School of Social Work and Social Policy

An Investigation of the Relationship between
Intensity of Grief and Coping Patterns
Of Parents of Individuals Affected by Psychotic Disorders

Kanthi Perera

This thesis is presented as part of the requirements for
The award of the Degree of Master of Social Work
Of the Curtin University of Technology

February 2003
Declaration

This thesis contains no material, which has been accepted for the award of any other degree or diploma in any university.

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

Signature: ....................................

Date: ........................................
# TABLE OF CONTENTS

ACKNOWLEDGEMENT .................................................................................. III

ABSTRACT ...................................................................................................... IV

CHAPTER 1: INTRODUCTION ...................................................................... 1

1.1 THE WESTERN AUSTRALIAN CONTEXT ............................................. 3
1.2 THE PROFESSIONAL CONTEXT ......................................................... 5
1.3 RATIONALE FOR THE STUDY ........................................................... 8
1.4 OBJECTIVES OF THE STUDY .............................................................. 9
1.5 RELEVANCE OF THE STUDY ............................................................. 10
1.6 LINKING RESEARCH AND PRACTICE WISDOM ............................... 12
1.7 METHODOLOGY ................................................................................ 18
1.8 THE STUDY DESIGN .......................................................................... 19
1.9 THE SETTINGS ................................................................................... 20
1.10 THE SAMPLE .................................................................................... 20
1.11 ETHICAL CONSIDERATIONS ............................................................ 21
1.12 MEASUREMENT PROCEDURE ........................................................ 22
1.13 VALIDITY AND RELIABILITY OF MEASURING SCALES ................. 31
1.14 DEVIATION FROM ORIGINAL PLAN ............................................. 32

CHAPTER 2: PSYCHOTIC DISORDERS, GRIEF AND LOSS .................. 33

2.1 NATURE OF PSYCHOSES ................................................................. 33
2.2 TYPES OF PSYCHOSES ................................................................. 34
2.3 A HISTORICAL REVIEW OF THEORIES OF AETIOLOGY ................. 35
2.4 GRIEF AS A CONCEPT ................................................................. 40
2.5 THE IMPACT ON PARENTS OF PSYCHOTIC DISORDERS IN CHILDREN 56
2.6 PSYCHOSES, GRIEF AND LOSS ..................................................... 61

CHAPTER 3: COPING WITH GRIEF AND LOSS ................................... 66

3.1 DEFINITION OF COPING ................................................................. 66
3.2 COPING RESOURCES AND PROCESSES ..................................... 67
3.3 COPING WITH GRIEF AND LOSS IN BEREAVEMENT ................. 68
3.4 COPING WITH GRIEF AND LOSS IN MENTAL ILLNESS ............... 70

CHAPTER 4: GRIEVING AND PSYCHOTIC DISORDERS IN A CROSS SECTION OF PARENTS IN WESTERN AUSTRALIA .......... 75

4.1 PROFILE OF RESPONDENTS AND THEIR CHILDREN AFFECTED .... 76
4.2 THE INTENSITY OF GRIEF IN THE PARENTS OF THE STUDY .......... 77
4.3 DO THE FINDINGS OF THE PRESENT STUDY REPLICATE INTERNATIONAL STUDIES? ................................................................. 92
TABLE 1: CATEGORISATION OF COPING ................................................... 27
TABLE 2: MURRAY’S INDIVIDUAL PHASES............................................. 45
TABLE 3: DESCRIPTION OF FEELINGS AT TIME OF DIAGNOSIS AND AT TIME
OF STUDY .................................................................................................. 78
TABLE 4: GRIEF REACTION GROUPS OF FASHINGBAUER ET AL (1977) .... 87
TABLE 5: RELATIONSHIP BETWEEN LEVEL OF PAST BEHAVIOURS AND
LEVEL OF PRESENT GRIEF................................................................. 88
RESPONSES (BY PER CENT) ............................................................... 93
MIV-TIG - PART 1 (PAST BEHAVIOURS) .............................................. 93
TABLE 7: COMPARISON OF THE STUDY OF MILLER (1990) & PERERA
(2002), RANK ORDER OF “COMPLETELY OR MOSTLY TRUE”
CATEGORY ........................................................................................... 94
RESPONSES (BY PER CENT) ............................................................... 96
RANK ORDER OF “COMPLETELY OR MOSTLY TRUE” CATEGORY ..... 98
TABLE 10: CORRELATION ANALYSIS OF CHARACTERISTICS OF THE
DISORDER OF CHILDREN AND PRESENT LEVEL OF GRIEVING OF
PARENTS ............................................................................................... 103
TABLE 11: FREQUENCY OF THINKING “HOW THEIR CHILD COULD HAVE
BEEN IF NOT FOR THE DISORDER” AT TIMES OF EXACERBATION ..... 104
TABLE 12: COPING STRATEGIES CONSIDERED AS MOST HELPFUL BY
PARENTS .................................................................................................. 108
TABLE 13: FREQUENTLY USED METHODS OF COPING GROUPED INTO
CATEGORIES ........................................................................................... 113
TABLE 14: FREQUENTLY USED FOCUSES OF COPING GROUPED INTO
CATEGORIES ........................................................................................... 115
TABLE 15: LEVEL OF PRESENT GRIEF AND METHOD OF COPING ........... 121
TABLE 16: LEVEL OF PRESENT GRIEF AND FOCUS OF COPING ............ 122
TABLE 17: GENDER DIFFERENCES IN GRIEF/PRESENT FEELINGS OF GRIEF
(GROUPED) ........................................................................................... 125
TABLE 18: GENDER DIFFERENCES IN METHOD OF COPING (1) ............. 126
TABLE 19: GENDER DIFFERENCES IN METHOD OF COPING (2) ............. 126
TABLE 20: GENDER DIFFERENCES IN FOCUS OF COPING .................... 127
TABLE 21: GENDER DIFFERENCES IN COPING STRATEGIES ............... 128
FIGURES

FIGURE 1 - BRIDGES OF PRACTICE WISDOM ........................................... 17
KLEIN W.C. & BLOOM M (1995) ................................................................. 17

FIGURE 2: PAST BEHAVIOURS OF GRIEF/TIME SINCE DIAGNOSIS ....... 82

FIGURE 3: PRESENT FEELINGS OF GRIEF/TIME SINCE DIAGNOSIS ...... 84

FIGURE 4: PRESENT LEVEL OF GRIEF (MEAN)/AGE OF
RESPONDENT/GENDER ........................................................................... 85

FIGURE 5: GRIEF REACTION GROUPS ....................................................... 87

FIGURE 6: METHOD OF COPING GROUPED ............................................ 114

FIGURE 7: FOCUS OF COPING GROUPED ............................................. 115
I gratefully thank all of those persons who have assisted and supported me in this study, “An Investigation of the Relationship between Intensity of Grief and Coping Patterns of Parents of Individuals Affected by Psychotic Disorder”.

I would like to thank:

- The many parents who gave of their time to participate in this study. A special thank you to Mr and Mrs C.D. and Mrs B.C. for assisting with the testing of the research tool.
- Dr Don Chandraratne for his invitation to make application for study towards a Master of Social Work degree.
- Dr Ranjit Kumar for initial academic support as supervisor.
- Dr Trevor Lee who took on this responsibility upon Dr Kumar’s resignation from Curtin University of Technology. Dr Lee’s patience and flexibility together with his knowledge assisted me adapt to the “loss” experienced by Dr Kumar’s resignation half way through the project.
- Julie Dickinson for academic support and her practice wisdom.
- Dr Frederick Miller, Director of Psychiatry, Evanston Health Service, North Western University, Chicago for the loan of the Mental Illness Version of the Texas Inventory of Grief, his valuable feedback and practice wisdom.
- The family counsellors of A.R.A.F.M.I. for feedback and practice wisdom.
- Joanne Thorpe, David Shub, Lindy Hall and Jill Hawkins (social workers), Tracey Harrison and Nada Murphy (Clinical Psychologists), Dr Siri Galheneghe and Dr Bridget McManus (Consultant Psychiatrists) who assisted me with the categorisation of the Coping with Grief/Sadness-Self Assessment Scale.
- Jenny Lalor from the Centre for Educational Advancement, Curtin University of Technology for her assistance with data arrangement.
- Pamela Kodituwakku for her assistance with typing questionnaires and measurement scales.
- Marjory Taylor and Robyn Hull from the Psychiatric Services Library, Health Department of Western Australia for their assistance with literature searches.
- My son Gehann, for his patience and encouragement throughout the two years of this study.
Abstract

This study investigated the relationship between intensity of grief and coping patterns of parents of individuals affected by psychotic disorders.

The study investigated the intensity of grief in a sample of parents of individuals with psychotic disorders in Western Australia to determine if the results replicate international studies. It further examined if the characteristics of the psychotic disorders of children, had an impact on the grief reactions of parents and if the disorder had a measurable impact on the nature of the relationship between parents and children.

The study also identified specific coping strategies that parents consider as being most helpful to them in dealing with their grief, the relationship between intensity of grief and coping patterns of respondents and gender differences in grieving and coping strategies.

The research findings suggest that there is measurable grief in a cross section of parents of individuals with psychotic disorders in Western Australia with many similarities to studies done internationally. The findings also suggest that this grief increases in intensity from the time of first diagnosis and peaks at 1-2 years after diagnosis and again 20 years after diagnosis. There was a strong association between past behaviours related to grief reactions and present feelings related to grief. To the best of my knowledge, these findings have not been reported before.
Certain characteristics of the disorder of children had an impact on the grief reactions of the parents. Higher levels of grief were reported in parents whose children needed frequent assistance with personal care and children with a late onset of the disorder. There was a positive correlation in parents who had a close relationship with the child before the onset of the disorder and following onset of the disorder suggesting that the disorder did not affect the relationship. To the best of my knowledge, these findings have not been reported before.

While this research has replicated other studies, it has also researched coping strategies that have not been identified before. Although cognitive coping strategies were most frequently used by parents and subjectively found to be more helpful, parents using predominantly behavioural methods of coping showed less intensity in their grief. Parents oscillated between approaching the feelings of grief and distracting themselves from them, which highlighted the idiosyncratic nature of coping. Although there were no gender differences in the intensity of grief, there were distinct differences in coping strategies used by fathers and mothers.

These findings have important implications for social work practice and policy development within the mental health settings of Western Australia.
CHAPTER 1: INTRODUCTION

This thesis is a study of grief and coping by parents when a child develops a psychotic disorder. The thesis was undertaken to determine if grief exists in a cross section of parents of individuals with psychotic disorders in Western Australia. The second broad dimension of this research looked at the coping processes of these parents as part of the responses to the psychotic disorder of their child.

