), bipolar disorder (2), and multiple disorders including either schizophrenia or bipolar disorder (3).

Dunn (1993) used a semi-structured interview in three parts. Part 1 covered demographic information. Part 2 consisted of questions about the participants’ childhood relationships with their mothers and other family members and friends, and their contacts with mental health professionals. Part 3 asked for participants to discuss their current relationships with their mother, other family members, and mental health providers.

Five themes were developed from participants’ experiences. Abuse and/or neglect was commonly reported and included maternal withdrawal, minimal supervision, lack of basic care such as bathing or dressing, and sexual or physical abuse. As a result, participants often became caregivers for both the mother and younger children. Fathers were often reported to be either physically or emotionally unavailable. For example, four of the fathers were alcohol dependent, and three left the family early in the participants’ lives. Isolation was experienced by participants in terms of peers, their families, and the wider community. Most participants also did not have their mother’s illness discussed with
them as children, even when the mother was hospitalised, and there was a general lack of acknowledgment of the mother’s illness by family members. The psychotic phenomena their mother displayed were also unacknowledged by others, which resulted in fear, bewilderment, loneliness, pain and a confused sense of their own reality. The participants described feeling different to other ‘normal’ people, of alienation due to their mother’s distorted reality, and a sense of never quite belonging. Many participants were reluctant to invite others home because of the stigma attached to their mother’s illness and behaviour (Dunn, 1993).

Despite these often painful and distressing experiences, many participants also maintained a deep loyalty to their mothers. Guilt was often tied to the loyalty, with some participants believing they had caused or contributed to their mother’s illness, feeling guilty when separated from their mother, due to hospitalisation for example, or removal from her care. They felt ‘survivor’ guilt over being healthier and/or more accomplished than their mother, or moving away to make their own lives (Dunn, 1993).

Eight of the nine participants in Dunn’s (1993) study reported negative experiences with mental health services, including unexplained hospitalisations and/or concern for their mother’s welfare/possible mistreatment whilst in hospital. Direct contact with mental health providers was even more strongly seen as unpleasant or even harmful, with some providers blaming them for their mother’s illness and/or telling them they needed to more understanding of their mother. These contacts were experienced as generally hurtful or even damaging. Notwithstanding this experience, eight of the nine participants subsequently entered therapy as adults, although whether they had specific symptoms and/or diagnoses were not known apart from one male participant who had schizophrenia and another who reported having had a ‘breakdown’. Participants did find therapy helpful in terms of understanding the impact of their mother’s illness on them and their family, discussing fears for their own sanity, and learning to set limits with their mother. All the participants saw social support as a lifeline. Grandparents, neighbours, family friends, and teachers or coaches were found to be safe and supportive people who provided care, attention and reality testing in environments that were outside the chaotic family situation.
Dunn’s (1993) findings can be seen to support many of empirical findings in Chapter 2 in that the development of children growing up with psychotic parents may be significantly adversely affected by such an experience. Dunn (1993) reported that her results also confirmed previous findings, including those of empirical studies, in that disorders of mood and/or thought that occur with psychosis were found to impinge on the ability of the person to be an effective parent. Feelings of guilt and loyalty, including that of survivor guilt, emerged as comparatively uncommon findings. Dunn (1993) postulated that these may have influenced the participants’ negative and conflictual experiences with mental health professionals. She recommended further study into the nature and quality of sustaining social supports for children of parents with psychosis and their ability to benefit from them, and acknowledged it would be important to explore the consequences of also having a father with psychosis. As this was the first published work of its kind, this study has become a seminal work which continues to influence later researchers.

In the same year as Dunn (1993), Lancaster (1993) reported adult children’s experiences of growing up with a mentally ill parent. She was therefore unable to incorporate or advance Dunn’s findings in her work. Using a phenomenological approach, Lancaster (1993) explored the experiences of 12 adult children of parents (7 mothers, 5 fathers) with mental illness. Bipolar illness was the most common parental disorder (8), then depression (2) and psychosis (2).

Whilst finding a number of similar themes and issues to those of Dunn (1993), there were also a number of new insights into these ACOPMIs’ experiences. These included the experience of emotional reactions to the transitional period from living at home with their parent to living on their own, and significant turning points in their lives such as finding religion, standing up to the mentally ill parent for the first time, going to college, and seeking help from others. At these times participants realised they were able to take control of their lives. Other themes that added to the knowledge on ACOPMI were the ‘seeking of love and acceptance from parents’, as well as ‘seeking a sense of self’, and ‘escaping from the mentally ill parent and/or the life they were living’. Lastly, the ‘resolving of issues related to growing up with a mentally ill parent’ was also a prominent theme.
Marsh et al. (1993a), and Marsh, Appleby, Dickens, Owens & Young (1993b) reported on two national surveys with a total of one hundred and thirty five adult children and siblings (primarily women) of parents with mental illness in the U.S. (mostly serious mental illness such as schizophrenia). There were eleven thematic findings. These included an experience of ‘developmental risks’ (including parentification and developmental delays), ‘familial consequences’ (including family disruption, stress and conflict), and ‘education and career’ (including poor performance at school, super-achievement at the expense of a personal life, and a feeling of unfulfilled potential). A ‘personal legacy’ included concerns about self-identity, fear of developing mental illness, having poor-self-esteem, a need for control and perfectionism, and the experience of their own mental health problems such as depression. An ‘interpersonal legacy’ included problems in peer relationships, social isolation and alienation, fear of rejection and an over-concern with pleasing others.

‘Intimacy, commitment and sexuality’ were also issues, and included participants’ difficulty trusting others, an avoidance of intimacy, having ambivalent and/or conflicted relationships, and difficulty making a commitment. ‘Marriage and childrearing’ were further concerns, in that some participants chose not to have children to avoid the risk of passing on mental illness, married prematurely to escape the family, and/or were worried about the mental health of their own children. Participants also experienced ‘caregiving responsibilities’ and had concerns about their ongoing responsibility for their parent/sibling, including legal and financial responsibilities (Marsh et al., 1993b). This is supported by Jones (1997) who also found caregiver burden for ACOPMI to be a long-term experience, where participants initially experienced subjective burden in terms of feeling robbed of their ill parent as a child, and then had to continue caring for them as an adult.

Participants in Marsh et al.’s study (1993a) and (1993b) also described a number of ‘coping, adaptation and resilience’ responses which included seeking counselling, joining support groups, learning about mental illness, using stress management skills, and feeling stronger, more self-reliant, independent, and compassionate as a result of their experiences.
In one of the few studies to specifically address the coping skills and strengths of adult children of parents with mental illness, Kinsella, Anderson, and Anderson (1996) explored the subjective experiences of ten adult children (5 men, 5 women) of parents with schizophrenia and bipolar disorder as part of a study also exploring the experiences of ten siblings of people with mental illness. A number of thematic findings emerged. A new finding was participants’ acknowledgement of, and distinguishing between, using healthy coping and unhealthy coping strategies. In addition to the coping skills identified by previous studies, these participants identified constructive strategies such as physically and/or mentally escaping their environment, seeking support from others such as grandparents, and having spiritual faith. Unhealthy strategies including internalising feelings, including dissociative responses and unhealthy alcohol and/or drug use, isolating themselves, and using rigid self-control to manage the chaos they experienced at home. As a positive effect of their experience, participants also described their development of personal strengths such as independence and self-reliance, resourcefulness and creativity, resilience and the ability to manage problems, assertiveness, and developing a broader and more grateful perspective on life.

In terms of parental psychosis, in 1998 Caton et al. (1998) explored the childhood experiences and adult adjustment of thirty nine primarily adult children (29 women and 10 men ranging from 13 - 48 years of age, with median age of 26 years) of parents (primarily mothers) with schizophrenia. Participants were asked about their experiences with mental health professionals treating the parent, what they were told about their parent’s illness, whether they had ever participated in family therapy with the parent, and whether they had used mental health services for their own mental health problems.

Using descriptive statistics, but no thematic or other analysis, major findings from the study by Caton et al. included participants’ identification of problems with their parents such as embarrassing (69%) or frightening behaviours (69%), psychotic symptoms (66%), physical abuse (54%), verbal abuse (34%) and insults (41%), medication refusal (63%), and/or parents ‘sat around and did nothing’ (43%). Only a quarter (24%) of participants had been told about the parent’s illness by a doctor as a child. In support of previous findings, 36% of participants had received counselling to help them deal with
their parent’s illness, and up to 45% had performed a caretaking role for their parent and family at some point. Ten of the participants had developed major depression, schizoaffective disorder, or substance abuse, but none had schizophrenia. Depression was the most common problem (7). Four participants had never received treatment for their disorder (Caton et al., 1998).

From this point in time onward, although there were further studies into adult children’s experiences, a number of these did not refer to previous research and thus have not sought to develop previous knowledge. Some of the following studies have also not been included in subsequent research as they remain unpublished (see Camden-Pratt, 2002; Stevenson, 2002).

In one of the few studies to address both parental mental illness and drug or alcohol misuse (also referred to as dual diagnosis), in Australia, Stevenson (2002) explored the experiences of ten adult children (9 women and 1 man, 19-54 years) of dually-affected parents. Parental diagnoses included bipolar disorder (6, including 3 with alcohol misuse and 1 with personality disorder), unipolar depression (1, with alcohol dependence and anxiety disorder), and schizophrenia (4). One participant had both parents with mental illness.

In a two part process the Brief Psychiatric Symptoms Inventory (BSI) was administered to measure psychopathology. Then, using a hermeneutic phenomenological approach Stevenson conducted un-structured interviews. Nine themes emerged from analysis, the first two of which are the same as those found by Dunn (1993). Findings from the BSI revealed that 4 of the female participants were found to meet the criteria for both alcohol dependence and major depression, two female participants had bipolar disorder and met the criteria for post-traumatic stress disorder, and one male participant had an eating disorder and self-harming behaviour. Two participants had previously made suicide attempts and similarly to Dunn’s (1993) study, eight of the ten participants had engaged in psychological therapy. With respect to attachment and relationships, five participants reported ‘failed’ marriages and current relationship difficulties, and two had never established an adult relationship (Stevenson, 2002).
A further Australian study into the experiences of 12 adult daughters of mothers with mental illness was conducted by Camden-Pratt (2002). The methodology used, however, was a radical departure from all the studies in Chapters 2 and 3 as it was informed by a postmodern and poststructural theoretical perspective, and included the researcher’s own adult child experience through the use of critical autobiography. Using a cross-disciplinary feminist research approach, a grounded theory approach and content analysis was used to analyse verbal data. A variety of methods were used which included creative arts (such as collage and painting), focus group conversations, and one-to-one conversations. Notions of narrative and re-storying experience were prominent and findings were presented in the form of a written play and so are not easily reported here.

Using an unusual study design, the most recent study by Polkki, Ervast and Huupponen (2004) explored the experiences of both children and adult children of parents with mental illness. This included a focus on their needs and stress reactions, the impacts of their caring roles, their ability to cope and be resilient, and the kinds of informal and professional help they needed and received. The results of both sample groups were discussed together. The first sample group comprised six children (genders not specified), between nine and eleven years, five of whom had a mother with bipolar disorder and one with a mentally ill (disorder not specified) stepfather. A number of themes of their experience were developed.

The second sample group of 17 female ACOPMI (15 years – late adulthood) was gained from a writing competition where adult children submitted narratives organised around the theme of ‘How my life changed after a member of my family became mentally ill’. 4 of the 17 adult children were still in caring roles for their parents, whose diagnoses included psychosis and severe depression. Themes were developed which were similar to, but not the same as, those from the COPMI sample.

Polkki et al. (2004) reported that many of their results were similar to those of Dunn (1993), even though their findings related to parental mental illness in general rather than psychosis in particular. Key findings which added to previous understandings included that this group of participants, similarly to most other studies, had not received
information about their parents’ illness. They also described a generally chaotic and confusing life at home with their ill parent. Adult participants in this study, however, considered they had coped well overall even though they had experienced difficulties as children. Having hobbies, academic success at school, and strong social support from siblings or friends were all useful strategies, and participants emphasised the importance of learning and growing from their experiences. In contrast to the participants in Dunn’s (1993) study, only 2 of the 17 participants had received counselling as a child, and both were critical of its usefulness. As adults, 3 of the 17 had developed mental health problems (although these were not specified) and one had developed an alcohol problem.

Table 3.1 provides a summary of the studies on ACOPMI subjective experiences including criticisms and limitations.
Table 3.1: Summary of ACOPMI subjective experience studies

<table>
<thead>
<tr>
<th>Author/s</th>
<th>Methods</th>
<th>Findings</th>
<th>Criticisms and/or limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dunn (1993)</td>
<td>Retrospective study Self-selected purposive sample 3-part semi-structured interview Content analysis and categorising quotes</td>
<td>5 themes: Abuse and neglect Isolation Guilt and loyalty Grievances with mental health services Supports</td>
<td>Limited to participants with mothers with psychosis only Types of participants’ own mental disorder not obtained</td>
</tr>
<tr>
<td>Lancaster (1993)</td>
<td>Phenomenological study Purposive sample Demographic data and unstructured in-depth interviews Bracketing Themes validated by participants and nurse therapist</td>
<td>10 themes: Feelings of anger and grief Experiencing consequences; abuse and parentification Not knowing about and/or understanding about the PMI Experience of emotional reactions to transitional period from living at home to living on their own Experiencing significant turning points Seeking help from others Seeking of love and acceptance from parents Seeking a sense of self Escaping from the mentally ill parent and/or the life they were living Resolving of issues related to growing up with a mentally ill parent</td>
<td>Unpublished (U.S), phd Has not contributed to development of wider understandings ? excessive amount of themes, which may signify lack of synthesis of analysis</td>
</tr>
<tr>
<td>Marsh et al., (1993a); Marsh, Appleby, Dickens, Owens &amp; Young (1993b)</td>
<td>2 national surveys in U.S. ACOPMI and siblings of people with mental illness Structured and open-ended Qs Approach to analysis not given</td>
<td>11 themes: Subjective and Objective burden Developmental risks Familial consequences Education and career</td>
<td>Some demographic material not provided Siblings and adult children data combined</td>
</tr>
</tbody>
</table>
| Kinsella, Anderson, & Anderson (1996) | Self-selected sample, 10 adult children, and 10 siblings  
Brief demographic questionnaires and in-depth interview (1 ½ - 2 hrs)  
Interview guide  
Thematic analysis using method by Taylor & Bogdon (1984) | Coping skills and strengths themes:  
Constructive escape  
Seeking support  
Objectifying the illness  
Acquiring information  
Spiritual faith  
Internalization of emotions or unhealthy escapes  
Self-censoring behaviour  
Self-isolation  
Independence or self-reliance  
Ability to create or accomplish  
Empathy  
Resiliency  
Assertiveness  
Spiritual and life perspective | Approach to data analysis not specified – > some ambiguity in interpretation of results  
Lack of differentiation between findings from adult children and siblings |
|---|---|---|---|
| Jones (1997) | 3 phase comparison study of caregiver burden of parents, (adult) children, siblings and spouses of people with mental illness  
Telephone interviews including Caregiver Burden Instrument and systematic probe questions | Major findings for (adult) children caregiver burden:  
Feeling robbed of a parent  
Subjective burden associated with parent’s vulnerability and need for care | Numbers of participants and specific demographic data for each category, and analytical approach not provided -> difficulty interpreting results  
Very limited depth and breadth of ACOPMI findings |
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Major Findings</th>
<th>Other Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caton, Cournos, Felis, &amp; Wyatt (1998)</td>
<td>Sample gained from participants contacted in previous study 2 hr interview, including tools for demographic data; family section of Community Care Schedule; Structured Clinical Interview for DSM-III-R Descriptive statistics of data</td>
<td>Major findings: Embarrassing (69%) or frightening (69%) parental behaviours Psychotic parental symptoms (66%) Physical abuse (54%), verbal abuse (34%) and insults (41%) from parents Parental medication refusal (63%) Parents sat around and did nothing (43%) 24% had been informed of parent’s illness by doctor 36% had counselling re parent's illness 45% had performed caring role for parent and family 10 participants developed a mental disorder</td>
<td>Does not refer to Dunn’s study Lack of thematic or other qualitative analysis of experience data -&gt; limited representation of experiences</td>
</tr>
<tr>
<td>Stevenson (2002)</td>
<td>Self-selected purposive sample Two part study. Brief Psychiatric Symptoms Inventory (BSI) to measure psychopathology Unstructured interviews Hermeneutic phenomenological analysis of qualitative data</td>
<td>9 themes (2* the same as Dunn’s): Abuse and neglect* Guilt and loyalty* Abandonment and loss Defectiveness and shame Perfectionism/unrelenting standards Fear of getting their parents’ mental illness helplessness Confusion and unpredictability Dissociation and zoning out</td>
<td>Unpublished (Australian) Masters Has not contributed to development of wider understandings ? excessive amount of themes, which may signify lack of synthesis of analysis</td>
</tr>
<tr>
<td>Camden-Pratt (2002)</td>
<td>Feminist research, informed by postmodern and critical perspectives Creative arts, focus groups, individual interviews Grounded theory approach and content analysis of data</td>
<td>Findings presented in the form of a play. Not easily summarised</td>
<td>Unpublished (Australian) phd Has not contributed to development of wider understandings Daughters of mothers with mental illness only</td>
</tr>
</tbody>
</table>
| Polkki, Ervast, & Huupponen (2004) | 2 sample groups: 1 COPMI, 1 ACOPMI  
COPMI – audio-taped I/Vs  
Data coded and classified using grounded theory  
ACOPMI – written narratives  
Analysed using NUD*ist | 6 themes for COPMI:  
Family and parenthood  
Mental illness of parent  
Fears and worries  
The stress reactions  
Coping with daily life  
Social support from siblings, parents and others  
4 themes for ACOPMI:  
Experiences and feelings of the children at time of onset of parent's mental illness  
Family roles and parenthood  
Coping strategies and resilience  
Social support and professional help | Demographic detail often not provided  
Methodological process not specified at times  
Use of grounded theory unclear as no grounded theory developed  
Confusing report structure. Results discussed together |
Table 3.2 provides a summary of all the themes identified and grouped from the studies on child and adult child experiences of growing up with parents with mental illness which have been reviewed in this chapter and Chapter 2.

**Table 3.2: Summary of thematic findings from all COPMI/ACOPMI qualitative studies**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Studies</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Struggle to understand parental mental illness; confusion and unpredictability (including not knowing)</td>
<td>Garley et al (1997) (child)</td>
<td>6 (3F: 3M)</td>
</tr>
<tr>
<td></td>
<td>Farrell et al (1999) (child)</td>
<td>4 (all F)</td>
</tr>
<tr>
<td></td>
<td>Lancaster (1993) (adult)</td>
<td>12 (9F: 3M)</td>
</tr>
<tr>
<td></td>
<td>Stevenson (2002) (adult)</td>
<td>10 (9F: 1M)</td>
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<tr>
<td></td>
<td>Meadus et al (2000) (child)</td>
<td>3 (F)</td>
</tr>
<tr>
<td></td>
<td>Cogan et al (2005) (child)</td>
<td>20 (10 F: 10 M)</td>
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<tr>
<td>Mental illness of parent</td>
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<td></td>
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<tr>
<td>Lack of knowledge and understanding</td>
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<td>Alternative choice of language</td>
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<td>Distinction from physical health problems</td>
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<td>Source of understandings</td>
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<tr>
<td>Reasons for mental health problems</td>
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<tr>
<td></td>
<td>Garley et al (1997) (child)</td>
<td>6 (3F: 3M)</td>
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<tr>
<td></td>
<td>Farrell et al (1999) (child)</td>
<td>4 (all F)</td>
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<tr>
<td></td>
<td>Shih (1995) (child)</td>
<td>15 (6F: 9M)</td>
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<tr>
<td></td>
<td>Meadus et al (2000) (child)</td>
<td>3 (all F)</td>
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<tr>
<td></td>
<td>Polkki et al (2004) (adult)</td>
<td>17 (all F)</td>
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<tr>
<td></td>
<td>Cogan et al (2005) (child)</td>
<td>12 (gender NOS)</td>
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<tr>
<td>Managing the illness</td>
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<td>Coming to terms</td>
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<td>Coping with daily life</td>
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<tr>
<td>Coping strategies and resilience</td>
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<tr>
<td>Coping strategies employed by COPMI</td>
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<tr>
<td>Importance of siblings and friendships</td>
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<td>Extra roles assumed when parent unwell</td>
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<tr>
<td>Caregiving responsibilities, and subjective and objective burden</td>
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<tr>
<td>Coping, adaptation, and resilience</td>
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<td></td>
<td>Garley et al (1997) (child)</td>
<td>6 (3F: 3M)</td>
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<tr>
<td></td>
<td>Farrell et al (1999) (child)</td>
<td>4 (all F)</td>
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<tr>
<td></td>
<td>Shih (1995) (child)</td>
<td>22 (11 F: 11 M)</td>
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<td></td>
<td>Meadus et al (2000) (child)</td>
<td>6 (3F: 3M)</td>
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<td></td>
<td>Marsh et al. (1993b) (adult)</td>
<td>No. and gender NOS</td>
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<tr>
<td></td>
<td>Kinsella et al. (1996)</td>
<td>10 (5F: 5M)</td>
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<tr>
<td>Recognising the signs</td>
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<td>Views of psychiatric disability</td>
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<tr>
<td>Impact of hospitalisation and separation from parent</td>
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<td>Major episodes (e.g. parent hospitalisation)</td>
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<tr>
<td></td>
<td>Garley et al (1997) (child)</td>
<td>6 (3F: 3M)</td>
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<td></td>
<td>Farrell et al (1999) (child)</td>
<td>4 (all F)</td>
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<td></td>
<td>Maybery et al (2005) (child)</td>
<td>12 (gender NOS)</td>
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<td></td>
<td>Farrel et al (1999) (child)</td>
<td>6 (3F: 3M)</td>
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<tr>
<td></td>
<td>Maybery et al (2005) (child)</td>
<td>4 (all F)</td>
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<tr>
<td>Ripple effect of PMI on family</td>
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<tr>
<td>Unavailability of the ill parent</td>
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<tr>
<td>Family and parenthood</td>
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<tr>
<td>Family roles and parenthood</td>
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<td>Familial consequences</td>
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<td>Farrell et al (1999) (child)</td>
<td>4 (all F)</td>
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<td>Shih (1995) (child)</td>
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<td>Meadus et al (2000) (child)</td>
<td>3 (F)</td>
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<td></td>
<td>Polkki et al (2004) (adult)</td>
<td>17 (all F)</td>
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<tr>
<td></td>
<td>Marsh et al. (1993b) (adult)</td>
<td>No. and gender NOS</td>
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<tr>
<td>Stigma and isolation</td>
<td></td>
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<tr>
<td>Stigma of mental health problems</td>
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</tbody>
</table>

Chapter 3
83
| Support services required (including grievances with services) | Farrell et al (1999) (child) | 4 (all F) |
| Social support | Beardslee & Podorefsky (1988) (child) | 18 (10F: 8M) |
| Social support and professional help | Dunn (1993) (adult) | 9 (5F: 4M) |
| Request for information | Polkki et al (2004) (adult) | 17 (all F) |
| Riebschleger (2004)(child) | 22 (11 F: 11 M) |
| Cogan et al (2005) (child) | 20 (10 F: 10 M) |
| Experiencing the consequences (e.g. abuse and neglect; dissociation/zoning out) | Shih (1995) (child) | 15 (6F: 9M) |
| | Beardslee & Podorefsky (1988) (child) | 18 (10F: 8M) |
| | Dunn (1993) (adult) | 9 (5F: 4M) |
| | Lancaster (1993) (adult) | 12 (9F: 3M) |
| | Stevenson (1993) (adult) | 10 (9F: 1M) |
| Experiences and Feelings (‘good days’, ‘bad days’, guilt and loyalty; feeling different; helplessness; confusion, grief, fears and worries, love, hate, shame, abandonment and loss) | Dunn (1993) (adult) | 9 (5F: 4M) |
| | Lancaster (1993) (adult) | 12 (9F: 3M) |
| | Stevenson (2002) (adult) | 10 (9 F:1 M) |
| | Polkki et al (2004) (adult) | 17 (all F) |
| | Riebschleger (2004) (child) | 22(11 F: 11 M) |
| Escaping (from PMI) | Lancaster (1993) (adult) | 12 (9F: 3M) |
| Developmental risks | | |
| Education and career | | |
| Personal and interpersonal legacy | | |
| Intimacy, commitment and sexuality | Marsh et al, (1993b) (adult) | No. and gender NOS |

N.B. * only studies reporting thematic findings have been included in this summary.

### 3.6 IMPLICATIONS OF RESEARCH FINDINGS FOR THE PRESENT STUDY

The literature review in both this chapter and Chapter 2 has presented and analysed literature addressing the effects of parental mental illness on both children and adult children. Empirical research findings have indicated increased risks of psychosocial and other problems for COPMI from childhood through to adulthood. In addition, there is some evidence of inter-generational transmission of disorders and problems from parents with mental illness to ACOPMI, and then on to their children. Although there has been a heartening increase in studies focusing on children’s subjective experiences over the past few years, there has been comparatively little focus on adult children’s subjective experiences. An emphasis on sampling of daughters of mothers with mental illness in the adult child studies also reveals a need for research that is inclusive of the voices of both sons and daughters with fathers as well as mothers with serious mental illness including
psychosis. Significant silences are evident in terms of both women and men who have experienced their parents’ psychotic symptoms and behaviors, particularly from an Australian perspective. Many of the research findings have privileged negative adult child experiences, and some have not been disseminated widely as they have remained unpublished masters and doctoral theses. There is subsequently a small and disparate body of published work on the experiences of adult children of parents with serious mental illness with little resulting growth or development of understanding.

As a consequence, there is also next to no literature that addresses the professional support, and if required, treatment, of adults that have been raised by mentally ill mothers or caregivers (Sved Williams, 1998). The need for counselling has been identified by a number of the previously cited studies (e.g. Camden-Pratt, 2002; Dunn, 1993; Lancaster, 1993; Stevenson, 2002) where adult children reported their use of both individual and group counselling to assist them to work through issues from their childhood experiences.

These gaps in the literature can be addressed by further investigation into the meanings adult children have made from their experiences of growing up with parents with serious mental illness. Much may be learnt from adult children in terms of their experiences and development over time and this may be informative for current service providers and families where parents have a serious mental illness. Disturbing the silences surrounding this marginalised group may be useful in understanding how some children have grown up to understand their experiences, how they coped with them, and how these understandings may indicate their potential needs for support and therapeutic intervention and therefore how health professionals including nurses may better support them and their families. Using multiple methodological lenses through which to analyse the findings may bring fresh insights and alternate perspectives to the meanings that may be found in such experiences.

3.7 RESEARCH QUESTION

The research question for the study therefore is:

*What does it mean to be the adult child of a parent with serious mental illness?*
From a narrative inquiry perspective, the research design is descriptive narrative research, in that it is not focused on explaining why children of parents with serious mental illness had particular experiences, but rather, what their particular experiences were, and what meanings they ascribed to them. Descriptive narrative research therefore allows for alternative narratives and interpretations to be recognised (Polkinghorne, 1988). From a postmodern perspective this research question also recognises that local narratives do not seek to reveal grand ‘truths’ of experience, and can only claim to re-present some, rather than all, adult children’s experiences. From a phenomenological perspective, this question seeks to illuminate the meanings of adult children’s lived experiences and is pre-reflective as it investigates experiences as they are lived rather than as they are conceptualised (van Manen, 1990).

Related questions to be asked include how some adult children of parents with serious mental illness have coped with their experiences; and how service providers may assist adult children and their families in managing the experience of having parents with serious mental illness.

3.8 CONCLUSION

In conclusion, this chapter has extended the previous review of literature on the effects of parental mental illness on children to explore those of adult children. The review has demonstrated a need for further research into the meanings of the subjective experiences of both women and men who have grown up with parents with serious mental illness including psychosis. The following chapter moves now to explain the methodology, epistemology, and theoretical framework to be used in the study.
CHAPTER 4
ON THE ROAD TO FIND OUT – THEORETICAL FRAMEWORK AND METHODOLOGY

Musical lyrics removed for online publishing due to copyright
Reflecting ‘On the road to find out’

Cat Stevens’ whimsical song of exploration and journey illuminates some of my own experiences and discoveries in developing this study and its methodology. In slowly coming to a more sophisticated understanding of postmodernism, narrative inquiry, and interpretive phenomenology, I have read and re-read, interpreted and synthesised many a ‘good book’ and scholarly text. Like Cat, I have experienced some travail in this methodological journey and at times wandered, and wondered, through a maze of brilliant yet dense and complex philosophical works.

At this point in time, whilst I do not claim to know all, nor that ‘all the answers’ lie within the following chapter, I have arrived at the end of one part of this journey – the epistemological and philosophical underpinnings of the study...
**Theoretical Framework**  
Postmodernism

**Methodology**  
Narrative Inquiry

**Methods**

- Auto-ethnography
- Unstructured interactive I/Vs & member checks

**Dual analysis**

- Phenomenological Thematic analysis
- Postmodern Narrative Analysis
4.1 INTRODUCTION

Methodology is the science behind the research methods used to gather information. Thus, the methodological approach to a study situates the researcher and participant and defines what constitutes knowledge in this instance. In the following chapter, the theoretical assumptions of a postmodern lens are applied to the use of narrative inquiry as the study’s methodology. Consistent with the postmodern emphasis on multiple representations, the application of both a realist and de-constructive approach to field text analysis is then justified and discussed. Interpretive phenomenology is therefore outlined in terms of how it foregrounds the initial realist phase of analysis used in the study.

4.2 THROUGH A POSTMODERN LENS

As the theoretical framework for the study, postmodernism has an important role to play in this narrative inquiry. Whilst there are a number of perspectives on postmodernism, (or perhaps more accurately, postmodernisms), in this thesis it is understood as emerging from a period in history, beginning in the late 1950s, where critique of modernist ideology first became apparent in architecture (Jameson, 1984). This challenge to aesthetic constructions expanded to include other cultural forms such as art, literary criticism and the humanities (Jameson, 1984; Kvale, 1992), and led to what may be considered a pervasive cultural transformation (Lyotard, 1984).

Postmodern thought has been generally concerned with the condition of knowledge in society, and has been famously defined by Lyotard (1984, p.xxiv) as “an incredulity toward metanarratives”, or grand theories such as capitalism and modern science (Rosenau, 1992). Instead, Lyotard (1984) argued for recognition of smaller, local ‘mini’ narratives, so that knowledge became locally rather than globally determined. The use of local narratives offers the added benefit that the stories and voices of marginalised groups who may have traditionally been silenced – in this study, adult children of parents with serious mental illness – can be heard (Hevern, 2002). The postmodern perspective on knowledge therefore views specific understandings to more accurately reveal general cultural patterns that are political (Rice & Ezzy, 1999). These insights help justify and
shape the methods taken for the present study, which are used to explore the lived experience of a group of people in Australia who have had parents with serious mental illness, and to interpret meanings from that experience both thematically and socially using a postmodern lens.

Although there are various approaches considered to be ‘postmodern’, they share a critique of the underlying assumptions of modernism, and emphasise the multiple nature of ‘reality’ and the many positions ‘it’ may be viewed from (Cheek, 2000). A postmodern approach also describes a ‘crisis in representation’, which challenges the modernist notion that it is possible to re-present reality, make claims to truth, speak for others and achieve a universal and essential understanding. This has led to a resulting loss of faith in the grand narratives of truth, certainty, universality and centredness (Cheek, 2000; McAllister, 2001). Rather, postmodernism recognises a multiplicity of voices, beliefs, and approaches to analysing reality, and analyses what is absent from re-presentations as being at least of the same interest as what is present (Cheek, 1999, 2000). In this study therefore, the stories of the participants are of interest as much for what they do not say, as for what they do.

A postmodern perspective also does not consider reality to be either stable or permanent, and sees only surfaces rather than depth in structures (Kvale, 1992). Baudrillard (1988) demonstrated this concept in his use of the term ‘simulcrum’, where he asserted there was no reality as such, only ‘hyperreality’ – a simulation or copy of the original which masked the absence of a basic reality. Postmodernism refers then to the use of varying styles in cultural works, including pastiche, the use of copies, and repetition. It emphasises and celebrates language play, including irony, bricolage and parody (Gitlin, 1989; Jameson, 1984). This is illustrated for instance by Baudrillard’s (1994) definition of metaphor as being a “… ‘game’ that is played with truth.” (p. 2). The emphasis on language play in this thesis can be seen for instance in my use of a postmodern musical and poetic pastiche, where an eclectic collection of musical lyrics and poetry introduce and preface the contents of each chapter, and my interpretation of metaphors in the postmodern narrative analysis of participants’ experiences.

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3 The art of throwing different things together
Throughout the thesis I specifically speak from an affirmative postmodern position. According to Rosenau (1992), the ‘affirmative’ postmodern position has a generally optimistic view of the postmodern condition. In Rosenau’s nomenclature, ‘affirmatives’ such as myself, are those writers who are open to political action that is positive, through the use of resistance and struggle, and who espouse a non-dogmatic and tentative philosophy. The affirmative postmodern position on personal experience is one which considers that the exploitation of those who have been marginalised can be counteracted by a focus on the local, individual ‘ordinary’ experience through recognising traditional local narratives or storytelling. The de-centred self becomes privileged, and there is acknowledgement of an individual subjective ‘truth’ through personal identity and memory. These concepts may be considered useful in extending understandings of the experience of being the adult child of parents with serious mental illness, and is the reason why an affirmative postmodern theoretical position is the lens through which this narrative study is viewed.

### 4.2.1 Language and postmodernism

In terms of the postmodern use of language, Lather (1995) argues that from a postmodern perspective, dualisms or binary oppositions are considered inadequate for understanding issues in a world where a multiplicity of causes and effects interact with each other in complex, non-linear ways. Contemporary philosophical thinking provides an alternative to the limits of binary thinking by offering a dialectical worldview. Dialectics is a term used by many and famously coined by Hegel, the French philosopher, who conceptualised it to be a “…self-producing course of activity, maintaining its advance by turning back into itself” (1966, p.123). Dialectics is therefore a philosophical way of thinking that acknowledges concepts to be in tension and always existing – for instance, we are both masculine and feminine. Dialectical thinking replaces the dichotomous thought of binary thinking (either/or) with both/and thinking. After the initial thematic phase of analysis, therefore, I will be attempting to expose hidden binaries in participants' experiences and emphasise the possibility of seeing dialectics instead, in the postmodern narrative analysis.
From a postmodern perspective, language is considered a powerful medium for the social construction of reality. It is not a medium for the ‘truth’ as such, but rather is located within the context of power relations (Rossiter, 2000). Postmodernism is interested in exposing this social construction and plays with language, revealing dogmas, power, and differences. Postmodernist forms of thinking also emphasize the value of deconstruction. In terms of meaning, the reading of a text can depend on and refer to other texts, or stories. This ‘inter-textuality’ is an important concept that has been defined by Kristeva, the French semiotician, as being the “transposition of one (or several) sign-systems into another” (1992, p. 111). With inter-textuality then, what is present in one text points to another and the texts become linked (Kvale, 1992), which may result in a story that is told differently in the re-telling or re-inscribing of it (McWilliam, Lather, & Morgan, 1997). In a world of blurred boundaries, an experience may be interrupted, invaded, or affected by other experiences and events. The present may be affected by the past.

Contemporary painting may be interspersed with images of ancient art. For researchers it is of interest to attend to inter-textuality because it may flag a moment of interruption and the possibility that all is not as stable or predictable as it may seem. Language, and the critique of linguistic meaning in texts, is therefore central to postmodern thought, and so in the present study field text analysis will include searching for and contemplating the possibilities offered by inter-textuality.

In this thesis, the language used by adult children of parents with serious mental illness to describe their experiences can be seen to include cultural re-presentations of ‘truths’ which signify the meanings of the experience. The postmodern emphasis on multiple interpretations and blurring of genres is also evident in the use of ‘messy’ text throughout, where an objective scholarly writing voice is interwoven and interrupted by personal narratives and reflective writing. The previously de-centred voice of my-self as writer is brought to the centre, and the rigid boundaries between ‘high’ or scholarly writing and ‘low’ or personal writing become unclear. The result is a continuous yet fragmented narrative of the processes and outcomes of the research.

In terms of the emphasis on the use of language, postmodernism is frequently used interchangeably with that of poststructuralism. Both perspectives share commonalities,
seen in the following discussion on postmodernism and poststructuralist thought, although there are differences in focus and emphasis, and both remain contested concepts. In this study however, postmodernism refers to ideology, theory and research on society and culture, whilst poststructuralism refers to the linguistic perspective on theory and research, where the emphasis is on analyses of literary and cultural representations of reality (Cheek, 2000).

4.2.2 Poststructuralism

As with postmodernism, poststructuralism is a contested term that also includes a multiplicity of approaches, which nonetheless share key assumptions about language, meaning, and the nature of subjectivity. That a poststructuralist approach also values fragmentation and the inclusion of multiple voices may be seen in the lack of fixed meaning of the term (Cheek, 2000). A poststructuralist stance can be considered part of a continuum of social constructionism where language is viewed as socially constructed and inter-subjectively constituted between people rather than by individuals (Lupton, 1998), as well as constituting a philosophical response to the premises of structuralism. Poststructuralism seeks to de-centre the structures of structuralism and critique its underlying premises, whilst preserving the structuralist critique of the humanist subject (Peters, 2002). This is the reason that I attend to the realist tales of participants’ experiences first, by way of van Manen’s phenomenological approach to thematic analysis, before moving to the post-realist tales.