The 1993 National Inquiry into the Human Rights of People with Mental Illness highlighted an issue, which is central to this research:

Numerous carers spoke of a sense of continuing bereavement almost more painful than the loss of a loved one through death, since:

“It is an ongoing trauma, you lose your son during the illness but ... you can’t sort of grieve and [then] think you’ve got your life back again. Every time he goes into hospital we grieve all over again”

Carers described sadness and despair when they recalled what the patient had been like before the illness; some spouses experienced a sense of loss as if they had been ‘physically bereft of the person they had married’.

“Try to imagine our shock when, at the age of 18, our son develops symptoms of a mental illness. Try to imagine the grief that struck our family when this wonderful, active person with so much ability and potential for a good life was ‘crippled’ mentally”.

Report into the National Inquiry into the Human Rights of People with Mental Illness, (1993 page 469)
As a social worker working with families in the Mental Health Service, one hears such responses often, reflecting the complex nature of mental illness.

The first quotation of a parent reflects the cyclical nature of mental illness. Though each episode of sadness may resolve over time, renewed recognition of the losses at times of relapse and at times when the child is unable to achieve a developmental milestone may trigger this grief reaction again. This describes a grief reaction, which is in contrast to the traditional linear, time-bound mourning described by Kübler-Ross (1969) in her seminal work on *Death and Dying*. It describes a cyclical model based on the assumption that families undergo a series of recurring stresses in relation to a child’s mental illness that forces them through a process of continual adjustments.

The second quotation reflects grief brought on by the unexpected changes to a child’s personality and the loss of hopes and wishes that follows. The study of Lewine (1988) found that psychotic disorders generally occur after puberty, with peak age of onset in the early to mid-twenties for males and mid-to late twenties for females. Rutter (1980) states that the developmental changes of the puberty period are greater than those of any other period apart from early infancy. Major changes occur in the domains of social, emotional, physical and cognitive development that determines outcomes in adulthood. Identity formation and the establishment of independence are core developmental tasks at

---

1 For convenience the term “child” is used in a broad sense to represent the offsprings of all respondents and does not mean “juvenile”.
this time (Rutter, 1980). A young adult may not be able to consolidate these changes if he or she has to cope with a mental illness.

1.1 The Western Australian context

One in five adults are estimated to have a mental disorder with young adults 18-24 years having the highest prevalence rate of one in three (Australian Bureau of Statistics 1997). The care of people with early symptoms of mental disorders attracted increased attention in the 1990s, with realisation that early recognition of symptoms and effective intervention may improve the long-term outcome.

From November 1995 to December 2001, I was responsible for setting up the Early Intervention in Psychosis Service at the Fremantle Hospital and Health Service in Western Australia. This was a specialised service for people aged 18-40 years who presented to the service with early symptoms of a psychotic disorder. In order to reduce trauma of hospitalisation and prevent institutionalisation, a philosophy was adopted to treat these young people, wherever possible, within their own environment. From practice wisdom, I realised that the majority of these young people lived with their parents. Family Sensitive Practice was therefore an integral part of the service. Each of the clinicians working in a case management role was expected to attend the skills development course in Family Sensitive Practice (Perera, 2001), offered as part of the Advanced Clinical Skills in Mental Health Course of the Fremantle Hospital and Health Service.

Any system of healthcare is a product of its history and exists within a certain environmental and cultural context. The reduction of hospital beds in Western Australia started with Heathcote Hospital closing down
in 1993 and Graylands Hospital\(^2\) reducing the number of beds throughout the late 1990s. The Report of the Committee on Resources for Community Services of the Ministerial Taskforce on Mental Health in Western Australia (1996) regarded the lack of resources in the community and the imbalance between the resources allocated to community-based and hospital care as one of the highest priorities for attention. Therefore it can be deduced that the money saved by reducing hospital beds has not been invested in community services. Within the practice-setting, mental health practitioners in Western Australia realised that prevention of hospitalisation was not only to reduce trauma and institutionalisation to patients but also to save costs to the government. As such it appears that the cultural context of the healthcare system of Western Australia is one of economic rationalism.

Although there are policy documents about prevention and early intervention and holistic approaches to clinical practice (Smith et al, 1996), the paucity of resources allocated to mental health services has not given practitioners the opportunity to put these policies into practice. For example, family education and support programs are offered to carers in some services but there are no formal programs to address issues of loss and grief in parents. To the best of my knowledge, the Association for the Relatives and Friends of the Mentally Ill (ARAFMI) is the only organisation offering a formal program for parents to address issues of loss and grief. They run an annual workshop and their *Share and Care Groups* facilitated by carers also gives participants the opportunity to discuss such issues within a group context.

\(^2\) Major mental health hospitals in Western Australia
1.2 The Professional context

In the 10 years I have been working in mental health services, I have often grappled with the question, “how can I best assist these parents to cope with their grief?”

Brown et al’s (1972) study of expressed emotion together with findings that 30-40 per cent of patients with schizophrenia relapsed on medication fuelled many of the psychosocial family intervention programs (Lam, 1991). They speculated (quite early in their writing history) that high expressed emotion is related to a relative’s lack of knowledge about the illness.


1. Psychotic disorders were regarded as an illness.
2. The family was not implicated in the aetiology of the illness but enlisted as therapeutic agents.
3. Psychosocial interventions were offered as a treatment package in conjunction with routine anti-psychotic drug treatment.

The aims were to prevent relapse and improve the patient’s level of functioning. Although formal evaluation of these groups was not undertaken, practice wisdom told me that relatives’ subjective feelings of being more knowledgeable about psychosis could lead to improvement in the cognitive mastery of coping and hence reduce feelings of uncertainty, helplessness and hopelessness.
In his article *The Role of Relatives*, MacCarthy (1988, pp 207-277) argues that although knowledge is essential for understanding, planning or seeking assistance, providing information or education to relatives is also a moral issue. However, as time went by I understood that knowledge alone could not reduce the pain of loss. Most family education programs did not acknowledge that relatives are individuals in their own right and had their own pain and needs. Families of people with mental disorders have sometimes been seen as part of the patient’s disorder and sometimes as part of the treatment process, but rarely have their own psychological needs been given consideration.

Therefore my hypothesis in setting up subsequent programmes was, to be successful in empowering people, firstly we need to acknowledge their emotional experience of loss and grief and support them in their mourning (Perera, 1994). Miller (1996), further supported this hypothesis by suggesting that grief-therapy is a potentially appropriate complement to existing approaches to psycho-education. In order to offer grief therapy, practitioners need to understand the nature and various complexities of such grief.

Mevik (2001) quoting Gunn Engelsrud said the following during her lecture at a research symposium;

“Research is associated with the hunger for knowledge, pleasure in one’s work, and enthusiasm in gaining new scientific terrain”.

She goes on to say

“Research is associated with a presentation of this knowledge to a community which evaluates it, and may be
able to use it. The community involved is often a research community, but may also be a practical community”.

Researching grief and coping is quite complex. There are many theories and approaches to grief. Murray (2001) compares the many theories of grief as seen in the literature over the years as,

“Not a single definitive explanation but an evolving painting that begins as a set of loosely organised outlines to which each thinker and each new study adds a colour or a form towards a growing clarity of what was always known in the mind of the artist, in the experience of the griever.”

I believe studying grief in situations other than by death may increase our knowledge of grief and “add a colour or a form” to the evolving “painting”. By studying the losses incurred as a result of mental illness, it is hoped that knowledge on loss and grief experiences in mental illness will also be included in such a “painting” and as a result practice skills will be enriched.

Since the 1960s, the practice of community care and deinstitutionalization of people with mental illness has steadily grown (Agnetti and Barbato, 1991). With this trend, some of the care of people affected by mental illness has transferred to family members (Bloch et al, 1995). A complementary relationship between parents and healthcare professional in mental health services is crucial for the success of community care.
Following discussion of the rationale and the objectives of the study, I will discuss the relevance of the research and its links to practice wisdom. Details of the methodology, the study design, the setting, the sample, ethical consideration, measurement procedures, validity and reliability of measuring scales and deviations from the original plan will also be discussed in this Chapter. The broader literature related to psychoses, grief, loss and coping will be reviewed in Chapters 2 and 3.

1.3 Rationale for the study

The National Mental Health Plan (1992), National Mental Health Policy (1994) and National Standards for Mental Health Services (1997) recognise the importance of including family carers of people with mental illness in patient treatment, service development, management and evaluation. However the model, which has historically informed mental health, is largely focussed on the health needs of the individual. In contrast, the perspective of social workers in mental health practice is broader, taking into account the contribution of all aspects of a person within their social context. Capra (1982) says that by concentrating on smaller and smaller fragments of the body, modern medicine often loses sight of patients as human beings. Mental illness involves a complex interplay among the physical, psychological, social and environmental aspects of the human condition.

A study by Bland and Harrison (1995) shows that almost half the patients with schizophrenia discharged from hospital went to live with family members, mostly parents (60%), spouses (30%) and other family members such as siblings, children or grandparents. According to Bernheim et al (1979) over one-third of people with schizophrenia live
with their aging parents. With the rise of health care costs and dwindling of public resources, the above percentages are expected to increase.

The research I have undertaken for this dissertation addresses the current gap in psychosocial transitional adjustments. To the best of my knowledge, non-one else has undertaken such research in preventative mental health of caregivers. This is an important aspect of the National Mental Health Strategy (1992-1998; 1998-2003) the aims of this Strategy being to:

- Promote the mental health of the Australian Community
- Prevent the development of mental health problems
- Reduce the impact of mental disorders on individuals, families and the community
- Assure the rights of people with a mental illness

Researching and understanding grief by working with parents can be a direct contribution by social workers to promoting positive mental health. Further, the research will contribute to knowledge of the interactions that occur between biological, psychological and social factors in people’s lives. The increased knowledge will also assist mental health services develop good practice guidelines to target interventions to restore areas that have been disrupted by psychotic disorders and maximise mental health and well being among parents of the mentally ill.

1.4 Objectives of the study

This study on grieving and coping amongst parents of individuals with psychotic disorders contains six broad objectives. These are:
1. To investigate the intensity of grief in a sample of parents of individuals with psychotic disorders in Western Australia and determine if the results replicate international studies.

2. To examine
   a. characteristics of the psychotic disorders of children which may impact on the present grief reactions of parents, and
   b. the strength of the relationship between parents and children before and following onset of the disorder.

3. To identify specific coping strategies that parents consider as being most helpful to them in dealing with this grief.

4. To examine the relationship between intensity of grief and coping patterns.

5. To identify gender differences in grieving and coping strategies used.

6. To identify the implications of these results for social work practice in mental health services.

1.5 Relevance of the study

With a social work education, my practice embraces a systems view, which looks at the world in terms of relationships and integration. Wood (1996) traces the origins of social work with families from the profession’s beginnings in the late Nineteenth century and examines how Social Work, from these beginnings, emphasised the need to view people and their distress in a contextual and interactional way.