Poststructuralism focuses on exploring and analysing texts that are for example; written, visual, spoken or acted representations of reality (Cheek, 2000). From a poststructuralist stance, language as a system is a cultural form that exists due to the cooperative of individuals who use it according to shared conventions or grammatical rules, in order to be understood (Crowe, 1998). Subsequently, the poststructuralist notion that discourses produce meaning and subjectivity rather than simply reflecting them means that language and subjectivity are contested sites (Weedon, 1999). Poststructuralist thought considers discourses to play an integral role in shaping and constructing knowledge, identity, experiences, relationships and social institutions and practices (Lupton, 1998).
Poststructuralist thought on language also challenges the assumption that there is no given or natural meaning in the world. Instead, language is used to identify and interpret signs and understood to give meaning to reality but not to reflect it. Meaning itself is an effect of language and therefore culturally and historically specific (Cheek, 2000; Crowe, 1998; Weedon, 1999) and cannot be permanently fixed.

Although the concepts of postmodernism and poststructuralism have been separately addressed in this chapter, the epistemological foundations for this study are inclusive of both perspectives. Whilst mindful of the contestable nature of the terms, in this study the postmodern theoretical framework also recognises the poststructuralist concern with language, although the emphasis remains on the postmodern approach to knowledge and re-presentations rather than discourse analysis and interrogation of texts.

In summary, postmodernism and the linguistic critique of poststructuralism emphasise multiplicity and difference. They call attention to diversity and are suspicious of totalising discourses such as modernism (Huntington & Gilmour, 2001), whilst also attempting to re-structure and de-centre dominant ways of thinking. They recognise the authenticity of many ‘voices’ and many ‘worlds’ and are concerned with producing knowledge through open discourses and the use of popular language where there is a co-existing meaning system (Stringer, 1999). Postmodernism does not produce or claim theory, and the use of a postmodern framework in this narrative inquiry will be evident in the questions raised and the concepts troubled or problematised, rather than laying claim to the ‘truth’ of being ACOPSMI. This is why in this study, the final outcome will be to surface diverse and shared experiences that are located in particular contexts, and to raise questions that may help to advance the conversation on what it means to be an adult child of a parent with serious mental illness. So as to provide interpretations which both illuminate as well as trouble conventional understandings of the experiences of ACOPSMI, a dual approach to analysis of the field text will be used.
4.3 DOING A ‘DOUBLE SCIENCE’

As identified in Chapter 1, and consistent with postmodern epistemology which privileges multiple re-presentations, in this study the analytic phases are dually approached from both a realist and de-constructive lens.

My decision to produce multiple interpretations of the field text was informed by particular epistemological and re-presentational concerns which have been cogently argued by Lather (1997). Calling on Butler’s (1993) work on subversive re-iteration, or the use of both realist and de-constructive approaches in the same research, Lather (1997) argues that both ‘doing it’ (realist approaches) and ‘troubling it’ (de-constructive approaches) recognises that the limits of re-presentation and the production of knowledge are never innocent. In using this approach I am seeking to address the question “what becomes possible when empirical work is intentionally positioned as both within and against normalised disciplinary conventions?” (Lather, 1997, p.25). This approach therefore is a double practice of both/and science and anti-science. Doing a ‘double science’ argues for the production of unusual forms of science which address the concerns of a crisis of re-presentation through making explicit the paradox of both ‘knowing’ and ‘not knowing’.

In conducting a dual analysis, I position myself as an affirmative postmodern researcher who recognises the understandings gained through modernist interpretations whilst also troubling the limits of an essentialist knowledge that assumes a reductionist approach to texts. Contesting this through use of a de-constructive approach to the same text provides an opportunity to enrich interpretations through a lens which acknowledges differences and attends to multi-vocality and multi-plicity.

Therefore, although the methodology is that of narrative inquiry and the emphasis is on a narrative analysis of field text, the first analytic phase of the study will consist of a phenomenological thematic analysis. The use of diverse analytic approaches to the same field text, including both thematic and narrative analyses, is supported by other qualitative researchers (Coffey & Atkinson, 1996; Ollerenshaw & Creswell, 2002;
Savage, 2000). They too have recognised the limitations of producing a single interpretation in a postmodern research context, and argued that diverse, although perhaps also complementary, approaches can be useful.

In this study, using a thematic analysis as well as a narrative analysis may result in findings which, rather than necessarily leading to markedly differing interpretations, can also offer varying emphases as to meanings in the participants’ experiences. Each interpretation may be seen as meaningful (Savage, 2000). The overlap between the findings produced from this double science will be discussed in terms of how the two texts can inter-act and combine to form an inter-textuality of meanings.

Nevertheless, as Coffey & Atkinson (1996) have argued, in doing so it is not the intent to produce an aggregated or singular re-presentation from the two analyses, but rather, to provide rich and complex interpretations of the same field text. This approach seeks to expose varying facets of the experience which may otherwise be unavailable using a single tradition. In accordance with Savage (2000, p.1499) “…these seemingly opposed traditions may be more usefully understand as dialectical or mutually informing”.

As identified in Chapter 3, the subjective experiences of ACOPS MI have been almost exclusively investigated from a realist perspective, using phenomenological and/or thematic approaches. In the first instance I therefore aim to add to and extend the existing literature through a phenomenological thematic analysis. The additional use of a postmodern de-constructive lens from which to analyse participants’ experiences aims to shed fresh light on the issue and in doing so further extend and develop existing understandings. Initially, in order to develop the existing literature which has for the most part used a realist approach to exploring the experiences of adult children of parents with mental illness, I will be using an interpretive phenomenological thematic approach.
4.4 INTERPRETIVE PHENOMENOLOGY

As an early twentieth century philosophical movement developed particularly by the work of Husserl (Spiegelberg, 1982), phenomenology may be understood as one of the epistemological antecedents contributing to the development of narrative as inquiry.

The term ‘phenomenology’ has been considered to refer primarily to “a concept of method” in that it characterises the ‘how’ of research (Heidegger, 1927, p. 72). In general terms, phenomenology can be defined as a study of the ‘lifeworld’ (Lebenswelt), the world of lived experience. The aim is to gain a deeper understanding of the meaning of everyday lived experience through asking what the experience is like pre-reflectively – “as we find it” - before the person has tried to categorise or explain it (van Manen, 1990, p.18). In this way, phenomenology’s emphasis on understanding the meanings of experience as it is lived and the concern with the use of language to structure experience, (van Manen, 1990) are concepts shared with narrative, although phenomenology’s realist emphasis on deep essential meanings for instance, is divergent with narrative’s postmodern understanding of multiple surface meanings.

Phenomenological work such as Heidegger’s, however, is considered to have anticipated and opened the space for postmodern thought (Dreyfus & Hall, 1992; Kvale, 1996). There are a number of phenomenological traditions, including Husserl’s descriptive phenomenology, but interpretive or hermeneutic phenomenology was established with Heidegger’s seminal work ‘Being and Time’ (Sein und Zeit) in 1962 (Spiegelberg, 1982). In his treatise, Heidegger introduced the ontological notion of Being-in-the-world (Dasein), an aspect of being human which understood itself in terms of its existence (Heidegger, 1927), and referred to how human beings made sense of the world and their place in it (Conroy, 2003). Time is an important aspect of Being in that Heidegger understood Dasein as essentially temporal in nature or lived in time (Spiegelberg, 1982).

van Manen (1990) explains that to do interpretive phenomenology is to attempt to construct rich interpretive descriptions of aspects of the lifeworld such as the experience of lived time, lived space, lived human relationships, and lived body. In the present study,
therefore, initial analysis of participants’ experiences will employ van Manen’s interpretive phenomenological approach to thematic analysis.

The major focus of this inquiry, however, is experience as it is understood narratively, and this chapter moves now to discuss the methodological and philosophical underpinnings of narrative inquiry.

4.5 ACTUAL STORIES, POSSIBLE INTERPRETATIONS: NARRATIVE INQUIRY

As discussed, narrative inquiry has a basis in phenomenology in so far as the main goal is the rigorous study of meaning of experiences (Emden, 1998a). Narrative is considered to refer to the ways one makes new meanings out of experience (McEwan, 2001), as phenomenological understanding of human experience views it as being lived autobiographically. That is, past, present and future are always in the present. A person’s historical experience influences the present and projects into possibilities for the future.

Over the past twenty years there has been a growing recognition that individuals and their ‘identity’ may be constructed by the stories they tell of themselves and their lives. This ‘narrative turn’, which privileges language and texts as the basis of knowledge of society, considers everything to contain a storied re-presentation. Whilst postmodernism is generally taken-for-granted as being part of the epistemological foundation of narrative inquiry (Josselson, Lieblich & McAdams, 2003), and in this study narrative is viewed through a postmodern lens, a narrative approach to human experience can be taken from a range of modern and postmodern positions. In the discipline of psychology, with which the topic of this study is most closely aligned, the narrative approach is also considered social constructionist in orientation due to these attempts to explore individual experiences within their broader cultural and social structures (Crossley, 2003; Hevern, 2002; Kirkman, 2002).

Narrative inquiry is a systematic epistemological approach that seeks to understand subjective experiences by focusing on the stories that structure and recall those
experiences. As a methodology it therefore sits within the interpretive research paradigm. This type of inquiry is characterised by the revealing and re-presentation of personal experience which serves to provide accounts that enable others to understand how the events and issues experienced by the individual has affected their daily lives. Studies located in the interpretive paradigm are consequently based on certain assumptions. These include that the study is particularistic. It explores and evokes a particular time and space and focuses on finding meaning about a specific issue or problem within that context, such as the experience of some adult children of parents with serious mental illness. It does not intend to speak for all, and indeed acknowledges that it cannot. The primary purpose of interpretive research is to produce thick and rich accounts that reveal the experience of particular participants in order to extend understanding of a particular issue (Stringer, 1999). Interpretive research honours subjectivity, and sees people as reflective and able to articulate their experiences in language, such as telling stories.

4.4.1 Defining ‘narrative’ and ‘story’ for this study

The use of the term ‘narrative’ in research is not necessarily based on epistemology (Clandinin & Connelly, 1994; Cole & Knowles, 2001). In the literature for instance, the terms ‘narrative’ and ‘story’ are often used interchangeably. ‘Story’, however, has been distinguished from that of ‘narrative’ by some authors in that a story is a re-presentative account of peoples’ actions (Sarbin, 1986). A story may be seen as the closest a person can come to experience as either they or others tell it (Clandinin & Connelly, 1994).

Stories are also considered a part of one’s personal identity and of one’s culture. In terms of the ‘self’, the story allows us to construe who we are, and in terms of culture, it gives unity to shared beliefs (Gudmundsdottir, 1991). From a very young age, for instance, children are told ‘bedtime stories’ by their parents, which have at their basis the cultural, moral, social, political, legal, ethnic and gendered values of the time, or of times past. Frank (personal communication, 8th August, 2003) refers to these as culturally-specific or idiomatic narratives which are constructed on the syntactics of the person’s particular language.
A narrative, though, can be defined as “the performative process of making or telling a story” (Denzin, 1997, p. 158), hence narrative specifically refers to the structure, knowledge and skills that are needed by the person in order to construct a story. In this thesis, the phenomenon or experience over time of having parents with serious mental illness as recounted by the participants will be referred to as their ‘life story’, whilst the research inquiry and product will be referred to as ‘narrative’, where the participant tells their story and the researcher describes and interprets these through writing of narratives and use of narrative inquiry.

In narrative inquiry, the participants are the narrators and the field texts collected, known in conventional research as data, are their stories (Emden, 1998a). Narrative inquiry allows participants to tell their own stories, and give voice to their experiences and the meanings they have drawn from these. Particular attention is paid to the plot – the temporal or chronological unfolding of events (Hones, 1998; Poirier & Ayres, 1997), and temporality is a central feature of narrative thinking. The event(s) recounted have a past, a present, and an implied future (Clandinin & Connelly, 2000).

4.6 PHILOSOPHICAL UNDERPINNINGS OF NARRATIVE INQUIRY

In addition to postmodernism there are a number of theoretical perspectives, including hermeneutics, interpretive phenomenology, and social constructionism, which have influenced the epistemology of narrative inquiry. In particular, the guiding assumptions of hermeneutics will be outlined in the following section. Ricoeur’s views on time and narrative identity and the interpretive act of mimesis (1984, 1991), considered some of the most influential work in postmodern philosophical hermeneutics (Wood, 1991) and in the development of later work by narrative theorists such as Bruner (1986) and Polkinghorne (1988), is the focus of discussion.

4.6.1 Hermeneutics

Contemporary theory in narrative has borrowed a number of concepts from modern hermeneutics. Hermeneutics, whilst conceptualised from various perspectives and used as both a method and philosophy, may be defined as the philosophy or theory of the
interpretation of meaning (Bleicher, 1980; Ormiston & Schrift, 1990), in that it is considered there may only be interpretations by the self of others’ interpretations of the meaning of existence (Bleicher, 1980). Hermeneutics has more recently emerged as a postmodern philosophy that informs a range of existential issues. Hermeneutic philosophy emphasises the social and historical nature of inquiry and argues that an understanding of any aspect of reality cannot be separated from the standpoints and social interests we assume in being cultural agents (Thompson, 1990).

The work of Ricoeur (1976) has been identified with narrative theory development from the perspective of hermeneutics, in that he referred to narrative as being fundamental to the human experience of time. Ricoeur’s theory of interpretation considered the construction of a written or spoken text to provide a window into subjective existence. The structural analysis of language was an integral aspect of his work, where language, as well as being a sign system, was seen as a temporal event or discourse in itself which can be understood as meaning in the present moment (Bleicher, 1980; Ricoeur, 1976). Meaning therefore refers to both what the speaker meant or intended, and what the sentence(s) mean in terms of language function, in a dialectic of event and meaning which Ricoeur argued as being the “utterer’s meaning has its mark in the utterance meaning” (1976, p.13). From this perspective, the meaning of one person’s experience cannot directly become the experience for another. More accurately, it is the meaning of the speaker’s/writer’s experience, rather than the experience as it is lived, that is communicated from one to another through language. The lived experience itself remains private to the person, but the meaning of the experience becomes public (Ricoeur, 1976).

Ricoeur (1990) also considered the issue of ‘truth’ to be linked with that of method in construction of the text. Understanding of the text is seen as the exposure of the reader’s self to the text, where what is contained in the text gives subjectivity to the reader or listener. Furthermore, Ricoeur (1974) considered that a text can have multiple meanings, for instance; historical and spiritual, and there is subsequently a need for interpretation where the reader/listener is matched to the text through intention to overcome the ‘foreignness’ of it, so that its meaning is incorporated into the reader’s/listener’s self-
understanding. In this way hermeneutics, like many philosophies, assists individuals to better understand the ‘self’ (Thompson, 1990).

In a pivotal work, a trilogy titled ‘Time and Narrative’; Ricoeur (1984-1988) provided a number of key constructs of narrative and its relationship to self-identity. In his work, drawn in the first instance from literary theory, Ricoeur (1984) identified that what was at stake in narrative, including ‘truth’ claims, was the temporal nature of human experience. Time became “human time to the extent that it is organised after the manner of a narrative” (p.3). Narratives became meaningful then in terms of the extent to which they portrayed aspects of temporal experience - the life story or history - as every narrative unfolded within a temporal world. Narrativity and temporality were considered by Ricoeur to exist together within a ‘healthy’ hermeneutic circle, where they mutually reinforced each other.

Plot was also a central feature of Ricoeur’s discussion of narratives, in that he considered all narratives to be structured through plot, or the narrative organisation of events. From the plot within each narrative, Ricoeur (1984) argued that opportunity, goals, and causes were brought together temporally to unite into a complete action. He further argued that time was fundamental in the development of two major types of cultural narrative that existed; historical and fictional. Historical narratives were those that claimed to re-present historical events through narration and the unfolding of a temporal plot. Fictional narratives, on the other hand, were those drawn from literary genres and included all creative works such as novels and folk stories. These were distinguished from historical narratives, in that they were not ‘true’ narratives, concerned with creating a claim to truth (Ricoeur, 1985). Both historical and fictional narratives could be dialectically combined however, into a narrative identity. By this, Ricoeur (1988) referred to the agent or author of the narrative as being the named ‘who’. To determine personal identity was to tell the story of a life, which was about the actions of the ‘who’. To answer the question “Who am I?” then, was to answer with a narrative, and the story of a life or ‘narrative identity’ could be continually re-formed over time by each of the ‘true’ or fictional stories the subject told of themselves.
Ricoeur (1984) combined the concepts of lived time, plot and narrative, and provided a significant contribution to interpretive understanding of experience in his development of a three stage endless and progressive circular spiral of ‘mimesis’. Here, he demonstrated how personal narratives are constructions that help form narrative identity (Flaming, 2005). Drawing from the work of Aristotle, Ricoeur (1984) considered ‘mimesis’ to be the creative (or poetic) imitation or re-presentation, through the use of narrative, of events or experiences by one person in order that others may also experience the event. This was a temporal construction which helped the person make sense of who they were ontologically – how they understood themselves as a human being - as it included past, present and future action (Flaming, 2005), and was therefore a “plot of lived temporal experience” (Ricoeur, 1984, p. 31).

Mimesis$_1$ referred to the pre or existing understandings (pre-figured time) of the world that influenced the person to act. These assumptions could explain what had motivated the person’s actions (Flaming, 2005). In mimesis$_2$ (con-figured time), which Ricoeur (1984) considered the turning point or pivot of the mimetic process, the person emplotted or constructed their events and experiences. The plot was the mediation of events or incidents that transformed them into a story as a whole, and mimesis$_3$ (re-figured time) was the time of action. It marked the intersection of the world of the text with that of the hearer or reader of the emplotted story, where the person told their story of events as they had understood them, which in turn influenced others in the hearing or reading of the narrative. The relationship between mimesis$_1$ and mimesis$_3$ is so close then, that when we interpret others’ stories we are also interpreting our own selves. The ‘interpreter’ (the other person) becomes the ‘interpreted’ as our own pre-figurations influence our interpretations of their narratives (Flaming, 2005).

### 4.7 APPLICATIONS OF NARRATIVE INQUIRY

In psychology, the development of a narrative paradigm has been particularly attributed to the seminal works of Bruner (1986), Sarbin (1986), and Polkinghorne (1988), who built upon Ricoeur’s notions of narrative. In the first instance, the work of Bruner (1986) was influential in explicating between two modes of cognitive thought which provided
ways of constructing reality and experience – the paradigmatic (logico-scientific), which had been the traditional mode of thought in psychology, and the narrative. Although he considered them as being complementary to each other, Bruner argued that any attempt to reduce one to the other was to ignore the diversity of thought which could be found in using both. Applying Ricoeur’s argument that narrative was concerned with the human condition, Bruner (1986) contended that a narrative mode of thought led to captivating and lifelike historical accounts of experience which were located in time and place.

Narrative inquiry offers many benefits, especially in relation to this research. Using a narrative approach to understand the participants’ personal experiences can be seen to overcome some of the limitations of traditional psychological and sociological approaches, so that neither the social’ nor the ‘individual’ is privileged (Andrews, Sclater, Rustin, Squire, & Treacher, 2000; Murray, 2003). Rather, they are constructed in relation to each other in a psycho-social dialectic. The narrative turn then, may be viewed as a process of re-integration of the humanities and sciences after a post-Enlightenment estrangement (Andrews et al., 2000). The ‘self’ is viewed as a narrative and psycho-social production which is inclusive of social conditions and discourses, and woven within narrative practices to shape itself and its various identities (Denzin, 2000). In narrative, the ‘self’ is not considered a substance, but rather, a process (Polkinghorne, 1991). Individuals are seen to ascribe meaning to events and situations in their lives through the construction of storied accounts of them (Sankey & Young, 1996). In this way, the ‘self’ and narrative are indivisible, as narrative arises out of experience whilst also giving shape to it (Ochs & Capps, 1996).

In narrative inquiry, the stories the researcher tells of their experiences may also be combined with those of participants, as seen in this study. It can be a powerful method of bringing together the stories of the ‘self’ and ‘other’ so that both may come to understand themselves differently. Thus, stories may also be transformative in that the process of sharing them can provide opportunity for transformation of the story, the narrator/s, and the listener/reader (Hones, 1998).
In keeping with postmodern thought, therefore, narrative inquiry does not assume objectivity. Instead it privileges subjectivity and positionality (Reissman, 2002). Narrative inquiry attends to both the structuring and analysing of narratives and thus narratives themselves have a dual nature as they are both created and interpreted by different people. Narrative inquiry is also characterised by an awareness that the ‘story’ may be contested ground, as a reader may not interpret the meaning of the story in the same way the narrator does (Poirier & Ayres, 1997). From a postmodern perspective, stories can also be seen to represent contradictions and hesitations. There may be a tension between the nature of ‘truth’ and knowledge’ (Lincoln & Denzin, 1994).

4.7.1 The notion of ‘truth’, knowledge and memory in narratives

Truth, the evocation of memories and their verification in objective reality is a major consideration in this study. Whether or not events actually took place is not as important to this inquiry as the perception and impact these memories have for ACOPSMI. Notions of truth and memory are therefore considered in the section to follow.

The concept of truth in regard to the veracity, and hence plausibility of personal narratives, has been extensively discussed and debated in the research literature. However in terms of narrative research, it is generally understood that participants “reconstruct reality in giving meaning to their lives.” (Hill Bailey, 1996, p.1). It is the construction of meaning, rather than ‘truth’, that the researcher wants to achieve (Hill Bailey, 1996). Nevertheless, from a postmodern perspective although it is recognised there is no one singular truth of a situation, there are local versions of truth. These refer to factors that are ‘true’ to, or fit, the knowledge and experience of people who are in certain discursive situations such as ACOPSMI. For each individual, what we know as the ‘truth’ is situational and contextual, however these ‘truths’ can overlap even if they are not identical for everyone (McWilliam et al., 1997). In this study it is recognised that some of the ‘truths’ of being ACOPSMI expressed by the participants will resonate for others who identify with this experience. No one person’s total experience however, will resonate for all.
In conjunction with the notion of ‘truth’ lies the issue of memory. When asking a participant to recall past experiences, we are relying on memory processes. Crowe (1998) argues against the assumption that past experiences recalled through memory and communicated can be viewed as ‘true’ re-presentations. Instead, memory processes may be viewed as being as culturally determined as they are constructed within particular cultural mores. From this perspective, memory is a social construction. Hence memory retrieval is as much re-constructed as it is recalled. Research that claims to capture ‘truth’ through re-presentation of another’s experience needs to be viewed with caution. This study does not lay claim to capturing the whole ‘truth’ of the participants’ experiences, as the concept of truth from a postmodern narrative inquiry perspective is laden with ambiguity. There are many truths. As Fontana (2002) argues, a single interpretation that is commonly accepted as ‘truth’ does not provide a choice amongst what may be many possible truths. This research can only lay claim to the construct of meaning in the multiple experiences of adult children of parents with serious mental illness.

A narrative inquiry methodology, informed by a postmodern theoretical framework, is particularly relevant to the exploration of the subjective experience of adult children of parents with serious mental illness as it provides an avenue for participants to recount their experiences in the form of stories. Stories can offer one of the more comprehensible methods of learning about a person’s inner world and their experienced reality. They can represent the self-narrative or life story, and may be seen to imitate life as it is understood by the person (Lieblich, Tuval-Maschiach, & Zilber, 1998).

4.8 LIMITATIONS AND CAUTIONS IN THE USE OF NARRATIVE INQUIRY

Narrative inquiry, as with all forms of research, has limitations and criticisms of its use. Due to the subjective nature of interpretation employed in narrative inquiry, an objective recounting of another’s story is also not possible, and as Koch (1998) has argued, this form of interpretive inquiry brings with it a number of challenges. In addition, the seeming directness of a narrative may actually be indirect and contain multiple layers. Stories may therefore be liable to misinterpretation on the part of the researcher, or
contain contradictions on the part of the narrator. A narrator may also neglect relevant structural factors that may have affected their life or present them in a biased manner (Denzin, 1989; Poirier & Ayres, 1997).

In narrative inquiry, stories are simply interpretations, and the stories people tell are self-stories. All stories may be considered as fictions (Denzin, 1989; Poirier & Ayres, 1997). Thus, narrative inquiry has been criticised for not representing the ‘truth’ of participants’ experiences, which highlights the difficulty of ‘accurate’ re-presentation of a person’s life (Denzin, 1989). Whilst narratives do not produce generalisable findings in the statistical sense, they can be generative, and the researcher may also be accused of manufacturing stories. There may also seem to be no specific method for ensuring rigour in this form of research (Koch, 1998), although this issue will be addressed in the following chapter on the study methods. Narrative inquiry has further been criticised for being more ‘art’ than research, as it can be viewed as being based on talent and intuition, defying clear order, and being difficult to teach (Lieblich et al., 1998), although these may also be considered strengths depending on the perspective from which they are viewed.

4.9 IMPLICATIONS OF THE METHODOLOGY AND FRAMEWORK

This study is based on the assumption that individuals socially construct reality, and that class, culture, race, gender, authority and local experiences may shape their view of reality. Thus the study aims to explore and evoke participants’ experiences and stories of their experiences of being the adult child of a parent with serious mental illness. As the researcher I will be interpreting the experiences and analysing these stories using both phenomenological and narrative analytic techniques and re-present them in both forms. Because this study is also informed by a postmodern theoretical framework, the narratives will contain and illustrate practices of power, contradictions, common and uncommon experiences, and will foreground difference and resistance. Postmodern tools of inter-textuality, language-play and pastiche will be utilised. Rather than looking for a grand narrative of the experiences of being ACOPSMI, this study will look for alternate stories and local narratives and be cautious of any essentialist notions that may falsely suggest linear pathways and causal links between factors.
4.10 CONCLUSION

In summary, this chapter has discussed the theoretical and philosophical premises of narrative inquiry as an interpretive methodology, and outlined concepts of interpretive phenomenology. The theoretical underpinnings of hermeneutics and a postmodern theoretical framework have been explored as they apply to the present study, so that the epistemological foundations of narrative inquiry may be further illuminated. Chapter 5, ‘The Study Methods’, discusses the specific research methods to be used in this narrative inquiry.
CHAPTER 5
INSIDE OF ME - THE STUDY METHODS

Musical lyrics removed for online publishing due to copyright
Reflecting on ‘Inside of Me’

Madonna is considered to have written *Inside of Me* as a tribute to her mother who had died of cancer when Madonna was a child. The song clearly evokes the longing and grief she feels at the lack of her mother’s presence, yet also illuminates how she continues carrying these emotions with her through life.

In this chapter, *Inside of Me* refers not only to the feelings that the physical and/or metaphorical lack of parental presence can evoke for children, but also to how these private experiences can be elicited through research. The use of my own experiences through auto-ethnography, and my qualities and skills as a researcher, are also germane to the following discussion of the methods used in this study to gain access to the personal experience of growing up with a parent with serious mental illness.
5.1 INTRODUCTION

The previous chapter explained that to evoke and explore the experience of being ACOPSMI, and to attend to silences and new ways of thinking, both a realist exploration and a postmodern analysis would benefit understanding. In this chapter the methodology previously discussed will be applied to a detailed plan for gathering information and analysing findings. The chapter explains the divergent approaches to field text collection and analysis, how participants were selected, and the methods for collection of field texts. The chapter also details the ethical and rigour considerations addressed throughout the course of the study.

5.2 FIELD TEXT COLLECTION

In narrative inquiry, ‘field texts’ (otherwise known as ‘data’) refer to the types of information the researcher collects whilst in the ‘field’. As such, they are already storied interpretations of experience which the researcher has consciously, and perhaps less consciously, constructed and/or co-constructed (Clandinin & Connelly, 2000). In this study, field texts include research interviews, auto-ethnographic writing, field notes and written member checks. In the tradition of postmodern writings, the overall approach to the gathering of field texts and their analysis in this study is by way of a reflexive, dialogical and meta-analytical stance, which is discussed in the following section.

5.2.1 Reflexivity

The use of reflexivity, in alignment with greater acceptance of researcher subjectivity in qualitative research, has become an increasingly common phenomenon in research over the past two decades (Northway, 2000). Reflexivity is based in the notion of critical self-reflection (Macbeth, 2001), where the researcher engages in an overt and self-aware analysis of the research process (Finlay, 2002). Reflexivity requires that for the duration of the study the researcher critically examines their actions through each stage of the research process. This includes issues such the participants’ responses to the researcher, how the researcher is collecting the field text, what they are seeing and hearing, and how
they are making their interpretations. It may lead to alterations to aspects of the design and/or implementation of the research. The resulting reflections need to be written up as part of the research report in order to make reader evaluation of the research possible through the process of transparent and auditable documentation (Horsburgh, 2003; Northway, 2000; Webb, 1992). In this study, reflexivity is evident in my use of personal reflective comments, in auto-ethnographic excerpts, and in provision of a clear audit trail through detailed explanation of the research processes.

A reflexive orientation is to be self-conscious about how the researcher plays a part in constructing meaning in the research; he/she does not simply describe the participant’s reality. Even by engaging in a conversation with the participant, the researcher will be creating reality with him/her – subtly influencing and shaping the opinions shared, the stories evoked, and the meaning made. A reflexive orientation seeks to make visible the beliefs and values that the researcher uses, sometimes consciously, that shape interpretations of field text.

Within the researcher-participant relationship, a reflexive stance wherein the researcher is involved and engaged can assist participants to feel more comfortable with sharing information (Ellis & Berger, 2002). It may promote dialogue rather than interrogation. In an interactive context, participants become narrators who improvise stories in response to the questions. For the dialogue to continue, researchers are required to listen empathically, identify with participants, and show respect for participants’ emotionality. In this process, multiple interpretations are likely to be valued, including those of participants. Thus, findings are more likely to be a co-construction. Using research techniques such as reflexivity, which give participants the opportunity to be actively involved in the construction of knowledge about their lives, is also an important way for researchers to confront and moderate the power differentials often present in research relationships.

So I have, in telling the story of the research, been reflecting on the personal experiences that brought me to the topic, what I learnt about and from my-self and my emotional responses during reading about them, writing on them, and interviewing and responding
to and with the participants, as well as how I’ve used my knowledge of self and/or my own experience of being an ACOPS MI to understand what the participant was saying (Ellis & Berger, 2002). This added layer of auto-ethnography aimed to produce findings that seek to add a contemporary and authentic dimension to the existing knowledge on the experiences of ACOPS MI and to the methodological use of self in research.

**But what will people think? ‘I’ and ‘Me’ – an internal dialogical debate**

“I can’t tell my own story and then include it in the analysis. What will people think?”

‘Why are you so worried about what people think? You’ve opened the door by saying you’re an adult child anyway. Don’t you think if you don’t tell your story, or if you do and then you don’t include it for analysis like the others, they’ll be wondering why?’

“It seems narcissistic. And, I’m a nurse academic. We don’t really do this kind of research”

‘So? What’s wrong with including your own story for heaven’s sake? It’s interesting. And it’s definitely relevant. And if you were a participant who volunteered for the study your story would add something none of the others do – you’re the only one who was put into institutional care’

“But it’s embarrassing. And it’s difficult. Well, it’s not really difficult, it’s just...personal. I feel really exposed. I worry about what people will think”

‘Okay. Don’t do it. Leave it out. There’s not much you can do about what people will think’

“But I’ve got something relevant to say. And I think it’s important researchers don’t always pretend these things happen to everyone but us”

‘Then say it’

**5.3 COMING TO AUTO-ETHNOGRAPHY**

At the commencement of this study I had not actually considered using autobiographical method. Instead, I was more concerned at the time with bracketing my experience as an adult child of a parent with serious mental illness as I had initially considered using phenomenology as the study’s methodology. However, having subsequently shared my story through conference presentations and writing, I gained insights into my experience and a subsequent shift in my perspective such that I saw that my story was an integral
part of the research and could not be separated through the use of bracketing, which was an inappropriate notion in this situation. Indeed, I realized that my experience could be used as a starting point from which to explore the issue with the participants. From an ethical perspective I also felt that if I was presuming to ask others to share their experience of being an adult child of a parent with serious mental illness, I needed to be willing to do so myself. The issues of authenticity and reciprocity were central to this concern. Subsequent searching of the literature for use of self in research led to a surprising but exciting discovery of a body of work in auto-ethnography, which was synchronous to my emerging interest in and understandings of narrative, and my developing beliefs about the use of self in research.

5.3.1 Auto-ethnography

As acknowledged by other researchers (e.g. Walker, 2002; Yow, 1997), the choice of research topic, interviewing process and interpretation of field text are inevitably influenced by the researcher’s personal responses to the topic, field text and participant(s). The choice of topic is therefore neither random nor accidental (Walker, 2002). Indeed, Clandinin and Connelly (2000) argue that narrative inquiry is intensely autobiographical. The researcher’s research interests come out of their own narratives of experience and shape the inquiry’s plotlines. The use of auto-ethnography is therefore consistent with, and arguably, fundamental to a narrative methodology.

In auto-ethnography, researchers focus on the use of self as a starting point for field text collection and analysis, and from which broader socio-cultural issues can be explored. The individual’s personal account is used to interrogate a social issue (Cole & Knowles, 2001). There are a number of similar terms used to describe the use of self in research including but not limited to those of autobiographical ethnography, narrative ethnography, native ethnography, self-ethnography, narrative auto-ethnography, reflexive ethnography, evocative narratives, and memoir. The way auto-ethnography is defined and used varies across a continuum where the researcher’s personal experience is important primarily in terms of how it sheds light on the culture that is being studied. Auto-ethnography ranges from starting research from one’s own experience, to studies where
the researcher’s experience is explored alongside those of the participants, through to stories where the researcher’s experiences of conducting the research become the actual focus of investigation (Ellis & Bochner, 2000).

Although it is an emergent method in mental health nursing research (Foster, McAllister, & O’Brien, 2006), auto-ethnography has been used in ethnographic and anthropological research, in educational research, in sociology, and from a feminist perspective (Ellis & Berger, 2002). The approach has four key features: use of personal ‘accessible’ writing; ‘outing’ the researcher’s experiences and shared humanity with participants; rejection of claims to objectivity; and valuing subjectivity and researcher/participant inter-subjectivity.

In terms of writing, auto-ethnography may be considered a form of resistance to the ‘othering’ of the researcher, and a move away from distanced, objective theoretical writing to that which describes the individual and imaginative aspects of the researcher as agent (Burdell & Swadener, 1999). The act of writing itself becomes a way of being and knowing. Auto-ethnographic writing values ordinary language over scientific language, and the use of metaphor, satire and irony to engage more fully with descriptions of life (Foley, 2002). Halley (2003) for example, in a situation bearing similarities to my own, used experimental writing to explore her experience of childhood trauma, stigma, ostracism and paternal sexual abuse when her mother divorced her father.

Conle (1999) has argued that as a mode of research, the customary distance between researcher and participant could hinder narrative inquiry. The use of the researcher’s personal history should therefore be openly addressed during the inquiry, and is legitimate ground from which to proceed throughout the study. It may be seen as the medium through which theory and life can be connected. Due to my personal experience as the adult child of a mother with schizophrenia and my decision to research this topic, I saw the use of auto-ethnography as an appropriate and indeed necessary method to use within the framework of a narrative inquiry. There are a number of issues though, that may arise in the course of using this method. In the following section the use of empathy,
the issues of identification and counter-transference, and the inter-subjective nature of the encounter between researcher and participant are addressed.

Inter-subjectivity refers to the connection between two persons, where neither exists as separate, or as subject/object, but in connection. The relationship between the two (in this study, between my-self and the participant) is inseparable (McAllister, 2001). Walker (2002) considers the concept of inter-subjectivity to be a process of counter-transference. This term was originally derived from the psychoanalytic theory of Sigmund Freud who applied it to the therapeutic relationship between therapist and client. Whilst there have been various definitions and meanings ascribed to it, for the purposes of this study counter-transference will be taken to mean the therapist/nurse’s unconscious response to the client (O’Kelly, 1998).

From a research perspective, Walker (2002) contended that the conscious application of counter-transference to interpretation of research data illustrates a connection between her identity as a clinician and researcher, which may in fact lead to a more meaningful interpretation of the experiences of the participants in the study. In concurrence with Walker’s perspective and experience as a psychiatric/mental health nurse, I also consider that the notion of being influenced by, and in turn, influencing my research, is a valid and important aspect of this study. In fact, it is inescapable. Having identified myself as experiencing the same phenomenon as the participants, I cannot help but have preconceived notions of the topic, and of them, which I inevitably bring to the analysis of their narratives.

The use of autobiographical data on the part of the researcher has been considered narcissistic and self-indulgent, and even exhibitionist (Clandinin & Connelly, 2000). As a developing researcher I certainly do not wish to be accused of such undesirable attributes! Nonetheless, in regard to the issue of re-presentation I have come to the question also posited by Koch & Harrington (1998, p. 883), who recommended that the researcher ask themselves “how do we study the other without studying ourselves?” From a methodological viewpoint I assert that my own experiences, comparative in some respects to those of the participants’, can be an asset that enables a depth and perspective of understanding of their narratives that may not be available to a researcher who has not
had the same experience. Similarly to the situation of mental health nurses who are consumers as well as clinicians, my subjective perspective on the topic can also enable a connection with the participants that may lead to even greater rapport and self-disclosure on their part.

5.4 TEXT SOURCES/SELECTION OF PARTICIPANTS

In this study purposive sampling has been used, as the participants were selected based on the characteristic of being adult children of parents with serious mental illness (Higginbottom, 2004). Sampling was also opportunistic in that the male participants were recruited in order to add a further dimension to understanding the experiences of adult children of parents with serious mental illness (Llewellyn, Sullivan & Minichiello, 2004).

At the time of ethics approval the sample size for the study was anticipated to be a minimum of 5 and maximum of 10 participants. This number reflected the phenomenological and narrative analysis to be applied to the field text, but included the need to have a variety of experiences of ACOPSMI (Sandelowski, 1995). Previous studies exploring the experiences of adult children of parents with mental illness (i.e. Camden-Pratt, 2002; Dunn, 1993; Stevenson, 2002) had particularly focused on female ACOPMI who had mothers with psychosis. As Dunn (1993) acknowledged however, it was also important that future studies explored the consequences of having a father with psychosis. Therefore the participants for this study were selected with the re-presentative issues of age, parental diagnoses, participant and parental gender and range of backgrounds in mind, so as to provide as diverse a re-presentation of experiences as possible.

The selection criteria for participants were relatively broad. In order to be considered as adult children of a parent with serious mental illness, the person needed to be over the age of 18 years and to have spent time living with one or both parents who had experienced serious mental illness such as psychoses. These included schizophrenia, mood disorders such as major depression and bipolar disorder, schizoaffective disorder, and delusional disorder. Parental mental disorders such as dysthymia, anxiety disorders, personality
disorders, and adjustment disorders were excluded. If the participant themselves had a mental illness of any sort, this was not criteria for exclusion from the study unless the person was actively unwell at the time of interview, in which case I considered it would be unethical to interview them.

As evident in the Information Sheet (Appendix B) and Consent Form (Appendix C), I had originally intended to explore the experiences of adult children whose parents specifically had psychotic illnesses. However, I realised in the first few interviews that participants understood the term ‘psychosis’ in many ways, some of which did not appear to be ‘psychosis’ in the psychiatric sense of having hallucinations, delusions and thought disorder, but included other serious mental illnesses such as major depression which could also exert severe and long-lasting effects on the parent’s behaviour and functioning. Rather than exclude these stories and experiences from the study, which I considered inappropriate as they were just as important as any other, I modified the study to that of the slightly broader term of ‘serious mental illness’, hence my use of this term throughout the thesis.

5.4.1 Seeking the participants

Initially an advertisement for the study was approved by the relevant Ethics Committees (Appendix D) and placed on the Mental Illness Fellowship North Queensland website and in their bi-monthly newsletter, which was sent out to consumers, carers and other members across North Queensland. There was, however, no response from these efforts. During this time, I also presented a paper on the issue of ACOPMI at a national conference, and three potential participants contacted me via email and phone afterward to express their interest in participating in the study. Each of them was located in separate states of Australia. However, the first potential participant who had received the information sheet and agreed to a date and time for interview, phone text-messaged me the night before to withdraw from the interview. No reason was given for her withdrawal and in order to respect her decision I chose not to question her further. The remaining two participants were later interviewed.
As there was a need to recruit more than the initial two participants who had agreed to be in the study, I also went on local radio to discuss the general issue of COPMI during national Mental Health Week, and was interviewed for a local newspaper article on the issue of COPMI. This resulted in a further three participants (from the newspaper article) and one participant (from the radio interview). Later, another participant from outside the state contacted me via email as she had heard of the study via word of mouth. This resulted in seven participants who were interviewed over the following four month period. As these participants were all women, and due to my growing awareness from their interviews that their brothers’ experiences were also important, I also sought to find male participants through specific advertisements in local newspapers. This resulted in a number of men contacting me, and a total of two male participants who were finally interviewed. Another potential male participant, who would have been the final one in the study, became unwell with a psychotic episode at the time for scheduling of the interview and had to be excluded for ethical reasons. This resulted in nine participants who were interviewed for the study over a nine month period. The inclusion of my-self as researcher resulted in a total of ten participants in the study – eight women and two men.

Throughout this time, minor amendments were sought from both Ethics committees so that the selection sample was broadened to include participants from states other than Queensland, and advertising was widened to include the use of radio and print media for advertisements.

5.4.2 Selecting and meeting the participants

The process for all participants included a phone conversation to gain initial information and inform them of what was involved in the study. At this point I also told them of my own identity as an adult child of a mother with schizophrenia, although I did not elaborate on my experiences. If both I and the participant agreed to their inclusion in the study, the Information Sheet (Appendix B) was sent to them either electronically or by mail to read. If they were still interested, this was followed by the participant contacting me to organize a time to meet that suited their schedule, and for those participants in other states, dates that also suited my already planned trips for work, study or personal
commitments. Each participant chose the time and place to meet that was most suitable for them. In total, four participants chose to come to my place of work to be interviewed, two participants chose to be interviewed at their place of work, two participants chose to be interviewed in their homes, and one participant chose to be interviewed in a private room at a local library. In the case of my place of work and the library, I undertook to organize and book a quiet room where there was minimal chance of being disturbed.

Prior to each interview I encouraged each participant, in addition to the identified counselling options available from the study, to also have a support person who they might wish to talk with to debrief after the interview. Before the interview commenced, each participant was provided with a copy of the Information Sheet, and asked to read through the Consent Form (Appendix C). They were encouraged to ask any questions they had about the study and reminded that they could withdraw their consent at any time during the research process. Once they were satisfied, both the participant and I signed two consent forms, and each of us kept a copy. At the beginning of the taped interview, I also asked them to clarify their understanding of their participation in the study, so that this was recorded as part of the study.

Participants were encouraged to select a pseudonym for their transcript. Some participants did so, but others said they were not concerned with being anonymous. Due to the need to protect their anonymity according to ethics requirements, I chose a pseudonym for these participants’ transcripts. All names of people and identification of institutions and places were also removed or altered in de-identification of information.

5.5 INTERVIEWING THE PARTICIPANTS

5.5.1 Phenomenological and postmodern aspects of interviewing

The major focus in this inquiry has been on collecting and analysing narratives of experience. As I was also conducting an initial thematic analysis of field text using an interpretive phenomenological approach, I did, though, need to use an interview style which was suited to both phenomenology and narrative.
In interpretive phenomenology, the interview has specific purposes which include exploring and gathering information of experience that may lead to richer and deeper understanding of the phenomenon in question. The interview is used as a way to develop a conversation about the meaning of the participant’s experience, and needs to be organised according to the research question (van Manen, 1990), which in this study meant that one over-arching question inquiring about what it was like to have grown up a parent with psychosis was asked at the beginning of each interview, with further questions throughout, as needed, which asked for elaboration of experiences and/or specific instances that illustrated the experience.

From a postmodern perspective, interviewing has moved away from methods that are more traditional. For instance, in postmodern-informed interviewing the boundaries of the respective roles of participant and researcher may become blurred, such that the communication between them is collaborative and together they co-construct their narratives, as was the case in this study. Traditional hierarchical relationships between participant and researcher have also been criticized, and ways to bring forward previously silent voices, explored. Furthermore, the question of re-presentation of interview field text has arisen where postmodern-informed reporting has used experimental writing such as plays (e.g. Camden Pratt, 2002), as well as poetry and auto-ethnography, to represent interview narratives (Fontana, 2002). Fontana (2002) has asserted that from a postmodern perspective, conversational and other innovative forms of interview communication are now emerging, where the researcher and participant collaborate together in constructing their narratives.

5.5.2 Reflecting on the choice of interview

In this narrative inquiry, I had originally chosen to use the reflexive dyadic interview process outlined by Ellis & Berger (2002), where the typical question and answer structure of an interview is combined with the interviewer sharing their personal experience on the topic, and/or reflecting on the process of communication within the interview. According to Ellis and Berger (2002), this is not designed as a tactic to
encourage participant disclosure, although it may have this effect, but rather, is a reflection of the researcher’s reciprocal desire to disclose in response to the participants’ revealing of intimate personal details. This type of interview is conducted in a conversational tone as opposed to the more traditional hierarchical question and answer exchange in order to moderate hierarchy and power differentials between researcher and participant.

Being an ‘insider’ in this research, I considered the reflexive dyadic interview, where I might also disclose my experiences of growing up with a mentally ill parent, as most suited to what I hoped would be a relatively non-threatening and reciprocal approach to gaining the participants’ stories of their experiences growing up with a parent with a serious mental illness.

**Changing the interview type**

*Paula and I sit down facing each other across the table. She is the first participant in the study. The room is quiet and still. Paula waits. I organise the tape, check the microphone, look at my notes and remind myself what I need to do. I take a breath, and say to her “okay, well as I explained before, in a minute I’m going to turn the tape on and ask you a broad question and then just leave it to you as to how you want to answer it. And as I’m also an adult child, during the interview I’ll be sharing my own experiences as well sometimes”. Paula’s face changes. I catch the look in her eyes. Uh oh. Wrong thing to say. She doesn’t want me to talk about myself – she wants to share her story. I understand. I’ll listen and keep my own experiences out for the time being.*

**5.5.3 Using un-structured interactive (narrative) interviews**

As a research tool, interviews involve an inter-personal connection between the researcher and participant that allow for the sharing of inner thoughts and feelings about particular issues. In order for the participant to feel able to reveal what are often private thoughts, concerns and perceptions, it is important that time is spent by the researcher developing trust and rapport in order to create an open and safe space for the participant to voice their experiences (Minichiello, Madison, Hays, Courtney, & St John, 1999). In
this study, due to logistical and geographical constraints preventing multiple interviews with each participant, I conducted one audio-taped un-structured interactive (narrative) interview with each participant of between 60-90 minutes, and followed this up with phone conversations and/or email communications to clarify issues. An opportunity was also provided for participants to member check the interview transcripts before I commenced the analysis.

Un-structured interviews are commonly used in narrative research, as the use of a broad opening question encourages participants to be narrators who share their story on the particular cultural issue under inquiry. In the narrative interview, the relationship between participant and researcher therefore becomes one of narrator and listener (Chase, 2005). An un-structured interactive (narrative) interview acknowledges that participants can have significant control in the interview process, as they decide where to begin their story, what they will speak about, in what order, and in how much detail. The researcher’s role in this type of interview is active in the sense that they provide attentive listening and may ask questions, probe, and respond to questions, but the focus throughout remains on the participant and their story (Corbin & Morse, 2003). In their interviews, participants were asked one broad question: ‘Can you tell me what it was like growing up with a parent with a psychosis?’ During the interview related questions on how they coped with growing up with a parent with a psychosis, and what they would have found helpful in assisting them to cope with their experiences, as well as general probe questions, were also asked.

In narrative interviews it is considered that the participant and researcher co-construct, within the context of the interview, the participants’ narratives of their experience. This recognises that narratives may shift according to the particular time, place and person/s they are constructed within. The narratives gained within this research therefore, can be considered as resulting from the relationship developed between my-self as researcher and each of the participants, and the manner in which, and context within, the interviews were conducted (Gergen, M., 2004).
5.6 ETHICAL CONSIDERATIONS AND RIGOUR

I have been conscious from the beginning of this study that due to the personal nature of the topic, and that I will be asking participants to share their potentially sensitive stories, I need to be particularly cognisant of ethical considerations in conducting the research, especially in terms of protecting participants from harm. As identified by the National Health and Medical Research Council (NHMRC) (1999), the chief purposes of ethical conduct in research are to facilitate research that benefits the community whilst specifically aiming to protect the rights and well-being of the participants involved in the research. In the first instance, as required for a researcher using human subjects, ethical clearance was sought and gained from the University Ethics Committee, and from the Ethics Committee at my place of work, as this was a requirement for all staff engaged in research.

I was also concerned that involvement in the project will not result in exploitation of participants. To reduce the risk of exploitation of participants, I contracted to provide written feedback of the findings of the study and additionally offered to provide feedback in the form of general information on the topic of Children of Parents with Mental Illness. A number of participants were interested in issues related to COPMI and I was able to reciprocate their participation in the research with providing information references on research into ACOPMI, and information from another study into ACOPMI (Paula), references for books on COPMI (Olivia), and references for information on sibling position (Marnie).

Each participant was also allocated a pseudonym in order to attempt to maintain anonymity and confidentiality of information gained through the interview process. I transcribed verbatim six of the nine interviews, including pauses, emotional responses such as laughing and crying, and emphases in verbal expression. The remaining three were transcribed by a professional transcription service who undertook a confidentiality agreement with me prior to transcription. These transcripts were closely checked by me and required extensive corrections so that they were as accurate as the other transcripts. As per the University’s requirements, all field text transcriptions and participant details
were kept in a locked filing cabinet at the researcher’s place of residence, and will be kept for five years after the completion of the study, when they will be destroyed.

5.6.1 Rigour and ‘goodness’

In interpretive research, rigour refers to the strictness in the conduct of the study that is used to ensure that each step of the process has been clearly set out and undertaken with careful attention to detail. Rigorous conduct of research allows others to scrutinize the inquiry for methodological worthiness (Roberts & Taylor, 1998). In recognition of the influence of postmodernism on criterion for evaluating research, Emden & Sandelowski (1999) prefer to use the term ‘goodness’ in order to reflectively address the issue of evaluation of the quality of research, whilst appreciating that knowledge (and criteria) retain ambiguity and uncertainty (Christensen, 1996).

Although the evaluation of research may differ according to the approach employed, there are fundamental principles and criterion that may be used to evaluate the plausibility and trustworthiness of the research and its relevance to theory and practice (Emden & Sandelowski, 1999; Horsburgh, 2003). The term trustworthiness is used in qualitative research to refer to how the study meets evaluation criteria for rigour. Harrison, MacGibbon and Morton (2001) acknowledge that the characteristic of reciprocity may lie in tension with that of trustworthiness. In this study, the giving and taking of self-disclosure during interview conversations, and asking participants to member check interview transcripts for example, resulted in rich, thick descriptive text. It may also have been empowering to the participant whose experiences may have previously not have been heard. Self-disclosure may serve to produce deeper exploration of our understanding of both ‘self’ and ‘other’ during all stages of the research process. In doing so, I as the researcher needed to be mindful of issues concerning the development and maintenance of the research relationship, and the nature of the collaborative venture I purported to have with participants.

It is essential to note that reciprocity, whilst potentially adding great depth to the research and producing new knowledge, also brings with it potential difficulties and a
responsibility to be trustworthy in its truest sense. The personal is political. What we do in the process of research reflects who we are as individuals, which in turn reflects back on the research we produce.

In terms of the credibility of a qualitative study, the truth-value of the research also needs to be evaluated. This refers to the discovery of experiences as they are perceived and lived by the study participants. It is therefore subject-oriented rather than defined by the researcher. A credible study is one that presents interpretations that are true to the participants’ experience such that they could recognise their own in the descriptions provided by the researcher. The truth-value of a study is enhanced when researchers describe and interpret their own behaviour and experiences in relation to those of the participants. Sandelowski (1986) advocates that this may be achieved if researchers are viewed as being participants in their own research. The use of reflexivity throughout this study, the use of ‘I’ by the researcher, the extension of this through auto-ethnography, reflective writing, and the inclusion of the researcher’s story in analysis of field text, can be seen to strengthen the truth-value of this research.

In further determining the quality of the study, and hence ethical conduct, it is important that the decisions and actions of the researcher are documented for the duration of the study. Auditability refers to the clarity of the decision-making trail that the researcher provides for others to follow (Sandelowski, 1986). The audit trail is the record of the research process and provides for external review in assessing the rigour of the study (Byrne, 2001). Boman & Jevne (2000) also advocate that the researcher records in story form the problems and pitfalls they encountered during the research. The personal involvements, stress and discomfort of the research endeavour add to the authenticity and reality of the process. In this study, auditability is evident in the detailed explanations of each step of the research process, and in the reflexive comments and auto-ethnographic writing about aspects of conducting the research.

Throughout the study, multiple field texts were used, including field notes, transcriptions from interviews, and discussion with expert researchers, in order to provide a rich and detailed construction of the processes, actions and reactions that occur throughout the
progress of the research. In addition, the use of this form of member checking, whilst viewed by some as perhaps interfering with the veracity of information, is appropriate in this postmodern narrative inquiry where claims to truth are not made, and the emphasis is on honoring the participants’ perception of their experiences rather than assuming there is only one interpretation to be made.

5.6.2 Member checking process

Member checking includes participants’ examination of interview transcripts and early interpretations of texts for ‘accuracy’ of information and/or interpretations. This process has been considered a means for researchers to enhance reciprocity as well as trustworthiness through dependability of the research texts (Harrison, MacGibbon, Morton, 2001). In this study, member checking of verbatim interview transcripts was offered to participants. Once each transcript was completed and had been closely checked against the tape for accuracy, I contacted the participant by phone to let them know their transcript was ready and to enquire as to how they wanted to me to send it to them (i.e. either by email or in hard copy by mail). This also provided an opportunity for me to informally talk with participants and see how they were going after the interview.

As some participants had requested information on various issues related to COPMI, I was also able to provide them with these details, along with the delivery of their transcript. A letter was provided with each transcript and this outlined the purpose of the checking process and suggested what participants might choose to do with the information they had provided on their experiences (see Appendix E). The transcripts which were sent in hard copy also included a stamped addressed envelope so participants could return it to me when they were finished. I also offered participants a copy of their transcript to keep, and a number of participants (Paula, Eccles, Sue) took this option. This was a reciprocal gesture I could make in return for their participation in the study.

Each participant returned their transcript to me via email or hard copy, and/or sent me email confirmation that they were happy with the contents and did not wish to alter anything. Some participants (Paula, Jane, Tom, Eccles) had corrected a few words and/or
added in words that could not be heard from the tape. Two participants (Sue, Olivia) returned their transcripts with extensive additional written comments which further elaborated or clarified issues they had raised in their interview, and I then typed and included these with their original transcript. Other participants (Naomi, Marnie, Nancy Rose) simply sent confirmation that they were satisfied with the transcript contents. Of importance, no participant removed or changed the content in their transcripts or attempted to re-story their experience. This was a little surprising to me, as Olivia for instance had commented during her interview on an issue about an important person in her life, and then seemed worried about including this disclosure in her interview. She did not however, remove or alter this in her transcript, even though she had clearly read the transcript and commented extensively on a number of issues throughout.

In this study therefore, member checking was used to enhance reciprocity and diminish power differentials through the opportunity for participants to check their re-representations of experience before the formal analytic process began. Member checking also gave participants the opportunity to re-story or remove any information they felt uncomfortable with sharing, or even to remove their interview from the study, although they did none of these. I believe this opportunity enhanced their confidence and trust in my respect for their experiences. In these respects I consider member checking to have been a useful part of the field text collection phase in this study.

I did question however, whether it may have been valuable to take my initial phenomenological thematic and narrative analytic findings back to participants for their comment as to how these compared to their own understandings of their experiences. Both van Manen (1990) and Emden (1998b) suggest that this particular form of member checking can enhance the trustworthiness of emerging interpretations in phenomenological and narrative analyses. I was also mindful, however, that member checking in qualitative research has been contested, in part because the postmodern belief in multiple realities has been considered inconsistent with the notion that criteria for judging trustworthiness of individual experiences is possible (Seale, 1999; Tobin & Begley, 2004). Furthermore, given the dual analytic processes of the study, ongoing
engagement with the research may have been considered burdensome by some participants, and so I chose not to use this form of member checking.

Transcribing

Tap. Tap tap, tap
stop
check
no, that needs an ‘s’
rewind the tape
can’t hear that word
rewind
what did she say?
her accent’s making it hard to hear
or maybe it’s the tape
rewind
listen
feel

Tap. Tap tap, tap tap
I can’t do this for too long
it’s mind numbing
just need to make it to the end of page 26 and that’ll do for today
how many more pages to go?
I feel so tired
But it’s not that hard
why am I exhausted?
Again and again, the voices
telling stories
sharing their pain
crying
laughing
yeah, that is funny!
talking about them, us, me
their mother, my mother
their father, my brother, her sister, his aunt
our family.
I’m exhausted
horrible headache, squeezing tight
can’t do this for too long
but it’s so interesting
and sad, funny, moving, upsetting
memories.
Ah
now I understand.

5.7 FIELD TEXT MANAGEMENT AND TEXTUAL ANALYSIS

5.7.1 With/in and against – performing a dual analysis of the field text

As discussed in Chapter 4, I have chosen a dual analytic approach to field text in this study. In the first phase of analysis, the field text are analysed for themes according to the realist approach of van Manen’s (1990) phenomenological thematic analysis method. In the second phase, the field texts are approached through a de-constructive lens in a narrative analysis where narratives have been constructed to re-present the meanings of the experiences of adult children of parents with serious mental illness. These multiple interpretive lenses have sought to provide a thicker explanation of a largely unknown phenomenon, and can be seen to provide diverse dimensions to a complex social issue.

5.7.2 van Manen’s phenomenological thematic analysis

The thematic interpretative approach used in the first phase of analysis was informed by van Manen’s (1990) interpretive phenomenological approach. The philosophy of the phenomenological approach includes the exploration of the personal and individual ‘lifeworld’ against a context of understanding the nature of the ‘other’ - the communal or social world. It involves a search of what it is to be human, and so this approach aims at a deeper understanding of the meaning of everyday lived experiences through asking the question ‘What is this experience like?’ The research process of interpretive phenomenology is essentially one of describing the phenomenon through writing, where
research and writing are seen as being part of the same process, which aims to make explicit the universal meanings of experience.

The purpose of using the interpretive phenomenological approach to thematic analysis was to capture the essential meanings of the phenomenon of being the adult child of parents with serious mental illness. In this context, meaning has many dimensions and is multi-layered. The essence or *eidos* of the experience is gained through uncovering phenomenological themes which are the experiential units of meaning that make up the experience. As van Manen (1990) advocates, this process is one of discovery and artful insight. It involves acts of ‘seeing’ meaning in what is said, and capturing the phenomenon of which understanding is sought. In this way identification of essential themes gives control and order to the research. The process, though, always involves a reduction of notions in order to make sense of the experience.

Two of van Manen’s (1990) three approaches to thematic interpretation were adopted in this study. Initially the holistic reading approach was used, where I read each transcription and listened to the tapes a number of times in order to gain an overall understanding of each participant’s experience. A sententious description of the main significance of the experience for each participant was developed. The selective approach was then used, where I re-read the texts several times and highlighted phrases which isolated thematic statements that seemed particularly revealing about the experience of being the adult child of parents with serious mental illness. These summarised statements were written in the participant’s own words where possible in the left margin of the transcript page. Other comments and reflective notes were written in the right hand margins. Fuller notes and developing thematic phrases throughout the process were also kept in a separate analytical log.

Once this process was completed, all thematic statements, with page and line references, were collated into lists under the heading ‘Meanings of the experience of being adult children of a parent with serious mental illness’. Various aspects about the nature of the experience included identification of the meaning of particular events, issues, emotions, situations, personal relationships, and sense of self. The intense process of condensing
and then removing redundant themes and grouping and re-grouping of thematic statements then occurred. Thematic statements were clustered and organised into patterns and essential themes were named and then re-named in a constant clarification and re-writing. During this interactive process, I continued to ask the question: ‘Would the experience of being an adult child of a parent with serious mental illness still be adequately described if I changed or deleted this theme?’ (van Manen, 1990). In this way, themes that were not considered essential to being an adult child of a parent with serious mental illness were put aside. The remaining themes structured the written descriptions of Being an Adult Child of a Parent with Serious Mental Illness (Chapter 6).

5.7.3 Postmodern narrative analysis of the field texts

In the second analytic phase of the study, a postmodern narrative analysis was undertaken. Implementing narrative analytic techniques can enhance narrative inquiry. In general terms, narrative analysis refers to the examination of various stories or conversations that people engage in (Gubrium & Holstein, 1999). Narrative analysis takes as its focus of investigation the actual story itself (Reissman, 1993). Interpretation of narratives is inevitable, as the stories themselves, told as they are by individuals, are representations of experience. Narrative analysis therefore provides a way of understanding the person’s experience that is consistent with the way people make sense of their lives. The analysis opens up the forms of telling about the experience, not just the content of it (Reissman, 1993; Rice & Ezzy, 1999). The researcher asks, “why was the story told that way?” (Reissman, 1993, p.2). It is important to note that narrative analysis is distinguished from other forms of qualitative data analysis in that it attends to the structure of the story as a whole rather than fragmenting text into small chunks such as the thematic categories in the first phase of analysis. This analytic approach instead searches for larger units of discourse or story, and codes these structures and content (Rice & Ezzy, 1999).

In this study, as I could not find a postmodern narrative analytic approach that I considered useful for this particular inquiry, I chose an eclectic approach to analysis. This was drawn from a number of perspectives on postmodern narrative, primarily based on
McAllister’s (2001) series of critical questions as a guiding analytic framework. These questions were modified and extended, and the final analytical approach included components drawn from the work of Charmaz (2002), Denzin (2001), Emden (1998b), Poirier & Ayres (1997) and Roof (1993). Table 5.1 details the analytic framework and includes rationales for each critical question used.

### Table 5.1 Postmodern Narrative Analytical Framework

<table>
<thead>
<tr>
<th>What meanings are produced in the story?</th>
</tr>
</thead>
<tbody>
<tr>
<td>What meanings are standard? What dualisms are evident?</td>
</tr>
<tr>
<td>- because these may indicate modernist views of the issue</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What postmodern motifs recur?</th>
</tr>
</thead>
<tbody>
<tr>
<td>i.e. inter-textuality, disunity, marginality, fluidity, multiple surfaces, decentring of the subject, disorientation, diffuse boundaries</td>
</tr>
<tr>
<td>- because these surface realities may reveal the fragmentation of deep social structures (McAllister, 2001; Roof, 1993).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What images and metaphors are used?</th>
</tr>
</thead>
<tbody>
<tr>
<td>- as these linguistic devices reveal the meanings they hold and in surfacing them there is possibility they can be re-framed)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What resistances, usually concealed, are revealed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>- because sites of resistance may indicate the dominant paradigm isn’t being successfully reproduced, and indicates a possibility for transformation to take place (McAllister, 2001).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What voices in the margins can be heard?</th>
</tr>
</thead>
<tbody>
<tr>
<td>- because this might allow more discourses on the issue of ACOPS MI to emerge (McAllister, 2001).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What silences* and endings are evident?</th>
</tr>
</thead>
<tbody>
<tr>
<td>- because these may indicate issues which have been repressed by dominant views and/or suggest possibilities for change (Charmaz, 2002; Poirier &amp; Ayres, 1997).</td>
</tr>
</tbody>
</table>
What does this re-reading illuminate about the issue?
- because this may thicken the alternate story of being ACOPSMI and provide new insights which may be transformative for current COPSMI & ACOPSMI and assist service providers to provide more effective support (McAllister, 2001).

*referring to both personal (as per Poirier & Ayres, 1997) and social silences in the story (as per Charmaz, 2002).

Initially, following Emden (1998b), each interview transcript was re-read a number of times to grasp their content, and interviewer comments and questions and any other words that detracted from the key idea of each sentence or group of sentences were deleted, and information not relating to the experience of being an adult child of a parent with serious mental illness was removed. This resulted in the reduction of 10-15 pages from each transcript (originally between 40-55 pages in length). My own life story was taken from Chapter 1 and combined with the auto-ethnographic excerpts in Chapters 2 and 3 and analysed using the same framework.

I then looked for small stories within each participant’s life story, as per Denzin’s (2001) identification of stories. That is; a story contains a beginning, middle and end, has a plot, narrators and characters, settings, crises and resolutions. The critical questions in the narrative analytic framework (Table 5.1) were then applied to each identified small story. Initial textual analysis of the field text also included identification of characters and narrators, and the plot – the temporal unfolding of events.

In analysing the texts, and in the re-presentative process of writing up the findings, over-reading was the starting point of interpretation. Over-reading refers to the researcher’s attention to inconsistencies, repetitions, silences and endings that may be present. Silence for instance, has subjective meaning. It signifies an absence either of words and/or emotions. Why is the person silent? Is it intended or involuntary? The reader attends to what is not said as much as that which is. Consequently, I was also mindful that over-reading may be seen as intrusive in that it is prying into a person’s often previously private secrets (Charmaz, 2002; Poirier & Ayres, 1997). In choosing this method of analysing the participants’ narratives, there was a dilemma I needed to address – what
were the limits of what one person (my-self as researcher) can say about another’s (the participants) stories? This involves an ethic of concern where the researcher may assume an intellectual claim of being able to speak the truth of others’ stories better than they could themselves (Frank, 2000), and so I was very mindful of the limits of interpretation in this analytic process.

The fragmentation of social structures (Roof, 1993) that underpins the philosophy of postmodernism was also used in interpreting the field texts, and I searched each small story for signs or motifs that revealed this. Being attentive to resistances and inconsistencies in the story for example, could reveal the complexity of the issue and possibly trouble previous assumptions about being ACOPSMI. This could provide a new or fresh approach to a situation that had historically been considered ‘difficult’ (McAllister, 2001), and allow for the possibility of new and/or differing discourses on ACOPSMI to surface (Cheek, 2000). The stories were also searched for metaphors. Metaphors are literary devices which combine one familiar concept with another, and in so doing, provide powerful connections between ideas and offer fresh possibilities for the meanings of experiences (Jensen, 2006). Thus, they may be re-illuminating because they can serve as useful lessons and guides for others. This analysis therefore sought to thicken the ‘alternate story’ of being the adult child of parents with serious mental illness.

5.7.4 Including my own story in the analysis

As have Camden-Pratt (2002), Kirkman (1999), and Smith (2005), I have included my own story as part of the study and hence in both phases of analysis. Although conceptualising their experiences from varying yet similar frameworks (eg. Camden-Pratt as critical autobiography, Kirkman as autobiography, and Smith as auto-ethnography) like me, each of these researchers were insiders who shared the same issue as the participants. Choosing to include my own experience in the study has not been without a great deal of reflection, questioning and critical examination as to appropriateness. As noted, I have particularly struggled with the concern that my story should not overshadow that of the participants, and that (somewhat ironically) the inclusion of my own experience might be viewed as narcissistic. I have eventually come to realise however,
that my experience is just as valid as the participants, and that although this may be considered an unusual approach by some, it is an appropriate and indeed necessary one to take in this instance. Furthermore, I analyse the field text from the position of insider (Foster, McAllister & O’Brien, 2005) and inevitably my experience also forms part of the analytic lens I use.

As Kirkman (1999) rather wryly notes, I also “didn’t interview myself” (p.32), although according to Boufoy-Bastick (2004) self-interviewing may be considered a feasible method when using auto-ethnography. Instead, I have included my own story (as written at the beginning of the thesis and auto-ethnographic excerpts throughout) in both the thematic and narrative analyses. In addition, comments I made from my own experience in some of the participants’ interviews have been included in the thematic analysis.

In this study therefore, the field texts including member checks and the researcher’s own story have formed the subject matter for stories constructed by the researcher and represented in the thesis to encapsulate, embody, evoke and reveal the prominent themes and experiences of adult children of parents with serious mental illness. The tools of the narrator – metaphor, imagery, turning points or epiphanies, and other literary devices were also employed, as these are often used by narrators in the creation of their stories, and thus, in interpretation of the narratives (Clandinin & Connelly, 2000; Denzin, 1989).

5.8 CONCLUSION

This chapter has illuminated the study methods of auto-ethnography and unstructured interactive interviews and detailed the processes used throughout the research. A dual analysis of the field text can provide multiple interpretations of the experiences of being the adult child of parents with serious mental illness which enrich the interpretive process. The use of auto-ethnography and unstructured interactive interviewing methods exemplifies the reflexive and inter-subjective nature of the study, and postmodern narrative analysis of field texts contains features of critical and de-constructionist as well as interpretive paradigms. The following Chapter 6 ‘Phenomenological Findings’ presents the findings of the first phase of analysis.
There was a child went forth every day;  
And the first object he look’d upon, that object he became;  
And that object became part of him for the day, or a certain part of  
the day, or for many years, or stretching cycles of years...

His own parents,  
He had that father’d him, and she that had conceived him in her womb,  
and birth’d him,  
they gave this child more of themselves than that;  
they gave him afterward every day – they became part of him.

The mother at home, quietly placing the dishes on the supper-table;...  
The father, strong, self-sufficient, manly, mean, anger’d, unjust;...  
The family usages, the language, the company, the furniture – the  
yearning and swelling heart,  
Affection that will not be gainsay’d – the sense of what is real – the  
thought if, after all, it should prove unreal,...

These became part of that child who went forth every day, and who now  
goes, and will always go forth every day.

(Whitman, 1900)
Reflecting on the child who goes forth

In his elegant poetry of the child as he, or she, makes their way throughout life, Walt Whitman weaves a story of the influences that family and parents exert and how they can become part of the child’s identity over time. Unlike the other poetic and musical excerpts in this thesis, this poem was created in the nineteenth century and hence the language is particularly illuminating of historical and cultural influences.

As Whitman emotes, parents’ behaviours, what they do and don’t say, what they teach their children, and how these shape family life, are pivotal influences on the child’s eventual sense of themselves and their world. As the following chapter reveals, what is ‘real’, and whether it proves to be ‘unreal’, can also be important in the experience of the child who has grown up with parents with serious mental illness.
6.1 INTRODUCTION

This chapter discusses the phenomenological thematic analysis of the interviews, researcher’s narrative, and member checks provided by the participants in this study. Although I am one of the participants, for ease of reading throughout the rest of the thesis I have chosen to discuss participants’ experiences in the third person, as is the convention for research theses. Because their experiences were recounted flowing back and forward between the present and the past, the following description also moves between child and adult experiences whilst illuminating the temporal unfolding of the lived experience of being the adult child of a parent with serious mental illness. In this phase of analysis the following four essential themes were developed: Being Uncertain, Struggling to Connect, Being Responsible, and Seeking Balance. The themes are essential in that they each represent aspects of the phenomenon of being an adult child of a parent with serious mental illness and without any one of them, the phenomenon could not be fully understood. Thus, although each theme is discussed separately they are also interwoven and linked with each other. The themes have further been divided into sub-themes. The following table lists each theme and associated sub-theme of participants’ experiences of being the adult child of a parent with serious mental illness.

Table 6.1: Phenomenological themes

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6.2 INTRODUCING THE PARTICIPANTS

To begin the chapter, a profile of each participant is provided. These provide a background from which to understand the following thematic findings from their experiences.

6.2.1 Participant 1: Paula

Paula is a young woman of 31, originally born overseas, who worked in a carer organization and also volunteered in COPMI-related activities. The insider/professional knowledge she has gained through these experiences was evident throughout our discussions. Paula self-selected for the research after hearing me present on the topic of the research at a conference, and emailed me afterward to express her interest in participating in the research. Paula was married but had no children as yet, although as she told me during our interview, she did hope to have them at some point.

Paula’s mother has been variously diagnosed with schizophrenia and bipolar disorder, but was understood by Paula now to have the diagnosis of schizoaffective disorder. Her father had struggled with alcohol dependence, but has been sober and involved in the Alcoholics Anonymous movement for some years. Her brother, with whom she had limited contact, lived overseas and Paula considered him to have a substance use problem. Paula herself had struggled with an eating disorder, which she managed through being a leader at Weight Watchers. As an adult she has also had psychological counselling for depression and issues relating to the experiences of her childhood.

6.2.2 Participant 2: Olivia

Olivia is a 43 year old married homemaker, born in Australia, who self-selected for the study after hearing me speak on local radio about COPMI. She had no prior knowledge about COPMI issues. During childhood, Olivia understood her father to have had a severe depression which necessitated hospitalisation, electroconvulsive therapy and medication. Her mother had told her when Olivia was an adult that she too had been depressed after
Olivia’s younger twin brothers were born and had had a ‘nervous breakdown’ for which she took medication.

Olivia is the middle girl of four brothers. As a child, she was treated for depression and saw her father’s psychiatrist, who put her on anti-depressants. During childhood, Olivia experienced emotional abuse by her father and also witnessed her brothers being physically abused by him. In young adulthood, before she married and had children, she experienced depression again, and saw a psychiatrist and took anti-depressant medication which she found helpful in relieving her symptoms. After experiencing problems coping with her role as a parent after the birth of the second of her three sons she sought counselling, which she also found helpful. Olivia has generally found parenting a challenge and attributed this to the lack of effective role-modelling from her parents. Olivia’s two older sons were teenagers, but she was concerned about her 11 year old son as she saw him as having inherited the depressive nature of her father and herself.

6.2.3 Participant 3: Jane

Jane is a 35 year old woman who contacted me about being in the study after hearing me talk on the local radio on the issue of COPMI/ACOPMI during Mental Health Week. She worked in the hospitality field and had no previous knowledge about the issue of COPMI. Jane’s parents are divorced, and her mother has been dually diagnosed with bipolar disorder and drug and alcohol dependence. Jane’s mother had attempted suicide and been hospitalized in various psychiatric settings, along with admissions for substance abuse detoxification. At the time of interview she lived in a nursing home. Jane’s father had been in recovery from alcohol dependence for some years and was attending Alcoholics Anonymous meetings. He had remarried and lived with his second wife.

Jane is the youngest of five children (3 boys and 2 girls). Her eldest sister was adopted out before her parents married and Jane and her brothers were born. She only discovered she had a sister when her mother told her at the age of 14, and believed that her own relationship with her mother had been overshadowed by her mother’s guilt at giving her older sister up for adoption. Jane recounted a turbulent childhood in which she rebelled
against authority, got into fights, was expelled from school, and went to court for fighting. Jane considered herself to have been mentally and emotionally abused by her mother, and whilst she said she was not physically abused, she witnessed her brothers being beaten. Jane has been divorced and was now living with a de-facto partner and her two children to a previous partner, an 18 year old daughter and 16 year old son.

Jane identified that as an adult she has had a problem with abusing drugs and alcohol, but has been abstinent since the age of 21. She also recounted a number of self-harming episodes as a teenager, where she cut herself, and an experience of postnatal depression after the birth of her son, for which she initially sought medical treatment but eventually chose to use alternative therapies which she considered to be more effective.

6.2.4 Participant 4: Sue

Sue is a 50 year old married woman who was born in Australia and has two sons. She worked within the field of juvenile justice, but initially trained as a nurse. Sue self-selected for the study after hearing about it through word of mouth, and seeing a newspaper article where I had spoken about the issue of COPMI. She had some knowledge of COPMI issues through her work. During her childhood Sue understood her mother to have been diagnosed with, and hospitalized for, paranoid schizophrenia. As her parent’s marriage broke down when Sue was 10, she then spent the rest of her childhood in a single parent family with her mother and three younger brothers. Sue was only to see her father again in her early thirties when, after a twenty year gap, she was able to go overseas to meet him.