Harries (1999) identifies 3 principles that must at all times be at the forefront of thinking and practice in social work:
1. Social workers need to learn about and value the lived experience of consumers and carers.

2. Social workers should recognise and value the healing potential in the relationship between consumers and service providers and carers and service providers.

3. Social workers should recognise and value the ongoing potential for recovery of people within the mental health system.

Harries (1999, p.57-58) further says, 

“Whilst these affirmations appear pivotal intuitively to good social work practice, the challenge they present is an ability to work constantly at the interface between the lived experience of the people social workers serve and knowledge that is informed by multiple lived experiences, as well as research”.

Bland (1995) says that while much of the formal policy in mental health, group consumers and carers in a way that suggests they are one group with common issues, it is important to recognize the diversity of interests so represented. The family self-help and advocacy movement developed quite separately from the consumer movement, and the needs and demands of carers and consumers have distinct differences as well as similarities. (The Development of Competency Standards for Mental Health Social Workers, September 1999).

From my own practice, I have observed that understanding high ‘expressed emotions’ in family members as a grief reaction may enhance social work communication with carers and facilitate therapeutic intervention. Miller (1991) supports this statement when he says that, although grief is only one dimension of a family’s reaction to the
psychological changes in an ill relative, it may explain various affective and behavioural phenomena in the family. The present research is undertaken in an attempt to broaden social work knowledge of the particular lived experience of carers and in particular parents of people with psychotic disorders

1.6 Linking research and practice wisdom.
Kirby and McKenna (1989) define research as a means of gathering, making sense of information and acting responsibly with that information. They define method as a way in which we gather the information and analyse it. Epstein (1996) says that for decades social work educators like him have struggled to integrate research methodology and research-based findings into social work practice. He says this was in an attempt to enhance the knowledge base of social work and to promote the effectiveness and efficiency of social work practice. He goes on to say that the decades of epistemological words between social work educators has provided little more than qualitative and quantitative segregation.

In 1998 all Australian Health Ministers made a commitment to collect outcome and casemix data on a routine basis in all public mental health services. The National Mental Health Strategy (1998-2003) states:

*Quality, effective mental health services require improved consumer outcomes across the life span. Identifying and agreeing on service delivery and clinical practice standards, as has begun through the development of the National Standards for Mental Health Services (Australian Health Ministers Conference, 1996) are critical first steps in monitoring and evaluating quality and effectiveness. Establishing benchmarks and identifying models of best practice ensures continuous quality improvement. Evidence-based practice is encouraged, however incentives need to be provided to support innovative clinical practice.*
In Western Australia, the Mental Health Division circulated Issue 1 of the Newsletter of the Clinical Training Project, *Good Outcomes*, in April 2002. According to this newsletter (p. 2) The Clinical Training Project is designed to:

- Deliver training to Mental Health Clinicians in the use of outcome measurement
- Ensure the adoption of continuous quality improvement in the clinical setting.
- Enhance the relationship between consumer, carer and clinicians.
- Enable consumers’ health status to be monitored by consumers and clinicians alike.
- Ensure routine outcome measurement is integrated into clinical practice and processes.
- Inform clinical practice and assist in monitoring consumers’ mental state.

The Mental Health Division sees this project as benefiting consumers and carers as it will provide a point of feedback and dialogue to evaluate the treatment they receive. They say,

*...for clinicians, routine assessment of consumer outcomes will be used to evaluate the effectiveness of the care or treatment provided and to monitor the consumers’ progress. Outcome measures are seen to provide more quantitative information to support clinical judgement.* (Good Outcomes, April 2002, p. 3).

At the broader system level, outcome data will be used to inform a variety of other processes that guide policy, service development and developing a casemix model. They say,
“At present the information obtained is inadequate to guide policy development or to assist mental health services in service development. The data obtained will provide information on the needs of those people living with mental illness. (p. 3)

Klein and Bloom (1995) offer a conceptual scheme for integrating practice wisdom and empirically based practice. Epstein (1996) sees this as an opening to epistemological change and a peace offering to the paradigmatic other. Klein and Bloom (1995) suggests that well-developed “practice wisdom”, as it is defined in their article, offers the opportunity to draw from empirical research, theory, direct practice experiences and personal subjective views in a comprehensive approach to recognising and applying knowledge.

These authors reconceptualise practice wisdom as “an integrating vehicle for combining the strengths and minimizing the limitations of both the ‘objective’, or empirical, practice model and the ‘subjective’ or intuitive-phenomenological, practice model in the development of efficacious knowledge in social work”. They define practice wisdom as a “personal and value-driven system of knowledge that emerges out of the transaction between the phenomenological experience of the client situation and the use of scientific information”. They say that “the result of this transaction is tentative, often unarticulated knowledge that forms the basis for on the spot practice hypotheses that enable progress to be made on a case in the absence of fully tested methods” Klein and Bloom (1995, p. 799).

Similarly Middleton and Raphael (1987) argue that for mental health professionals to offer intervention to the bereaved who potentially may
benefit from skilled intervention, there needs to be considerably more science merged with the current state of the art. They make reference to the personality theory of Kelly. They say Kelly’s theory of Personal Constructs was built on his conviction that all persons behave “as if” they are scientists and out of a fundamental human need to understand the world, create and test hypotheses about the behaviour of significant others.

Middleton and Raphael (1987, p. 329) say,

“*In the case of bereavement, it is probably impossible to clearly separate the art of those that observe and work with the bereaved from the way in which such “art” forms the basis of scientific evaluation. Lest the meaning of “art” appears to be straightforward, they say it is useful to ponder the words of Aristotle, the greatest philosopher and scientist of the ancient world, who, among other things, originated the study of formal logic.*

“The aim of art is to represent not the outward appearance of things, but their inward significance; for this, and not the external mannerism and detail, is true reality”.

Murray (2001) argues that the very best practitioners in the area of loss and grief are those who both treasure and combine the art and the science of what they do. She says that by using the knowledge generated by science to challenge our practice and offer us hypotheses concerning the grief of those for whom we care, we can enhance the art of what we do.

The impetus for this research study rose from *practice wisdom* developed through working in the mental health service over the past 10 years. The incomplete understanding that resulted from previous empirical work
(Miller et al 1991, Atkinson 1994 and Solomon and Draine 1996),


This study will follow the model suggested by Klein and Bloom (1995) in Figure 1 of *The Bridges of Practice Wisdom*. It will *challenge the scientific problem, test the hypothesis and gain new knowledge* with a view to confirming pre-existing subjective and objective knowledge. Klein and Bloom (1995) say that practitioners are ethically bound to use the best available information to guide practice decisions. This study will be built on the empirically validated knowledge base of loss and grief by incorporating the practitioner’s qualitative experience of the client-worker relationship. The practice hypothesis is that there is measurable grief in parents of people with psychotic disorders. It is envisaged that knowledge gained from this study could then be presented to a community of mental health practitioners for the *challenge of practice problem* and *testing of mini-hypotheses.*
FIGURE 1 - BRIDGES OF PRACTICE WISDOM
1.7 Methodology

Kumar (1996) classifies research from three perspectives: the application, the objectives in undertaking the research and the type of information sought. However, he goes on to say that these three classifications are not mutually exclusive – that is, a research study classified from the viewpoint of ‘application’ can also be classified from the perspectives of ‘objectives’ and ‘type of information sought’.

From the above perspectives, this study is classified as *applied research*. Kumar (1996) says that most of the research in the social sciences is applied. The research techniques, procedures, and methods that form the body of research methodology are *applied* to the collection of information about various aspects of the phenomena of grief in parents of people with psychotic disorders so that information gathered can be used in other ways – such as for understanding of the phenomena, clinical practice and policy formulation.

The study is classified as *descriptive* as it will attempt to describe systematically the phenomena of grief as such parents experience it. It is also *correlational* research, as it will attempt to discover or establish the existence of a relationship between two or more aspects – i.e. to examine characteristics of the psychotic disorders of children which impacts on the grief reactions of their parents and also to examine the relationship between intensity of grief and coping patterns.

The third perspective relates to the *type of information sought*. The study takes a combined approach as it attempts to quantify the variation of the phenomena of grief in parents of people with psychotic disorders by incorporating the practitioner’s qualitative experience of the client-
worker relationship. The research questions grew out of a well-nurtured understanding of the contexts in which practice exists. As Klein and Bloom (1995) conclude, theory development and hypothesis testing are at their best when they draw from the rich experience of the practice world.

1.8 The Study Design
Bonanno and Kaltman (1999) say that bereavement researchers have used both cross-sectional and longitudinal designs. Although cross-sectional designs do not allow for examination of predictor variables, it has proved useful in identifying the phenomenological features and correlates of grieving at different points in the mourning process.

This study takes the form of a ‘Before-and-After’ study, in that two sets of cross-sectional data were gathered on the same population to find out the change in the phenomenon between two points in time. A self-report questionnaire gathered data on the behaviour of parents in relation to their grief at the time of diagnosis of the psychotic disorder in their child and their feelings in relation to their grief at the time of the study. In many ways, a longitudinal study would be preferable, as it would enable one to follow the same individuals over a 15 or 20 year period. However, this was beyond the scope of this study in terms of time and resources.

It is a retrospective study in that it investigates the phenomenon of grief on the basis of respondents’ recall of the situation. It takes the form of a non-experimental study in that the researcher started from the effects (grief) and is attempting to determine if it replicates previous studies. As one of the objectives was to determine if it replicates international studies, a quantitative study was chosen so that the same methodology may be followed, mainly that of Miller et al (1990). It is acknowledged
that for some respondents the time of diagnosis of a mental illness of their child may be longer and for others it may be shorter. This will be taken into account when analysing the data. It is also a cohort study in that it is based upon the existence of a common characteristic in the study population – parents who have a child diagnosed with a psychotic disorder.

1.9 The Settings
Participants were recruited from biological parents of people presenting to adult inpatient and outpatient services of the Directorate of Mental Health Services of Fremantle Hospital & Health Service (FH&HS), Rockingham/Kwinana and Peel Mental Health Services and members of the Association of Relatives and Friends of the Mentally Ill (ARAFMI).

1.10 The Sample
The period of recruitment was 1 July to 31 December 2001. Due to time and budgetary constraints a sample size of no more than 100 was planned.

Recruitment was by self-selected quota sampling. Members of the geographical teams were informed of the study by the researcher at team meetings. They were given written information (Appendix A) about the study so that they could discuss it with parents of their clients. A notice was placed in the newsletter of ARAFMI about the study (Appendix B).