Sue described the loss of her father, and her mother’s continued negativity about him, as being particularly significant issues in her childhood. She experienced her mother as being mentally and emotionally abusive, particularly in relation to telling Sue that her father was evil and did not love her. After fighting yet again about this with her mother just prior to going overseas to meet her father, Sue also experienced a depressive episode.

Sue had, however, maintained a supportive role for her mother into adulthood, and at the time of the interview had just accepted her mother back into her home to live, because
she had been asked to leave a nursing home. After the member check process however, Sue contacted me to say that her mother had just committed suicide, and expressed her anger at a health system which she believed had failed both her and her mother.

6.2.5 Participant 5: Naomi

Naomi contacted me and offered to participate in the study after seeing one of my advertisements in the newspaper. She had no previous knowledge about COPMI issues. When she first contacted me, Naomi was concerned with whether I would want her in the study as she thought she might have been ‘too old’. She is 53 years old, married with 2 adult sons, and worked as a librarian. Naomi was born overseas and moved to Australia as an adult. She is an only child.

During her interview, Naomi spoke of her experiences growing up with her now 80 year old mother who had been diagnosed with bipolar disorder during Naomi’s childhood. After 40 years of marriage Naomi’s parents divorced and she has since assumed a supportive caring role for them. Her mother was living in a nursing home and her father had dementia but remained living in his own home.

During our conversation, Naomi spoke at length of her hobby of amateur acting, which she described as being a way that she could safely express herself and her emotions. She also spoke of feeling constantly anxious and having previously sought psychiatric treatment for depression.

6.2.6 Participant 6: Marnie

Marnie is a 49 year married old woman, born in Australia, who self-selected for the research after hearing about the study through word of mouth. She had no previous knowledge of the issue of COPMI. During her interview, she explained that her mother had been diagnosed with schizophrenia after Marnie’s birth. As the eldest of four children, Marnie had assumed responsibility for the running of the household from a very
young age. As an adult, Marnie had continued her caring role in her occupation as a nurse, as well as remaining in a carer role for her mother.

Marnie’s younger brother had also developed schizophrenia, and for Marnie, seeing the effects of the illness had on him had been even more disturbing that seeing it with her mother. One of the major decisions Marnie had made as a result of seeing her mother and brother struggle with the illness, was to not to have children. This was so that there was no genetic risk of passing the illness on.

6.2.7 Participant 7: Nancy Rose

Nancy Rose is a 25 year old young woman, born in Australia, and studying as a full-time postgraduate university student. She is single and has no partner or children. She self-selected for the study after hearing me speak on the issue of ACOPP at a conference. Due to her involvement with COPMI activities as a volunteer, Nancy Rose was very knowledgeable about the issue. Her mother had been diagnosed with schizophrenia during her childhood, but Nancy Rose had only become aware of her diagnosis after a family member accidentally divulged it when she was 15. Nancy Rose was the middle of three children. Her father who was the primary carer, died when Nancy Rose was 15. Soon after this, Nancy Rose left home and became self-sufficient, living alone and putting herself through the rest of high school and then through university.

6.2.8 Participant 8: Eccles

Eccles is a 57 year old man, born in Australia, who was a carer specialising in working with people with psychiatric disabilities. He was single at the time of interview, but had briefly been married and had one adult son with whom he considered he had a good relationship. Eccles self-selected for the study by responding to a newspaper advertisement specifically inviting men who were adult children of parents with psychosis to participate. Eccles had no prior knowledge of the issue of COPMI. He understood both his parents to have had severe depression during his childhood, although during interview this did not appear to have been of psychotic depth, and had not been
confirmed by diagnosis from a doctor. The lack of diagnosis appears to have been linked with his family’s geographical and social isolation during much of Eccles’ childhood. Until Year 8 of school, Eccles had been home-schooled and had little contact with other children or adults. Although Eccles parents did not divorce, they had effectively separated for long periods, as during Eccles’ adolescence his mother moved with the children to another town in order for them to go to school.

At the time of interview Eccles had been taking anti-depressant medication and was in counselling in order to address his own depression.

6.2.9 Participant 9: Tom

Tom is a 37 year old Australian born man who runs his own business. He had no prior knowledge of COPMI issues, and responded to an advertisement I put in the newspaper which specifically invited men who had a parent with a psychosis to participate in the research. At the age of 71 his mother had been diagnosed for the first time with bipolar disorder in 2004. Tom also reported his mother using alcohol on a daily basis throughout his childhood, and being prone to outbursts of anger and verbal and physical abuse toward him and others when drinking. Tom’s father, who had a long history of diabetes, had died of diabetic complications in the previous year. Tom had an older sister who he described as being a heroin addict and having been in jail a number of times. She lived with their mother at the time of interview.

Tom separated from his wife in the previous year and at the time of the research was going through a property settlement. He had no children. He described himself as having a similar mood disorder to his mother, but was reluctant to have his self-diagnosis confirmed by a doctor or to seek medical treatment for it. He also expressed concern about his own levels of drinking, and acknowledged that part of the reason his marriage broke down was that his wife considered him to be an alcoholic. During the member check process, Tom told me he was moving to live nearer his mother and sister in order to be of more support to them, and that he and his mother were about to go on their first overseas trip together.
6.2.10 Participant 10: Kim

Kim is a 44 year old Australian born woman who is a mental health nurse academic. She has one teenage son and is in her second marriage. She has extensive knowledge of COPMI issues through her research into the issue. Kim’s mother has paranoid schizophrenia which was only diagnosed when her mother was in her 50s. Her parents separated when Kim was about eight years old and they later divorced. Kim is the eldest of six children; three boys and three girls born over a nine year period. Two of her siblings have died – one brother at the age of three months, the other brother at the age of 19.

During her childhood, due to her parent's eventual marriage breakdown and her mother’s increasing illness, Kim was separated from her brothers and one sister. With one of her sisters she spent many years of her childhood living in a variety of welfare institutions. Whilst she lived at home with her parents, her mother was suicidal at times. During adulthood, Kim had experienced depressive symptoms and had also sought counselling to address the effects of her past.
6.3 PHENOMENOLOGICAL THEMES

6.3.1 BEING UNCERTAIN

This first theme reflects the uncertainties of daily life that participants experienced during childhood and into adulthood. During childhood particularly, there was a sense of not knowing what was going to occur within the family from one day to the next. As Naomi explains, “you’d think ‘this roller coaster is never going to stop’, you know?” For Olivia, the sense of chaos she experienced was particularly evident throughout her conversation:

…there was always that fear, and insecurity is another thing that comes up…nothing seemed, even though everything was stable in the sense that it didn’t really change, it felt very chaotic and very unstable…the outward stability with the internal chaos is a feature carried forward to my present life.

6.3.1.1 Knowing something is not right

Throughout childhood, participants knew there was something was not quite right about their ill parents, although they did not necessarily associate this with mental illness. As Naomi commented, “I never thought I had a mad person in the house”. As children though, there was a feeling of not wanting to bring other people home because the house was “messy”; participants were embarrassed about our ill parents who they saw as being “weird”, “lazy”, or “different”; and/or their family did not encourage visitors. Nancy Rose said:

I knew from a fairly early age that there was something definitely weird about her, and that she wasn’t sort of quite right, but…we didn’t know that she had schizophrenia. Nobody sort of said to us ‘your mother has a mental illness’. I didn’t find that out until I was 15 and that was by accident [her aunt had mentioned it assuming she already knew].
Depending on the onset of a parent’s illness and/or when (and in some cases, if) they had been formally diagnosed, during adolescence some participants were still not aware that their parent had a mental illness. Looking back to his childhood, Tom describes his understanding of when his mother started to show signs of her bipolar illness, although she had only been diagnosed for the first time in the previous year at the age of 70:

…it was really from a teenager onwards I guess that I could see that mum used to go through these highs and lows, but before that, mum was just a good mum…it wasn’t really until last year that mum was diagnosed with Bipolar Disorder. But when I’d read a little bit about it and explored it, everything seemed to just slot into place.

Indeed, gaining information about a parent’s illness seemed a hard-won battle. Most participants had not been informed about a parent’s illness unless they asked their other parent, or made active efforts to gain information from health professionals. Sue for instance explains how she found out about her mother’s diagnosis:

…I think I was about 14, at that time I had, yeah, a real need to find out what was going on, and made that visit that I told you about to the psychiatrist. I made the appointment and got on the bus and…went over there, and he basically gave me the diagnosis [paranoid schizophrenia], and it’s the first time and the only time that I believe anybody in the family has actually been given a diagnosis.

Because they had often not been told about the nature of their parent’s illness, some participants spent their childhood viewing their parent and the illness as being one and the same. Not knowing that the parent had a mental illness sometimes contributed to being unable to distinguish between the illness and the person. Said Nancy Rose:

but yeah, looking back when I was little, because I didn’t have that label or I didn’t have anything to sort of distinguish her weird behaviour from her, that was just her, it was all her…I’m not sure how that, if that would have been different
had I known that she had a mental illness…it might have worked out a little more respect for her.

In some cases, the uncertainty about a parent’s illness continued into adulthood. Although participants used particular diagnostic labels for a parent’s illness during their interviews, and described psychotic symptoms such as delusion and hallucinations, some were still unsure what the term ‘psychosis’ meant. This became particularly apparent throughout the interviews. As Sue said: “she has got false beliefs, but I wouldn’t call it psychotic in the sense of, I’m not sure what the definition of psychosis is.”

6.3.1.2 Sorting out what to believe

Throughout childhood and adulthood, wondering whether or not to believe the ill parent’s comments was a common issue. Sue for instance explains how her mother’s comments about her father not loving her made her feel: “I think much of my childhood was spent probably in a…confused sort of, not confused, a mixed state of kind of jumping from believing her to not believing her.”

Sue also explained the impact that her mother’s paranoid beliefs had on her, and how she questioned the veracity of her mother’s paranoid beliefs:

My mother was all wrapped up with nuclear warfare and she really believed the world was going to end…we really grew up believing that…I grew up being told that I wasn’t going to live a very long life. The whole world was going to end, mum knew that quite clearly. She was basically a messenger from god here to tell the planet that the world was going to end, so, I mean I knew that that wasn’t real. I had enough sort of connection, I’m thinking of my high school years now…I’d grown up enough to know that what my mother was saying couldn’t possibly be real, but it meant that you couldn’t talk about the positives in life, you couldn’t.

A further aspect of parents’ illness was that they also often saw them as being in denial about their illness. This was frustrating as made it more difficult for participants
and family members to challenge the parent’s comments and deal with their behaviours. Sue explains:

> there’s been a permanent and constant denial of my mother’s illness on her part, and that’s probably the biggest part of the struggle I think, in many ways...because of the fact that she was determined to hold herself together and her kids together, and keep everybody else out of it and refuse all treatment, there were never as far as I know, anybody in the family who had a full understanding of her condition.

6.3.1.3 Feeling unsafe

Whilst living at home with them, participants experienced the ill parent as having a variety of ‘faces’. Sometimes the face was loving and supportive, at other times it was angry and even abusive. Participants felt that ill parents often treated them and other family/friends in this dual way. Their behaviour could be unpredictable and swing between being pleasant and loving to negative and critical. Experiencing the loving face included being parented in positive ways although this was much less common than participants’ experiences of parents’ negative behaviours. The positive experiences sometimes contributed to their overall sense of uncertainty. Nancy Rose said:

> she used to tell me stories before I used to go to bed, even though I didn’t really believe any of them, it was still fun...she’d come in sometimes and just sort of sit and just...talk to me about stuff or things that happened when she was a little girl...I quite liked her just sitting there chatting, so that was nice.

Sue, in explaining apparently conflicting aspects of being parented by her mother, summarises her and her siblings’ overall impression of her mother’s parenting:

> although we all four of us would say that we’d never go back and do our childhood again, we also, strangely enough, no matter what we say about our mother, we all agree that she was a brilliant mother. That she was a very loving mother, that she really did love us... and she really wanted us to be a particular way, so she mothered us very carefully.
For many participants though, displays of anger by their ill parent were the most common and distressing aspect of being parented by them, and was a prominent issue throughout their conversations. For Olivia, her father’s expressions of anger meant that at times she saw him as being two people: “there has been and still is, so much anger…it’s really unbelievable the extent, and that is the word that describes dad [anger]…almost like a Jekyll and Hyde.” Sometimes parents were also seen as presenting a different face to the rest of the world than the one they presented at home. Olivia adds: “he had this outside face for the world, and only we could see the other face…it was dark.” Eccles used a similar analogy to describe both his ill parents: “it was sort of almost a Jekyll and Hyde type of situation for my parents, because they were literally on their best behaviour…out in public, but very different at home.” For Eccles, the impact of both his parents’ chaotic behaviour was particularly exacerbated by his family’s social isolation, and the lack of contact they had with others whilst he was growing up:

the reason I’m still having problems with it all is because, I guess partly at least, I never got to talk about it with other young people my own age. We lived on this isolated property. The nearest habitation was four miles away. We were lucky if we saw a car go past once a week. It was extreme isolation, and the only two adults virtually in my world were my two parents.

Frequent expressions of anger from parents also meant participants were sometimes afraid of them and tried not to aggravate the situation. They described themselves as being “compliant”, “tried hard to be good” and “obedient” in order to protect themselves from further upsets. Said Sue:

you were afraid of what she might do, of the temper more than anything…she was never physically violent, but emotionally and verbally, a very strong person who really doesn’t, or never did, countenance any difference in an opinion or point of view, so you learnt to keep your mouth shut.

When a parent was becoming mentally unwell, participants sometimes became aware of this through changes they saw in parents’ eyes. These changes usually heralded
unpredictable behaviour which could be frightening and where they felt unsafe. Mamie explains the impact of recognising her mother was having another episode of illness:

...you grew up with, you knew when she was going off, she’d get these wild eyes and she’d look like a caged animal, and that was really scary, you knew she was going off. And dad would ring the doctor and mum would go off again.

Parents’ psychotic experiences expressed with anger and other disturbances in behaviour at times also contributed to participants feeling emotionally, and at times physically, unsafe. This was usually related to episodes of abuse, and for some participants, abuse seemed to be the most prominent aspect of their experience. Said Eccles: “It’s amazing and sad, even now I’m a survivor of child abuse…We never had the sense of feeling safe, secure in that environment.” Emotional forms of abuse included the perception the ill parent was deliberately trying to be hurtful toward them. As Naomi explains: “I do remember she’d say the most devastating things, and with intent I always felt.” In order to protect themselves from the ill parent’s hurtful comments, some participants withdrew emotionally. Naomi adds: “I just learned eventually to go ‘bugger this, I won’t tell her anything! So I mean that, it gave me armour. You know, that which doesn’t kill us makes us strong.”

When parents became unwell, their parenting was sometimes also associated with physical and/or sexual abuse, sometimes also from their other parent, and at times, from both. For the male participants, there was a combination of both emotional and physical abuse from parents. This was particularly difficult to deal with. Eccles said:

The other major problem...is that my parents were both extremely unpredictable and inconsistent, and so in other words, they could be really sort of easy going one day, and yet the very next day, let’s say for instance I was playing with my younger sister...my mum would come out swinging the strap and shouting extremely abusive things...I had extreme difficulty coping with it.
Although the female participants were not usually physically abused, some observed their brothers being hit by the ill parent or their other parent, and this had various effects on them including wanting to protect their brothers or even becoming violent themselves. Jane said:

"I was a violent child and I would fight... 'cause that’s, I guess that’s what I saw at home... but I had no... forethought of how that person felt after I hurt them, because I guess I saw, I didn’t really see much forgiving in the house, but I went to court for fighting.

In her interview, Paula also matter-of-factly described being sexually abused in childhood by her mother when she was psychotic:

"I think I was 11, mum had a psychotic episode and got very confused about the feelings that she was having, the feelings of love for me and my brother and she actually molested the both of us, and then, after that episode we lived with my father. There was nothing said, it was just more that she’d realised that it would be better off if like me and my brother, if we lived with my dad. And she’d gone into hospital for an admission I think that time.

Jane too described being sexually assaulted as a teenager, but this was by a stranger, where her mother failed to intervene. Like Paula, Jane had also never discussed this with her mother, because she didn’t want to cause her any more pain or “bad memories” than she already had. Jane recalled:

"when I was in my bed the taxi driver got in the house somehow, and he was on me, and he was raping me, and... mum come in. All I remember is I opened my eyes and this big smelly guy’s on me, and mum’s come in and opened the door and looked in... and closed the door and walked away, and I don’t even know whether she, I’ve never spoken to her about it... but, why didn’t she help me? Why didn’t she come in and, do something? Why didn’t she turn the light on? Why didn’t she... you know what I mean?"
A parent’s behaviour could also change whilst they were having psychotic episodes, and this added to participants’ sense of disruption and chaos. When they were psychotic, parents could behave in ways which were out of character and quite embarrassing. Marnie explains:

*Mum just being crazy would be the…mum's a very quiet person…but she would have these episodes that she – she’s really quite prudish – and then she would just take her clothes off and go running down the street.*

The ill parent’s behaviour could also be unsafe. Marnie describes another episode where her mother had become unwell and had to be taken to hospital:

*I remember as a child…about 6 I suppose I was, and …we were on my uncle’s farm, and the bush fires hit up near [names town] and we had to leave, ‘cause we had to go down to the creek and hide in the creek ‘cause it was the only safe place, and the flames went over the top of us before they could evacuate us, and mum had a psychotic episode in the car going home, and tried to jump out of the car. There was …dad calling the doctor and an ambulance coming, and…dad couldn’t leave us with anybody ‘cause there was nobody that would help because it wasn’t a physical thing. So he had to put us in the car and he’d be driving behind and mum would be trying to jump out of the ambulance, which was pretty difficult.*

Sometimes a parent’s behaviour could become dangerous to others. Marnie describes a further incident when she was 4 years old where her mother had thrown her 12 week old younger sister out of the window because she had been hearing voices telling her the baby was evil:

*[I was] shocked, well I mean you could see it happening and I couldn’t stop it…she chucked my sister out the window…I ran around out to…the back door and came around and found and she was fine…’cause luckily there was grass and she bounced and she was asleep…I got her up…and I, what would I know as a 4 year
old whether the baby was alright? But I knew the baby was breathing and was okay so I popped her back in the cot until dad came home that night.

6.3.1.4 Who am I? - being unsure of self

Experiencing childhood and adulthood as chaotic, with an uncertain family life, also seemed related to an uncertainty about self-identity. Eccles for instance described his difficulty in trying to find a career path as an adult, and attributed this to finding it hard to cope with the negativity and mixed messages he’d received from his parents during childhood:

I still couldn’t find a niche for myself…I was still just so hopelessly muddled up in my thinking. I sort of now wonder how I even worked at all, because I couldn’t concentrate on anything, especially my work, and I was always sort of drifting off into, you know…this endless task of trying to make sense of my world… and doubting my own essence…my own place in the world, even my identity, like, “who the hell am I really?” you know.

Self-esteem was also affected, and participants acknowledged a continuing struggle with self-confidence and self-assurance. Fluctuations in their moods and the ability to manage their emotions were further concerns in their adult lives, and participants still found it difficult to identify and deal with anger, sadness and anxiety. Said Paula:

anger and sadness were so tangled up, I didn’t know the difference, and for many years I didn’t know when I was angry. I think that’s probably why I was so shocked when a couple of times I acted explosively.

As adults, some participants were also unsure of themselves in that they were concerned they might inherit a mental illness from their parents. In conversation about this, Kim and Paula discuss the impact this awareness could have:
Paula: when I get into a negative mood, I find it hard to get out of it, and then I get scared about being, getting depressed...while whenever I was really happy, then I would freak out that I was going into a hypermania...so...my moods, I was really uncomfortable with them

Kim: yeah, oh I can relate to that too...I’ve had lots of similar, I guess, feelings, and the anger was a big thing for me too, and depression...I think I probably have inherited a bit of the same sort of tendency, you know, that depression, but knowing about it is half the [battle].

6.3.2 STRUGGLING TO CONNECT

In being unsure of themselves, relating with peers, family, friends and our parents were also sources of struggle for all participants. Throughout discussion of their experiences, the relationships with those around them were a constant feature. Even in adulthood these remained an ongoing concern.

6.3.2.1 Being different – trying to fit in

As children, participants had often questioned how they fit in to their social world. During childhood, feeling different to other kids was an uncomfortable and often lonely experience, although this was not necessarily based on being teased or ostracised. Olivia explains:

I felt, not separated but singled out, and that was only my perception, because …I didn’t get any flack from school, so there was no substantiation of that, even though probably people around the area knew that my father had the classic, was then, ‘a breakdown’, so it’s not that I was bullied at school, there was no external stuff that was happening to me, it’s just my perception, and that probably came also from my mother’s reaction I think, so it’s what’s happening in front of you, because it doesn’t come from like, the teacher or kids or everyone. When I look
back now, probably no-one even cared or knew, but I felt a bit segregated, in that I knew something was different.

Paula explains that although she too was not teased at school because of her mother’s mental illness, she did have difficulty being accepted by her school mates and found it hard to fit in:

I was teased a lot at school, but not about having a parent with a mental health problem, I was teased because I was socially awkward. I didn’t know a lot about how to look after myself in terms of standing up for myself, physical boundaries, I didn’t know a lot about how to do that, how to look after myself and my physical safety, in as much as being teased and stuff. I didn’t know a lot about how to dress myself, and I think when I look back now, it’s probably because mum was often depressed and often didn’t have the energy to look after the house, look after me. I didn’t like bringing friends back to the house, ‘cause it was usually extremely messy, and that was really embarrassing, and I think probably I wouldn’t have known how mum would be either.

Some participants though, were teased about their parent’s mental illness. Nancy Rose describes one incident at school where a schoolmate had teased her about her mother:

yeah, some people at school teased me a bit, and, I remember the only fight I ever got into was about mum. Because this girl said ‘your mum looks like a retard or something’… and I said, ‘come here and say that’, and she did so she goes right up in my face and goes, ‘your mum’s a retard’, and I thought ‘fuck’, so I punched her right in the nose. That’s the only time I’ve ever been violent in my whole life, and …that was before I knew she had a diagnosis of schizophrenia, but I was still like, ‘you can’t say that about my mum’…so definitely…I got sort of teased about it, and then, I was always embarrassed about her.
Having a parent whose behaviour and moods fluctuated also contributed to participants’ difficulty in relating to peers. Sue explains how her mother’s illness impacted on her ability to fit in at school:

[The] emotional up and down of the relationship with my mother also made it hard for me to make friend with my peers. I developed an adult aloofness, I think, which alienated me from some girls and boys of my own age.

6.3.2.2 Feeling a lack of connection

For all the participants, there was quite a lot of difficulty emotionally connecting with their ill parents. We attributed this to various reasons. In a literal sense, as children some participants were physically distanced from their parents through being sent away from home for schooling or being placed in welfare institutions. This contributed to feeling lonely and emotionally estranged from them. Other reasons related to the impact of the parent’s illness on their behaviour and ability to relate to the family. They could be difficult to live with. Consequently, during childhood and through to adulthood participants had often struggled to feel close to their ill parents, and their relationship with them fluctuated. For Jane, the lack of connection she felt with her mother during childhood was linked to feeling unloved:

there was no family. I felt no attachment to my family whatsoever. None. No, I didn’t feel like mum loved me at all. I felt like …she wasn’t doing things for my best interests…she had her own agenda, you know what I mean, and she was treating me… like I was part of her agenda, not that I had my own life.

Marnie described the impact that a reversal in parent/child roles had on the level of emotional closeness in her relationship with her mother:

I really don’t know what a relationship is really between a mother and a daughter, as a normal one, because it’s always been in the reverse…the disadvantages [of having a parent with serious mental illness] …the biggest one would be my
relationship with my mother, that I lost that, that it was never, it was always in the reverse, so I haven’t got that closeness.

For others, the relationship with the ill parent was generally experienced as being close, but changed when the parent became unwell. Olivia explains:

*I was just very attached to my parents… [but] when he [her father] was ill, there was no connection. It was just like there was this other human being…so when dad was sick, to me he was non-approachable.*

Having difficulty in relating to a parent also meant that many participants felt a sense of loneliness and distance from the parent. They were unable to talk with them about things that really mattered. Feelings of loss, sadness, and resentment were often experienced about this lack of closeness. As Sue said:

*it all meant that I had no mother or father to share my insides with. That was emotional emptiness – having no parent to share with on a deep level. It was like always having a big secret between you and your best friend – your mum.*

Trust was also an important element in the emotional closeness of the relationship with ill parents and impacted on the perceived quality of the relationship. Paula explains the negative effect that her sexual abuse by her mother had on her ability to trust her, and how her eventual understanding of the illness mediated this:

*I never trusted her again, and I still often don’t, it’s taken a long time to repair…it’s been 20 years and I’ve got to the point now where I can hug mum and not feel that I feel sick. I’m not angry with her like I was, I was so angry for so long, had a right to be angry, but I now know that…it wasn’t her, it was her doing it, but it was the illness that was driving the behaviour, and that makes it more understandable for me.*
During childhood though, relationships with siblings were clearly very important to participants. Throughout our conversations, all participants who had siblings spoke often of brothers and sisters. Many participants had assumed protective and/or caring roles for our siblings and in some cases had taken on a parental role. Unfortunately, in adulthood these relationships had sometimes become estranged, although some participants had been able to maintain strong connections with their siblings. In a number of cases, the lack of connection had developed because the sibling now had their own drug and alcohol and/or mental health problems which impacted on their relationship with participants. Marnie for instance, describes an incident with her youngest brother who had developed schizophrenia in adulthood:

he and I were probably super, we were super close and now we’re not...he had a psychotic attack when I was in the car with him and he tried to kill me, so, I haven’t really forgotten that and those scars are pretty deep on that one. He ran a car into a pole with me, lining me up, so, a psychotic episode, so, he’s really not well.

Indeed, in reply to a later question about what particularly stayed in her mind about the whole experience of having a mother with serious mental illness, Marnie said: the hardest thing is seeing my brother go through it now, and that’s really bad... that’s been super hard, and he’s cut, the distance has been cut.

Issues with developing and maintaining relationships with their ill parents also extended to other relationships in participants’ adult lives, including their partners and children. They described difficulties in trusting partners, being able to maintain an intimate emotional connection with them, and being willing to commit to marriage. Parenting was also challenging for some participants. Olivia explains how her sense of detachment as a child had impacted on her own difficulty in connecting now with her sons:

I used to do the survival stuff for them, but I felt that there was a detachment from me to them, and...I still sense that now. I have to really try hard to connect with my children. That’s an awful thing isn’t it? But, I think the fact that I’m aware helps
me to, sometimes I have to just play the game, ’cause it’s not coming spontaneously.

6.3.2.3 Building relationships

For many participants though, often in contrast to their relationship with the ill parent, the connection they had forged with their other parent was often quite close. This seemed in part to be a form of compensation for the lack of emotional closeness with their ill parent, as well as the other parent’s ability to care for them and assume a parental role. As Naomi explains about her relationship with her father:

we’ve always been extremely close…and the events that I remember…from my childhood of having fun, are my dad teaching me to ride a bicycle, my dad taking me camping, I mean mum came along, but I always remember the fact that it was dad…and all the problems that I remember being solved, were solved by dad and me…it really was dad you know, my memories of pleasant things are all centred around dad.

Other people in participants’ childhoods were also sources of affirmative support and connection. These included childhood friends, grandparents, teachers, adult friends of the family, and neighbours. Grandparents were an important support, and Tom describes his relationship with his grandmother and what she offered to him that was different to his relationship with his mother:

I must have been unhappy for some reason as a kid, because even at a young age I was leaving home, and I was going down to Nan’s and sometimes I’d stay for a day or two…Nan was just fantastic…[I could] talk to her about anything – didn’t get judged, didn’t get judged, yeah…Nan just listened. She was great. Yeah, she just had that sort of something. Gee, I wish mum was like that too.
6.3.3 BEING RESPONSIBLE

Both as children and as adults, due to the effects of their parent’s illness participants came to assume responsibility for the family in various ways. Being responsible included a sense of inevitability as participants usually felt there was no choice about it. As Naomi explains, “she would just go off [referring to her mother’s illness] and somebody had to hold the fort. Somebody had to cope. And if you’re the only somebody, that means it’s you.” Sue adds:

_I think I grew up in a hurry, took on responsibilities very early in life…which no-one asked me to take on, but which I probably took on as a method of survival really. There didn’t seem to be any other way or anybody else to take on those responsibilities… probably much of what I did was driven by a fear that the family unit would be even further disintegrated that it already was._

6.3.3.1 Managing the household

Assuming caretaking roles in childhood included taking responsibility for the practical aspects of running the household. Marnie explains, “my role as the child was never as a child, mine was as a parent, and so I had to raise my younger brothers and sisters and do the cooking, so I probably learned to do the cooking when I was 3.”

One of the main impacts of parents’ illness and treatments, particularly anti-psychotic and anti-depressant medications, was their need for rest and sleep. This was a common concern for participants as it meant they had limited time to be with their parents and often had to look after themselves as well as take over the running of the household. Marnie said of her mother:

_I just think it’s a credit to her that she managed to get to school and teach those kids, but then, it was just the drugs would kick in. She would sleep for the rest of the day then, like she’d get home, she’d go to bed at 4, and then she’d get up at 7 o’clock in the morning._
Many participants therefore assumed responsibility for managing the household chores and everyday life, often in conjunction with the parent who was not ill. Naomi said: “I guess it was always me and my dad, coping with whatever, you know, the housework.” Taking responsibility for the household chores and other practical roles was understood by some participants as being normal. Marnie for instance, said:

*I didn’t know any different, so it didn’t mean anything to me, but I just thought that that was normal, that you had to get up in the morning and cook and do all the lunches and put all the kids off to school, and take them to school. I used to take full responsibility for them.*

In some respects, being responsible was viewed as a positive experience, and was seen by participants in adulthood as having contributed to the development of independence and having gained them positive attention from others. Sue said:

*other adults used to tell me how responsible I was, and what a grown up young person I was. And I think from the time I was 12 I always looked very grown up, and…I think young people generally will, if they get their strokes in some particular way…that’s the side of themselves that they will develop. And so, that probably helped me develop it even more.*

### 6.3.3.2 Looking after family

One of the major aspects of assuming responsibility was looking after the rest of the family and taking emotional responsibility for them as well. Olivia explains that for her, this included protecting her siblings from her father’s anger.

*And there was that part of you that wanted to protect the person…who he was angry at, who the anger was directed to, so there was that sense of responsibility and protection…the responsibility to do something about the person being angry, so there was this pull, you know, to, the chaos…and never any end to that.*
Participants often also assumed responsibility for their ill parent’s well-being, and began caretaking them which in effect reversed the usual parent/child roles. As Nancy Rose said: “I guess growing up when I was little the main thing that comes to mind was that I sort of felt like I had to look after Mum, rather than her looking after me.”

For some participants, their sense of responsibility for their ill parent became even more developed as adults because the parent had deteriorated significantly by that point, and/or because the illness had only been diagnosed later in life. Parents and other family members could be demanding of the adult child’s time and energy and expect them to continue or assume greater responsibility for the parent’s well-being. Participants sometimes felt angry and resentful at these expectations, although they felt an obligation to fulfill them. Attempts to focus on themselves and their own families, and/or to assume less responsibility for a parent, could result in strong feelings of guilt. As an adult, Jane describes the sense of burden she felt about caring for her increasingly unwell mother as well as looking after her own children:

that was really hard for me, because I had my 2 kids - were about 3 and 4 then, and… she’d give me a phone call and say ‘I’ve cut my wrists!’ I’d have to pack up my whole children and walk to her house, and make sure she’s not dying. And times I went to check on her and she’d be so drunk, passed out on the bed, and I’d look through the window and I couldn’t see her, her breathing was so suppressed I couldn’t see her breathing and I thought ‘oh, this time you know, she’s dead this time’. So I broke in the house and rang the ambulance, and she wasn’t. Laying on that bed, I felt like I wanted to punch her you know…I said ‘you scared me so much’.

Sue adds:

[as a young adult training to be a nurse]…I was travelling back home every weekend and…I was actually paying, I wasn’t living at home but I was still paying her money every week to help keep the boys…I’d go home for the weekend and
pay board…I wasn’t just going home to visit, I was going home to put money in her pocket as well.

As both they and their parents continued to age though, the ongoing burden of caring for sometimes both parents who were now elderly and needing support had become increasingly difficult. For some, this continual sense of responsibility entailed making a decision about where and how their energy could be spent. Naomi explains:

[since her ill mother went to a hospital with dementia] …I haven’t actually seen her since then. Not that I think it would matter, but I’ve just been having my hands so full with dad, that I just, there was no room at the inn for her anymore, feeling. There just wasn’t any more left.

6.3.3.3 Dealing with health professionals

In assuming responsibility for many facets of family life, and assisting their ill parents, all the participants had had contact with health professionals, including psychiatrists, general practitioners, counsellors, case managers and/or nurses. This was either in an attempt to gain information about a parent’s illness; and/or as part of the management of a parent’s illness. In adulthood, it was also sometimes to deal with participants’ own mental health concerns, including depression, anxiety, anger, and difficulty managing conflict. Experiences of dealing with health professionals were mixed. Participants were often quite critical of health professionals’ attitudes towards them and/or their parent, and/or for a lack of initiative in recognising and addressing their needs as distinct from their parent’s. Paula discusses this in terms of finally finding out her mother’s diagnosis at the age of 21:

what the psychiatrist did do was explain a bit about mental illness and give me some brochures. That was the first information I’d ever been given, so that was huge. Mum had been sick since I was 7, so you know, 13 or 14 years of her being unwell, and being for most of that time, my primary carer. Most of the time I lived with my mum, they’d never ever given...me any information about illness, mental
illness. Never that I know of, tried to find out that she had kids, or, you know, how old they were or anything like that.

For Nancy Rose, her mother had been visited by a mental health worker each month for some years to give her depot anti-psychotic medication. Nancy Rose recalled her resentment at only being given attention by the worker when her father died suddenly when she was 15:

I remember like after dad died and the mental health worker started coming round more and started realising that mum wasn’t really getting any help besides…an injection every month and…I said something about mum and she said, ‘how do you feel about that?’ and I said ‘piss off. Don’t give that psychobabble to me’. So I was just really resentful of the fact [that] ‘now you want to come now that all this other stuff has happened, but what about the last 15 years?’…I felt really resentful about it and I was like ‘I’ve dealt up until now, I will keep on dealing and I don’t need your help’.

One of the particular difficulties participants had in dealing with health professionals involved the issue of confidentiality. This was often an impeding factor in their quest to find out what disorder their parent had, and/or what was happening with their parent’s treatment. Tom described flying interstate to find out what was happening with his mother and his frustration at being unable to gain any details of her newly diagnosed bipolar illness from her doctor. He eventually resorted to looking it up on the Internet:

I got quite cross, because, he wouldn’t speak to me…apparently I needed both mum and dad’s signature or something. I went in to chat to him once, and…he gave me the usual spiel, and I said, “yeah, I know you’ve got your duty or legal”, I said, “but it’s mum and I’ve come down from [names town] and you can tell me”, but he wouldn’t… he did say, “…I’m not supposed to divulge information even to the son”, but … he did say that mum has Bipolar.
6.3.4 SEEKING BALANCE

This final theme describes an important aspect of having with parents with serious mental illness. Threaded throughout our conversations was participants’ need for balance in their lives. The strategies they used to help them in their quest for balance included a sense of wanting to gain mastery over their lives and circumstances, which they had often experienced as being out of control.

6.3.4.1 Finding ways to care for self

During childhood, when parents were unwell and/or fighting, participants had looked for ways to care for themselves. These included a variety of activities they found comforting and helped them feel more secure and/or enabled them to escape from what was happening in the family. Sleep was a particular issue for some participants, and they struggled to find ways to get off to sleep at night. Tom explains:

*mum and dad had their fights and arguments and that sort of thing. I remember as a little kid, I used to rock myself to sleep sometimes because I didn’t want to hear them yelling at each other, and stuff like that.*

Although later in his interview, he added: “*although to be honest with you, I don’t think it was so much getting away from the yelling, it was more to do with getting to sleep.*”

During childhood, some participants also looked for ways to escape from the house so they could get away from parents’ conflict and/or family atmosphere. Said Eccles:

*the only time when I sort of felt partly okay…was when I could really get out in the sort of wide open spaces out there… trees and plants and nature…you know, on a horse, or walking or hiking or something, and just get miles away from the house and my parents and just sort of be surrounded by nature. I at least sort of felt halfway safe there.*
As adults, many of these self-caring strategies were still being used to good effect. For some participants though, they had become problematic. Tom talks about other strategies he had used to calm himself which were now a problem in terms of his self-acknowledged problems with alcohol abuse:

*I used to go out the shed. I always had a shed wherever, whichever house we were in I had a shed... and I always had my music. I guess I used that as an escape thing... from a young kid I was allowed to have a drink and I used to go out even at 14 and 15, I'd have my beer fridge full in the shed.*

Paula explains too, that for her as a child reading had been a solace, although as an adult she had become concerned that this way of calming herself was potentially addictive. She had also developed a problem with binge-eating:

*I read a lot ...reading was one [of my] coping strategies...I'd read the back of a cereal packet...absolutely anything. I love science fiction, fantasies...and I still [do]... Reading can be a coping strategy, or it can be a bit of an addiction...so yeah, it's something I watch, the same with food. It probably helped me get through a lot, but then there's an addiction kind of stuff goes on with a lot of the foods that I eat as well."