Case Managers/key workers collected names and telephone numbers of parents interested in participating which were then given to the researcher. The researcher then contacted each of these parents by telephone. The parents were given a verbal explanation of the aims and
objectives of the research. Parents who agreed to participate were sent written information of the research together with a consent form (Appendix C) to be filled in. A stamped addressed envelope was attached. When the consent form, duly filled and signed was returned, participants were sent the questionnaires (Appendix D, E-1, E-2, and F) with an attached stamped envelope.

This being a voluntary study, the sample is expected to have some bias, as the experience of parents who volunteered to participate may be different to the experience of those who did not volunteer. As there was no consolidated register of parents in mental health settings, there was no suitable sampling frame from which parents could have been selected randomly. As such, the findings cannot be generalised to the total population of parents with children who have a psychotic disorder as the individuals included in this study may have had characteristics that were unique to them and not necessarily a truly representative of the broader population.

1.11 Ethical Considerations

The study proposal, copies of written information to parents, consent form and questionnaires were submitted to the Human Research and Ethics Committees of Curtin University of Technology and Fremantle Hospital and Health Service. This process ensured that the study design and measures safeguarded the participants and met compliance standards. No identifying data was requested in the questionnaire. Participants retained the right to withdraw at any time.

It was possible that participants may have experienced increased grief reactions or interpersonal conflict in relation to the information requested
in the questionnaire. An agreement was obtained from case managers/key workers of the clients who knew the parents participating to be available for parents should they experience any distress or interpersonal conflict. Family counsellors of ARAFMI agreed to be available should the need arise.

It has been agreed that following examination of the thesis, a written or verbal presentation of the findings of the study will be made to both parents and case managers upon completion of the study. A copy will also be given to the Psychiatric Services Library of the Health Department of Western Australia.

1.12 Measurement Procedure

Participants were required to fill in three questionnaires.

The first questionnaire (Appendix D) contained 22 questions of demographic information divided into seven parts.

The first and second parts sought personal characteristics of respondents, to establish if there is a relationship between the intensity of grief and some personal backgrounds of parents. The third part sought information about the characteristics of the psychotic disorder to establish if there was a relationship between the intensity of grief and characteristics of the disorder.

The fourth part sought information to establish if there is a relationship between the intensity of grief and characteristics of the disorder of the child. The fifth part sought information relating to the nature of the
respondents’ relationship with their child to establish if there is a relationship between the extent of grief and nature of a relationship.

The sixth part sought information relating to the respondents’ feelings at the time of diagnosis of psychotic disorder in their child and feelings at the time of responding to the questionnaire. The purpose of these questions was to establish the changes in feelings experienced by parents over a period of time. The seventh part sought respondents’ subjective experience of how they were coping with their grief at the time of responding to the questionnaire.

The second questionnaire was the Mental Illness Version of the Texas Revised Inventory of Grief (MIV-TIG) adapted by Miller et al. (1990). It contained two parts (Appendix E-1 and E-2). Both parts contain categorical three-directional Likert scales. Part 1 (E-1) contained eight questions seeking information of respondents’ past behaviours relating to the grief experience. Part 2 (E-2) contained 16 questions seeking information of respondents’ present feelings relating to the grief experience.

Although many coping scales were cited in the literature such as Ways of Coping (Folkman, Lazarus et al. 1986), Coping Health Inventory for Parents (McCubbin et al, 1979), these scales did not reflect the unique problems associated with mental illness. Therefore a questionnaire entitled Coping with Grief/Sadness – Self Assessment was specifically developed for this study (Appendix F).

Using McCubbin et al’s (1979) Coping Health Inventory as a guide, a scale with 45 coping strategies was used to develop the new scale. The
strategies incorporated were those that were identified from practice wisdom to be commonly used by parents in coping with their distress of having a child diagnosed with a psychotic disorder. This was named *Coping with Grief/Sadness – Self Assessment*. This was circulated among four social workers working in Mental Health clinics and hospitals and three counsellors working for the Association of Relatives and Friends of the Mentally Ill (ARAFMI). Following feedback from these clinicians, the scale was amended and reduced to 36 strategies.

The new scale was then distributed among three parents who had a child with a psychotic disorder and their feedback for ease of reading/completing the questionnaire was incorporated.

The failure to incorporate strategies that people utilise to distract themselves from painful emotions such as consuming alcohol, cigarettes, and prescribed and non-prescribed medication was a major omission. These are not strategies people often talk about; nevertheless they do give clinicians an understanding of coping processes.

Moos & Schaefer (1993) say that although no single method for categorising coping processes has yet emerged, most researchers have used one of two main conceptual approaches to classify coping processes. One approach emphasises the *focus* of coping; a person’s orientation and activity in response to a stressor. An individual can approach the problem and make active efforts to resolve it or try to avoid the problem and focus mainly on managing the emotions associated with it. In the development of this scale the word “distraction” was considered to be more appropriate for the strategies that parents use to cope with their grief rather than the word “avoid”. A second approach
emphasises the *method* of coping people employ, whether a response entails primarily cognitive or behavioural efforts.

The above two approaches of Moos and Schaefer were combined to develop a more integrated conceptualisation of coping process as suggested by them. As some of the coping strategies in the new scale involved a combination of a cognitive and a behavioural method, the following 6 basic types of coping processes were proposed:

1. Cognitive-approach
2. Cognitive-distraction
3. Behavioural-approach
4. Behavioural-distraction
5. Cognitive/Behavioural approach

The new *Coping with Grief/Sadness – Self-Assessment Scale* was then distributed among six clinicians working in mental health services or working as grief counsellors. These were two social workers, two psychiatrists and two clinical psychologists. They were then requested to categorize each of the 36 strategies into:

- Avoidance or Distraction
- Cognitive, Behavioural or Cognitive/Behavioural

The following explanation of Moos & Schaefer was given as a guide:

*Cognitive-Approach* – Logical analysis and positive reappraisal. These coping processes encompass paying attention to one aspect of the situation at a time, drawing on past experiences, mentally rehearsing alternative actions and their probable consequences, and accepting the reality of a situation but restructuring it to find something favourable.
Behavioural-Approach – Seeking guidance and support and taking concrete action to deal directly with a situation or its aftermath. It also includes openly venting one’s anger and despair and behaviour that may temporarily reduce tension.

Cognitive-Distraction – Responses aimed at denying or minimizing the seriousness of a crisis or its consequences, as well as accepting a situation as it is and deciding that the basic circumstances cannot be altered.

Behavioural-Distraction – Seeking alternate rewards by trying to replace the losses involved in certain crises by becoming involved in new activities and creating alternate sources of satisfaction.

Cognitive/Behavioural-Approach - Strategies that adopt both a cognitive and a behavioural action to address the loss. This would involve speaking to people about the loss and attempting to understand the disorder.

The majority of responses from the six clinicians were incorporated into categorising the scale as described below:
Table 1: Categorisation of Coping
COPING WITH GRIEF/SADNESS - SELF ASSESSMENT

<table>
<thead>
<tr>
<th>COPYING STRATEGIES</th>
<th>Distraction or Approach</th>
<th>Cognitive, BEHAV. OR Cog./Behav.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sleeping more than usual</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>2. Eating more than usual</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>3. Crying more than usual</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>4. Allowing myself to get angry</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>5. Relying on my spiritual belief</td>
<td>Approach</td>
<td>Cognitive</td>
</tr>
<tr>
<td>6. Finding time for myself</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>7. Working (outside employment)</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>8. Becoming self reliant and independent</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>9. Being able to get away from the home care tasks and responsibilities for some relief</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>10. Telling myself that I have many things I should be thankful for</td>
<td>Distraction</td>
<td>Cognitive</td>
</tr>
<tr>
<td>11. Being involved in hobbies (eg. art, music)</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>12. Physical activities</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>13. Being involved in social activities with friends</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>COPYING STRATEGIES</td>
<td>Distraction or Approach</td>
<td>Cognitive, BEHAV. OR Cog./Behav.</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>14. Building close relationships with people</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>15. Believing that things will always work out</td>
<td>Distraction</td>
<td>Cognitive</td>
</tr>
<tr>
<td>16. Developing myself as a person</td>
<td>Approach</td>
<td>Cognitive</td>
</tr>
<tr>
<td>17. Building a closer relationship with my spouse</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>18. Investing myself in my children</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>19. Doing things together as a family</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>20. Going out with my spouse on a regular basis</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>21. Talking over personal feelings and concerns with my spouse</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>22. Talking over personal feelings and concerns with someone other than a professional counsellor</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>23. Entertaining friends in our home</td>
<td>Distraction</td>
<td>Behavioural</td>
</tr>
<tr>
<td>24. Encouraging child with mental illness to be independent</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>25. Being able to explain our family situation to relatives, friends and neighbours so they may understand</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>26. Gaining knowledge about the mental illness affecting my child by reading</td>
<td>Approach</td>
<td>Cognitive</td>
</tr>
<tr>
<td>COPYING STRATEGIES</td>
<td>Distraction or Approach</td>
<td>Cognitive, BEHAV. OR Cog./Behav.</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>27. Being sure prescribed medication is being taken by child as required</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>28. Believing that my child is getting the best medical care possible</td>
<td>Approach</td>
<td>Cognitive</td>
</tr>
<tr>
<td>29. Reading about how other people in my situation cope</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>30. Sharing my experiences with others in similar situation</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>31. Being involved in Care &amp; Share groups of the Association of Friends &amp; Relatives of the Mentally Ill (ARAFMI)</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>32. Being involved in Information &amp; Support groups run for families by Hospitals and Clinics</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>33. Assisting others in similar situation</td>
<td>Approach</td>
<td>Behavioural</td>
</tr>
<tr>
<td>34. Discussing my sadness/grief with a member of the treating team in my own home</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>35. Discussing my sadness/grief with a member of the treating team in the clinic or hospital</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
<tr>
<td>36. Discussing my sadness/grief with an appropriate health professional who is not a member of the treating team</td>
<td>Approach</td>
<td>Cognitive-Behavioural</td>
</tr>
</tbody>
</table>

The newly developed scale of 36 strategies consisted of:
4 Cognitive-Approach strategies

8 Behavioural-Approach strategies

2 Cognitive-Distraction strategies

10 Behavioural-Distraction strategies

12 Cognitive/Behavioural-Approach strategies

The strategies that were omitted would have been categorised as Cognitive/Behavioural Distraction strategies. A more comprehensive understanding of the process of coping with grief in parents when a child develops a psychotic disorder may have been gained if these processes were included.

The newly developed questionnaire contained three parts. Part 1 was a categorical, three-directional Likert scale containing 36 strategies used to cope with grief reactions. Respondents were required to tick the column to indicate if they had ever used the strategy. If they had, they were then requested to tick the appropriate column to indicate the usefulness/harmfulness of the strategy.

The second part requested respondents to list three coping strategies that they have used but were not listed in Part 1. They were then requested to indicate the usefulness/harmfulness of each of these strategies by indicating in the appropriate column.

The third part requested respondents to indicate the three most useful and the three most harmful strategies either from Question 1 or Question 2 of the questionnaire.
SPSS (Statistical Package for Social Studies) Version 8.0, software was used for statistical analysis of data.

1.13 Validity and Reliability of Measuring Scales.
Miller et al (1990) developed the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG) by adapting the Texas Revised Inventory of Grief of Fasschingbauer (1981). Following development of the MIV-TIG, they circulated the instrument among four experts on grief and mourning for further validation. A test of the instrument was then conducted with 58 family members. The study suggested that there was measurable grief among family members of severely mentally ill persons and that such grief may be comparable in magnitude to the grief suffered by families who have experienced a death. They concluded that further investigation of this instrument using a larger and more random sample is clearly needed.

Atkinson (1994) used the MIV-TIG in a study to measure levels of initial and current grieving in 25 parents with a child diagnosed with schizophrenia. Solomon and Draine (1996) used the MIV-TIG in a study with 225 family members of seriously mentally ill individuals.

Therefore, I believe this instrument has validity and reliability to meet Objective 1 of this study: To investigate the intensity of grief in a cross section of parents of individuals with psychotics disorders in Western Australia and determine if the results replicate international studies. However, the limitations of the instrument are that it relies on recollection of feelings and emotions, in some instances many years later. Such recollection of feelings and emotions are subject to distortion as this relies on the individual’s memory and sometimes various coping
strategies they may use to deal with feelings and emotions, such as suppression.

The *Coping with Grief/Sadness – Self Assessment Scale* was developed specifically for this study using the *Coping Health Inventory for Parents* (McCubbin et al, 1981) as a guide. Being a new measuring scale, the piloting and review procedures that were followed require more extensive testing than was possible within the scope of this research to establish a high level of validity and reliability. The *Coping with Grief/Sadness – Self Assessment Scale* developed for this study could be used to test the reliability and validity of the scale if other researchers wish to conduct studies on the coping processes of carers of people with mental illness.

**1.14 Deviation from Original Plan**

Information Sheet (Appendix A) informed participants that six people would be selected randomly to participate in a face-to-face interview. However as the results unfolded, it became clear that a large amount of data was generated and it was not possible to embark upon ‘in-depth’ case studies in the scope of this study. This does not imply that a qualitative component to this study may not have been important. I believe it highlights an area for future research.
CHAPTER 2: PSYCHOTIC DISORDERS, GRIEF AND LOSS

Chapter 2 will discuss six key areas of literature that I consider necessary to review before presenting the research findings of the study. These areas are:

1. Nature of psychoses.
2. Types of psychoses.
3. A historical review of theories of aetiology.
4. Grief as a concept.
5. The impact on parents of psychotic disorders in children.
6. Psychoses, grief and loss.

2.1 Nature of psychoses
Psychoses as defined by the Early Psychosis Prevention and Intervention Centre (EPPIC, 1997) refer to a group of disorders in which there is misinterpretation and misapprehension of the nature of reality. Psychoses are reflected in certain symptoms, particularly disturbances in perception (hallucinations), disturbances of belief and interpretation of the environment (delusions), and disorganised speech patterns (thought disorder). The above symptoms are called ‘positive’ symptoms because they ‘add’ something to a person’s experience of the world.

‘Negative’ symptoms are so called because they ‘take something away’ from a person’s abilities. Some common negative symptoms that people affected describe are loss of interest and motivation where every task that needs to be done becomes an effort. They further describe everything going at a much slower pace, difficulty organising themselves and structuring activities and their world. Difficulty communicating and
expressing themselves to others is another common negative symptom described by people with psychotic disorders. They speak of feeling ‘blunted’ or ‘empty’ and isolated. As a consequence they may withdraw from friends, acquaintances and external reality. They often start to neglect hobbies previously held, clothing and personal hygiene. Bloch and Singh (1997, p. 159) say, “A direct result of these defining features is that a person’s competence as a person is called into question, at least temporarily, and so, his or her status as a ‘person’ may be seen as undermined”.

### 2.2 Types of psychoses

A diagnosis of a particular type of psychosis is usually given depending on a person’s symptoms and the duration of these symptoms. For the purpose of this study, psychotic disorders are defined as any of the psychoses classified under The International Classification of Diseases – 10th edition (ICD-10), published by the World Health Organisation. According to the ICD-10, the term ‘disorder’ is not an exact term, but it is used to imply the existence of a clinically recognizable set of symptoms or behaviour associated in most cases with distress and interference with personal functions.

In *Organic Psychosis* symptoms appear as part of a head injury or a physical illness, which disrupts brain functioning, such as a tumour, AIDS, or encephalitis. In *Drug Induced Psychosis* symptoms appear with use of, or withdrawal from, alcohol or certain drugs. Symptoms may resolve as the effects of the substance wear off, however in some cases the symptoms may last longer but begin with drug-induced psychosis. With *Delusional Disorders* the symptoms are mainly of false beliefs and interpretation of the environment – the most common of
which is paranoia or the belief that one is being persecuted. In *Brief Reactive Psychosis* symptoms follow shortly after major stress. It may last a matter of weeks, usually with full recovery.

*Psychotic Mood Disorders* may occur in people experiencing mania or depression. In depression, a gradual worsening of the mood state may lead to delusions of guilt and self-accusation, whereas in mania it may lead to a person believing that he or she has special powers. When a person has both a mood disorder and psychotic features but there is no clear-cut relationship between them, the diagnosis of *Schizoaffective Disorder* is considered. When psychotic symptoms last for a period of at least six months, a diagnosis of *schizophrenia* is given.

### 2.3 A historical review of theories of aetiology.

A search for meaning of the loss is common in grieving. Frankl (1984), having survived the Holocaust, subsequently described man’s need for ‘meaning’ as a fundamental human motivation. Theories of aetiology are usually of concern to the family as they try to grapple with the questions of ‘why?’ and ‘how?’ There are more theories of aetiology about schizophrenia than any other psychotic disorder. Hatfield (1987 pp 9 -13) summarises the history of these theories as in relation to families as:

*The schizophrenogenic mother* was given serious attention in 1948 by Fromm-Reichmann. According to her theory a mother who was cold and distant conveyed feelings of rejection to a child. This lack of affection and warmth impeded the development of the necessary psychological and social skills that led to a person developing schizophrenia.
The *Double Bind Hypothesis* was suggested by Bateson in 1956 who deduced that people with schizophrenia might have grown up in a situation in which they were receiving two or more messages that are incompatible on different levels of communication. This places children in intolerable situations where they eventually behave as if they have lost the ability to discriminate, leading to schizophrenia.

The theories of Lidz *et al* in 1965 led to the term *Marital Schism and Skew*. According to them a person with schizophrenia comes from a family where one or both parents are extremely egocentric and display communication styles that reflect their self-centeredness. This familial disturbance is considered to be a precursor to the severe disturbance of thinking in offspring.

Wynne and his collaborators’ introduced the theory of *Transactional Thought Disorder* in 1978. They believed that the verbal communication of families of people with schizophrenia was fragmented where members, failed to acknowledge each other, were easily distracted and lacked closure. The disturbed behaviour of schizophrenia such as identity confusion, disturbed perception and communication was seen as a way of internalising the family’s social organisation and its way of deriving meaning. Wynne acknowledged that people with schizophrenia may show extreme response patterns, that is, they may have stimulus sensitivity, a tendency to augment or reduce stimulation and display other psycho-physiological disturbances. However he did hypothesize that these characteristics may be genetically predetermined.
Haley and Madanes coined the term *Hierarchical Incongruity* in the early 1980s. They preferred adjectives such as ‘mad’, ‘eccentric’ or ‘problematic’ to that of schizophrenia. They rejected the possibility of a genetic or organic basis for the disorder and believed that the aetiology was in the present rather than the past. They believed the eccentric behaviour was brought on by the offspring’s attempt to hold the family together. They further believed that basic to the problem are the parents’ marital difficulties. In their thinking, strange alliances develop within the family that cause the authority of one parent to be undermined and the child then begins to assume dominance by displaying symptoms. According to them, the disorganised behaviour is a reflection of the disorganisation of the family.

The scientific basis of the above theories has been strongly challenged (Howells and Guirguis, 1985). According to Terkelsen (1983) such theories not only lacked validation but also have served to alienate families and mental health clinicians.

Bland (1995) identified four different images of families in the research literature:

1. Family as aetiological agent,
2. Family as source of environmental stress,
3. Family as bearer of burden,
4. The family as suffering from the impact of illness.

Willick (1994, p. 14), a psychiatrist and also a father of a child diagnosed with schizophrenia says,

“To the best of our knowledge, schizophrenia is a biological illness, but there is still a great deal of
controversy about the complexity of the aetiology. The illness certainly does not follow a simple hereditary model such as is found in Huntington’s Chorea. Just as we were becoming convinced by the adopted-away studies that environment plays a minor role in the aetiology of the illness, a Finnish study (Tienari et al, 1987) concluded that healthy family rearing is a protective factor in the children given up for adoption by mothers with schizophrenia. So we fall back on the idea that the illness is heterogeneous with multiple aetiologies, including biological, psychological, and social factors”.

Although science has not yet progressed to the point at which it can give conclusive answers, De Hert et al (2000) amongst many others say there are indications of an imbalance of certain chemical substances in the brain, known as neurotransmitters. These abnormalities may be caused by hereditary factors and disorders during the development of the embryo. It is believed that these biological differences reflect an excessive sensitivity to stress or pressure.

Among mental health practitioners in Western Australia the 1990s were known as the ‘decade of the brain’, where there were extensive advances in research into biological causes of psychotic disorders. This has resulted in the marketing of the newer or ‘atypical’ antipsychotic medication. It is believed that they are less likely to produce extrapyramidal side effects than conventional antipsychotic medication. They are also believed to be more efficacious in the treatment of negative symptoms (EPPIC, 2001, p. 40).
Diagnostic criteria for mental illnesses are not static: they change over time. For instance, Kutchins and Kirk (1993) say that shortly after the *Diagnostic & Statistical Manual of Mental Disorders -III* was released by the American Psychiatric Association, a social worker who was a text editor of the manual, published a lead article in *Social Work* to inform her profession about the advances that had been achieved in the new manual. She reported that, a feature that is of special interest to social workers is the specification of five different areas of assessment. She observed that the new multiaxial system represented the American Psychiatric Association’s acknowledgement of the importance of a holistic approach to mental illness and that it encouraged the recognition and management of certain social factors.

In Western Australia *The International Classification of Diseases* is used and this is now in its tenth edition (ICD-10). Whatever the classification system used, in clinical settings there is wide agreement that a bio-psychosocial approach to service delivery needs to be adopted by clinicians. EPPIC (2001) states current approaches to psychosis emphasise the fact that the disorder can change over time, and it is closely related to the individual’s development and environment. Each person can be viewed as functioning within a dynamic system that includes biological, psychological and social elements – the biopsychosocial system.