Jane described how she mentally tried to protect herself after her experience of being sexually abused as a teenager. This reflected her sense of having difficulty coping with stressful situations, as she felt she had not been taught effective ways of coping by her parents:

*I think I had a special ability of putting things to the back of my mind and not dwelling on them and just letting them be there and just get on with what I was doing, like...the next year was pretty full on with drugs and alcohol. I got into...injecting speed and stuff like that and...went really down hill, but just running I guess, just from the next, to the next, and the next...into the next bad situation, because I had no coping skills.*
6.3.4.2 Wanting to feel safe – being in control

Needing to regain a sense of control was a common issue for participants. They recognised this was a particular concern as they had felt unsafe and experienced a lack of control in their lives as children. Naomi summarised this in saying, “the way I grew up, I had to be in control of the situation, not necessarily of other people, but of the situation, so that awful things wouldn’t happen”. Naomi explains how as an adult she had found a way to stay safe and in control in her everyday life:

\[
I \text{ was always an actor, and interestingly, when I think about it, that’s why I’m a good actor. Because the things that I will not allow myself to express, my self and myself, it’s great. On stage you know how it’s going to turn out. You can be mad, you can cry, you can laugh, because you know where it’s going. It’s safe. And you can express your emotions safely...because the story’s written. You know how it’s going to come out and so you can be somebody else, you can have all these feelings that you would never allow yourself to be seen having, you know, a loss of control.}
\]

Being out of control was particularly associated with their parents and the effects of their mental illness. Paula, in describing her reluctance as an adult to experiment with recreational drugs, explains her need to stay in control:

\[
I \text{ think underlying it all was that not ever wanting to lose control, not ever wanting to be like my mum...who has a mental health problem, or my father who’s an alcoholic, never wanting to go there.}
\]

6.3.4.3 Learning to accept help and support

In dealing with the effects of their childhoods however, there was also a resistance by participants to asking for support from others, even when they were experiencing difficulties coping. As adults, they saw this as related to the independence developed in childhood when they had assumed responsibility for the family. Olivia explains:
I’m a very independent person. I would never ask for help, ‘cause I assume that people should come in, that’s my assumption, they should come in and offer.

Resistance to asking for help also related to asking for and accepting it from others, including health and other professionals. Participants also saw this as being related to their ways of coping which had continued into adulthood. As Paula said:

I think probably the overwhelming thing was how lonely and isolated and how little I talked and reached out to people, and that it continues to this day. I have to make a conscious effort to reach out for help. I tend to try and deal with things by myself…then when I finally do ask for help it’s usually when I’m at crisis point.

A part of some participants’ reluctance to accept help from others, including health professionals, was based on a concern that they would be seen as being unwell like their parent, that they would be pitied, and/or that unless others cared about them they were not entitled to share their concerns. Jane explained why she has been reluctant to talk about her past with others:

you would be the first stranger that I've ever spoken to about [this], just because, if they don’t care, then they’ve got no right knowing, alright? If they don’t care how it felt for me, or how it felt for mum…I don’t really say anything, because it’s not something that you can’t care about, and I don’t wish to tell people and have them brush it off like, you know, ‘whatever’!... and a lot of my friends…they still don’t know about it…if I had a room full of people that actually were in the same boat that would benefit from it…I would do it…but as far as people that come from…normal homes…they would just look at you and go ‘oh my god!’ and then you can see them looking at you like ‘you poor thing’ and that’s the last thing I want.

Yet for some participants, there was recognition that their adult understanding of their parent’s illness had enabled them to accept help more easily, although this had not always been the case. Nancy Rose explains:
I don’t sort of feel like this now but certainly at that stage… it [counselling] was putting me in the category with mum which is exactly where I didn’t want to be and would imply that I was not coping and that I needed help, which I felt that I didn’t, and which I sort of prided myself on not.

6.3.4.4 Reaching turning points

As adults, participants had reached important turning points, particularly in their relationships with their ill parent. These incidents and/or realisations were pivotal in that they enabled them to find a more balanced approach to their relationship with their parent, and changed their understandings of their parent and their illness. Realisations they had during these events also included new, and sometimes quite disturbing, understandings of themselves. A common aspect of these experiences was putting limits on parents’ behaviour and therefore helping to reduce the negative impact of their illness on the participant’s own life. Sometimes this was the first direct act of non-cooperation they had ever shown with their parent. For Paula, one such turning point involved an incident with her mother who was experiencing a psychotic episode and had locked her in the house. Paula had called the police for help, but because of her distress the police had thought she was the one with the mental illness:

When they arrived, mum did everything she could to try not to let them in, so eventually they broke the door down, and they realised that actually it was how I’d described it, that was a pivotal, absolutely pivotal moment for me, because until then I’d never demanded to know anything about her illness, and I didn’t really want to know, and at that point mum’s mental health nurse actually called me, and I demanded, like I just went off, going ‘nobody’s ever talked to me about this’, and… ‘what the hell’s happening?’, and she made an appointment for me to see my mum’s psychiatrist…so it was pivotal for that reason… it changed how I saw her, the information about the medication changed somewhat how I felt about her, it changed some of the anger that I felt towards her, ‘cause I realised at that point, well perhaps it’s not her fault, because all of this time I’d been thinking that you know, she could have done something about it, why wasn’t she? And that was
also pivotal that time because it changed the way I felt about myself. And I don’t think I’d ever been conscious of being concerned about my own mental health until that point when I read those brochures and realized that I was at risk.

Sue also described an important turning point in her relationship with her mother. Having not seen her father for over 20 years since he had divorced her mother and left the family, Sue had organized to go overseas to see him. On the eve of her departure her mother had made, as she often did, negative comments about him. But Sue had reached a point where she was unwilling to tolerate further interference from her mother in her relationship with her father. She became so enraged with her mother she thought she might harm her, and called the police to deal with the situation. Sue then described the aftermath of her decision to both call the police and defy her mother by developing a relationship with her father:

it was a long time before she would speak to me after that, so it was quite a big shift I suppose in the dynamics of the family really. It was a huge shift. That incident created a huge shift in the relationship between myself and my mother, and the relationship between her and my own family - my husband myself and my two children at that time and it was a very, very pivotal point really…and so, our relationship got to a point then where I was not kidding or going along with any rubbish anymore. It was basically ‘hey mum, been there done that, not doing that any more. This is how it is. Keep your dirty letters to yourself. If you send me a dirty one, I’ll send you back some truth’, and, so we went on in a quite different relationship from then on.

For some participants, a significant turning point also came with the birth of their own children. Knowing that they were now responsible for their own child brought a new awareness of their self. Jane explains:

And then when I had my daughter at 17, everything changed. I completely changed…I still drank a little bit, but it was like my whole world just took on new meaning. And then because I felt like I had something that would love me, and
that I could love, and that I would be good enough for, you know? And that was...really amazing. And when I had my son and I stopped drinking, everything, yeah, everything was different.

6.3.4.5 Making choices

These turning points and adult awareness of childhood experiences also included the need to make a number of life choices. This was based on the mental, emotional and practical impacts that their chaotic childhood had had on them. For all participants, making choices involved dealing with the varying impacts of these experiences. For some, it also included how to manage their own mental health issues, whether they would even have children, and if they had children, conscious choices about how they would parent them in ways that were different to how they had been parented.

Kim discusses the general issue of choice for adult children of parents with serious mental illness during conversation with Nancy Rose:

Kim: this is something...that I think’s coming out as well, is...this thing about the choice, you know, to view it in ‘this way’, or ‘this way’ and that for a lot of people they don’t realize that there is a choice...even for me doing this study, learning about all this, it has altered my perception of things somewhat. Not, you know, not necessarily, it hasn’t changed the memories or whatever, but, how I view myself and my life, has altered

Nancy Rose: yeah, I think... that’s spot on.

In managing their own mental health issues, most commonly depression, participants acknowledged that they could choose how to view their problems, and could accept or reject the treatments offered to them by health professionals. In fact, some were quite defiant in their rejection of medical explanations and treatments for their issues. Jane for instance, explains her response to the doctor she went to see about depression she experienced after having her second child:
I went to the doctor and he said to me ‘is there any depression in your family?’ and I said ‘yeah my mum’ and he says ‘well, probably by the age of 30’ he said ‘you’ll be, you’ll be right there and you’ll be getting it and you’ll be feeling the symptoms and it’ll be coming on’, and I looked at him and I went ‘I don’t think so’. And he says to me ‘well, you can’t choose it’. I smiled and said ‘I can choose’. I said ‘I can damn well choose’, I said…‘I won’t allow myself to slip into that way of thinking, chemical imbalance or no chemical imbalance.’

Along with Jane, many participants sought alternative treatments and ways of managing their mental health issues including using therapies such as meditation and reiki, attending self-help groups, and focusing on spirituality. Many participants though, had also sought counselling and used anti-depressants for varying lengths of time to manage our feelings of anger, depression and anxiety. As had been apparent in the turning points they experienced, managing the mental and emotional impact of having a parent with serious mental illness also involved knowing they had choices in terms of how to respond to their parents, and that these could differ to those they had taken as children. Whether or not to have children was itself an important choice, and was related to a concern with our potential to pass on a genetic vulnerability for mental illness and whether they should become a parent if they were at risk of developing a mental illness themselves. For some participants who had not yet had children, whilst they were aware of the potential risk/s they considered they could manage these and were prepared to take the risk. Again, they did not want to be like their parents. Nancy Rose explains:

in terms of like seeing myself as a future parent…I’ll just learn from her mistakes and I will never do that. You know, I’ll never sort of be like that, I’ll make sure I’m always there for my kids and…I mean I’ll probably go the opposite way now – I’ll be really organised and everything running smoothly and under control and that kind of thing.

For Marnie, her concern about the risk of passing on a mental illness to a child meant that she had made a deliberate choice with her husband not to have children at all:
I think the biggest impact probably of mum’s schizophrenia has been that we chose not to have children, so that wasn’t passed on. So it’s probably had some pretty long-term lasting events, ‘cause I just didn’t want anybody going through that. And my husband’s side of the family, his mother suffers from manic-depression, so, he’s grown up as the oldest in very similar circumstances, having to do the same, so we chose not to have children.

For those participants who had children there was often a deliberate choice about how to parent them, and having children was a significant motivating force in deciding to deal with issues from their past which impacted on their own parenting, such as expressing love and managing their own anger. This was usually in conscious contrast to their experiences of how they were parented by their parents. Jane said:

I would say that having my children is what’s kept me going…and looking at them and going, ‘well I’m not going to be the same [as my mother]. I want to be better than that…I modelled myself on not being like my mother, and knowing that even for all the bad…there is good in them too, and trying to find it, and picking it out and claiming that as my own …‘I’m like my mother because of this reason’, and forgetting about all the other reasons.

In concluding about her experience with her ill father and family, Olivia offers a parable to explain her understanding as an adult of the choices she could take about her past, and affirmed her resistance to repeating these experiences in her current life:

[as] a kid, you’ve got no idea that there are choices. It’s only in adulthood that you know…Now I think, it’s a choice. Like, there’s a saying that really made an impression one me, it was [from] William Glaser, and it said, ‘there were two sons. The father was an alcoholic. One became an alcoholic [starts to cry] because of his father, and one went on the straight and narrow because of his father’, so, the two viewpoints, and I just don’t want to be like that [like my father] [continues crying].
6.4. CONCLUSION

Through the use of van Manen’s phenomenological thematic analysis, this chapter has shared concerns, emotions, situations and understandings that this particular group of adult children has experienced in their continuing journey with parents who have a serious mental illness. In managing the impact of their experiences and seeking balance in our lives, there has been a need to take control and make decisions about important life choices. These findings re-present a realist interpretation of participants’ experiences and complete the first phase of the dual analytic approach. In the following chapter, a thicker explanation of these same experiences is now produced through the de-constructive phase of analysis, where the realist interpretation is troubled through a postmodern narrative analysis and interpretation of the field text.
CHAPTER 7
‘NEVER-ENDING STORIES’ -
POSTMODERN NARRATIVE INTERPRETATIONS

Musical lyrics removed for online publishing due to copyright
Reflecting on Never-Ending Story/ies

This lovely song of fantasy and adventure brings with it the image of an endless story, evoking the protagonist’s eternal quest for answers. Yet although the following stories can be seen to contain some potential answers to questions about the nature of our experiences, unlike the words in this song we do not seek to have the answer. Ours are stories of complex, multiple and diffuse experiences, where rhymes, metaphors and other cultural texts unfold to reveal new possibilities.

In yours and others’ hands, and through your readings of and between the lines, there is the potential that our stories may lead to new understandings and the possibility of new stories for parents and adult children where parents have a serious mental illness. Perhaps they may be part of the emergence of a fresh era for families such as ours.
7.1 INTRODUCTION

In the following chapter, selected small stories told by the participants are presented. Each of the following stories has been interpreted through application of the critical questions in the postmodern narrative analytical framework (Chapter 5). From the 10 participant life stories 143 specific small stories were identified and analysed using each of the questions in this framework. After initial discussion of the narrative structuring of the stories, the chapter focuses on some of the important small stories participants told within their overall life story of having a parent with serious mental illness. These selected stories were considered important in that they contained multiple meanings of events, incidents and situations and illuminated diverse dimensions of the experience of having a parent with serious mental illness. Whilst they have all been analysed using the analytical framework, in different ways each of the following stories offer potential for transformation for ACOPSMI. They show a new way of thinking, and assist in illuminating how ACOPSMI and others may alternatively understand and manage such experiences. Whilst the following stories overlap with many of the phenomenological themes in Chapter 6, this postmodern reading has particularly sought points of difference in order to thicken the alternate stories and meanings of being ACOPSMI. The conclusions reached in interpretations of these stories should, however, necessarily be viewed as tentative whilst also providing potential opportunities for transformation for current adult children and their families.

7.2 ‘HOW WERE THE STORIES TOLD?’ - NARRATIVE STRUCTURES

Throughout each adult child’s life story of their experience of having parents with serious mental illness, small stories were identified which contained conventional or common endings, as well as those which also contained novel or uncommon endings. Some stories were only a couple of paragraphs long and spoke of a particular event or incident. Others were complex, detailing a number of issues and events, and extended for a number of pages. I asked of each story ‘what is the point of this story?’ as this can be seen to indicate the meanings the narrator has derived from their experience (Mishler, 1986). In each case therefore a plot, and in some cases, a moral, was identified. For many small
stories, there was also a prelude which provided contextual explanation for the associated story that then exemplified and/or explained the point the participant had been making. In some life stories participants told numerous small, often connected stories of events and experiences which segued from one to the other with little intervening discourse. In others, there was extensive intervening discourse interspersed with fewer small stories that evoked the experience or illustrated an issue or point the participant had raised. These life stories were presented in more of a discourse without many specific stories told. Whilst participants quite often signalled a story with linguistic devices such as “I remember one time…” or “then years later…” more often their stories were not so clearly signposted. In these cases, I looked for temporal and linguistic signifiers of the beginning of the story such as “so there was quite a bit of that, and then…” As McCance, McKenna and Boore (2001) also experienced, I did find it challenging at times to identify the end of a story, particularly when there was an unclear delineation between where the story ended, and discourse on a related issue began. In these cases, I identified the ending where the particular event or situation the participant was discussing seemed to finish.

A further interesting discovery was that fragments of stories were common. That is, there was an apparently ‘promising’ start of a potential story with comments such as ‘I remember one time’, which then did not go further. Instead, these were memory fragments which did not develop into stories with attendant plot structures and temporal sequences of beginning, middle and end. Sometimes there were also a series of memories that were not connected in a way that revealed plot development. Overall, in my identification of each completed small story within the overall life stories I based my decision as to whether or not it was a story according to the guidelines for story identification provided by Denzin (2001), as discussed in Chapter 5.

7.2.1 Explanatory stories

In analysing each of the 143 stories, I came to see that some of them could be viewed as major or ‘explanatory’ stories within the participant’s life story. These were often dense and multi-layered accounts which told of significant issues for the participant and usually contained ‘breaking points’ which they identified as being pivotal or important to them in
some way. Often, participants referred back to these stories a number of times during their life stories and so they appeared to hold particular meaning through being ‘explanatory’ of a number of issues.

Breaking points were those incidents, usually between participants and parents, where a crisis in their relationship resulted in the participant, often for the first time, laying down boundaries and/or limits as to what they would accept in terms of their parent’s behaviour toward them and their family. These episodes generally resulted in a different and more respectful relationship between participant and parent from then on and some of these stories are presented here as they are informative of the many meanings that can be made of being an adult child of a parent with serious mental illness.

In some cases, explanatory stories were also found within a series of sequential stories which unfolded in a manner similar to scenes of a play (Reissman, 2002). The challenge here was to find the story or scene which was the major or explanatory story of the issue the participant was illuminating. The following stories ‘The Surprise’ and ‘The Breakdown’ are examples of explanatory stories within multiple scenes relating the unfolding of a particular issue.

7.2.2 Prologue

For the remainder of this chapter, selected stories told by participants of their experiences of having parents with serious mental illness are now presented and then interpreted through a postmodern narrative lens. The stories have been presented using a temporality which may be seen as my own narrative construction of participants’ experiences of being the adult child of parents with serious mental illness. That is, the stories presented here begin with one participant’s adult experience with her mother, with subsequent participant stories which look back to childhood experiences, progressively moving back and forth through time to present day experiences. In their interviews, many participants told their overall life stories in a similar way; illuminating the impact that meanings of pivotal life events, refracted memories and the co-constructed nature of the interview setting can have on the recall and recounting of past experiences.
As Gergen (2004) has argued, the potential in this postmodern narrative approach to participants’ stories is the possibilities available in telling a story afresh, with a different plot. Counter-stories, which resist dominant or conventional understandings of marginalised groups, can be constructed to replace oppressive narratives and command greater respect from those who may be viewed as ‘oppressors’ (Nelson, 2001). In postmodern times there is now a capacity to give voice to stories of the self so they are re-claimed from dominant discourses (Frank, 1995). In this way, alternate stories of being adult children of parents with serious mental illness may also provide opportunities for transformation. Re-storying has the potential for new trajectories in a person’s life, and so the re-presented stories that follow have also been chosen to illuminate some of these possibilities. Each of the stories is presented as the participants voiced them, with minor editing to enhance readability. The words in bold font indicate verbal emphases used by the participants as they recounted their stories.

7.3 STORY 1: THE SURPRISE

The following story illuminates a number of recurring postmodern motifs and explores the potential for transformation that can exist for ACOPSMI. In leading up to this explanatory story, which was the first one she told in her interview, Paula had given me an overall view of her-self and some of the effects of her experience growing up with a mother whom she initially understood to have bipolar disorder. Paula explained that as a child she had overheard her mother tell a friend that whilst she was in hospital another patient had said to her she must be ‘manic depressive’. Up until the point where the following story begins this was how Paula had understood her mother’s illness. During childhood she could not recall having talked with anyone else about it, including her father and the health professionals who had been caring for her mother. And then her story began:

When I was about 21, I’d been overseas for 3 years and I came home and decided it’d be a good idea to surprise mum, and that wasn’t a good idea, strangely enough. She’d become very paranoid, and didn’t take the medication that she should have taken, and I look back now and she was becoming unwell and me turning up out at the blue was too
stressful for her to cope with, but that incident resulted in her locking me in the house and me calling the police and getting them to break me out. But that incident had a huge impact on me, because the police dispatch officer on the phone… she actually thought I had the mental illness, and she asked to speak to mum. I put mum on the phone, and it sounds funny now, but it really wasn’t funny at the time. Mum just switched over from being really out of touch and really loopy, to completely sounding so sane, and saying to the lady on the phone, ‘yes I know, I’m very worried about her’, and I just had this feeling, like when you’re watching a Hollywood movie or pantomime, and you’re going ‘look behind you’ – or that feeling of ‘don’t do that’, that you’re heading for impending doom, or knowing that a character’s heading for something and you can’t do anything to stop it, and I just had that feeling then that I was heading towards something I couldn’t stop.

And when the police arrived they said in fact they’d been told ‘there’s a daughter that was mentally unwell, and her mum had locked her in for her own good’, but of course when they arrived mum did everything she could to try not to let them in, so eventually they broke the door down, and realised that actually that it was how I’d described it. That was a pivotal, absolutely pivotal moment for me, because until then I’d never demanded to know anything about her illness, and I didn’t really want to know, and at that point mum’s mental health nurse actually called me and I just went off, going ‘nobody’s ever talked to me about this, and you know, what the hell’s happening?’, and she made an appointment for me to see my mum’s psychiatrist. Mum was hospitalised after that incident for some weeks and true to form they didn’t actually ask her for permission to disclose to me about her illness. What the psychiatrist did do was explain a bit about mental illness and give me some brochures. That was the first information I’d ever been given, so that was huge…Most of the time I lived with my mum they’d never ever given me any information about mental illness. Never that I know of, tried to find out that she had kids, or how old they were, or anything like that… But he did say to me, when I described how I’d seen programs on TV where people had bipolar or manic depression and they took medication and everything was fine, and I said how angry I was with mum because obviously she wasn’t taking her medication, the doctor said sometimes even taking the medication people don’t have no symptoms at all and that sometimes people don’t fit neatly into one diagnosis, and he said ‘I can’t talk to you about your mother’s diagnosis, ‘cause that would be breaching confidentiality’, he said, ‘however, what I will tell you is sometimes people don’t fit into the bracket of schizophrenia, sometimes they don’t fit into bipolar, and we call that schizoaffective disorder’, and that was the first time
I’d heard that term, and I think that came up because I was confused about why he was giving me information on schizophrenia because I saw mum through the frame of bipolar…this incident when she shut me in the house was the first time I’d seen her out of touch with reality, yet not high. So it was really weird for me, it was a completely different experience to what I was used to, so it was pivotal for that reason.

The information about the medication changed somewhat how I felt about her, it changed some of the anger that I felt towards her, ‘cause I realised at that point, well perhaps it’s not her fault, because all of this time I’d been thinking that you know, she could have done something about it, why wasn’t she? And that was also pivotal that time because it changed the way I felt about myself. And I don’t think I’d ever been conscious of being concerned about my own mental health until that point when I read those brochures and realized I was at risk. I can remember, I was in the car with my boyfriend, and we were driving a 4 hour drive to where we were going to be living for the next year or so, and I remember reading these brochures in the car while he was driving, and just crying my eyes out and being terrified. It affects your choices about whether you have children. I imagine for a lot of people it might mean choices about the lifestyle. I never had been a drinker, and I’ve never been a smoker, and I mean by smoking, I mean pot. I think underlying it all was that not ever wanting to lose control, not ever wanting to be like my mum, who has a mental health problem, or my father who’s an alcoholic, never wanting to go there…Any time I’ve been tempted to use recreational drugs I just can’t bring myself to do it, I just can’t, it’s just not worth the risk to me. I think that there’s not enough known about the impact of drugs on psychosis and if I have inherited the tendency then that might be the thing that pushes me over the edge, and it’s not worth it for one night, you know, or a few hours of fun, or whatever. I was never into it before and that sort of meant that now it’s a closed door to me, and most of the time it’s not a problem, but there’s been a couple of times when I’ve felt very resentful of that. Other people go off and get stoned or get drunk and don’t think about the impact.

7.3.1 A conventional reading

Paula has told a complex and multi-layered story which can be seen to contain both conventional and novel meanings. The conventional meanings include that a parent’s psychosis is frightening and distressing for the child, no matter what their age (Marsh, 1993b), and this could mean they seek a greater sense of control in order to compensate
for feelings of fear and insecurity. There is evidence that COPSMI’s contact with health professionals can be experienced as negative and unhelpful (Dunn, 1993). The conventional meanings in this story can be seen then as confirming a cultural narrative that the mental health system has generally failed to adequately inform and support children who have grown up in families where parents have a serious mental illness. Yet there are also novel meanings that can be found in Paula’s account.

### 7.3.2 Resistances and struggles

There are some sites of resistance in Paula’s story. One is where Paula resists the perception of the police that she is the person with the mental illness. Another resistance can be seen in Paula’s refusal to remain passive about her mother’s illness. She demands to be informed about the illness, apparently so that she can better understand her mother. As the ending of the story suggests, in doing so, she also seeks to better understand herself. Paula’s adult assertion of power and agency with regard to her mother’s illness can be instructive. Adult children of parents with serious mental illness, whilst sometimes experiencing chaotic situations, have choices as to how they perceive and manage these experiences. They do not have to accept the passive child role and maintain an external locus of control – a psychological construct used to describe a perception that events in life are due to external factors over which they have no control (Pervin & John, 1997). As Paula shows us, her refusal to maintain a childlike ignorance of her mother’s illness resulted in information that helped to positively re-shape her views of her mother and also enabled her to make life decisions in her best interests that she may not have made without it.

### 7.3.3 Confusion and diffuse boundaries

Paula’s distress at her mother’s behaviour and the resulting perception by police that *she* was the person with the mental illness also illustrates the diffuse boundaries between a parent’s story of serious mental illness, and the child’s story of having a parent with serious mental illness. In the current mental health system, the person with the mental illness is usually considered the identified client, with family members and their needs
approached separately, if they are addressed at all. From a postmodern perspective though, forcing clear boundaries around the identified person with the mental illness is possibly counter-productive. As Paula’s story reveals, mental illness can have a diffuse effect on all those closely involved with the identified person. Persisting with the notion of maintaining clear treatment boundaries perpetuates an individualistic approach which does not necessarily take into account the influence of inter-subjectivity between the mentally ill person and those around them. A collectivist approach to mental health care, where families are considered as unique and whole, may provide support which is perhaps more suited to the needs of all involved.

### 7.3.4 Possibilities for transformation

There are a number of metaphors used by Paula in her story. These can be seen as rich in meaning, and drawn from various cultural texts. For instance, in describing her perception of being in a Hollywood horror movie or pantomime, Paula shows us how one cultural text can be used to construct another. This inter-textuality between ‘Hollywood fiction’ and Paula’s ‘reality’ can also be re-framed. If the chaos of having a parent who is psychotic can be experienced as being headed for ‘impending doom’, imminent tragedy may also be averted if help arrives in time. In this case it appeared to be, as the police arrived and the immediate situation was resolved. Movies, however, which contain cultural stories and images, also have the power to transform protagonists’ experiences through changing the script. The crisis may be averted if the potential problem is identified before the situation evolves. In this instance then, the crisis may never have occurred if intervention had been provided, for instance, by the mental health nurse before Paula’s mother reached the point of psychotic breakdown. As an adult, Paula could also be supported to re-frame the metaphors she uses for her experiences. In her own life script the ‘horror movie’ could perhaps become an ‘adventure’ film, where her experiences were seen as a challenges rather than distressing crises.
7.4 STORY 2: THE CAR

This story addresses the multiple meanings and apparent silences and endings that may suggest possibilities for change. Prior to this first small story in her overall life story, Olivia had started to paint a verbal picture for me of life with a father who developed severe depression when she was a child. Her story so far had been one of feeling ‘different’, ‘scared’, and ‘responsible’. She began to describe her father’s descent into a debilitating depression from which he had never seemed to completely recover. And then she told this story:

I know there’s a particular medication that he was on, which I think is the Parnate, mum said, and it was because you had to be careful with this and careful with that, and it seemed to make my dad very aggressive, very, not violent to the point where he’d hit us, but I was afraid that he would, and it was like someone else had taken over his being? He’d changed and was different.

And I think the other thing was, he wasn’t to drive when he was on that medication and he would insist to be at that wheel, with all of us in the car, and I remember at one stage I was put in the front, and I actually grabbed the wheel, ‘cause I felt, whether he was over the white line or not is not the issue, I felt, maybe because I knew that he shouldn’t be, I felt that he was moving onto the other side of the road, and I grabbed the steering wheel to pull it back, and I remember him being outraged, probably his pride as well, what did I know as a kid? But there was always that fear, and insecurity is another thing that comes up, nothing seemed, even though everything was stable in the sense that it didn’t really change, it felt very chaotic and very unstable.

7.4.1 Conventional readings

Olivia’s small story of confusion, fear and an attempt to regain control can be read as a common theme in being the child of a parent with serious mental illness. Being in this situation can mean struggling with the fear experienced by the unpredictable behaviours of an out-of-control parent who sometimes acts unsafely, as revealed in the phenomenological sub-theme ‘Feeling unsafe’ in Chapter 6. In addition to the effects of the symptoms of serious mental illness, antidepressant treatment such as Parnate (or
Tranylcypromine) requires avoidance of particular foods that contain tyramine, an amino acid, otherwise the person can experience a number of adverse effects including hypertension. Aggression and hostility however, are not usually effects of this drug (Therapeutic Guidelines: Psychotropic, 2003), and perhaps her father’s aggressive behaviour was related more to his severe depression (Alpert et al., 2003). Olivia’s story can be seen then as confirming a cultural narrative that parents with severe mental illness can be unpredictable and their parenting may be compromised as a result.

### 7.4.2 What do kids know? - Alternative readings

Yet, read in an alternate way, this is also a story about power. Olivia’s action in taking over control of the car can be seen to briefly reverse power in the parent/child dualism. In this common cultural binary, the parent is in the dominant position which traditionally holds the balance of power within the relationship. Olivia’s recognition of this may be inferred by her comment “…what did I know as a kid?” In this situation the parent/child dualism exposes a taken-for-granted cultural assumption that children do not know and parents (adults) do. From this social construction, children are required to acquiesce to parents’ moral authority and make decisions only with their parents’ permission. Yet Olivia exerts agency in a situation in which she appears to have little. Although she experienced her situation as chaotic and unsafe she acted to prevent further potentially harmful outcomes knowing full well there could be reprisals for her. Thus, her act can be seen as one of courage and strength in the face of adversity, as well as a resistance to her father’s moral authority as a parent. By association, Olivia’s actions can also be seen as a resistance to the medical authority of the doctor and the possible effects of the medication prescribed to alleviate her father’s symptoms.

From this perspective, the dualism of parent and child can be viewed as having diffuse boundaries. Parents are not always all-knowing and all-powerful. Children are not always subordinate, powerless and lacking knowledge. Sometimes, power becomes diffused between them. Considered in this way, there is potential for movement between the two polarised positions so that both parent and child are recognised for having power and agency. As McAllister (2001) argues, an inter-subjective connection between the two
where they came together in a connected relationship could diminish the isolation each may feel. Both may learn from the other.

There is also a moral to Olivia’s tale. Her explanation for crossing the traditional parent/child boundary and taking control was that “maybe because I knew that he shouldn’t be”. Her comment implies a moral judgment – parents’ actions have an impact on children and therefore children have a right to judge them. With power comes responsibility and accountability. Olivia exerts her own moral agency by attempting to correct her father’s perceived wrong. As the child of a parent with serious mental illness, Olivia may be considered to have had her narrative identity ‘damaged’ by being part of a less powerful social group (COPSMTI) which has traditionally not been accorded full moral respect (Nelson, 2001). Yet her act of resistance can also be viewed as resisting diminished moral agency and providing a narrative ‘repair’ which adds to a counter-story of COPSMTI that has the potential of commanding greater cultural respect.

7.4.3 Apparent silences and endings

Within Olivia’s story there is also a curious silence. She makes no mention of her mother or her siblings. Theirs are the voices in the margins of this story. She does not say what, if anything, they were doing or saying during this situation, although they were all in the car. This is a significant silence. As Charmaz (2002) contends, such silences are not completely individual; they emerge within social, cultural and historical contexts. It may be that her mother and siblings did or said nothing. Or it may be that Olivia was concentrating on her own experiences, and therefore did not remember or recount what they did. But her silence about them raises some questions. What is the role of the other parent when the parent with serious mental illness behaves in unsafe ways? What is it like to have a partner who has a serious mental illness and insists on doing things which may be harmful to the family? Do siblings all experience their parent’s behaviours in the same ways? We might wonder too why the doctor has prescribed a medication that appears to produce adverse effects, or why it appears the family is dealing with this situation alone, without other family or professional help or support. Recognition of these silences serves
to bring marginalised others and previously concealed issues into the centre of the story, and in doing so, provides potential for them to be acknowledged and further explored.

Olivia’s story also has an incomplete ending and its overall narrative tone is one of pessimism. What will happen now? The ending suggests an uncertain future for all involved. Her father will probably continue to behave unpredictably, and she will therefore probably continue to find her situation frightening and chaotic. Yet as McAllister (2001) reminds, stories are not actual experiences but simply an account of them. Olivia’s act of agency suggests there is the potential for another kind of ending. This seemingly straightforward account is multi-layered. All may not be what it seems (Poirier & Ayres, 1997). Olivia’s small act of resistance provides the possibility for further acts which may alter the trajectory of her future. Nothing is yet determined. This reading of her story reveals that even the bleakest of futures for children and adult children of parents with serious mental illness has the possibility to be re-written if they can be supported in re-framing them.

7.5 STORY 3: LITTLE BO PEEP

This story particularly illuminates metaphors and images that may hold potential for re-framing the experience of being ACOPSMI. Prior to the following story, Marnie had been explaining to me the course of her mother’s illness over time, and had described the treatments her mother had been given for her schizophrenia, including electroconvulsive therapy and psychotropic medications. Marnie explained that although her mother was able to go to work as a schoolteacher during the day, due to the effects of her medications she needed to sleep for long periods when she came home. She then told me this story:

She was in and out of hospitals all the time. And then we had a really good reign, like we’d see that she’d go a bit off, but you could manage her at home, and then, oh that was the hardest thing that I ever watched in my life, when they changed the medication. She was as crook as. It was hideous. Like she’d be playing the piano, dad had these really important papers that needed signing and it took him a month to get the paperwork, and I said to him, ‘dad I don’t know why you’ve still got her doing any guardianship, any legal
stuff’, ‘cause, you know, she’s not of sound mind’. So he finally gets this paper and he sits down and he gets mum to sign the paper and she signs her signature ‘little bo peep’, and dad nearly killed her. Oh he was so angry ‘cause it had taken him so long to get it. Well he’s told me, and I was of no sympathy at all ‘cause I thought it was the most hilarious thing, and it’s about a 2 mile walk for me to walk home and so I was walking down the hill, and I’m thinking ‘anybody driving past will think this woman needs locking up’, ‘cause I was rocking I was laughing so much, and I’ve got tears pouring down my face thinking, ‘cause she thought she was back in the classroom, and I thought it was hilarious - ‘little bo peep’ - so there’s some funny things along the way. A black comedy definitely.

7.5.1 Conventional readings

Marnie’s story clearly evokes the episodic and unpredictable nature of serious mental illness. It reveals that living with a family member who experiences frequent shifts in their contact with ‘reality’ can be a disturbing and frustrating, albeit sometimes humorous, experience. The effects of serious mental illness can also be exacerbated through changes to psychotropic medications such as antipsychotics. As their name implies, these medications are designed to reduce rather than exacerbate symptoms, but changes to type, dose and route of administration can result in relapse and short-term worsening of psychotic symptoms (Therapeutic Guidelines: Psychotropic, 2003). The conventional meanings in this story therefore confirm a cultural narrative that people with serious mental illness often lack agency and can be incapable of making rational judgments, hence Marnie’s use of the metaphor that her mother was “…not of sound mind”. There are also, though, other meanings to be found in Marnie’s story.

7.5.2 It’s a black comedy? - Metaphors and meanings

Marnie paints a vivid and humorous picture with her story, and her metaphor of a ‘black comedy’ seems an apt description. It is not difficult to picture her laughing until she cries at the absurdity of the situation – both that of her parents and then her own as she walks home down the hill. A ‘black’ comedy though is one that contains dark and possibly tragic aspects from which humour is then derived. The effects of Marnie’s mother’s
mental illness on her capacity to comprehend what was required, and her father’s anger and frustration with his wife’s continued inability to respond to his needs, can be seen as one of the ‘tragic’ elements of life with a person who has a serious mental illness. There is evidence that families where parents have a serious mental illness experience high levels of emotional and practical burden due to these kinds of daily frustrations (Marsh et al, 1993a). Goodall (2005), based on the work of Burke (1984), suggests that past events such as Marnie describes can be viewed through tragic or comic lens, but only a comic perspective will enable the person to survive or rise above the situation. Indeed, having a good sense of humour is considered a protective factor and can build resilience (McGrath, 2001).

Goodall (2005) found that applying the comic perspective to his own family situation enabled him to understand his family and his past in ways that de-pathologised both them and him-self. Rather than viewing individuals such as parents as being at ‘fault’, he saw it as possible to understand the situation as being one of a dysfunctional family ‘system’. Applying Goodall’s premise to families where parents have serious mental illness, Marnie’s comic perspective on her situation (rather than of her mother per se) has enabled her to frame it in a way that is potentially helpful for her and her relationships with her family. Rather than seeing the family as a dysfunctional system though, it may be possible to view their situation within the broader cultural context of mental illness as being stigmatized, with a concomitant lack of recognition and adequate social and professional support for families. From this construct, Marnie, her father and her mother can also be seen as responding ‘normally’ to an ‘abnormal’ situation. Through this lens, neither individuals nor the family as a whole is dysfunctional, but perhaps the situation where they have been left to manage mental illness without adequate supports, is.

The story also contains other metaphors. Marnie’s mother’s use of ‘little bo peep’ as her signature also holds meaning. It can tell us something new about her ‘reality’ (Ricoeur, 1976). Hers is a voice in the margins of the text, which, if Marnie as subject is de-centred, can be brought to the centre. The metaphor of the little shepherdess who has lost her sheep is an example of a cultural fairytale (Frank, 1995), and as such has broader social implications. This well-known nursery rhyme evokes images of youth and inexperience
but ends happily with the charming promise that that which is ‘lost’ can eventually be ‘found’. It offers hope. The bewildered shepherdess can be seen as an appropriate image that Mamie’s mother has used to illuminate her own predicament. As an adult and mother she is responsible for her children, but in experiencing shifts in her identity, at present she does not know how to guide them. Even though she is purportedly ‘not of sound mind’, such a metaphor holds the promise this confusion will be temporary. There is potential for her treatment to assist her in regaining her mislaid agency. This implies there is hope for her family as well. Perhaps all is not lost.