- **Biological** factors include the individual’s genetics, physiology, biochemistry and physical constitution.
- **Psychological** factors include the individual’s upbringing, emotional experiences and interactions with people.
- **Social** factors reflect the individual’s present life situation and the sociocultural context.
Links between the different elements of the bio-psychosocial system can be severely disrupted by psychosis. For example the biological impact of having an active psychosis will be complicated by the individual’s psychological reaction to the experience and the impact of illness on environmental factors such as relationships with family and friends or its effects on stable accommodation, education or employment.

Acknowledging the interactions that occur between biological, psychological and social elements can assist in:

- Analysing the factors that may have precipitated the onset of psychosis and then factors that may perpetuate the disorder.
- Identifying areas of a person’s life which are affected by it.
- Targeting interventions to restore areas, which have been disrupted by psychosis.

2.4 Grief as a concept.

This thesis is not about developing a theory of grief, but it is worth drawing on work already done in the area of loss and grief, as it relates strongly to the focus of this study.

Most of what we know about grief and mourning is what we have learned by studying or observing people in bereavement through death. Murray (2001) says, “we may talk of grieving other losses, but this work is still in its infancy”. She goes on to say, “Whether what we know about grieving and bereavement will also apply to grieving other losses is yet to be determined but suspicions are high!”

Murray (2001) reported that she and her colleagues at the School of Population Health at the University of Queensland conducted a large
literature search of the concept of ‘loss’ in divergent situations ranging from bereavement to chronic illness, unemployment and social rejection or relationship breakdown. For this broader approach, they used the definition of loss adopted by Harvey (1998) which describes loss as:

*Produced by an event which is perceived to be negative by the individuals involved and results in long-term changes to one’s social situations, relationships and cognitions.*

In their search for themes of loss that were common across these diverse situations, they found some themes that were consistent and unifying, so much so that the motto of their work became: Loss: Unity in Diversity. The five themes identified by Murray (2001) were:

1. Grief is a normal process.
2. The experience of loss is integrated into the basic psychological functioning of a person even from the earliest ages. Therefore there exists both the potential for personal growth and personal deterioration.
3. Losses rarely exist alone.
4. Grieving is an individual, mostly private and even at times lonely experience.
5. Loss threatens our sense of safety, mastery and control.

I have used Murray’s taxonomy of grief in which, she identified five themes. In discussing these I have integrated my own review of the literature. There is quite a lot of discussion around Theme 1, but the others are dealt with more briefly.
Theme 1: Grief is a normal process
Murray says that grief is an experience that has been with humankind since the beginning of time and of which the individual has unique and personal knowledge. In the last century, scientists have tried to explain this universal phenomenon, and while our deep collective knowledge of the essence makes us aware almost by instinct that a person with whom we come into contact is grieving, we still have not been able to fully express the essence of that universal experience in words and concepts. However, it is still worth considering some of these broad schools of thought:

1. Psychodynamic Theory.
2. Attachment Theory.
5. Constructivist (narrative) Theory.

Each of these broad schools of thought is reviewed briefly. Again, this includes my own literature review with the broad overview of Murray (2001).

The Psychodynamic School of Thought
A prominent advocate of the psychodynamic theory was Sigmund Freud. According to Murray, Freud in his book Mourning and Melancholia written in 1917, attempted to compare grief and depression. This theory mainly concentrates on the individual adaptation to loss. From this perspective, mourning is an exchange process whereby the activities carried out by the mind in terms of repeatedly examining aspects of the relationship with the lost object are exchanged for a relinquishment of the libidinal bonds that bound the mourner to that, which was lost. The
concept of ‘grief work’ was central to Freud’s theory. The goal of grief work is to free the mourning individual from:

   a) Attachments to the lost object
   b) Inhibitions to becoming a person separated from the lost object
   c) Conflicts of ambivalence over the lost object.

From a review of the literature for this study, I understand that Lindemann’s seminal study in 1944 on the Symptomatology and Management of Acute Grief (cited in Horacek 1991) is similar to Freud’s understanding of the grief process. He described three stages of grief:

   d) Shock and disbelief
   e) Acute mourning
   f) Resolution of the grieving process

The primary tasks of grievers include: “emancipation from the bondage of the deceased”, adjusting to the loss in one’s environment, and the ability to form new relationships. According to Lindemann failure to do ‘grief work’ will usually lead to morbid and pathological grief reactions.

The Attachment Theory School of Thought

A prominent advocate of this theory was John Bowlby (1971) who developed his theories following his study of the effects of separation and loss in early childhood. Attachment theorists introduced the importance of taking an interpersonal perspective with respect to mourning.

Bowlby theorized that attachment needs are adaptive and present from birth. He stressed that attachment is necessary to ensure personal and species preservation, and that the loss of attachment is at the core of
grief. The intensity of the pain of separation led Bowlby to suggest that certain reactions such as anger, anxiety, denial, depression and searching that had, up until that time, been considered as signs of pathology, were normal manifestations of grief.

In psychodynamic theory grief work is used to bring about severing of bonds with the object that no longer exists, however attachment theory argues that grief work is a normal response to the breaking of bonds of affection and aims to recover proximity to the lost object.

Common to both the Psychodynamic and Attachment Theories is the idea that long-term problems in grieving are likely to be related to the previous relationships with the deceased.

Bowlby was the first to suggest that mourning could be understood as a process that moved through a number of phases from a point of complete disorganization to a point at which the person was able to make new attachments or accept a new reality. Although many other theorists have described grief in terms of the model of phases or stages, the labels that have been used to describe the individual phases have been different. Murray (2001) summarises these as:
Table 2: Murray’s Individual Phases

<table>
<thead>
<tr>
<th>Theorist(s)</th>
<th>Phases/stages described</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freud (1917)</td>
<td>Loss of capacity to invest energy in love energy&lt;br&gt;Withdrawal of energy into self where reorganization occurs&lt;br&gt;Gradual reinvestment of energy in new objects, people or activities</td>
</tr>
<tr>
<td>Parkes (1971)</td>
<td>Shock and disbelief&lt;br&gt;Yearning and protest&lt;br&gt;Despair and disorganization&lt;br&gt;Resolution</td>
</tr>
<tr>
<td>Kübler-Ross (1969)</td>
<td>Shock&lt;br&gt;Denial and isolation&lt;br&gt;Anger&lt;br&gt;Bargaining&lt;br&gt;Depression&lt;br&gt;Acceptance</td>
</tr>
<tr>
<td>Hardt (1978-79)</td>
<td>Shock/Denial&lt;br&gt;False acceptance&lt;br&gt;Pseudo-reorganisation&lt;br&gt;Depression&lt;br&gt;Reorganisation/Acceptance</td>
</tr>
<tr>
<td>Matz (1979)</td>
<td>Denial&lt;br&gt;Undoing efforts&lt;br&gt;Depression and Helplessness&lt;br&gt;Re-engagement</td>
</tr>
</tbody>
</table>

Murray says some practitioners have incorrectly adopted these phases as a rigid formula for grieving, expecting those experiencing loss to move
through a set of definite, time-limited, clearly delineated stages in a specific sequence. They assume that to reach resolution of grief, one phase must be fully completed before a person entered another phase.

Advocates of the task models of mourning have combined psychodynamic and attachment theory approaches to explain the process of adjusting to bereavement, rather than just describing its progress. The focus of these models is the undoing of attachments through re-establishing new relationships. Two major advocates of these models are William Worden (1991) and Therese Rando (1993). Worden’s Four Tasks of Mourning are:

1. To accept the reality of the loss
2. To work through the pain of grief
3. To adjust to an environment in which the deceased is missing
4. To emotionally relocate the deceased and move on with life

The four tasks of Worden have been observed by Miller (1996) to describe a format for grief therapy directly related to mental illness and grief:

1. Making the loss real
2. Expressing overt and latent affect
3. Accommodating to the loss through relationships other than that with the mentally ill relative, and
4. Accommodating to the loss through the relationship with the mentally ill person

The fourth task of Miller diverges most from Worden’s fourth tasks for persons who are mourning the death of someone close to them. While Worden’s fourth task involves detaching from the deceased and may include actually saying “goodbye” to the deceased, in contrast Miller suggests assisting relatives to say “hello” to the healthy partial self that
exists in all mentally ill persons. A primary goal in this task is to help the client embrace the idea that all mentally ill persons still have a healthy aspect or partial self.

Murray goes on to say that the realization that we are trying to explain a very complex yet universal experience means that there constantly have arisen dissenters to popular thought at various times. Researchers have challenged popular thought when results of studies conducted have not supported the thoughts or in some cases, have contradicted them. Following an examination of the empirical literature, Wortman and Silver (1989) challenged four of the major assumptions that had been held popularly about mourning:

1. Expectation that depression is inevitable following loss
2. Distress is necessary and failure to experience it is, indicative of pathology
3. It is necessary to ‘work through’ or process a loss
4. Recovery and resolution are to be expected following loss.

From my own review of the literature, the assumption of ‘recovery and resolution’ brings us to Worthington’s (1994) notion of ‘cyclical grief’, which he says is more appropriate to the grief of children with chronic illness or developmental disabilities and their families. The cyclical model assumes that families undergo a series of recurring stresses that force a family through a series of continual adjustment. He says that to assume that families will ‘get used to’ these stresses is not appropriate.

Other schools of thought that have added ‘colour and form’ to the traditional theories are:
Social Constructionist/Social Learning Theory of Grieving

Some advocates of this school of thought were Glick et al (1974), and Rosenblatt (1988). They argue that loss occurs within a social context and this context affects the grieving associated with that loss. Some of the social factors that these writers suggest affect grieving are:

1. The meaning of the loss for the individual will often have been determined by the social context of the loss.
2. Social and emotional adjustments will be necessary after the loss. From practice wisdom I believe that with losses incurred as a result of mental illness, the paucity of community care has a significant negative effect on the social and emotional adjustment necessary following an episode of psychosis.
3. The social environment dictates many of the rituals and mores that will form part of the experience of loss. Doka (1989) introduced the term ‘disenfranchised grief’ where the social environment dictates the degree of support, offered following loss. In the case of losses, which had occurred following mental illness, often the grief was not recognised or the griever was not acknowledged. For example, (MacGregor, 1994, p. 164) gives a personal account of grief in parents of the mentally ill, by saying “because the loss with mental illness is psychosocial and not physical, the community often does not perceive the family’s loss and does not expect or join in with expressions of sadness and pain”.
4. Social factors affect the course of recovery and adjustment. With losses incurred as a result of mental illness, EPPIC (2001) advocates that social factors have a close relationship with the individual’s recovery and adjustment to a psychotic disorder. For example assistance with relationships, stable
accommodation, education/employment and financial security, are some of the social factors that are considered areas for intervention by case managers working with young people experiencing early symptoms of a psychotic disorder. This complements Murray’s review that loss occurs within a social context and this context affects the grieving associated with that some.