### 7.6 STORY 4: ELVIS AND I

This story illuminates the parent/child dualism and the postmodern motif of diffuse boundaries. It indicates the potential for alternate endings if dominant views are resisted. The story is the middle of three connected stories told by Nancy Rose at the beginning of our conversation, when she was explaining to me what it had been like growing up with a mother with schizophrenia and the delusions her mother had had when Nancy Rose was growing up:

Like I remember her telling me that her and Elvis were together. I just remember thinking, ‘that’s bullshit’. That’s just **absolute** bullshit, and she’s going ‘yeah, yeah, and you know he postponed one of his shows so that he could be with me’ and, ‘all the other fans got really angry, because he wasn’t doing the show, but that’s because he wanted to spend time with me’, and I was like, ‘well when was this mum? She’s like’ oh, maybe a couple of years ago’. And I was like, ‘but you’ve been married to Dad all that time, when did you go? She’s like, ‘oh well’. I was like ‘well when was this mum? She’s like’ oh, maybe a couple of years ago’. And I was like, ‘but you’ve been married to Dad all that time, when did you go? She’s like, ‘oh well’. I was like ‘that’s crap, that’s so not true.’

It’s weird looking back because I remember simultaneously thinking that’s so not true, but also knowing that she believed it. So I knew from a fairly early age that there was something definitely **weird** about her, and that, you know, that she wasn’t sort of quite right, but I also knew that I sort of had to act to her as though I did believe her otherwise it would, you know, not be good for her. I sort of knew, like I had insight into that from a really early age. I don’t know how that came about. I think that just sort of ended up doing two things; it sort of made me more independent in one way, because I was always felt like I was looking after her and I knew that if Dad wasn’t home that I could basically
do what I wanted, but it also ended up meaning that I would sort of take advantage of her at times as well because if Dad wasn’t home then I really would do what I wanted and she would sort of try and tell me what to do sometimes and I would be like, ‘there’s no way that I’m listening to you’. I just knew that she didn’t have any authority over me cause I just felt that she didn’t sort of have it together so there was no way that she was going to tell me what to do. I would trust dad, but that was all.

7.6.1 A conventional reading

This story can be understood as a typical one of the loss of parenting authority and roles through the chaotic effects of mental illness. It can also be read as an example of the risk to the child’s cognitive constructions of reality when a parent is experiencing psychotic symptoms. This ‘folie a deux’, where the child may also come to believe the parent’s irrational beliefs, has been recognised as a potential risk for children of parents with a psychotic mental illness (Anthony, 1969). Nancy Rose’s story also reveals the uncertainty and sense of responsibility children can feel in their daily life with a parent experiencing serious mental illness (Marsh, 1993a). It confirms the cultural narrative that parents with serious mental illness can struggle to effectively fulfill their parenting roles.

7.6.2 Attending to alternate readings

This is also a story with multiple dualisms and a diffuse ambivalence. The motif of marginality is a feature of postmodern narratives (Roof, 1993) and children of parents with mental illness have been considered a marginalised group (Foster, O’Brien, McAllister, 2004/5). Ambivalence is a common quality of such stories (Roof, 1993), and in this respect, can be viewed as one of potential. Nancy Rose says “…I remember simultaneously thinking that’s so not true, but also knowing that she believed it”. She is both contemptuous yet protective of her mother and views her experience as ‘making’ her do two things – become more independent whilst also becoming less respectful of her mother’s authority as a parent. Her story also contains the dualism of ‘good’ parent (in this case her father), and ‘bad’ parent (her mother). In the role of ‘good’ parent her father remains the privileged and favoured one, who, by virtue of not having a mental illness,
has been cast in the role of ‘saviour’. His is the only voice Nancy Rose will listen to. She becomes the ‘good’ child (respectful) with him and the ‘bad’ child (contemptuous) with her mother. The risk of such rigid and hierarchical positions is that her mother, father and Nancy Rose each remain fixed in their respective roles. The potential is the recognition that neither parent is ‘good’ nor ‘bad’ but has positive, negative and neutral qualities, regardless of whether they have mental illness. If COPSMI can be supported to understand mental illness and to respect their parents whether they have such an illness or not, they may develop fuller and more satisfying relationships with them. Indeed, later in her life story Nancy Rose commented on how, once she had been informed of and understood her mother’s illness, she was able to develop a closer and more respectful relationship with her. Instructively, she also expressed strong guilt and remorse for her previously disrespectful behaviour which had been based on ignorance of her mother's mental illness.

7.6.3 Resistances and endings

Nancy Rose’s story also reveals the diffuse boundaries that may exist between ‘reality’ and ‘unreality’. Yet she resists her mother’s adult authority and questions her assertions, challenging her apparently irrational beliefs. As her story suggests, COPSMI can be assisted by health professionals and other supports to develop a greater sense of agency and respectfully resist an unquestioning acceptance of parental beliefs when there is potential for harm/distress to the child.

Her story moves on to end in an apparently negative manner. Nancy Rose only trusts her father. But as this reading has uncovered, this was not a fixed ending. There was the potential for Nancy Rose to develop a greater understanding of her mother’s illness, and therefore her mother. Her life story went on to demonstrate this, and the meanings in her small story can be understood as existing within the temporal flow of her overall narration (Ricoeur, 1984).
7.7 STORY 5: THE PINK PARTY DRESS

This story illuminates further postmodern motifs of de-centring the subject, and how resistances to dominant views may lead to alternate understandings. It is one of my own stories of living with a mother who had paranoid schizophrenia, who throughout my childhood was also preoccupied with dirt and germs. I was about 5 years old at the time of this story. It is one of the relatively few memories I have from childhood. It is also one of the family stories occasionally referred to by my mother, where, with a shake of her head and in a mildly disproving tone, she jokes about what a naughty child I was:

I remember one time when I was about five where I’d gone to a birthday party and my ‘good’ pink and white party dress had got chocolate on it. I hid it right down the back of the wardrobe hoping she wouldn’t find it because I knew I’d be in a lot of trouble if she did. Of course she did eventually find it and I still recall the force of her anger as she stood in front of me with the dress, saying “Look at it. Look at these marks! They’ll never come out. You’re a naughty girl Kim”. My sense of guilt and shame were huge. I told her I’d be good and promised not to get the dress dirty again. Then it was as if everything went grey around the edge of my vision, and I fainted. Apparently I did that more than once, my mother told me later, although I only remember this one time. I can remember coming around after fainting, and lying on the couch with a blanket over me and having a really sore chin, because apparently I went stiff as a board and fell on it when I fainted. My mother asked me whether I was awake now, and told me the doctor said I did this just to get attention. She was still annoyed with me, but at least she’d stopped yelling and was looking after me and letting me lie on the couch for a while, so I did feel better.

7.7.1 Conventional readings

This story can be read as one of a ‘powerful’ parent standing over a frightened child. Being a child of a parent with serious mental illness can be frightening when the parent is mentally ill (Marsh, 1993b), and these parents can be experienced as omnipresent and omnipotent (Dunn, 1993). There is also evidence that children of parents with schizophrenia in particular may have an increased rate of anxiety disorders (Hans,
Auerbach, Styr & Marcus, 2004), and triggering events can lead to fainting and associated falls in children with anxious characteristics (Naschitz et al., 1998). Thus, the story can be seen to confirm a cultural narrative that having a serious mental illness can impair parents’ ability to provide positive care for their children. In this story too, parent/child dualisms are again evident. I am the ‘good’ child when I keep my clothes clean and ‘bad’ when I don’t. My mother is the good parent when she looks after me and ‘bad’ when she yells at me.

7.7.2 Evoking cultural fairytales

This small story can also be seen to evoke a well-known cultural image of the ‘wicked witch’- an ‘evil’ female character common to a number of well-known fairytales; the malicious witch in the Wizard of Oz, the jealous stepmother in Snow White. Through this inter-textuality the plot appears to be of tragedy - there is a villainous antagonist and a victimic protagonist (Polkinghorne, 1996). It may evoke sympathy for the child’s plight. But perhaps this is not the only interpretation to be found. My fainting, which effectively ends my mother’s castigation, also succeeds in gaining positive attention from her. From another lens, this could be seen as an act of resistance on the child’s part. It reverses the power within the parent/child dualism. I have found a way out of my troubles, and not only that - my mother looks after me and calls the doctor to check on me. From this perspective, can the story still remain that of a victim succumbing to the villain’s power? Like the character of Dorothy in the Wizard of Oz, have I found a way to protect myself from danger? In looking after me, is there another face behind the apparently ‘wicked’ one of my mother’s?

In de-centring my-self as subject, my mother’s voice can be brought to the centre. What was it like to have a serious mental illness and parent a number of small children with little support from health professionals? How much did my and my siblings’ behaviours and problems impact on her own health? There is some evidence that COPMI’s behavioural and psychosocial problems can negatively impact on their parents’ health (Rutter & Quinton, 1984).
This story, told through the lens of the adult child, can be seen to shed light on a number of issues. Children of parents with mental illness may not always be powerless. Parents who are perhaps struggling with their role may behave in ways that are nurturing and supportive as well as potentially detrimental. Parents and children are neither all good, nor all bad. Nothing is irrevocably determined.

7.8 STORY 6: WHO AM I?

This story particularly illuminates disunity and the diffuse boundaries that may be seen in postmodern identity. These may be helpful in re-framing the experience of being ACOPSMI. In the opening statement to his life story Eccles told me he was, even now, the survivor of child abuse by both his depressed parents, a theme he repeated throughout subsequent small stories. Eccles spoke of his parents’ inconsistent and unpredictable behaviour and their life-long concern with maintaining family privacy and a ‘respectable’ public persona, often at the expense of his and his siblings’ wellbeing. Throughout the stories he went on to tell, Eccles repeatedly referred to a literally and metaphorically ‘isolated’ childhood in which he often felt “…like a fish out of water”. In the middle of telling his life story, Eccles told three detailed and connected stories about his generally traumatic and unhappy schooling experiences during which his parents were quite unsupportive when he was sent away to school from his remote family location and bullied by schoolmates and became depressed. Then prior to the following story he told me about his parents’ marriage, which his mother had defended as being ‘alright’ even though they had been living apart for 40 years. He then shifted back to tell me what life was like for him after he left school:

And then, do you know what happened? - going back to myself as a teenager and having a couple of disastrous jobs - almost the day I turned 17 I bought an old car and drove myself down to [names city]. I couldn’t get out of there [home] bloody soon enough. And I actually stayed with my grandmother, my mum’s mum. And she was sort of quite an oasis in my sea of turmoil, because she was kind and gentle and understanding and I could even talk to her and she even sounded like a normal sort of rational human being. She had quite a positive influence on me. But unfortunately even when I got to [the city] it was still the same old round of dead end bloody hopeless jobs, and I still couldn’t find a
niche for myself, and I was still just so hopelessly muddled up in my thinking. I sort of now wonder how I even worked at all, because I couldn’t concentrate on anything, especially my work, and I was always sort of drifting off into still this endless task of trying to make sense of my world, and some of the time thinking black was white and vice versa, and no wonder I just couldn’t really get my head into work, because I was still so hopelessly mixed up.

I doubted my own knowledge and doubted my own essence, my own – like I say - my own place in the world. Even my identity – like “who the hell am I really?”, you know. As I sort of said to my counsellor, the only way my parents probably would have been remotely pleased with us would have been if we all four of us grew up to be as near as possible carbon copies of them, which is a pretty sick sort of a thing to say, but that’s still my sort of reading of it, and all this business about, you know, “yous are all a bunch of no hopers”.

7.8.1 A conventional reading

Eccles’ story of difficulties finding a path in life, making sense of the world, and in determining what was real and what was not can be read as a typical account of someone who has experienced childhood abuse. Repeated derogatory statements to a child such as ‘yous are all a bunch of no hopers’ can be considered a form of emotional abuse (Tomison & Tucci, 1997). It is perhaps not surprising that as an adult Eccles was experiencing difficulties with a sense of agency and his self-identity. Childhood trauma and abuse can result in unfocused responses to later stress (van der Kolk, 2005).

7.8.2 A diffuse identity

Self-identity is a process of constructing meanings from personal experience in the form of narratives that include understandings which give form and structure to people’s lives (Polkinghorne, 1996). Eccles encapsulates his confusion about himself and his role in life when he says “…who the hell am I really?” A diffuse self-identity is not unusual for survivors of child abuse (Lowenthal, 2002). Through the inter-textuality of the metaphor of being “…a fish out of water”, Eccles evokes his sense of dislocation and separation from others in his world. His is not a stable identity.
Yet a fractured, diffuse self-identity such as he describes may also be considered part of the postmodern condition (McAllister, 2001). In postmodern times the self has become de-stabilised and saturated with multiple voices. It is in a continual state of construction and re-construction (Gergen, K., 1991). Situated within socially constructed language, the ‘self’ therefore becomes a process of narrative invention (Gubrium & Holstein, 1994). The apparent disunity Eccles is experiencing in terms of ‘self’ and his relation to others can be understood as a temporary state which acknowledges difference and offers potential opportunity for change and growth. He, like other survivors of abuse, could be supported by health professionals to work through his identity confusion rather than see it as a weakness or an insurmountable problem.

7.8.3 Victimic and agentic life plots

In this story, evident throughout Eccles’ overall life story, the plot contains victimic elements. Polkinghorne (1996) explains that in this type of plot the protagonist considers themselves as powerless and re-presents their life as being out of control. They are oriented more towards negative than positive possibilities, and view their life as having been shaped by others’ (such as parents) actions, which have determined their life’s outcomes. A victimic plotline can be considered as being analogous to the psychological construct of having an external locus of control.

Yet Eccles’s story also contains elements of an agentic plot (or internal locus of control), where protagonists overcome obstacles, have purpose and commitment, and are confident of achieving intended goals (Polkinghorne, 1996). Eccles uses the metaphor of “…an oasis in a sea of turmoil” to evoke the image of the soothing and healing influence of his grandmother, whose supportive presence acts as a protective factor against the risks of his childhood (Werner, 1995). A further agentic aspect of his story is Eccles’ reference to having a counsellor. This can be read as a form of resistance to the victimic role. Despite his seeming passivity throughout much of his account, at the age of 57 Eccles was attempting to work through his traumatic experiences and strengthen his ability to determine his life outcomes. Polkinghorne (1996) argues that narrative identities are not fixed and can be changed throughout life. Health professionals can assist individuals who
may have victimic constructions of their past to transform these to more agentic life plots. Therapeutic endeavours can support the person through a series of phases in a move toward adaptive actions which facilitate their life goals. In this way, adult children of parents with serious mental illness such as Eccles can also be assisted by counsellors and health professionals to transform their experiences of trauma into more positive trajectories.

7.9 STORY 7: THE BREAKDOWN

In this story the silences and potential for alternate endings is particularly illuminated. These can suggest further issues to be considered in such experiences. This explanatory story is the middle in a sequential series of scenes Sue narrated which focused on what she referred to as her ‘biggest pain’ during childhood – her father had left the family when she was 10 and divorced her mother. Her mother had then spent the rest of Sue’s childhood saying negative things about him and telling Sue that her father didn’t love her. Sue had acknowledged throughout her life story that as an adult one of her most important goals had been to be re-united with her father, and at the age of 32 – the time of this story - she had finally been able to organise a trip overseas to meet him again.

Immediately prior to the following story Sue had set the scene by telling an initial story of her mother coming to stay with her just before her overseas trip, and that one night in the kitchen her mother had again made negative comments about her father. Sue explained that for the first time in her life she had become so enraged by her mother’s comments that she thought she might physically harm her and stab her with the knife she was holding at the time. Sue had then asked her mother to leave the house, but she refused to go. After a heated argument Sue eventually called the police. Her next story begins here:

Anyway, she must have overheard the phone call and she came to her senses and agreed to go the next morning, so the drama blew over. But we ended up having to delay the trip… I got so sick that we changed it all… And actually, she still couldn’t stay out of it. She went to the caravan park, and then from there she rang my GP. I took myself to my GP… and asked for sleeping tablets, and this female doctor was so bloody nasty. I was
really angry with her—she refused to give me the sleeping tablets. I was quite sure that all I needed was sleeping tablets so I could get myself packed and get out of here! Looking back on it, she was probably right, I needed more than that. But anyway, I was angry with her too because she didn’t give me what I wanted and referred me on to a counsellor… I said no, and we were heavily involved with the Catholic church and there was a priest there I was really close to. I went to see him and just happened to tell him…and I mentioned the name of this counsellor, and he said ‘look’, he said ‘you go and see this lady ‘Janet’, she really is very good. I know her very well’. And she’s also a medical practitioner, but she’s just brilliant, absolutely brilliant. She came into the house and just made herself a part of my life, and we’ve been the firmest of friends ever since. I think without that one person who really was able to just, I don’t even know what kind of counselling she did really, it was just ‘I’m here. Whatever the hell you’re going through, I’m jumping in this boat with you, and let’s go, we’ll do it together’, and that was the feeling that you got…and so we puddled through it together… eventually, two weeks later I got to leave, so yeah.

At the time Janet kidded me along and told me that it wasn’t a breakdown, but now, basically I was in a breakdown state for 3 days. It led straight into a depression which I carried with me overseas to visit my father – that’s the regret – the reason why my visit with him was not what I had dreamed for so long that it would be, I wanted him to get to know a happy daughter. At the time of the breakdown I was seeing things and not making sense, not to other people anyway. Made a lot of sense to myself, and when you’re there on that edge it really feels real and you know that everything you can see and everything you can hear is so loud and so clear you really believe. For me the whole experience of having that breakdown was very real and very clear. Right or wrong, no matter what anybody else believes, I was very much in touch with my God at the time and really felt very strongly of his presence right there. But I might not have felt that if Janet had not been there, because part of her practice actually involves using religion …so we did a lot of praying together and things like that. She helped me get to a point where I was physically rested enough to be able to pack my bags and go overseas on this ‘journey of my lifetime’… It was more that just a goal – it had become my “scary dream” – my biggest challenge in life – ‘Would I ever get there? Would I ever find him and be with him again?’…

When I look back, because of that experience when I went there I was ill and my father could see it in my face. Although he hadn’t seen me for twenty two years and didn’t know me, he knew when I got there that I was ill… So whilst it was a wonderful trip and
I enjoyed it. I’d have to say for me there was a flatness to the experience. It was about the fact I think that I’d worked so hard all my life that my biggest goal in life was to see my father and there I was, I’d worked hard at just being fit and healthy and attractive looking when I went over there, and then she came up and did that. I was skinny and tired and bags under my eyes, and I knew I hadn’t presented the physical image to my father that I wanted to present, you know?

7.9.1 Postscript

In the connected story immediately following this, Sue acknowledged that after the incident with her mother, her trip overseas to meet with her father, and then a lengthy period of estrangement between her and her mother, they were able to reach a new kind of relationship which was much more ‘courteous’. Sue had become firmer about what she would and would not accept in terms of her mother’s behaviour. Sue also identified this as the point at which “I finally grew up, and I could call myself an adult.” She then explained that the incident with her mother had been a pivotal point in her life.

7.9.2 A conventional reading

Sue’s story is one of confusion, disruption and sadness. There can be a strong sense of loss and grief for children when a parent leaves the family, and Sue’s parent’s marriage breakdown is not unusual for families where parents have a serious mental illness. Marital conflict and potential for marriage breakdown is common in families where a parent has serious mental illness (Rutter & Quinton, 1984). Sue’s story also reveals that a parent’s serious mental illness may not be the only or even main concern for COPSMI. There is evidence that the risk of developing psychosocial problems when a parent has serious mental illness is more likely associated with related psychosocial disturbances in the family such as parental hostility and aggression, than with the effects of the mental illness itself (Rutter & Quinton, 1984).
7.9.3 A ‘scary dream’

In her use of the ‘scary dream’ as a metaphor for her lifelong goal of meeting her father again, Sue vividly evokes her ‘reality’ at the time. Yet dreams are also constructions and so they hold the potential for re-construction. With support, A/COPSMI such as Sue can be assisted to re-construct ‘scary’ into ‘exciting’ dreams and the “…journey of a lifetime” may become an adventure odyssey rather than a ‘do-or-die’ quest.

7.9.4 Attending to the silences

Sue’s apparent psychotic breakdown and experience of what appears to be visual hallucinations can be seen as an example of a diffuse boundary between her own brief experience and her mother’s experience of psychosis. Her description of ‘seeing things’ and ‘not making sense’ are similar to her mother’s symptoms which Sue had previously described to me. Yet in her silence about this similarity she does not seem to have made the connection between her own experiences and those of her mother. Perhaps it had not occurred to her. If it had, perhaps she just did not say so. Perhaps, as Poirier and Ayres (1997) point out, her omission was a sign of her discomfort or avoidance of a potentially difficult issue. If Sue recognised the commonalities between her experiences and those of her mother, would she need to revise her perception of her mother’s control over her behaviour? In saying “…when you’re there on that edge it really feels real and you know that everything you can see and everything you can hear is so loud and so clear you really believe…” she is acknowledging that psychosis can be as ‘real’ to the person as others’ ‘reality’ is to them. How is she to reconcile this with her perception of her mother as being deliberately manipulative? The potential in Sue’s apparent silence is that developing understanding and empathy with a parent’s experience of mental illness may require adult children to acknowledge their parent’s point of view and perhaps re-construct their own life scripts to accommodate this.

Sue does, however, reveal her resistance to her mother's silences and negative constructions of her absent father throughout this and other small stories in her life story. Sue’s quest to find her father can be read in part as an attempt to develop her own
construction of, and relationship with him, which was not mediated by her mother’s negative frame. The term narrative inheritance refers to stories such as these that are told to children by and about family members (Goodall, 2005). Stories that are narratively inherited provide a lens through which the child subsequently constructs their own identity. Sometimes, as in Sue’s story, children inherit incomplete narratives by and of family members which fail to tell the fuller story and contain lies, secrets, omissions, distortions or silences. These ‘toxic’ stories may be passed on to future generations, replicating the distorted storyline to subsequent family members (Goodall, 2005), and thus continuing the potential to affect future identities.

Previously in her life story Sue had told me she found documents which had passed between her mother and father and revealed alternate stories to those her mother had told throughout childhood. The papers provided evidence that countered many of her mother’s negative claims about her father. This uncovering of her mother’s silences, distortions and possible untruths about her father can be seen as contributing to Sue’s narrative repair of her toxic inheritance. Sue’s resistance to her mother’s influence and her subsequent trip to meet with her father also assisted her in part – because we can never know the whole – to narratively re-construct a new understanding of his, and perhaps therefore her own, identity.

In families where parents have serious mental illness, silences on mental illness, abuse, violence, and other toxic secrets can be countered with a resistance to maintaining them. A narrative culture of speaking about what may have been considered previously shameful secrets can mitigate inter-generational legacies of shame, guilt and loss. Sue’s story also shows that provision of professional counselling which is approached from an attitude of providing support rather than being the ‘expert’, can be most therapeutic.

### 7.9.5 A disorienting story

The notion of a ‘break’ between the past and present is repeated in various ways throughout Sue’s story. She speaks of her own ‘nervous breakdown’ and of her parents’ marriage breakdown. The incident with her mother can be seen as a ‘breaking point’ in
their relationship. From one perspective, the ‘break’ with what has previously been so – in Sue’s case, her break with reality, and the breaks within the marriage and the parent-child relationships, could be viewed as negative events. They speak of change and disruption. This rupturing between old and new has the potential for pain and distress, which Sue depicts. It also has the potential for new and possibly improved situations, which Sue’s story moves on to reveal.

Ruptures in personal experience can entail the abandonment of one life script for another. Sue has told a series of disorienting stories of shattered hopes and relationships. Her life story has been disrupted through these ‘breaks’ in its continuity. Typical of a postmodern tale, it is situated amidst three connected stories and does not have a clear beginning, middle and end. Yet the potential in Sue’s story is the opportunity to re-script her life (Roof, 1993). Out of adversity has come new hope. The ending to Sue’s story, whilst apparently negative “…I knew I hadn’t presented the physical image to my father that I wanted to present, you know?”, also contains a concealed story. She has triumphed over her mother’s negativity; her own mental ill-health; the previous lack of relationship with her father; and gone on to achieve her lifelong goal to meet him. She went on to achieve a new relationship with her father, her mother, and perhaps more importantly, her-self.

7.10 STORY 8: SINK OR SWIM?

Dualisms and metaphors are particularly evident in this story. These may offer fresh understandings of such experiences. Prior to telling me the story, Nancy Rose had been explaining that she had seen her experience of growing up with a mother with schizophrenia as being a “…good thing…” and that she felt she had gained a lot of strength from it which she used in various ways in her life. Certainly Nancy Rose’s positive demeanour and activism in the area of COPMI was evident throughout her life story, which I had regarded as particularly resilient. As with all the participants with siblings, during our conversation Nancy Rose had also spoken about her brother and sister and how she considered they had managed the experience of having a mother who was psychotic. Towards the end of our conversation she was musing about why some
people coped differently with their experience. She said for her it had been a case of “…sink or swim…” She then told this story:

Like, my brother is a perfect example. Even though I do recognise that he had a harder time than me because he was the oldest, and also, I was lucky in that I’ve generally always been pretty smart so I did well at school and I had that as my thing…I was going to do well at school and go onto to uni and I’d do this and that’s what I did. But my brother, he’s generally not that intellectually smart and so that in itself made it a little bit harder for him and he’s just the complete opposite to me. He just sees everything that happened as this terrible thing and it’s just awful and it’s still there and you know, any little thing that mum does that’s slightly weird when he goes round there…he’s still just really dwelling on it…And when I told him I did that speech [on her experience as a COPMI] …I told him and said ‘this is what I’m giving the talk about’ and he sort of said ‘well I could talk for ages about that, rah rah rah’. And I said ‘well I’m really trying to focus on the positives’ and he just laughed and he thought I was joking and he said ‘what are you talking about? What positives?’ And I was like ‘no, I’m serious. The positives’ and he’s like ‘what positives?’ He just had really never considered that there were actually positives…you know, learning to deal with difficult things, being independent. It had really never occurred to him before to see it as anything but this really horrible negative thing and that made me think ‘wow, I really am lucky that I’ve been able to do that because it’s one thing to be able to choose, but how do you choose to be able to choose?’ He just didn’t know. He had no idea that he could choose and he still doesn’t, even though I said that to him and spoke to him about it he’s still gone back to the way he was because that’s sort of the only way he knows how to deal with it and his way of dealing with it is more ‘oh it was terrible, this horrible thing that happened is my excuse for everything’. Sort of a real victim mentality which is I think how some people deal with it but really just leads you down. There’s no sort of avenue out of that.

7.10.1 A conventional reading

This story clearly describes the multiple perspectives and experiences that siblings within the same family may have about the same issue – having a parent with serious mental illness. It illustrates the important point that being a child in the same family does not guarantee the same experience. As Nancy Rose acknowledges, there is evidence that
some children, by virtue of their birth order, gender, and/or personal characteristics such as level of intelligence, degree of optimism and type of temperament, may be more or less protected against the potential risks of having a parent with serious mental illness (Rutter & Quinton, 1984; Seligman, 1995; Werner & Smith, 1992). It has been found that negative parental behaviours can be focused more on some children than others in the family where a parent has serious mental illness, and that boys with more ‘difficult’ temperaments may be more susceptible to adverse outcomes than girls (Rutter & Quinton, 1984).

7.10.2 Sinking, swimming, and treading water?

From the perspective of outcomes, Nancy Rose uses a number of metaphors to explain her understanding of the differences she perceives between her and her brother’s responses to their experiences. In explaining her own attitude, she says it was a case of ‘sink or swim’. This image of drowning versus surviving is both a metaphor and a dualism. It is a common cultural expression of triumph or defeat through adversity. In also using the metaphor of her brother as having a ‘victim mentality’, Nancy Rose draws the analogy further. In her opinion she has survived the experience, been resilient, and flourished. He has not. One third of children where parents have serious mental illness have been found to experience enduring psychosocial problems, and an additional one third may have short-term difficulties (Rutter & Quinton, 1984). Yet, as Falkov, Mayes, & Diggins (1998) also acknowledge, these children can move between various levels of risk over their lifetime. Just because a child or adult child appears to be ‘sinking’ at present, does not necessarily mean this is the case forever. Extending Nancy Rose’s use of the metaphor, it is possible that rather than being an either/or situation, COPSMI may shift between ‘sinking’, ‘swimming’, and simply ‘treading water’ at various stages throughout their life. This construct implies there is still potential for Nancy Rose’s brother to be supported to move towards a more agentic frame for his experience.
7.11 STORY 9: IT’S NOT A DEATH DRINK

This story emphasises the multiple meanings, resistances and potential for alternate endings that may be evident from such an experience. They may provide useful alternatives for others to consider. Of all the participants’ life stories, Jane’s had particularly struck me as being one of deprivation and difficulty; she had vividly recounted episodes of violence, abuse, troubles with the law, and financial hardship. Hers was the life story that most troubled me. At times I had found it emotionally distressing and difficult to transcribe, perhaps also because some of her life circumstances resonated with my own. Yet during her interview I was struck by her determination to overcome her many apparent adversities. In addition to telling her mother’s story of bipolar disorder and substance dependence, and her father’s story of alcohol dependence, Jane had also spoken of her personal difficulties with alcohol and drug abuse and how she had deliberately chosen to stop drinking after the birth of her second child. Towards the end of our conversation, she then told me this long and complex story:

But I would say, to give credit where credit’s due, I would say that having my children is what’s kept me going. Having **them** there, and looking at them and going, ‘well I’m not going to be the same [as my parents]. I want to be better than that’. And I modelled myself on not being like my mother, and knowing that even for all the bad that has been in both of them that there is good in them too, and trying to find it, and picking it out and claiming **that** as my own. I’m like my mother because of **this** reason, and forgetting about all the other reasons, and the same with my dad.

…When I stopped drinking, that was it then. ‘I’m **not** going to be like that’…‘cause after I had my second child, six weeks I think, I went into just a little bit of postnatal depression. Not very much. Closed all the blinds, stayed inside, just didn’t want to talk to anybody, just wanted to be left alone. But I didn’t have any deep-seated sadness or anything like that, or feel I couldn’t cope…I didn’t know about postnatal depression. After a couple of weeks I was feeling a bit freaky, like this is not right, this is not me. And so I went to the doctor and he said to me ‘is there any depression in your family?’ and I said ‘yeah my mum’ and he says ‘well, probably by the age of 30’ he said ‘you’ll be right there and you’ll be getting it and you’ll be feeling the symptoms and it’ll be coming on’, and I looked at him and I went ‘I don’t think so’. And he says to me ‘well, you can’t
choose it’. I smiled and said ‘I can choose’. I said ‘I can damn well choose’. I said ‘I won’t allow myself to slip into that way of thinking, chemical imbalance or no chemical imbalance’, you know what I mean? I will look at one thing **every** day that I’m grateful for. I mean I don’t feel good every day, I feel shit some days, and I look out there and I’ve got a beautiful place to live, I’ve got food on the table, I’ve got great kids. Now, I’m not slipping nowhere. But I was really pissed off at him to put that thought in my head. I was **really** pissed off with him, and I thought that you shouldn’t just come out and **say** that to somebody, you know what I mean? Like, that’s not **fair**, that’s not, and then I went through this whole big thing about labelling people, and I’m like ‘whoa, yeah’, and I was like ‘don’t you call me that! Don’t you say that about me.’

As soon as he said that I was out of there. I’m like ‘thanks, see ya!’ And I’ve looked for alternative ways. And I still do alternative ways for everything. I believe in the universe’s energy and stuff like that…because I am catholic I believe in god, and I always search for something that is natural, because, I think too I was brought up catholic that I do believe in a higher power and I do believe that, regardless of what’s going on now, it’s all part of a bigger plan. Like, disease as well, I went through all of that. I might not even know and I might never know, or it might be to teach your children, or it might be because in the next ten years I’m going to get a job, you know, I don’t know why. But I know it’s for a reason, or it might be to make me who I am, and for me to teach people things.

I knew about the 12 step program and that was a good thing because you can just apply that in your own life, to do with anything… I went for the first year after I stopped drinking, because the fact was that the way I was drinking was a binge drinker…And I think because I’d been around AA [Alcoholics Anonymous] since I was 7 that it’s all programmed in me, whether I know it or not, and just the simpleness of it, without getting too complicated, because just all the clichés and stuff and it’s a very simple program, and it’s not hard to do…

What did I do? I learnt about the universal self, the power of. And I believed in it, and I believed in god obviously, and I mean you don’t have to have a lot of things that you do, you just have to believe on one of them strongly enough to know that there’s something better…So I think I was lucky because I had three things I believed in, and also I believed in myself as well, more so than probably anything else. And I knew I could do it, because taking the bad things out of the equation of my parents, and putting the good things, if there was no alcohol and no mental illness in it, they would have been fantastic parents, and a bit more education they would have been great, because without any bad
influences, you know, on paper their good points are like, you beauty. So, I knew that it was going to be alright for me. These choices have been an ongoing process, it didn’t happen in a flash of light, it didn’t come to me in a dream. It’s been an ongoing process of me being confident in myself and learning to deal with things from the time I stopped drinking. So that’s like 14 years, and I often think some days ‘how did I get to this point where I am at now?’ I don’t have one answer. It’s just been progressive, in the fact that I always look at myself. I always look at what I’m doing and make sure it’s for the right reasons. And make sure my actions don’t hurt anybody. It’s just all basic courtesy, you know…that I wasn’t taught, but as an adult, you know stuff. You don’t just go through life ignorant because your parents – well, some people do – because your parents were like that ‘okay well that’s what I’m going to be like’. It’s not right. You’re not your parents. You’re an extension of them, which doesn’t necessarily mean it has to be a bad one. You can gather up all their experiences and, put ‘em in a blender, add a pinch of salt, and it comes out sweet! It doesn’t have to be a death drink. And I’ve got a great sense of humour too! And that helps.

7.11.1 A pastiche of meanings

In many respects, this is a remarkable story. From a conventional reading, Jane has told a story replete with meanings. It can be challenging and difficult to overcome the negative effects of the past, and it is important to have support when attempting to do so. There is evidence that children of parents with substance abuse and mental illness (dual diagnosis) can be at greater risk of psychosocial issues such as depression and substance abuse through inherited biological risk as well as environmental factors such as disrupted parenting (Hegarty, 2005). In going to the doctor for treatment of her depression, Jane has also implicitly acknowledged the dominance of medical explanations for her symptoms which could then require medical treatment. In this respect, Jane’s story confirms a cultural narrative that the biological inheritance of vulnerability to mental illness is common for children of parents with serious mental illness.

There is also a dualism repeated throughout Jane’s story. The binary of good parent/bad parent is evoked when Jane says of her parents “…for all the bad that has been in both of
them... there is good in them too”. She returns to this at the end of her account when she says “…You’re an extension of them, which doesn’t necessarily mean it has to be a bad one”. As previously discussed, in the good/bad parent binary, the parent is cast in one of two roles. They are either ‘good’, or they are ‘bad’, or they swing between the two poles. There is no middle ground. Yet Jane’s story is unusual in the respect that she recognises her parents as having both positive (good) and negative (bad) characteristics which can co-exist together in a dialectical relationship. As previous stories have uncovered, parents are not one-dimensional and can have characteristics which warrant neither positive nor negative moral judgments.

7.11.2 Resistances and struggles

Jane also tells of her resistance to dominant explanations for her symptoms and her active resistance to being labelled and categorised according to the medical model. She rejects the passive patient role and deterministic explanation of having a ‘chemical imbalance’, and instead asserts power and agency when she argues with the doctor that she “can damn well choose” what happens to her. Frank (1995) proposes that in the modernist illness experience the obligation to seek medical care can be viewed as a ‘narrative surrender’. Yet in her story Jane refuses to surrender to the doctor’s medical explanations and treatment for her issues and thus her resistance opens the possibility for new meanings and new stories to emerge.

Jane also rejects the negative aspects of her parents’ biological and environmental inheritances through claiming only their positive characteristics to take as her own. She re-enforces this in her choice of metaphor at the end of her story.

7.11.3 The potential of metaphors and endings

Jane uses the metaphor of a ‘sweet drink’ rather than a ‘death drink’ to explain how she has positively re-constructed the influence her parents have had in her life. This marks a triumphant ending to her tale. She acknowledges this was a conscious choice, and thereby implicitly suggests that she could well have made other choices, such as assuming her
parents’ negative attributes and thus, a passive acceptance of her fate. This implies a very different potential ending for her tale, which could just as easily been those described by Frank (1995) as being ‘chaos’ and/or ‘restitution’. Instead, Jane’s story can be seen to contain elements of what Frank (1995) identifies as the ‘quest narrative’ - a hero’s journey where the protagonist who has suffered tells of a search for alternative ways of being ill and then seeks to use their experience in the belief that something can be gained from it. In Frank’s (1995) view, this type of narrative structure affords the most distinct voice for individuals and foregrounds their experience from their own perspective rather than that of dominant cultural narratives such as medicine.

Jane’s quest for alternatives can be instructive and adds to the counter-story of being an adult child of a parent with serious mental illness. Her story shows us that adult children can have agency in their experiences, and do not have to passively acquiesce to dominant cultural views of their situation. Similarly, health professionals may also learn from Jane’s story. The taken-for-granted assumptions within medical understandings of mental illness are but one way of understanding and managing this complex situation. There are many others that can be equally beneficial in supporting families where parents have serious mental illnesses.

A bricolage, or mixing and matching of approaches and therapies, may be valuable for adult children and families where parents have serious mental illness. Jane’s experience of 12 step self-help groups such as Alcoholics Anonymous, which can include the language of victimisation and denial, also include a discourse of recovery. This has the promise of re-scripting lives (Roof, 1993). Self-help groups may provide an opportunity to tell self-stories. This act itself can be therapeutic and may aid the development of cohesion with others in the group (Polkinghorne, 1988). Thus, the therapeutic pluralism suggested in Jane’s story could be expanded to incorporate conventional understandings as well as alternative ones, so that the dualism of traditional versus alternative could become a postmodern dialectic of both traditional and alternative, where neither approach was dominant.
7.11.4 The wounded healer - lessons learned from adversity

In her explanation as to the ‘alternative’ ways she has used to manage her issues, Jane constructed meaning from her experience by suggesting that one of the reasons she has experienced difficulties from having parents with serious mental illness and substance dependence is that it “might be to make me who I am, and for me to teach people things.” Using conventional theoretical understandings, Jane’s story can be seen as an example of resilience, where individuals overcome adverse situations through effective coping and go on to provide inspiration and support for others who may be experiencing difficulties. Indeed, Jane’s story contains many examples of protective factors such as religious faith, having strong social supports, a sense of humour, and an internal locus of control.