In reviewing the literature on family systems theory I understand that such theorists advocate that mourning is a family affair. Gelcer (1983) says that although a review of literature indicates individual differences in relation to mourning are in abundance, very little work has been accomplished based on systemic understanding and directed toward working with whole social systems when working with people experiencing grief. In her work with families she identifies three basic commonalities, (Gelcer 1983, p. 501):

1. The selection of the identified patient is not coincidental to the stage of the family life cycle and to the role of the deceased member in the system.

2. Although death affects each individual differently, depending upon his or her relationship with the deceased, it continues to influence all family relations with equal power.

3. Non-resolution of mourning permits a ghost to become an integral member of the family system.

Ackerman (1966, p. 75), among the forefathers of family therapy also suggests “Conflict between the minds of family members and conflict within the minds of any one-member stand in reciprocal relation to one another”.

49
Cognitive/Behavioural Theories of Grieving

Cognitive-behavioural theories have focussed on the literature related to behaviour theory, stress and coping models. These theories views bereavement in the larger context of stressful life events. An advocate of this theory, Attig (1991-page 387) suggests:

“We must distinguish the specific emotion of grief from the more complex coping process, which is grieving. The emotion engenders helplessness and passivity, whereas the process presents challenges and opportunities and requires that energy be invested, tasks be undertaken and choices be made.”

According to Attig, while loss itself may not be under the control of the person, grieving is a process that is influenced by the cognitions and coping strategies employed by the individual. These theories further suggest that the griever’s interpretation of the events and the behaviours they use to cope with the loss can affect the progress and duration of grieving.

In my review of the cognitive/behavioural theories of grief I found a significant contribution by Meuser and Marwit (1999-2000, p. 377) who say that applying Lazarus and Folkman’s (1984) definitions of coping as a “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” is certainly applicable to bereavement. They say “the impact of loss to death must, of necessity, be continually appraised and a variety of grief responses be initiated as
ways of coping until grief-related adjustment is achieved” (Meuser and Marwit 1999-2000, p. 377).

**Constructivist (Narrative) Theory**

According to Murray (2001), the core belief of this theory is that there are no absolute truths or knowledge, as all reality is filtered and perceived uniquely by every individual. In my own review of the literature, Neimeyer (2000) suggests that from a constructivist perspective, a useful theory of grief would need to meet a number of criteria which stand in contrast to traditional theories:

1. It would reveal the personal reality of death or loss for different individuals, instead of assuming that death holds a universal significance for human beings irrespective of their historical, cultural, familial, or personal context.
2. It would view people as active in facing death’s challenges rather than being passive reactors.
3. The theory should be richly descriptive in elucidating personal meaning of loss, without being subtly prescriptive of what constitutes ‘normal’ grieving.
4. It would focus on passionately held meanings that shape our emotional, behavioural and somatic responses.
5. It would describe how one’s world is forever transformed by loss rather than suggesting a return to some premorbid state following ‘recovery’.
6. While maintaining a focus on the highly personal qualities of grief, it would allow for the consideration and employment of grief in larger social and family contexts.
The concept of ‘continuing bonds’ has been a further challenge to traditional view of mourning. This concept advocates that the work of mourning is about internalising the dead, continuing the relationship, and not disengaging (Klass et al 1996). White (1988) contrasts the saying “goodbye” aspect of the models associated with attachment theory with the saying “hello” again model. Miller (1996) as cited earlier in this report used a similar concept in saying “hello” to the healthy partial self that exists in all mentally ill persons.

**Theme 2: Integration of the loss.**

Murray’s second theme relates to the experience of the loss being integrated into the basic psychological functioning of a person even from the earliest ages. Within her theoretical understanding, there exists both the potential for growth and for personal deterioration.

Some theorists have combined the divergent schools of thought into a working model of adjustment to loss. These are known as the combination models:  

*The four component model of Bonanno and Kaltman (1999)*:

1. Context of the loss referring to risk factors such as the type of death, age, gender, social support
2. The continuum of subjective meanings associated with loss which goes from an appraisal and evaluation of everyday problems to the deepest existential questions of the meaning of life
3. The changing representation of the lost relationship over time, and
4. The role of coping and emotion-regulation processes.

The *Dual Process Model* of Stroebe and Schut (1999) attempts to integrate the many models of adjustment to bereavement, arguing that
there are many stressors that affect bereavement. They classify these stressors into the following two broad types:

1. Loss-oriented stressors are associated with a concentration and a processing of some aspect of the loss experience itself. These stressors may be associated with the grief work, the breaking of affectional bonds, or the denial or avoidance of the loss.

2. Restoration oriented stressors are consequences of the primary loss. These could be the many life changes, finding new connections or new roles.

The advocates of the Dual Process Model argue that people will fluctuate between confronting and avoiding these two types of stressors in a balance that will change over time. This oscillation between the two types of stressors aids adaptation, as does the oscillation between negative and positive affects associated with both types of stressors. What processes control this oscillation between the positive and negative affects, and loss-oriented and restoration-oriented stressors is yet to be determined.

**Theme 3: Losses rarely exist alone**

Murray argues that one loss can lead to many other losses. For example, the primary loss may be divorce. Secondary losses may be loss of status as a spouse, loss of financial security, loss of time to be a parent to children, loss of shared friends and family. For children the losses may be, among others, major life transitions without the expected involvement of both parents. For parents of people with mental illness, there are internal losses as well as external losses that are secondary to the primary loss. MacGregor (1994, pp 163) describes internal losses as loss of self-esteem and sense of competence as a parent; loss of dreams; loss of...
control; loss of pleasure in a child’s success and loss of a child’s role in the family and in society. Some external losses described by MacGregor (1994) are loss of normal and predictable family life, loss of privacy, loss of a social network and loss of financial resources.

**Theme 4: Grieving as an individual, mostly private and even at times lonely experience.**

There may be wide differences in the way people grieve. Murray groups the influences on individual reactions into three categories: 1) Internal factors, 2) Factors associated with the loss, and 3) external factors. Examples of these are:

**Internal factors:**
- Age
- Gender
- Previous mental health
- Mental capacity
- Individual coping behaviours
- Attributional style
- Resilience
- Spirituality
- Physical health.

**Factors associated with the loss:**
- Where there is sudden death, no body or mutilation
- Where there is protracted investigation into a death
- Mass losses
- Effects of shame and guilt associated with the loss
Where there is terminal illness

External factors affecting grief besides the cultural context:

- How does the family system react to the loss?
- What are the effects of concurrent stresses on a new grief?
- What is social support? How does an individual perceive it?
  What are the potential negative effects of social support? How is it best offered, and to whom?

To improve our practice in the area of sudden or traumatic loss, Murray suggests improving knowledge in the area of grief in reactions to trauma such as Acute Stress Disorder (ASD) and Post-traumatic Stress Disorder (PTSD).

In the literature on PTSD and ASD, Schnurr et al (2002, p.878) say that “PTSD can be distinguished from other psychiatric disorders in that there is a known etiological component: an event that involves life threat, serious injury, or death”. According to Schnurr et al (2002, p. 879) The American Psychiatric Association (APA) in their 4th edition (1994) of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) introduced the category of Acute Stress Disorder (ASD) for severe reaction to traumatic stressors during the month following a traumatic event. Schnurr et al (2002) suggest that the intensity of an initial reaction to a traumatic event predicts the subsequent development of PTSD.

**Theme 5: Loss threatens our sense of safety, mastery and control.**

Murray’s fifth theme draws on the work of Parkes (1971), Lerner (1980) and Janoff-Bulman (1992) who contributed to the literature of loss and grief by including the aspect of ‘assumptive worlds’. These are
assumptions that facilitate understanding, prediction, and organisation of the world, and hence provide security in it. Murray says Janoff-Bulman argued that there are three fundamental assumptions held by people in western cultures; the world is benevolent, the world is just and meaningful, and the self is worthy.

This leads me to the central theme of this study – what about theories and evidence that may influence our knowledge of grieving in other situations of loss, importantly the loss of the mental well being of a child?

2.5 The impact on parents of psychotic disorders in children.

To many parents, children represent a connection with the past and hope for the future. The birth of a child evokes certain hopes, expectations and ideals in parents. The onset of a psychotic disorder brings about changes in personality, cognition and functioning level, which require parents to undertake a major revision of their hopes, expectations and ideals for their child.

Willick (1994, p. 9) speaking of the changes that have taken place in his son who has been diagnosed with schizophrenia says,

"There has also been a significant cognitive impairment. Things that he was easily able to grasp when he was 14 years old are now much harder for him. He has lost considerable capacity for abstract thinking. His language is very concrete and has lost the richness and subtlety of expression it once had." "There is also a loss of a certain kind of emotional connectedness that is a consequence of some of the negative symptoms".
Early adulthood is a critical developmental period in the lifespan of an individual. During this period young people take steps to separate from parents and establish an individual identity. It is a time that they explore educational and vocational options, and peer group and intimate relationships. With the emergence of a psychotic disorder these developmental milestones may be derailed in a way that makes it difficult or in some cases impossible for them to handle critical adult roles. Parents then grieve over the loss of potential.

In the family life cycle, the stage when children reach adolescence and young adulthood is a time when parents explore life as a couple and prepare for their own retirement. With people living longer, many older adults are involved in caring for their aged parents. As such the onset of a psychotic disorder may cause considerable trauma and major losses to an individual and his or her family. Hirschowitz (1976) described such a phase as a ‘transition state’ with psychological stress being an expected part of adaptation, for transition from an old role to a new one. When a child develops a psychotic disorder parents may be required to modify their identity, images and roles and face an uncertain future. Hatfield (1987, p. 64) says “a state of transition aptly characterizes family caregivers of persons with mental illness as they shift their identity from that of a typical ‘normal’ family to one with difficult, special and stigmatising problems.”

Bland (1998) found a review of the research literature on families and schizophrenia provided a reference point for critical reflection on social work practice. His reflection involved both an analysis of the concepts of grief and guilt as they are defined and described in the mental health literature and as they are recognised and dealt with in his own practice.
Bland’s (1998) literature review drew on published first person accounts of the family experience of mental illness, the extensive literature of the self-help movement, and the broader mental health research literature. Practice principles derived from this analysis include the need for understanding and respecting the family experience of grief and guilt, the importance of empathy in response, and the importance of a teaching and supportive approach to family work. Bland (1998, p. 30) conclude that the grieving associated with severe mental illness is complex and prolonged and that the uncertain nature of the loss, the disenfranchised grieving, and the recycling of grief threaten the successful resolution of a normal grieving process such as that described by Worden (1982).