In addition to Frank’s (1995) ‘quest narrative’, Jane’s construction of having learnt lessons through her adversity can be extended through understanding the concept of the wounded healer. The myth of Chiron is an allegory of a centaur who, in contrast to other centaurs, was a wise and kind healer with many talents and skills. Chiron’s qualities were so great, he was considered fit to be a guardian and teacher of children and became one of the heroes in Greek mythology. He suffered however, from an incurable wound after accidentally being shot by a poisoned arrow, and eventually gave up his immortal status in order to live without pain. (Jackson, 2001). The myth of Chiron can be seen as useful for interpretation of Jane’s story, and perhaps also for other adult children of parents with serious mental illness. Even though his was a story of pain as well as strength, the wounded centaur re-presents protection of children whose parents have had serious mental illness in that they may be taught to heal their own wounds.

In this way, novel meanings of being an ACOPSMI can emerge. Wounds experienced in having a parent with serious mental illness can be healed and become a source of inspiration and hope for both the self and others if ACOPSMI are provided with opportunities to explore and construct their experiences through diverse cultural lenses. Jane’s quest for alternatives becomes a transformational story where, having full knowledge of the dark and light within, she has chosen to go with the light.
7.12 CONCLUSION

As illuminated by the stories and interpretations in this chapter, there are many meanings to be found and many possible outcomes for adult children who have parents with serious mental illness. This postmodern narrative analysis and interpretation has opened the possibility that new meanings and transformational potential can emerge from experiences which may have previously been viewed primarily as difficult and negative. The following chapter discusses the significance of both the conventional and novel meanings of being adult children of parents with serious mental illness found in the dual analytic phases of the study, and explores how they may separately, as well as together, apply to practice.
CHAPTER 8
‘TRANSFORMATION OF WOUNDS’ – A DISCUSSION

Poetry removed for online publishing due to copyright
Reflecting on the transformation of wounds - the metaphor of the pearl

The following chapter discusses my interpretations of the meanings of being an adult child of parents with serious mental illness, derived through the dual interpretive lenses of phenomenology and postmodern narrative inquiry. Whilst reading Jackson’s (2001) informative paper on wounded healers one day, I was struck by the beauty and potential meanings for adult children of parents with serious mental illness of the evocative poem of the pearl that he had included by Shannon (1976). I could see the potential usefulness of such a metaphor when applied to the experiences of participants in this study.

The notion of transformation from trauma to possibility can be helpful in understanding the meanings of the experiences of adult children with parents with serious mental illness. In sustaining of wounds from childhoods and adulthoods with parents who had serious, often debilitating and distressing mental illnesses that had at times brought chaos to the family, the adult children in this study have shown we also have choices. We could take our pain, our grief, sadness, anger and resentment at what life had brought us, and we could decide – ‘Is this how I want my life to be?’ ‘Is this what I have to accept?’ ‘Do I have to be negatively driven by my past?’

As the following discussion reveals, there is the potential for a satisfying present and hopeful future that may come from apparently difficult pasts. Similar to the development and eventual emergence of the luminous and beautiful pearl, abrasive, resistant outer shells may have been built from adversity. Yet these rough exteriors can also be protective, nurturing, and healing. It is possible that happiness, beauty of spirit, strength, and courage can develop from pain. These can be inspirational and potentially transformational not only for the ‘self’ but for ‘others’, and lead to positive changes for both.

But as the following discussion also illuminates, there is no fairytale ending to these stories. There is no guarantee that managing the past, whatever it may have been, will mean there is no lingering pain and there are no future challenges. Perhaps it may mean, however, there are possibilities for those who have previously felt there were few.
FIGURE 8.1

THE MEANINGS OF BEING AN ADULT CHILD OF PARENTS WITH SERIOUS MENTAL ILLNESS

Phenomenological Themes
- Being uncertain
- Struggling to connect
- Being responsible
- Seeking balance

Inter-textuality of meanings

Postmodern Narrative Interpretations
- Agentic resistances
- Attending to the silences
- Diffuse parent/child boundaries
- Fragmented narrative identity
- Metaphors as cultural texts
- Transformational possibilities and narrative repair
8.1 INTRODUCTION

In order to address the identified gap in knowledge as to the experiences of adult children of parents with serious mental illness, this study has explored the meanings derived from the experiences of ten such adult children. The findings from the study support a number of previous findings and contribute new information which adds to current understandings of the meanings that may be made from such experiences. Using a dual approach that sought to add to existing literature whilst also providing alternate representations, phenomenological themes have been illuminated and a series of lessons from a narrative inquiry have been produced. Together, this dual analysis has resulted in rich and diverse understandings of being the adult child of parents with serious mental illness. In this way, there is potential for adult children, whose needs have not been served adequately, to be more fully acknowledged and attended to by the healthcare system.

The following chapter discusses the study’s multiple findings in terms of previous empirical and subjective experience literature, as well as COPMI policy and service provision literature. Discussion also explores the implications these findings may have for adult children and the family where parents have a serious mental illness, and for health professionals. The chapter ends with my evaluation of the research, and my reflections on how this research journey has impacted on me as both researcher and participant.

Discussion of findings begins with an overview of major common findings, and then as per the diagrammatic re-presentation of the meanings of being an adult child of parents with serious mental illness (Figure 8.1), moves to the phenomenological thematic findings, explores the inter-textuality of meanings from both sets of findings, and ends with the lessons that have been learned from postmodern narrative interpretations.

Major common findings with previous literature include participants’ lack of understanding and lack of provision of information about their parents’ illness. Furthermore, six of the ten participants’ parents had not been diagnosed until adulthood,
which means that as COPMI they were not identifiable by health services. This finding has implications for accurate estimation of the incidence and prevalence of COPMI. In addition, in this study geographical isolation appeared to increase the risk of parents remaining un-diagnosed. This strongly supports the current guidelines which identify that children and families in remote and rural or isolated geographical areas need access to support and information (AICAFMHA, 2004). It also suggests, however, that some COPMI may continue to remain invisible to current service providers. The role of others such as education providers/schools becomes particularly important then in identifying COPMI, providing information on mental illness to children and families, and referring them to relevant support services.

Parentification and role reversal was a further finding consistent with previous literature, including the experience of subjective and objective burden in respect to caretaking responsibilities, which had often developed in childhood and continued to the present time. The high proportion (7 out of 10) of participants with mental health issues also supports the literature in terms of an increased risk of psychosocial problems for children of parents with mental illness.

8.2 PHENOMENOLOGICAL THEMATIC FINDINGS

The lived experiences of a person’s life gain significance by giving memory to them. Through acts such as conversation, meaning is assigned to phenomena that have occurred in everyday life (van Manen, 1990). This being-in-the-world is grounded in temporality, and so to determine the meaning of such experiences is to understand them as occurring over time (Heidegger, 1982). In this study, participants described their experiences of having parents with serious mental illness from their earliest childhood recollections through to their present-day experiences. Through sharing these lived experiences of being-in-the-world with parents with serious mental illness, a number of phenomenological thematic findings were uncovered. Many of these support the findings of previous research, and some have added fresh perspectives and new understandings.
8.2.1 ‘You’d think this roller coaster is never going to stop’

‘Being Uncertain’ was a strong theme throughout participants’ accounts of their experiences. They spoke of the chaotic, changeable and uncertain experience of having a parent with serious mental illness, and the sense of uncertainty they had about their parents’ mental health and how this impacted on their parenting and the daily life of the family. ‘Being Uncertain’ included participants’ awareness that as children they had understood there was something ‘not right’ about our ill parents, and had difficulty gaining information about their illness from either family or health professionals. Their parents’ symptoms also added to their confusion about what to believe. Participants’ concern with feeling unsafe at times, and being unsure about their self-identity as a result of their experiences, were also prominent aspects of Being Uncertain.

Heidegger (1993) explains that the nature of being includes a sense of ambivalence. Understanding ourselves and others in this way may result in a perception of contradictions which can lead to an impasse, where we could feel trapped. The participants in this study can be seen to have understood their parents in such a way. Their sense of uncertainty about the ill parent’s inconsistent and changeable behaviour and parenting was commonly referred to as being like a ‘Jekyll and Hyde’ situation, where the parent’s behaviour swung between two extremes of being nurturing and supportive, to being angry, critical and sometimes abusive. In these situations, participants felt a sense of confusion and of wanting to escape. This finding supports previous literature (Shih, 1995), and is similar to that of Riebschleger’s (2004) two themes of ‘good days’, and ‘bad days’, and the theme ‘source of understanding’ by Cogan, Riddell & Mayes (2005), in which COPMI described their recognition of the changeable nature of parents’ mental health in terms of ‘good days’ when the parent was attentive and interacted positively with them, and ‘bad days’ when the parent was emotionally inaccessible and/or irritable and angry.

Yet rather than leading to an impasse, where both child and parent become locked in apparent contradictions, perhaps the recognition by children, adult children and health professionals that feelings of ambivalence need not be fought or escaped from.
(Heidegger, 1993), but accepted and understood as being ‘normal’ or usual, may assist with managing the potential uncertainties of daily life with a parent with serious mental illness.

‘Feeling unsafe’ was also a prominent sub-theme where eight of the ten participants reported emotional, physical and/or sexual abuse, and the attempted infanticide of a sibling, by their ill parent. Abuse was at times also perpetrated by their other parent. These are significant findings which support studies where abuse and neglect by parents with mental illness, including psychosis, have been identified (Anthony, 1986; Beardslee & Podorefsky, 1988; Buist, 1998; Caton et al., 1998; Dunn, 1993; Lancaster, 1993; Shih 1995; Stevenson, 2002; Ulzen and Carpentier, 1997). Whilst partners (primarily men) of parents (mothers) with serious mental illness have been identified as not uncommonly having their own mental health and/or substance use problems (Dunn, 1993; Rutter & Quinton, 1984), there is a lack of literature reporting on abusive behaviours by them. This issue may require further investigation and has implications for the assessment and support of families by health professionals where one parent (particularly the mother) has a serious mental illness.

One striking feature of participants whose parents had severe depressive episodes was their description of the parent’s frequent expressions of explosive anger, and how distressing this was. This finding supports previous empirical literature (Alpert et al., 2003; Gopfert et al., 1996; Rutter & Quinton, 1984), and has implications for health professionals’ assessment and support of children whose parents experience depression with anger attacks (Alpert et al., 2003). Angry and abusive parental behaviours also raise issues regarding child protection. Parents may be understood as being a ‘safe ground’ and their role as providing ‘safekeeping’ through which the child begins to experience the world (van Manen, 1990). A tension may exist for health professionals when parents with serious mental illness are unable to fulfil this role effectively. When parenting is not ‘good enough’ and harm is occurring to the child, child protection may be needed (Cousins, 2004). Whilst health professionals are required to notify child protection services if a child is at risk, current guidelines also advocate maintaining family structures and recognising the family’s strengths (AICAFMHA, 2004). From this
perspective, the implications of the high level of abuse experienced by these adult children suggests that rather than placing blame on mentally ill parents for their behaviours, the provision of greater service provider and social support to parents, children and families would be more effective strategies in reducing this risk.

In terms of the impact of parents’ psychotic symptoms on the participants ‘Sorting out what to believe’ was an important finding. Empirical literature has identified that children may be at risk of ‘folie a deux’ (Anthony, 1969; Bleuler, 1974; Rutter, 1966). This was not, however, strongly evident in this study. Although they were confused by their parents’ stories and wondered what to believe, they also often questioned their veracity and challenged them at times. This may have been a characteristic of this particular group of adult children, who were perhaps resistant to their parents’ psychotic beliefs and/or protected from them in various ways including having a limited exposure to the psychotic behaviour, and having surrogate caregivers (Landau et al., 1972). Similarly to Beardslee & Podorefsky (1988) and Maybery et al., (2005a), the participants in the present study also found the presence of siblings with whom they could discuss and query their parents’ beliefs to be helpful. They seemed to be protective for them in terms of questioning parents' psychotic beliefs, and may be an important additional factor which health professionals can harness to facilitate their support of current COPMI.

**8.2.2 ‘We were super close, and now we’re not’**

The ambivalent quality of many participants’ experiences of their relationships with ill parents also supports some of the literature on attachment in children of parents with mental illness (Cunningham et al., 2004; D’Angelo, 1986). Although attachment style was not specifically assessed in this study, ‘Struggling to connect’ suggests that participants may have experienced issues in their close relationships as children, and similarly to participants in Marsh et al.’s (1993a & 1993b) and Stevenson’s (2002) studies, these may have impacted on their relationships as adults. Four participants in the present study had been divorced and three were currently single and not in relationships. Some participants had also experienced difficulty committing to relationships, and/or having relationship difficulties with partners and/or parenting their own children.
Although these issues may be attributed in part to the usual relationship issues that all adults can experience, this finding suggests that assessment for, identification of, and support with, attachment difficulties for parents with serious mental illness and their children may be important preventative strategies that health professionals can use to support families where parents have serious mental illness. These may in turn have inter-generational preventative effects in terms of the parenting of ACOPSMIs’ own children.

8.2.3 ‘I think I grew up in a hurry’

As one of the effects of assuming high levels of responsibility in childhood, parentification, also considered a form of child maltreatment (Clausen & Huffine, 1979; Devlin & O’Brien, 1999; Falkov et al., 1998), was apparent for a number of participants. This finding adds to the previous discussion on the abuse that children of parents with serious mental illness may experience and suggests that COPMI can be at significant risk of experiencing various forms of maltreatment and abuse as a direct impact of parents’ illness on their behaviour toward their children, and/or indirectly through parentification, neglect and/or vulnerability to abuse from others (including the ill parent’s partner/spouse).

The participants in this study also identified a range of emotional impacts related to their caregiving roles, including feeling fearful that if they didn’t assume responsibility for the family, then it would disintegrate even further. They reported feeling protective of siblings, feeling obligated to support parents and siblings, and having a sense of guilt if they were unwilling or unable to continue assuming these responsibilities as they grew into adulthood. ‘Guilt and Loyalty’ was a strong theme in Dunn’s (1993) study, and so this finding supports hers to some extent, although in the present study guilt was not a particularly striking aspect of participants’ accounts, and unlike Dunn’s (1993), issues of survivor guilt were not strongly apparent.

In assuming responsibility for their parents, as well as for them-selves, the participants all reported experiences with health professionals where they tried to gain information about their parents’ illness, and/or to manage their own mental health issues, both as children
and as adults. These were sometimes positive and helpful experiences, particularly with therapists they saw as adults for their own mental health issues, which support the findings of Caton et al. (1998), Dunn (1993), Marsh (1993a & 1993b), and Stevenson (2002). Participants more often, however, reported negative and challenging experiences with health professionals, including difficulty gaining information about their parents’ illness, being pathologised by health professionals, and/or having their needs and concerns overlooked or ignored. These support the findings of Caton et al. (1998) and Dunn (1993). Client confidentiality was a common issue as it impeded their ability to gain information on their parents’ illness due to health professionals’ unwillingness to impart information about them. These issues have implications for the role of children and adult children as carers supporting their parents with serious mental illness, and for the health professionals who work with them. Although current guidelines for service provision for COPMI recognise that parents with serious mental illness have a right to privacy (AICAFMHA, 2004), similarly to Wynaden and Orb’s (2005) study, the participants in the present study felt excluded by health professionals who they often experienced as reluctant to collaborate and share information with them.

An ethically sensitive approach to engaging the child/adult child and family in caring for the parent, where the level of information required and provided was negotiated at the beginning of treatment, and family members’ needs prioritised and addressed throughout, could assist in breaking down some of the barriers to effective collaboration with families (Szmukler & Bloch, 1997; Wynaden & Orb, 2005). This could also help to diminish children’s and adult children’s sense of isolation, frustration and confusion, and strengthen their willingness and capacity to support their parents.

A more uncommon finding in this study was that participants reported that their experiences of being responsible for family and parental functioning also brought gains, in that they felt they had become independent and developed a good ability to problem-solve. As children, this had also gained them positive attention from others, particularly adults. Similarly to the participants in Kinsella et al.’s (1996) and Aldridge and Becker’s (2003) studies, the participants in the present study recognised that being responsible had provided them with characteristics and skills which had served them well as adults, and
for which they were grateful. This emphasis on the potentially beneficial impacts of what has primarily been considered a detrimental impact is significant. For the participants, caregiving provided skills and developed abilities that might not otherwise have been cultivated. This has not been a feature of the experience of having parents with serious mental illness that has been emphasised in the literature to date, although it may be considered an indication of resilience and the development of an internal locus of control, and adds support to the notion that not all impacts of parental mental illness are negative ones.

Participants’ caregiving roles in childhood may also have had some impact on their later career choices. Like the participants in Beardslee and Podorefsky’s (1988) study, six participants in this study had also been attracted to the helping professions. Three of them had chosen nursing, two worked with carer organisations, and one was in the field of psychology. This may, though, have also been related to the sampling process, as three of the participants had been recruited through mental health-related conference presentations. There is recognition, however, that many health professionals have been attracted to caring professions due to their own experiences of personal difficulty and/or illness, and that these experiences can effectively contribute to their healing capacities (Jackson, 2001).

8.2.4 ‘I had to be in control of the situation, so that awful things wouldn’t happen’

Gadamer (1996) has described health as being a state of equilibrium or balance and argued that the field of mental health is concerned with managing individual disturbances in equilibrium. According to Gadamer (1996), to be ‘healthy’ is to sustain balance and proportion, and so health is a state of ‘hidden’ (or unconscious) harmony which is maintained by being part of nature. We are only aware that we have had a state of health when our sense of balance is disturbed. In the theme ‘Seeking Balance’ participants can be understood as seeking to manage their experiences of chaos and uncertainty in an attempt to regain their equilibrium and sense of health. In this way, equilibrium can be understood as involving a balance, not necessarily equal, between states of anxiety and
calm or peace. New and changing states of equilibrium may develop out of experiences of confusion and uncertainty through the development of different ways of coping.

In this study, participants used a variety of ways to manage their uncertain experiences. These included escaping, either literally or figuratively from the home and family, through hobbies and participating in voluntary work. These methods of coping support the literature on COPMI, ACOPMI and resilience, which have similarly found that hobbies such as these are protective factors which can be effective ways to deal with the experience and build resilience (Garley et al. 1997; Kinsella et al., 1996; Werner, 1995). Participants also described other constructive emotional and mental forms of coping including talking with siblings, having friends and supportive adults in their lives as children, having counselling, using alternative therapies, attending self-help groups, and using their spiritual faith. These findings also support those of previous literature (Dunn, 1993; Kinsella et al., 1996; Werner 1995; Werner & Smith, 1992).

Yet, similarly to Kinsella et al. (1996), the participants in this study also identified ways of coping with their situation that had not served them particularly well as adults. These included problems related to addictive behaviours such as over-eating and alcohol and other substance misuse, repressing their emotions and intellectualising, withdrawing emotionally from others including their ill parents, self-harm behaviours, and behaviours indicating dissociative responses which were also possibly related to their experiences of abuse. A high incidence of mental health issues was reported by the participants. Seven of the ten reported episodes of depression, including what appeared to be a brief episode of psychosis, depression as part of a possible bipolar disorder, and the experience of depression in the postnatal period. Participants also reported that some of their siblings had developed psychotic mental illness (1), depression (2), and substance use problems (2).

The relatively high incidence specifically of depression was consistent with only two of the previous subjective experience studies (Caton et al., 1998; Stevenson, 2002), as most of the previous research has not indicated the number of mental health issues experienced by participants. No participants in the present study reported experiencing a chronic
psychotic illness such as schizophrenia, although one participant reported a sibling with schizophrenia, and therefore the type of mental health issue experienced by participants in the present study generally did not support those empirical studies which have found a preponderance of mental disorders such as schizophrenia and schizoaffective disorders in children of parents with psychotic disorders (Anthony, 1986; Cantwell & Baker, 1984; Grunebaum & Cohler, 1982; Hans et al., 2004; Higgins et al., 1997; Parnas et al., 1993; Rutter & Quinton, 1984).

‘We are always our parents’ child’

Louise and I sit at the lovely timber dining table in a quiet kitchen one afternoon, discussing the initial findings that have come out of the study and some of the issues that are starting to arise from them. ‘There’s this ripple effect that goes on’, I say with feeling, ‘it affects the whole of the adult child’s life. It doesn’t magically stop when we reach 18 – and it also affects the whole of the family - our relationships, our children, our partners’. ‘Yes’, says Louise, ‘it isn’t just about being a child, because you remain your parent’s child for life’. I note her words down in my research log, and make a mental note to myself to explore this idea further.

Later I think more about what Louise has said. She’s put into words what I have been trying to articulate for some time. We are always our parents’ child. It’s a simple and perhaps obvious realisation, but with many possible implications. The impact of issues that arise in childhood can remain with us for the rest of our lives. Our relationship with our parents continues on even after we/they have moved thousands of miles away, we never see them, or they have died. They live on in our thoughts and feelings - our dreams, fantasies, and sometimes, our behaviours and choices. We make all sorts of constructions of the past, our relationship with our parents, and then of our-selves. Our child identities dwells alongside our adult ones. Together they form many shifting and sometimes competing identities. What influence will our child identities have over time? How can they be reconciled with our adult ones? How can our past be constructed so it supports the present and inspires the future?
8.3 WITH-IN THE DOUBLE SCIENCE: INTER-TEXTUALITY OF MEANINGS

As discussed in Chapter 4, the purpose of using a dual analytic approach in this study has not been to produce a singular or aggregated re-presentation of participants’ experiences (Coffey & Atkinson, 1996). Rather, this approach has sought to provide a thicker explanation of a largely unknown phenomenon through interpretations produced from multiple and differing perspectives. As Lather (1997) argues, this has been done in recognition of the limits of re-presentation. Such a repetition therefore subverts and displaces that which has enabled the repetition. For these reasons, the findings from each phase, based as they are in divergent epistemologies, have also been discussed separately.

Yet, in the subversive repetition, there are also commonalities and overlap to be found. In the spaces between the phenomenological thematic findings from the first phase of analysis, and the postmodern narrative interpretations from the second phase, intertextuality can be seen. Meanings of experience meet and mingle, overlapping, illuminating and emphasising varied aspects of what it means to be an adult child of parents with serious mental illness. I have found, as has Savage (2000), that rather than always leading to competing interpretations, using a dual analytical lens through which to analyse the field text also resulted in a diffuseness in the boundaries between such understandings, and illuminated a kaleidoscope of meanings (Figure 8.1). Through ‘doing’ the science of phenomenological thematic analysis and then ‘troubling’ it through a postmodern narrative lens, both interpretations provided meanings that illuminated the participants’ experiences.

In attending to the voices in the margins, and using literary device and stories rather than units of text, new possibilities for interpretation became available. As evident in Chapters 6 and 7, some of the same field text were used to illustrate meanings derived from each of these interpretive lenses. In particular, the sub-themes ‘Making Choices’, ‘Experiencing Turning Points’, ‘Who am I? – being unsure of self’ and the narrative interpretations of ‘breaking points’, ‘diffuse self-identity’, and ‘choosing to choose’ resulted in varying emphases on similar aspects of participants’ experiences. As these were key findings with significant implications for adult children, and families where parents have mental illness
including psychosis, as well as health professionals, they are discussed together as follows.

8.3.1 Pivotal turns and breaks: transformational moments

Participants in this study described a number of what they termed ‘pivotal moments’ in their experiences with parents with serious mental illness – those points in time when an event or situation, often perceived as challenging and distressing, resulted in a shift or turning point in our understanding of their parent and/or themselves, and changes in their behaviour. The concept of pivotal moments has previously been recognised in the literature (e.g. Helmeke & Sprenkle, 2000; Welch, 2005). Whilst lacking in specific definition, the term has been used to refer to experiences and processes which have made a difference and resulted in change (Helmeke & Sprenkle, 2000; Welch, 2005), and so participants’ use of this to describe particular experiences can be seen to signify their recognition of these as making a difference to their lives and resulting in changes for them and their relationships with others, particularly their ill parents.

In this study, the identification of pivotal moments as being ‘turning points’, however, can be seen to incorporate a more widely understood and used term from the literature on subjective experience and resilience (Lancaster, 1993; Rutter, 1993; Werner, 1995; Werner & Smith, 1992). Turning points are considered subjective emotional and cognitive changes that occur in response to particular events and often carry a strong emotional or moral message, bringing new beliefs, new courage, and/or a sense of having ‘had enough’ (Bruner (1994). They are constructions which the narrator has used to clarify notions of their ‘self’, which are, as Bruner (1994) asserts, thickly agentic in that self-agency is re-directed and often re-doubled. From an interactional moment of crisis has come a transformational experience (an ‘epiphany’) out of which the person is never quite the same again (Denzin, 2001).

In the present study, and supporting previous literature, the experience of having a child (Werner, 1995; Werner & Smith, 1992) and standing up to and resisting the parent’s authority, often for the first time (Lancaster, 1993), were important turning points for
participants. As Lancaster (1993) also found, these points signified to adult children that they could take control of their lives rather than maintain a passive acceptance of their situation. This is a characteristic of resilient persons who can rebound from adversity (Werner, 1995; Werner & Smith, 1992) through changing their perception of the situation (Rutter, 1993). Whilst Werner (1995), Werner and Smith (1992), and Rutter (1993) have discussed turning points in terms of resilience, due to the lack of publication of Lancaster’s (1993) findings in the broader literature, the present study’s findings draws attention to turning points as an important aspect of the experiences of these ACOPSMI.

The experience of turning points has particular implications for children, adult children, and parents with mental illness including psychosis. Understanding that what at first may appear to be yet another difficult and negative episode in their lives can also be an opportunity to strengthen the ‘self’ and form closer relationships with each ‘other’ is potentially very empowering. Health professionals who also understand the potential value of situations such as these can support families to manage them through the use of narrative, cognitive-behavioural, and/or other solution-focused therapeutic approaches, and so enhance their individual and collective resilience.

In contrast, the term ‘breaking points’ is a new finding from this study. Through a postmodern narrative lens, pivotal moments or turning points were freshly identified as ‘breaking points’ in that they signified a break between the past and present and a rupturing between old and new, with the resulting abandonment of one life script for another. Whilst the concept of a ‘break’ often carries negative connotations, in the present study participants’ experiences illuminated that breaking points, extended from those of ‘turning points’ to include psychotic ‘breaks from reality’, a ‘breakdown in a relationship’, and a ‘break from the past’, could also be opportunities for growth. Just as the Chinese symbol for ‘crisis’ identifies both danger and opportunity, adult children of parents with serious mental illness and their parents can be supported by health professionals to understand that replacing ‘old’ ways of coping with ‘new ‘ones holds opportunities for empowerment and increasing self-agency. These points in time in having a mental illness, and in being the child of a parent with mental illness, can bring a
freedom for new self-definition and the ability to choose a path in life rather than feeling it has been forced upon them.

8.3.2 ‘Choosing to choose’

‘Making choices’ and being able to choose were strong features of participants’ experiences. In contrast to some of their childhood experiences of disempowerment, as adults they had made conscious and deliberate choices to manage the impacts of their pasts and forge a future of their own making. They often demonstrated strong elements of an internal locus of control (being agentic), even though some of them had also appeared to understand and manage their experiences at various times through an external locus of control (being victimic). In identifying that they were able to choose how to respond to their past experiences, even though they still at times struggled with this, they illustrated how such experiences can be potentially transformative as well as potentially destructive. Each person could choose how they responded.

The notion of choice, however, is not evident in the previous literature on the subjective experiences of either children or adult children. Although choice is perhaps implied in findings such as ‘turning points’ and taking control of their lives (Lancaster, 1993) and ‘coping strategies and resilience’ (Polkki et al., 2004), this particular construct has not been made explicit. Furthermore, an awareness that adult children may ‘choose to choose’, that is, knowing there can be choices, is also not apparent in the literature. In some respects, this is a curious silence. In another respect, however, perhaps this silence may re-present in part the previous hegemony of the problem-focused constructs identified in Chapters 2 and 3, and/or the research designs and analytical approaches used.

There has been relatively little research into the experiences of ACOPSMI, and much of this has privileged the problems and burdens of such experiences rather than emphasising the potential benefits and possibilities of them (see e.g. Dunn, 1993; Lancaster, 1993; Stevenson, 2002). From this perspective, perhaps the lack of identification of choice is not surprising. Making choices implies agency. Agency implies strength. Strength implies
resilience. Resilience implies hope, and hope implies positive possibilities for the future. These have not been strong characteristics of the ACOPMI subjective experience literature to date, although they have been a feature of literature which has specifically explored the construct of resilience. Accordingly, the findings of ‘Making choices’ has significant implications for COPS MI, ACOPSMI, and health professionals. Understanding that positive constructions of experience can be made through, for example, solution-focused and narrative approaches, suggests that COPS MI and ACOPSMI can be supported by health professionals to re-frame their thoughts and emotional responses and choose how to respond to their experiences. They do not have to be prisoners of them.

8.3.3 ‘Like a fish out of water’ – diffuse self-identity

In terms of their understanding of themselves, some participants in the present study reported a diffuse sense of self-identity and the sub-theme ‘Being unsure of self’ included struggling with self-esteem, being unsure as to whether they might develop a mental illness, and finding it difficult to settle on a career path and develop a firm sense of self. This was a relatively uncommon finding in comparison to previous literature. Apart from Lancaster (1993), who reported the theme ‘Seeking a sense of self’, none of the other COPMI or ACOPMI subjective experience studies report this particular finding, although they do refer to children’s and adult children’s feelings of different and alienated from others and being concerned about developing their own mental illness (Dunn, 1993; Garley et al., 1997; Riebschleger, 2004).

From a traditional psychiatric and psychological construct, the notion of unclear self-identity is usually considered problematic. Yet from a narrative perspective, self-identity may be understood as a process rather than a discrete entity, where persons construct meanings from experience which, expressed through narrative, provide purpose and direction by linking actions to the accomplishment of goals (Polkinghorne, 1996). Although in a postmodern world the self is considered to be fragmented, this disunity may not necessarily be a deficit in that a diffuse self-identity offers the potential for the
acceptance of multiple identities, thus leading perhaps to a greater tolerance of difference and acceptance of change (McAllister, 2001).

According to Ricoeur (1988) self-identity is usually understood as including being the same (identity *idem*) and having self-sameness or constancy (identity *ipse*). Yet he has argued that identity is a dynamic notion which may be re-figured through narrative, and includes constancy as well as change and variability over a lifetime. Thus, it follows that if adult children were supported by health professionals through narrative therapeutic approaches to understand their many selves and experiences as including a sense of sameness (*idem*) yet also including change (*ipse*), they may come to understand states of fragmentation and diffuseness as being part of a ‘normal’ state of identity that can be re-configured to a more positive trajectory. As Flaming (2005) suggests, flux and change in identity can occur without the person becoming completely lost or unidentifiable.

**8.4 TOWARDS NEW UNDERSTANDINGS: LESSONS LEARNED FROM POSTMODERN NARRATIVE INTERPRETATIONS**

In turning to a postmodern narrative lens through which to explore the meanings of the participants’ experiences, a number of lessons have been illuminated. These included the contesting of taken-for-granted assumptions that children do not have moral agency or power, and that only parents (adults) do. Understanding children and parents as existing in dialectical relationships where power may be shared and inter-subjective connections may reduce their previously polarised positions, adds to previous understandings of these historically problematic issues. This fresh construction suggests there is the possibility that health professionals may support children and parents to understand and respect their own and each others’ agency, and assist them to draw together in mutually supportive and connected ways.

**8.4.1 Addressing inter-generational impacts: the legacy of narrative inheritance**

A further construct that has not been a feature of most of the previous literature is the inter-generational impact of being the adult child of parents with mental illness. Although the literature has acknowledged the risk of inter-generational genetic inheritance of
mental illness (Marsh et al., 1993a & 1993b; Weissman et al., 2005), there has been little focus on the construct of narrative inheritance. From a narrative frame, an inter-generational legacy of inheritance is significant and has a number of implications for health professionals, children/adult children and families where parents have a serious mental illness. Participants in this study spoke of the generally negative and stigmatised images and stories told of the parent with serious mental illness, and alluded to the impacts these had on their own identity constructions, understandings of their parents and mental illness, and how these were also passed on to the next generation - their own children - through their roles as parents. ‘Toxic’ inheritances (Goodall, 2005), where silences or distortions on issues such as abuse, mental illness, and violence are passed down through families, can have substantial impacts on inter-generational legacies of shame, guilt, disturbed self-identity, feelings of inferiority, and loss. They also perpetuate broader cultural narratives of stigma, stereotyping and deficit, and serve to maintain prejudicial social silences on mental illness (Hinshaw, 2005). It is important that a narrative culture of speaking out on mental illness as a social issue to be addressed, rather than from a stance that blames the individual, is encouraged within families and the community. Secrets only have power in silence, and resistances to maintaining such malignant silences can contribute significantly towards dismantling hegemonic prejudices towards mental illness and creating a supportive environment of non-blame. This may also serve to facilitate a collective approach in service provision for families where parents have serious mental illness.

### 8.4.2 Emerging from the ruins - metaphors as useful interpretive devices

A further lesson to be learnt from participants in this study was the usefulness of metaphors which re-presented the meanings they had made from their experiences. As linguistic devices, metaphors ascribe new and displaced meanings beyond the usual literal interpretations of words or sentences. In this way, they offer a potential for explanation which results in new and perhaps better understandings which may emerge “…from the ruins” of previous interpretations (Ricoeur, 1984, p.x). In searching for the meanings adult children have made of their experiences, the metaphors used by
participants in this study can also be seen to provide ‘new’ perspectives on an ‘old’ situation.

Participants said that being an adult child of a parent with serious mental illness can be *like a Hollywood horror movie* or a *scary dream* where parents are *not of sound mind* and seeing their psychotic behaviour is sometimes like being part of a *hilarious black comedy*. They can grow up feeling like *a fish out of water* and their parents can seem like *Jekyll and Hyde* and be *a wicked witch* when they’re angry, or like *little bo peeps who have lost their sheep* when they’re psychotic. Having grown up with this can feel like a case of *sink or swim* when they embark on the *journey of a lifetime* to deal with their past, and they can sometimes have a real *victim mentality* if they don’t know they can *choose to choose*. Yet having parents with serious mental illness doesn’t have to be a *death drink*. They can ‘choose to choose’ and support from other people can be an *oasis in a sea of turmoil* and have a very positive influence.

Sharing metaphors such as these can add to existing understandings of being the adult child of parents with serious mental illness and be useful for children, adult children and health professionals as they may hold meanings that resonate for others, assist in the generation of solutions to a challenging situation, and build a shared knowledge whilst retaining local meaning which is particular to each person (McAllister, 2000). They may also build self-identity and contribute to change. Beliefs about experiences may be embedded within the imagery that metaphorical language evokes and so may offer perspectives which are creative and provide constructive alternatives to conventional or standard approaches (McAllister & McLaughlin, 1996). Understanding the experiences of ACOPSMI through the allegory (or extended metaphor) of the wounded healer therefore may also provide comfort, hope and inspiration for other children and adult children. The journey of Chiron the wounded healer, similar to that of adult children, involved painful experience which was transformed through the development of strength, compassion, and understanding into healing which not only soothed the centaur, but provided support and inspiration for others.
Extending the use of metaphor further, health professionals can also be instructed by the implied requests made by participants for greater agency and decision-making capacity in terms of their parents’ mental illness. Health professionals who may have traditionally seen themselves in terms of being a ‘health professional as expert’ can perhaps move to viewing their role through a fresh lens of ‘tour guide’ or ‘companion’ (McAllister & McLaughlin, 1996). In this way, the power differential in the dualism of ‘expert’ (health professional) and ‘victim’ or ‘supplicant’ (adult child), can become more equalised. The dualism of health professional and adult child can also be inverted, where the adult child is seen as ‘expert’ of their experiences and in understanding their parent, and the health professional as ‘supplicant’, willing to be informed and instructed by the adult child’s expertise. In these ways, innovative understandings may lead to fresh approaches and more empowering experiences for children, adult children, and families where parents have a serious mental illness.

8.4.3 Possibilities for transformation – the mimetic spiral of narrative healing

Thus, the thematic and narrative findings of this study have provided an insight into the possibility that the meanings constructed by ACOPSMI of their experiences can involve choices that provides opportunities for transformation. From ‘being different’ and ‘seeking balance’, ACOPSMI can be supported by health professionals and others to new awareness of their experiences and the impacts these may have had on their structuring of both ‘self’ and ‘other’. In doing so, they may become more empowered (Paterson, Thorne, Crawford, & Tarko, 1999) through moving toward ‘agentic’ rather than ‘victimic’ stories (Polkinghorne, 1996).

The metaphor of the pearl which was used at the beginning of this chapter provides a representation of the transformative potential of wounding and healing that can be useful in understanding how adult children of parents with serious mental illness may be supported to re-frame their experiences. The wounds of their experiences, such as feelings of fear, anger, embarrassment and grief, having difficulty connecting with others, and feeling unsure about self, have the potential for transformation through the mimetic process of narrative healing.
Healing may be understood as an energy-requiring process which is co-created through caring relationships with others, where the self’s consciousness is expanded, resulting in a sense of wholeness, balance and transformation (Wendler, 1996). Ricoeur’s (1984-1988) three stage spiral of mimesis - the narrative emplotment of experience through time - can be instructive in illuminating the role of narrative in the transformation of wounds through healing. As discussed previously in Chapter 4, mimesis, or interpretation of experience, is not a linear process but continues to spiral through each imitative stage of past lived experience (Flaming, 2005).

Applying this construct of experience to a transformative healing process for adult children of parents with serious mental illness; in mimesis\textsubscript{1} (pre-figured time) the child or adult child can explore their hidden assumptions about the world that motivate their actions (Flaming, 2005) (e.g. their image of their parents, and/or of mental illness), which, in mimesis\textsubscript{2} (con-figured time) have impacted on their constructions or emplotment of events that have occurred (for instance with their parents), and which in mimesis\textsubscript{3}, (re-figured time) produce the narrative texts of their experiences that influence others’ understandings of the issue, and hence re-figures their lives, and through which the mimetic cycle is temporarily made complete or whole (See Appendix G for diagrammatic re-presentation of the proposed mimetic narrative healing process). As van Manen (1990) reminds, all recollection of experience is already a transformation of such experiences. From this understanding, narrative repair can be seen to offer transformative potential which recognises their ability to re-construct alternate stories of experience.

The concept of spiralling experience can also be understood from the construct of resilience, where the visual re-presentation of the ‘spring’ (or spiral) which ‘bounces back’ or rebounds from adversity (Marsh et al. 1996) also illustrates the ability of persons to recover from and transform past experiences which may have historically been viewed as ‘difficult’. As Luthar (2005) asserts, resilience is not an all-or-nothing phenomenon. It is not fixed in time, and is not an individual or personal trait, but rather, exists in relationships and connections with others who provide support that strengthens the child’s/adult child’s ability to positively adapt despite the presence of risks.
In this way, narrative healing from wounding may be seen as a story of transformation where the child or adult child can be supported, through inter-subjective connection with others such as health professionals, family and friends, to shape an alternate plot to that of the dominant discourse and cultural narratives on parental mental illness and its impacts. In moving in from the margins, children and adult children whose parents have serious mental illness may be accorded moral respect by others (Nelson, 2001). These counter-stories may also serve to re-claim experience and may provide possibilities for future action which were not previously available. Change may therefore also occur for the ‘other’, in that cultural understandings of parental mental illness and the risk/deficit balance for children and adult children of parents with serious mental illness may be understood through fresh interpretive lenses of wounding, healing, and transformation. Cultural narratives of burden, disease, powerlessness and despair in respect of parental mental illness may be transformed to those of wounds, connections, possibilities, and healing. As Roof (1993) has argued, even in a world without centres stories in quest of meaning and coherence are being told and re-written. This study’s interpretive construct of transformational possibility through mimetic narrative repair can be seen then, as part of a disorienting research story (Roof, 1993) which tells of the breakdown of previous cultural meanings and master narratives of adult children’s experiences.

8.4.4 A cultural shift from burden to possibility?

Understanding adult children’s experiences through a transformative lens therefore involves a paradigm shift from one primarily of burden (Yamashita, 1998), which has been present in previous literature, (e.g. Dunn, 1993; Marsh 1993a & 1993b; Stevenson, 2002) to that of possibility. This may well pose a number of challenges to mental health systems that operate from a disease or deficit-oriented approach. Although such a shift requires the surrender of hierarchical roles between health professionals and parents/family members, innovative interventions which are based on appreciating strengths and encouraging transformation through partnership have much to offer families where parents have serious mental illness (Mohr, 2000).
Through the use of narrative repair for instance, individual experience may be re-storyed and plots of trauma, tragedy, and loss transformed to those of agentic resistance, strength, and possibility. These counter-stories resist the previously dominant re-presentations of burden and disease, and so adult children of parents with serious mental illness may be supported by health professionals through inter-actions with them that facilitate a change in both the ‘self’ and ‘others’ understandings and behaviours. Narrative strategies such as ‘externalising the problem’ (White & Epston, 1990) can assist children and adult children to understand that they are not the problem; indeed, their parent is also not the problem, but that the problem itself is the problem. This encourages the child or adult child to intervene in the problem and identify times when they may have participated in an alternate story to the dominant and socially constructed master narratives of such experiences. This creative or poetic mimesis is linked with how the child/adult child perceives their ‘self, and so their view of ‘self’, and perhaps of ‘other’, may also shift. In this way too, potentially negative experiences such as depression, experienced by many participants in this study, may develop into more positive states (Clark & Standard, 1997). This spiralling process of recovery - of healing through narrative repair - may also be seen to provide a re-awakening of hope after despair (Ridgway, 2001), particularly for those children and adult children who have struggled to see their way out of a spiral of negatively constructed experience. They may begin to see their capacity to heal their own wounds and find solutions to maintain their well-being, rather than accepting a taken-for-granted disease-oriented explanation which emphasises their deficits and perhaps encourages their passivity.

8.4.5 The usefulness of therapeutic pluralism

One of the key findings in this study was participants’ use of a variety of approaches to cope with their experiences, and their quest to find alternatives to those of mainstream or conventional psychiatric approaches. In resisting the problem-focused master narratives of serious mental illness and being the child of parents with serious mental illness, participants used a bricolage or mixture of approaches including self-help information and/or groups, traditional counselling or therapy, psychotropic medications, spiritual faith and religion, and creative approaches such as music and literature. This pastiche of
therapeutic approaches, rather than a reliance on a deficit-focused medical approach, is instructive. Service providers who recognise, facilitate and/or offer a range of solution-focused approaches to supporting children/adult children and families where parents have serious mental illness may find less resistance from them. One size does not fit all. Multiple methods of supporting families where parents have a serious mental illness may build a discourse of recovery and transformation which resists dominant cultural narratives of burden, disease, and despair.

Re-turning to the silences: my own transformative experiences

As I have attempted to show in a number of chapters throughout this thesis, the research journey chronicled here has also been accompanied by a parallel journey of my own. Mine is the lens through which the study has been implemented, analysed, and discussed. Mine is the voice which lies threaded with-in and between every line of these pages. Mine too, is a voice amongst the participants. Together they have combined to tell a story of many layers - objective scholarly writing has been interrupted by personal and evocative accounts - reflexive awareness has dwelt alongside research interpretations. These many surfaces have inter-acted and weaved around and between each other in an attempt to privilege the ‘messiness’ of both personal experience and scholarly research. What a satisfying, difficult, tedious, demanding, emotionally turbulent, intellectually stimulating, and ultimately transformative journey it has been. I will never be the same again.

The transformations have come at many levels. It is not an exaggeration to say that doing this research has totally changed my life. In finding the courage to ‘come out’ and share my personal story at conferences in the beginning of the study, I, to my surprise, also met a man who was to become my husband. This meant I moved house (a number of times), state, and job. My life entered a new chapter in every way. This was a totally different environment than I had been used to. Friends and family had to be left behind and I ventured into unknown territory and navigated uncharted waters, much like conducting the research itself. It was exciting and terrifying. It was a time to start over. In many ways I had taken enormous risks. Yet as with all ventures that hold risk, the potential gains were significant. I met new colleagues and friends who have been instrumental in developing my scholarly and research skills and have patiently walked alongside me in the long journey of writing and researching.
My transformation has also been at the most private and emotional levels. It has been a painful and stressful journey in some ways. Reading literature on the risks for children and adult children of parents with mental illness both reassured and worried me. Reading the personal experiences of other adult children both heartened and saddened me. They reminded me of past and present sorrows, anger, and loss, as well as triumphs, strengths and opportunities. I felt vulnerable, anxious and apprehensive when venturing forth to present my own story at conferences. Many a night I tossed and turned whilst imagining my colleagues’ possible reactions to what I suspected could have been quite shocking revelations to some. My voice quavered and I quietly sweated my way through a number of such public performances of these previously private experiences.

Conducting and transcribing the interviews was exhausting and emotionally draining, and quite often I read or wrote work with tears in my eyes. I procrastinated and avoided writing about my own experiences until a deadline approached. At these times I usually developed rotten headaches, had difficulty sleeping, felt drained and exhausted, and became quite irritable, as my family will readily attest. I came to understand these physical pains as my body’s way of signalling me about the emotional hurts that were being touched and released. This may well be an ongoing journey. These experiences also served to focus my reflexive attention on myself and how I was to continue reconciling my past with the present and future whilst conducting the research. During these times I took the advice I had given the other participants in their information sheets, consent forms and interviews, and used supportive others who included a few close friends and my research supervisors, most of who were mental health nurses, with whom to share my experiences. They worked as supportive, kind and insightful sounding boards to share my queries and concerns as well as successes with. Keeping a research log, making phone calls and sending regular emails to my supervisors also helped me to debrief and release some of my thoughts, emotions and questions, and provided me with a detailed audit trail as I worked through the research process.

Yet throughout this long journey was also the distant, but constant, presence of my mother. She rang. I was reluctant to answer. She behaved in her usual ways. I was irritated. I read an article on what it is like for parents with mental illness, and felt compassion. In analysing and interpreting the findings through a postmodern lens, I was struck by the stories of parents in the margins. I began to understand more. I could see things as they might appear, hazily, never completely, through the lens of the parent. I looked at her differently. I was reminded again and again that my own story was in some
ways as much about her as it was about me. I worried about anonymity, and questioned my right to speak about her. It continued to be a debate that volleyed back and forth in my mind.

But I persisted. This journey has not only been mine, or even mine and my mother’s. It has also included the stories of many others – the other adult children in this study, the voices of children and adult children which resonated within the literature, and the many voices of children, adult children and families as yet unheard. As a colleague of mine who I hadn’t seen for some time recently said to me at a conference – “well kim, I wish you good luck with your mission” – and although her words evoked the somewhat unwanted image of a fervent and self-righteous zealot (!), I was also pleased. It seemed she had understood. My work had been part of a much larger quest, nationally and internationally, which aimed at making a difference, perhaps even to contributing to the transformation of some people’s lives. The personal has most certainly been political. I have sought to disturb the silences around the issue of adult children whose parents have a serious mental illness. I used my-self and my experiences as a vessel through which the experiences of some other adult children could also be heard, and through my emerging understandings of my-self, and then those of the other participants; I could build upon and extend previous understandings. Together, we have sought to share them with others such as you, who could perhaps begin to understand or even help to bring about changes that might be needed.

And so, as a postmodern story, there are many plots and characters to be found throughout this long and layered research tale. There has been comedy, tragedy, romance, disaster and adventure. There have been villains, victims and heroes, survivors, warriors, horrors and quests. As I have come to see, this has also been a story of love, persistence, triumph over adversity, and the potential for transformation. Perhaps our stories will resonate for others, and perhaps also, they may contribute to change and growth for others as well as our-selves.

And like other postmodern stories, this research discussion does not propose a neat and tidy ending, but necessity requires a conclusion of sorts.

As Paula and I decided at the end of her interview:
Paula: …I’ve done a lot of work, I’ve done a lot of therapy and I’ve done a lot of work … and I have a good understanding of the dynamics … I have a good communication network with her (my mum) now, and I can talk to her about stuff, and it’s still going to affect me for the rest of my life … What about those people that haven’t had the opportunity, who don’t know that carer education programs exist, or they don’t exist in their area? What about those people who don’t want to go to counselling because it’s scary and unknown and they’re not being given any information and are struggling on their own?

Kim: so that’s why we’re here, isn’t it?

Paula: mmm

Kim: yeah

Paula: yep. That’s kind of my fullstop.

8.5 CONCLUSION

This chapter has explored the understandings that have been developed from the multiple findings of this study and discussed them in relation to the literature surrounding children and adult children whose parents have serious mental illness. In the following and final chapter of this thesis, recommendations for policy, practice, research and education will be made.
CHAPTER 9
‘LETTING GO’ – MOVING ON FROM HERE

Musical lyrics removed for online publishing due to copyright
Reflecting on ‘Letting Go’:

In the musical story of the troubled personas of ‘Dr Jekyll and Mr Hyde’, Sir Danvers is the concerned father warning his daughter Emma of the perils of marrying a scientist as radical and experimental as Dr Jekyll. Will such an apparently unstable character be a good husband to his much-loved daughter?

The dualism of the ‘good’ Dr Jekyll and ‘evil’ Mr Hyde, a cultural metaphor used so often by participants in this study to describe their parents’ apparently polarised behaviours, can also be constructed in other ways. The age-old dilemma that parents and perhaps in this case adult children also face – if and when to let go of the past and move forward into the future – may be challenging but also bring relief and growth for both. The decision of the personally involved scientist such as my-self, about how and when to let go of a project that has consumed them for some time, may evoke pride and a sense of achievement as well as sadness.

Moving forward into an uncertain future does not have to mean there is a need to go one way or the other. The multiplicities of ‘good’, ‘bad’, and ‘average’ may co-exist together. And so, in making recommendations from this study there are some questions I have asked and sought to address in the following chapter:

What do we already have that may be helpful in working together to find solutions for identified issues?
How can adult children be supported by clinicians in addressing the impacts of their parents’ mental illness?
What is it that needs to be let go in order to move forward from here?
9.1 INTRODUCTION

In this final chapter, I discuss recommendations for the practice of health professionals including nurses, and for policy, education and research. These recommendations are based on a dual analysis which incorporates the phenomenological themes uncovered in Chapter 6 and the postmodern narrative interpretations developed in Chapter 7, as well as the subsequent discussion of both sets of findings in Chapter 8. Throughout the thesis I have argued that adult children of parents with serious mental illness have been marginalised and their needs not addressed adequately by the healthcare system. These recommendations conclude a thesis which has been informed by a postmodern theoretical framework and sought to privilege multiplicity and diversity and attend to the silences surrounding this group who have for so long remained in the margins. In disturbing the silences surrounding this group, the study has aimed to provide a thicker explanation of what has been a largely unknown phenomenon, and to contribute fresh perspectives on what has traditionally been viewed as a difficult issue.

The study found that adult children can experience a number of wounds from their experiences, but the support of others and a transformative process of healing may re-frame these into more positive and hopeful trajectories. The following recommendations incorporate the participants’ recommendations for practice, as well as the researcher’s recommendations based on the multiple findings developed from the study.

9.2 RECOMMENDATIONS FOR PRACTICE

9.2.1 Listen to what adult children have to say

In their interviews, participants made recommendations from their experiences which they considered would have been, and would be, helpful in supporting them and their families as children and as adult children, and as such could be useful for other families where parents have serious mental illness. I have privileged these and thus presented them before my recommendations for practice. See Table 9.1 for a summary of participants’ recommendations for practice.
As can be seen, most of these recommendations support current Australian guidelines for service provision (AICAFMHA, 2004), which reinforces the need to put these into practice. In addition, the participants made several recommendations for practice which are inclusive of the needs of ACOPMI, whose needs are not yet specifically acknowledged in the current guidelines (AICAFMHA, 2004) and who have, unlike COPMI, continued to remain un-acknowledged in even the most recent government reports on mental health, e.g. the ‘Not for Service’ report (Mental Health Council of Australia, 2005) and the Senate Committee Report on Mental Health (Select Committee on Mental Health, 2006).

Table 9.1 Participants’ recommendations for practice

<table>
<thead>
<tr>
<th>For support of the family:</th>
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<tr>
<td>• Ask parents as early as possible for their permission to disclose pertinent information to A/COPMI about their illness.</td>
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<tr>
<td>• Provide early and timely intervention for the parent</td>
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<tr>
<td>• Approach the family from a strengths rather than deficit perspective and support them to thrive, not just survive</td>
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<tr>
<td>• Address grief and loss issues for each family member, including the A/COPMI</td>
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<tr>
<td>• As much as possible, keep the family together rather than separating them or sending children away</td>
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<tr>
<th>For support of COPMI:</th>
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<tr>
<td>• Provide information about the parent’s illness which is age appropriate and given slowly over time</td>
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<tr>
<td>• Provide access to someone, for example an older child or adult outside the family (a mentor), for COPMI to talk to</td>
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<tr>
<td>• Remember to look for the quiet children who are apparently doing well, as well as those who are acting out or have obvious difficulties or issues</td>
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<tr>
<td>• Encourage and support children in their hobbies and strengths</td>
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<tr>
<th>For support of ACOPMI:</th>
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<tr>
<td>• Appreciate the lifelong impacts that parental mental illness can have on the child, and treat ACOPMI and their experiences with respect</td>
<td></td>
</tr>
<tr>
<td>• Approach ACOPMI from a strengths rather than deficit perspective. Don’t patronise or pathologise them, nor presume they have or will develop mental health problems</td>
<td></td>
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<tr>
<td>• If appropriate, provide individual and/or group counselling and support which addresses ACOPMI-specific issues</td>
<td></td>
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<tr>
<td>• Provide support and education about effective parenting of ACOPMI’s own children, including the development of loving connections</td>
<td></td>
</tr>
<tr>
<td>• Provide respite and support with managing ACOPMI’s carer responsibilities for aging parents.</td>
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</table>
9.2.2 Notice the adult children

As this study’s findings have highlighted, parents exist within the context of their family. What affects one member impacts on all members, including children, and this can continue throughout their lives. Subsequently, this study found that adult children who have survived a childhood marked by serious parental mental illness often continue to experience ordeals. Being an adult does not mean that one is released from the stressors of having a parent with chronic mental illness. Adult needs are different, however, from those experienced as a child. They are:

- To have acknowledgement and respect for the impacts that their childhood may have had on their attitudes toward, and relationship with, their parents
- That even though they may have coped with their roles in the family, they may still appreciate and/or need support and the opportunity to debrief in a non-judgmental environment
- That they may often have a need to debrief and process their feelings about their parents from the past and the present without fear of being negatively judged or labelled
- That they have the right to develop their own lives without continuing to assume the role of carer, if they cannot or do not wish to.

Yet clinicians may not always be sensitive to these needs. The suggestions therefore, are that clinicians:

- Reflect on what it may have been like as a child and now an adult who has endured a lifetime of stressors with a parent who was often not consistently available to provide nurturance, guidance and friendship
- Make time to talk with, and listen to, adult children’s stories and experiences. Acknowledge their roles and respect their perspectives
- Appreciate adult children’s strengths and what they contribute to the family
- Ask the adult children of a client what supports they need
• Provide information specifically developed for adult children, including written material about the parent’s mental illness and/or audiovisual and computer resources that they can refer to as needed
• Use therapeutic approaches in individual and/or group settings which create the space for adult children to process feelings of loss, grief, anger, and resentment, and then seek to re-frame negative experiences and look for solutions to identified problems
• Support the relationship between parent and adult child, whilst recognising that the adult child has the right to decide how close the relationship should be.

9.2.3 Use a family approach

As noted at the beginning of this thesis in Chapter 1, many mental health services continue to take an individualistic approach to care of consumers (Aldridge & Becker, 1999) and clearly this is not appropriate when whole families, neighbourhoods and communities are involved. If we want to create meaningful change in how mental illness is understood, and reduce the negative impacts of it on adult children and families where parents have serious mental illness, it is important that mental illness is first and foremost understood as existing within the context of family and the community. As this study’s findings have illuminated, mental illness is not an individual problem. This means it is vital that clinicians routinely assess and respond to the family as a whole and move beyond a preoccupation with an individual’s mental state and treatment plan.

Furthermore, the findings of this study indicate that some ACOPMI could benefit from access to specific therapeutic programs and information addressing their particular needs and concerns. I recommend:

• support group programs specifically for ACOPMI be developed and offered across mental health services and support organisations in Australia, and, similarly to material which has been developed for COPMI, that ACOPMI-specific information is also developed and widely disseminated
in terms of therapeutic strategies for ACOPMI, multiple approaches are used. Complementary and alternative therapies, self-help groups, and solution-focused and narrative approaches to therapy are potentially very helpful additions or alternatives to conventional strategies such as psychotropic medications and supportive counselling.

9.2.4 Include A/COPMI in nursing practice

As health professionals, nurses constitute the largest percentage of the health care workforce (Iliffe, 2000) and unlike most other health professionals; provide twenty four hour care in many health settings. The diversity of nursing practice means that nurses are likely to work with children and families in a range of settings including inpatient and community adult mental health services and child and youth mental health, school settings, as well as paediatric settings and women’s health/perinatal services. Nurses therefore have a unique opportunity to identify and support children, adult children and families where parents have a serious mental illness. I recommend that nurses, particularly in these practice areas:

- routinely include COPMI, ACOPMI, and parents with mental illness in their nursing assessments
- seek to more fully understand the experience of being A/COPMI through listening to the stories that COPMI and ACOPMI have to tell
- provide information to A/COPMI regarding parental mental illness
- refer COPMI, ACOPMI, and parents with mental illness to further information and relevant services as appropriate.

9.3 RECOMMENDATIONS FOR POLICY AND EDUCATION

Current mental health policy and planning in Australia includes the recognition that a lifespan approach should be used to meet the needs of the population, that mental health promotion, prevention and early intervention are important, and that the needs of COPMI should be given the same attention as those of adult consumers and carers (Australian
Health Ministers, 2003). The findings of this study support these policies, and strongly emphasise the relevance and importance of using a lifespan approach for COPMI.

What appears to be lacking in current policy development, however, is the understanding of the plight of the family as a whole when a parent has mental illness. As discussed, a continued focus on individuals in mental health services fails to recognise the family context within which they live, grow and change. It treats mental illness as occurring in a disembodied way, distanced from the inter-connected nature of human experience. Whilst a family-focused approach is emphasised in COPMI-specific projects, literature and guidelines (see for example AICAFMHA, 2001; 2004) this approach also needs to be evident in changes to national mental health policy and service provision. Otherwise mental health professionals and services will continue attempting to effect changes within a system which does not support their endeavours.

The study findings further confirm the need to attend to all family members where parents have a serious mental illness including adult children. Further recommendations for policy and education are:

- That the needs of adult children of parents with mental illness are specifically recognised and included in mental health policy and guidelines for service provision, as they are currently not specified within these documents

- That lifespan issues and long-term inter-generational impacts for families are recognised and incorporated in current service provision policy to strengthen mental health promotion, prevention and early intervention

Accordingly, as mental illness impacts on every family member and across every sphere of social life, there is a need for a range of professionals to be educated on the needs of children, adult children, and families where parents have a serious mental illness. Many undergraduate curricula are already over-burdened with issues to cover, so alternative strategies may be more effective in educating a broad range of professionals as well as family members.
I recommend that:

- Specific educational resources in a range of media options to maximise access, be developed on the topic of adult children of parents with serious mental illness, as these are lacking at present. This includes a video/DVD incorporating adult children’s stories of their experiences and how they have coped with them. This could be aired on television to a wide audience, and/or accessed online, via computer, and/or video-player.

- The video/DVD could be accompanied by a resource manual which included further information, readings and activities to draw out issues and deepen understandings illuminated by these stories. This manual could be used by health and other professionals to work with adult children directly, and/or as a resource for professionals themselves, including nurses, doctors, social workers, welfare officers, psychologists, occupational therapists, and other health workers in a wide range of healthcare settings.

- Professional development, information and education on COPMI, ACOPMI and families where parents have a mental illness be specifically provided for general practitioners, as this study has found they are often the first point of contact for adult children as well as parents who may be experiencing mental illness.

- That COPMI, ACOPMI and family issues where parents have a mental illness be included as appropriate, in curricula for the education of preschool, primary, and high school teachers, who have significant opportunity to identify and support children and families where parents have a mental illness.

9.4 STRENGTHS AND LIMITATIONS OF THE STUDY

A particular strength of this study was the methodological approach. The thorough inclusion of the many studies of both COPMI and ACOPMI experiences in the literature review was unique, and subsequently informed the dual analytic approach taken in the
study. The dual lenses applied to the analysis of field text have uncovered multiple perspectives on the meanings some adult children of parents with serious mental illness have made of their experiences. This has added to, and developed, understandings from previous studies. This dual methodological approach allowed for diverse insights to be gained from the participants’ experiences. The resulting phenomenological themes in the first phase of analysis and interpretation have been compared with those of previous major studies and have therefore built upon and developed understandings which have been absent from the literature to date. The development of a postmodern narrative analysis and interpretation in the second phase of the study has added a new methodological approach to the issue, and resulted in fresh and alternative perspectives on a topic often viewed as difficult. This has added new understandings to current perspectives on the experiences of adult children of parents with serious mental illness.

The sampling process which gained participants from diverse backgrounds has also strengthened the study through recognising differences in experience that may occur for adult children of parents with serious mental illness, an important facet of postmodern research. The breadth of range in geographical location, age, and gender mix has combined to form a diversity of experience which has previously been lacking in some research. Through auto-ethnography, the inclusion of my-self as participant so that insider as well as outsider perspectives have been applied to analysis has strengthened the interpretive process. Given the lack of publication of some of the previous ACOPMI research, it is also anticipated that knowledge gained from the findings of this study will greatly enhance the wider understanding of the experiences of adult children of parents with serious mental illness and may be of significant benefit to current service provision for families where parents have mental illness.

The study is limited in that the inclusion of ten participant voices means that many more, and possibly differing, perspectives were not included. The findings are therefore limited to this particular group of adult children although they may resonate for other adult children. The participants in the study were primarily Anglo-Saxon and Australian, and so the findings are also not inclusive of cultural diversity.
9.5 POTENTIAL FOR FUTURE RESEARCH

As noted, one of the major strengths of this study was its emphasis on understanding experience through stories. In using auto-ethnography, the researcher’s story added to understandings of the use of story as a methodological approach, and illuminated the value of story as a vehicle for understanding previously hidden social issues. In this study, narrative inquiry and auto-ethnography have been powerful mediums for conveying the richness and diversity of participants’ experiences and I thoroughly recommend their use as innovative methodological approaches of value for future research into the experiences of children and families where parents have mental illness, as well as broader health and illness-related research.

In terms of future directions for research relating to children and families where parents have serious mental illness, I specifically recommend that:

- Further exploration of a more comprehensive group of adult children from various regions across Australia, especially those in isolated areas and from a broader range of cultural and ethnic backgrounds, would be helpful in addressing the diversity of experiences of parental mental illness and add to existing understandings.

- A study using a narrative inquiry approach be undertaken on the experiences and needs of indigenous Australian children and families where parents with mental illness, as the needs of this specific group have not yet been explored. The use of narrative inquiry may be seen as particularly appropriate for cultural groups who use storytelling as part of their cultural practices.

The findings of this study have suggested that experiences and coping related to parental mental illness may differ between children from the same family. I also recommend:
• Specific exploration of the subjective experiences and coping methods of child and/or adult child siblings could illuminate further understandings of possible reasons for differences in coping.

The experiences of the adult children in this study have also indicated that the influence of their other parent was a significant factor in terms of their overall experience. Due to the focus of the study, this issue was not specifically explored. As the partners of parents with serious mental illness are likely to have their own issues and experiences, I recommend that:

• Further exploration of the experiences of partners of parents with mental illness may add to understanding of other family members’ experiences and strengthen approaches in service provision which aim to meet the needs of all family members.

• Exploration of the inter-generational experiences of parents with mental illness, their partners, their adult children, and grandchildren, would shed further light on the impacts of parental mental illness across the generations and may assist in advancing understandings of attachment, resilience and the impact of narrative inheritance. This could involve a mixed methods approach, where tools for assessing attachment styles and measuring coping and resilience were combined with narrative inquiry so that subjective experiences were privileged.

There has also been relatively little emphasis on the experiences of male children and adult children of parents with mental illness. As the findings of other studies (e.g. Rutter & Quinton, 1984) and this study have highlighted, it seems they may differ qualitatively in some respects from those of female adult children. I recommend that:

• A comparative study investigating the experiences, coping methods and psychosocial outcomes for male and female children and/or adult children could shed further light on gender issues which may require specific attention.
• As the effects of depression with anger attacks was a prominent feature of the experiences of participants in the present study, further investigation into the impacts of this particular type of parental mental illness may also add to understandings and approaches to support of both parents and children.

In addition, there has been a lack of research to date which attends to the subjective experiences of children of parents with serious mental illness as they develop over time. My final recommendation is that:

• A longitudinal prospective study into adulthood of COPMIs’ attachment styles, subjective experiences, and coping methods could be helpful in ascertaining any changes/developments that may occur and add to existing understandings of the developmental impact of serious parental mental illness for the child. This could involve the application of a variety of specific tools to assess developmental aspects of attachment and coping, as well as following the experiences of children over time through use of narrative inquiry.

9.6 CONCLUDING REMARKS

It has been my privilege to conduct this study and contribute towards uncovering the experiences of adult children of parents with serious mental illness, who have been such a marginalised group in mental health service provision in Australia and elsewhere. The findings of this study provide an opportunity for this silent and silenced group to be recognised and supported in managing the experience of having parents with serious mental illness. The lessons that have been learned from the experiences of these adult children provide a rich and potentially instructive way forward for health and other professionals. Letting go of previous misperceptions and problem-based constructs, understanding the transformative power of stories, and implementing constructive support processes have the potential to contribute to positive and hopeful futures for adult children and families where parents have mental illness.

There are many ways forward. Now is the time to act.
REFERENCES


Australian Infant Child Adolescent and Family Mental Health Association. (2001). *Children of Parents Affected By a Mental Illness Scoping Project*. South Australia: Mental Health and Special Programs Branch, Department of Health and Aged Care.


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APPENDIX A
LITERATURE REVIEW SEARCH STRATEGY

In order to gain a comprehensive coverage of relevant research, the literature was searched widely for research relating to a number of aspects pertaining to children and adult children of parents with mental illness. Only references in English were sought. There were no date parameters.

**Search terms used and databases searched:**

- **Search terms:**
  Databases searched using these terms were:
  Proquest, CINAHL, Medline, PsycINFO

- **Search terms:**
  ‘adult children of impaired parents’, ‘adult children of parents with mental illness’
  Databases searched using these terms were:
  CINAHL, Medline

- **Search terms:**
  Databases searched using these terms were:
  PsycINFO, Proquest, CINAHL

- **Search terms:**
  Databases searched using these terms were:
  PsycINFO, Medline, CINAHL

**Other search processes:**

- Google search engine was searched using the terms ‘children of parents with mental illness’, and ‘adult children of parents with mental illness’

- Some references were gained from hand searching of particular journals and review of reference lists in key journal articles

- References were also gained from reference lists in reports and documents on Children of Parents with Mental Illness such as those produced from the Australian COPMI National Initiative
APPENDIX B

Information Sheet
Silent voices: an inquiry into the experiences of being an adult child of a parent with a psychosis

Chief investigator: Dr Margaret McAllister
School of Nursing, Nathan campus
Telephone: 07 3875 6460
Email: m.mcallister@griffith.edu.au

Assistant Investigator: Kim Foster
School of Nursing, Nathan campus
Telephone: 07 4042 1548
Email: kim.foster@jcu.edu.au

Background

You are invited to take part in a study exploring the experiences of being the adult child of a parent with a psychosis. This study forms part of the assistant investigator’s (Kim Foster) PhD requirements at Griffith University. Kim Foster is also a member of staff at James Cook University.

To date there has been little investigation into the issue of adult children of parents with psychosis. Whilst the broad topic of children of parents with mental illness has become researched and reasonably well-documented within the last ten years, there is relatively little understanding of how adult children of parents with psychosis have lived and coped with their experiences. This study aims to understand what it was like to grow up with a parent who had a psychotic illness and what sort of coping strategies people have used.

What participation in this study involves

If you participate in this study you will be asked to take part in an interview that explores your experiences of being the adult child of a parent with a psychosis. The interview will take approximately 60 – 90 minutes in a place of your choosing that is convenient for you. The interview will be audiotaped. A transcript of the interview will be sent to you for checking and you can edit or veto any information you have provided.

Consent to participate

Your participation is entirely voluntary and you are not under any obligation to participate in this research. If you decide not to participate in the study you will not experience any penalty. If you choose to participate you may discontinue your participation at any time without penalty or without providing an explanation. If you
discontinue from the study all information obtained from you will not be used in the study. This study, whilst it may not benefit you directly, may have the potential to provide insights into the experiences of adult children of parents with psychosis that may add to the knowledge base on this issue and assist health care workers to better meet the needs of this group as consumers and/or carers within the health care system.

Risk

It is possible that in sharing your experiences of being the adult child of a parent with a psychosis this may raise upsetting memories for you and/or have emotional effects such as anxiety or distress. You will be free at any time to choose not to answer questions and/or to discontinue the interview process. You will also be given contact details of the following counselling services and encouraged to contact them for support if needed:

Contact counsellor: Ms Lyn Roubos  
James Cook University Counselling Services  
Cairns campus  
Telephone: 07 4042 1150

Contact counsellor: Dr Jenny Promnitz  
James Cook University Counselling Services  
Townsville campus  
Telephone: 07 4781 4711

Confidentiality

Confidentiality for each participant is respected and guaranteed throughout all stages of the research project. In order to protect your privacy, you will be encouraged to choose another name for the purposes of the published research material. Names of relatives can also be changed to protect each participant’s privacy and confidentiality. Other identifying details such as occupation or geographic location will also be changed. The information collected from this research will therefore be reported using pseudonyms and any identifying details altered in order to protect your privacy. All information will be kept confidential and in secure storage at the principal investigator’s place of work (Griffith University) for a period of 5 years before being destroyed. You will be sent a report of the general findings from the study when it is completed.

You may contact Dr Margaret McAllister if you have any matter of concern regarding the study that you wish to discuss, or if you prefer an independent person you may contact the Manager, Research Ethics: Office for Research, Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, Telephone (07) 3875 5585 or email research-ethics@griffith.edu.au

Griffith University thanks you for your consent and participation in this research.
APPENDIX C

CONSENT FORM FOR PARTICIPANTS

Silent voices: an inquiry into the experiences of being an adult child of a parent with a psychosis

I have read the information form and understand that:

- This research is to explore the experiences of being the adult child of a parent with a psychosis as part of the assistant investigator’s (Ms Kim Foster) doctoral studies. I understand that the assistant investigator is also a member of staff at James Cook University.

- I am being asked to participate in an interview about my experiences of growing up with a parent who had a psychosis.

- The interview will take approximately 60 – 90 minutes and will be audiotaped. I will receive a transcript of the interview to check and edit or veto any information I have provided.

- My participation in this research is voluntary and I may discontinue my participation at any time without penalty or explanation.

- Any reports or publications from this study will be reported using pseudonyms and any identifying details will have been altered to protect privacy.

- The data will be kept confidential at all times and in a locked filing cabinet in the chief investigator’s office for a period of 5 years before being destroyed.

- A report about the study findings will be made available to me.

I have read the information sheet and the consent form. I agree to participate in this study and give my consent freely. I understand that the study will be carried out as described in the information statement, a copy of which I have retained. I realise that whether or not I decide to participate is my decision and will not incur any penalty. I also realise that I can withdraw from the study at any time and that I do not have to give any reasons for withdrawing. I have had all questions answered to my satisfaction.

……………………………………………………    ………………….
Name and Signature        Date
……………………………………………………    ………………….
Investigator Name and Signature      Date
APPENDIX D

Silent voices: 
the experiences of adult children of parents with a psychosis

WILL YOU SHARE YOUR STORY?

As part of my PhD in Nursing at Griffith University I am researching the experiences of adult children of parents with a psychosis from a variety of backgrounds, and am looking for people who are willing to share their stories with me. In providing an opportunity for your voices to be heard, I would like the work we do together to make a difference to health care workers’ and others awareness, understanding and support for people who have grown up with parents who had a psychosis. Your participation is appreciated. Without your involvement there are no stories to be shared.

The research will involve conversations with me, and then your checking and approval of the written transcripts of our conversation. Confidentiality and privacy will be assured. Each person may leave the research at any stage. Griffith University Human Research Ethics Committee has approved my research, and I am under the supervision of Dr Margaret McAllister, Associate Professor, School of Nursing Nathan, Griffith University and Dr Louise O’Brien, University of Western Sydney.

If you are interested in knowing more and can say yes to the following:

- Are you 18 years of age or older?
- Did you grow up with a parent or parents who experienced a psychotic mental illness such as:
  - Schizophrenia
  - Manic-depression (bipolar disorder)
  - Schizo-affective disorder
  - Delusional disorder
  - Drug-induced (substance use) disorder?
- Do you live in Townsville, Cairns or a surrounding district?
- Would you be willing to share your experience of growing up with a parent who had a psychotic mental illness in an interview of one to one and a half hours?

Please contact me by email: kim.foster@jcu.edu.au , or at work on 07 4042 1548 and if I’m not there leave a message giving your name and a contact number and I will contact you.

I very much look forward to hearing from you
With thanks, Kim Foster
APPENDIX E

Kim Foster
PO Box 6811
Cairns 4870 Qld

Hello ........................................

As we have discussed, and as part of the agreement we had for your participation in the study, I am sending you a copy of the original transcript of your audiotaped interview with me last year. You will see in the transcript that I’ve changed names and removed identification of institutions and places as necessary. You’ll also see that how we speak in ordinary conversation isn’t grammatically correct, and that sometimes there are pauses, ums, and other normal parts of speaking and conversation. These are fine and don’t need to be altered.

Could you please take some time to read through the transcript, and so that you feel the interview accurately presents what you want to say about the experience of growing up with a parent with a psychosis, feel free to make any of the following changes you want to by either writing directly onto the transcript itself, on the back of the sheet, or on a separate sheet:

- Are there any points that you want to change to more accurately reflect what you want to say about your experience?
- Is there anything else about your experience that you want to add?
- Is there anything you want to remove from the transcript?

Of course, it’s also fine if you don’t want to make any changes to the transcript. Once you’ve gone through the transcript and are satisfied that it presents what you want to say, could you please send it back to me (with or without any changes/additions) in the envelope attached? I will assume by you doing this that you agree to have your experience included in the study.

I really appreciate your time and involvement in the study, and once I have your transcript back, will start to do the analysis of all the interviews. I hope to complete the study by the end of this year, and will be sending you a report of the findings. If there’s
any information or assistance regarding Children of Parents with Mental Illness that I can give you, please don’t hesitate to get in touch with me. If you have any questions about the transcript or the study, please don’t hesitate to contact me either on kim.foster@jcu.edu.au or on 07 4042 1548.

Warm regards, Kim
Transformational possibilities: The mimetic spiral of narrative healing