Bruce & Schultz (2001) use the term ‘non-finite loss’ to refer to losses that are contingent on development, the passage of time, and on lack of synchrony with hopes, wishes, ideals and expectations. The term emerged from their close involvement as counsellors, educators, and researchers with parents of children with an intellectual or other developmental disability. However, four decades before this term emerged, Olshanky (1962) introduced the term “chronic sorrow” to describe a phenomenon observed in parents of mentally retarded children and viewed this as a natural response for parents confronted with grieving a loss that was never-ending. Olshanky described this phenomenon as ‘pervasive sadness’ that is permanent, periodic, and potentially progressive in nature.

However, it is likely that there are major differences in the losses occurring through intellectual or other developmental disability and psychotic disorders. Intellectual and other developmental disabilities are
usually diagnosed at birth, however the onset of a psychotic disorder is usually in adolescence or young adulthood. From a family systems perspective of this stage of the life cycle Crawley (1985) argues that the parent-child relationships must change in order to allow the adolescent to move in and out of the family system, and that parents must begin to reinvest in their spouse and individual functions as their parental role diminishes in intensity. However, when a child develops a psychotic disorder at this stage of the life cycle the parental role increases rather than decreases in intensity and thus the parent’s energy to reinvest in their spouse and individual functions usually takes second place.

Further, the cyclical nature of psychotic disorders means that parents’ hopes are raised with the reappearance of the “former self” of the child, only to be dashed again following a relapse. This sometimes creates an uncertainty about the loss.

Although the term ‘non-finite’ emerged from their work with people with intellectual or other developmental disability, Bruce and Shultz (2001) say that the term is equally applicable in a host of other settings, among them the onset of an ongoing or degenerative disease. The term “non-finite grief” is described by Bruce and Shultz (2001, p. 7), as “losses that are contingent on lack of synchrony with hopes, wishes, ideals and expectations”. From this description, it could be argued that this term is the most appropriate to describe the grief parents experience when a child develops a psychotic disorder.

Practice wisdom has also given me the experience that treating teams often overlook the grief of parents. This leads to such grief often being disenfranchised as well. Meagher (1989,p. 315), quoting Doka, (1989)
defines disenfranchised grief as ‘grief that a person experiences when he or she incurs a loss that is not or cannot be openly acknowledged, publicly mourned, and/or socially supported.’

A study by Coghlan et al (2001) found that in Western Australia, suicide rates in people with mental illness were higher than those experienced in the broader population. They were highest in those who had received involuntary inpatient treatment. People who had received inpatient treatment for mental illness accounted for 90 per cent of all suicides. When they compared suicide rates by diagnosis, highest rates were seen for schizophrenia, affective psychosis and depressive disorder. Practice wisdom has given me the experience that parents of people with psychotic disorders often live with the fear of suicide of their child. Little is known on the effects of such anticipatory grief.

In a study by Winefield and Harvey (1993), they found parents of children with schizophrenia reported high levels of psychological disturbance and emotionally related health problems. From practice wisdom, I believe that underlying these high levels of psychological disturbance and emotionally related health problems exists a pervasive theme of loss and grief. Doka and Aber (1989, p. 189) say, “There is considerable documentation showing that those who experience dramatic change in a significant other or the psychosocial death of a loved one also experience grief reactions”. They refer to psychosocial death to those cases in which the psychological essence, individual personality, or self is perceived as dead, though the person physically remains alive.
An unexpected finding of Winefield and Harvey’s study was that those caring for female sufferers reported greater distress than those caring for males.

2.6 Psychoses, grief and loss.
Several studies have investigated the presence of grief experienced by family members when a relative develops a major psychiatric disorder. Empirical studies cited were by Miller et al (1990), Atkinson (1994), Solomon and Draine (1996), Doornbos (1997) and Davis and Shultz (1998).

Miller et al (1990) state that investigations of the grief reactions experienced by families when a relative develops a serious mental illness have been hampered by the lack of an appropriate instrument to measure such reactions. The authors devised the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG), adapted from the Texas Revised Inventory of Grief (TRIG) (Faschingbauer et al, 1977) to assess family members’ initial and present feelings about their relative’s loss of mental health. A test of the instrument with 58 family members of patients with schizophrenia or bipolar disorder revealed a surprisingly low level of initial grief but higher levels of present grief. They concluded that their results suggest that families of severely mentally ill persons may undergo a delayed grief reaction, possibly reflecting the difficulty of mourning in situations other than death.

The study of Atkinson (1994) compared grief among parents who had an adult child with schizophrenia with grief of parents who had ‘lost’ an adult child through death or a head injury that resulted in an organic personality disorder. The MIV-TIG was administered to the parents of
mentally ill children; the original version of the TRIG was used to assess grief in the other parents. Whereas parents with a child diagnosed with schizophrenia had significantly lower initial grief scores than the other parents, the results showed a statistically significant increase when current grief scores were compared with initial grieving scores. This was in contrast to the parents of children with a head injury who had a significant decrease from initial grief scores to current grief scores. Parents whose children had died had an even more significant decrease in grief scores. Based on these findings, Atkinson concludes that parental loss of a child through schizophrenia leads to a pattern of chronic grief.

In the study of Solomon and Draine (1996), results show that family member characteristics, social support, objective burden and subjective burden contributed to explaining the expressed grief of 225 family members of seriously mentally ill individuals. They used the MIV-TIG to assess grief reactions.

The study of Doornbos (1997) was part of a larger study in which a middle-range theory of family health in the families of young adults with persistent mental illness was tested and the strengths of these families were explored. The research questions were addressed by means of descriptive statistics through noting and collating percentages of subjects identifying specific themes. Of the 108 caregiver’s responding, 20 per cent identified grief as “the greatest problem they encountered as a result of having a mentally ill family member”.

The study of Davis and Schultz (1998) aimed to validate the presence of grief in mothers and fathers of children with schizophrenia, as well as to explore whether the hours of parental contact with the child influences
the strength of grief reactions. The mean age (62 years) of the 16 mother-father dyads constituted an investigation of older parents, for 43 per cent of whom the duration of diagnosed schizophrenia was over 10 years. Grief was conceptualised as a cognitive, behavioural, and emotional reaction to loss, and was operationalised by measuring current intrusive thoughts and avoidance behaviours, as well as emotional distress over reminders of time of diagnosis. The Impact of Event Scale (IES) was used to measure intrusive and avoidant processes.

Davis and Shultz used the Experience of Stress Scale (ESS) to measure distress due to reminders of the loss (time of diagnosis). In an effort to control for life events, which might compound the measurement of grief, the Schedule of Recent Events (SRE) was used. From their results they conclude that as hypothesised, both mothers and fathers grieve in relation to their child’s psychiatric illness. They found no difference between mothers and fathers in intrusive thinking, avoidance behaviours and distress related to recall of diagnosis. With the exception of intrusive thoughts, number of contact hours with the child was not an intervening variable of mothers’ and fathers’ grieving.

Eakes (1995), Tuck et al (1997), and Mohr and Regan-Kubinski (2001) have conducted qualitative studies on the experience of grief by parents of the mentally ill. The results of the study of Eakes (1995) found that 8 out of 10 parents experienced chronic sorrow as defined by Olshanky (1962). These grief-related feelings were most often triggered by the unending caregiving responsibilities parents described.
Nine parents who were the primary caretakers of an adult child with schizophrenia participated in the study of Tuck et al (1997). The thematic clusters emerging from their study were those of parents’:

1. Struggling to reframe events as normal
2. Seeking help
3. Transformation of the loved child
4. Living with changing levels of hope
5. Endless caring
6. Gathering meaning
7. Preserving the self

A sub-theme of the need to ‘know’, was subsumed under the thematic cluster ‘seeking help’. In their study, ‘time’ was clearly demarcated into *before* and *after the diagnosis*.

Mohr and Regan-Kubinski (2001) aimed to capture the process through which parents journey in the face of their child’s mental illness by conducting a series of focus groups.

Their sample consisted of eight participants. They concluded that families in their study experienced some of the symptoms of a grief reaction but they also experienced the symptoms of trauma. Findings of their study also suggested that there might be profound differences in the process and outcomes of seeking help for children diagnosed with mental illness, as compared with children diagnosed with chronic physical illnesses.

In summary, this study builds on previous work in grief and loss in mental illness and specifically draws on five quantitative and three
qualitative studies from the international literature. The findings suggest that families of severely mentally ill persons may undergo a delayed grief reaction that leads to a pattern of chronic grief. Whilst family members experienced some of the symptoms of a grief reaction, they also experienced symptoms of trauma. Family member characteristics, social support, objective and subjective burden contributed to explaining expressed grief in such situations. Whilst both mothers and fathers grieve in relation to their child’s mental illness, grief-related feelings were most often triggered by the unending care giving responsibilities.

To the best of my knowledge, there has only been one study conducted in Australia of grief in carers of the mentally ill. This study used different instruments to measure grief. No previous study has explored coping strategies used by parents of the of the mentally ill to cope with grief.
CHAPTER 3: COPING WITH GRIEF AND LOSS

The diversity of techniques people use to cope with grief is as broad as the theories of grief and types of losses experienced by people as discussed in Chapter 2 of this thesis. A full discussion of different typologies of coping is beyond the scope of this study. Therefore the discussion in Chapter 3 relating to coping with grief and loss is brief.

3.1 Definition of coping

Researchers have presented several different typologies of coping over the years. (Moos and Billings 1982, Lazarus and Folkman 1984, Moos and Shaefer 1993, Haan 1993). However, from reading the literature available, it is obvious that some of the basic questions of the definitions of stress and coping have not yet been resolved.

Lazarus and Folkman (1984, p. 14) defined coping as:

> Constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.

Lazarus and Folkman (1984, p. 141-142) identify limitations of traditional approaches as follows: firstly, it is “process-oriented rather than trait-oriented, as reflected in the words constantly changing and specific demands and conflicts”. Secondly, this definition “implies a distinction between coping and automatized adaptive behaviour by limiting coping to demands that are appraised as taxing or exceeding a person’s resources”. They suggest this limits coping to conditions of
psychological stress, which requires mobilization and excludes automatized behaviours and thoughts that do not require effort.

Thirdly, the problem of “confounding coping with outcome is addressed by defining coping as efforts to manage, which permits coping to include anything that the person does or thinks, regardless of how well or badly it works.” Fourthly, by using the word ‘manage’, they are attempting to avoid equating coping with ‘mastery’. They interpret ‘managing’ to include minimizing, avoiding, tolerating and accepting the stressful conditions as well as attempts to master the environment.

3.2 Coping resources and processes
Moos and Schaefer (1993) use the term coping resources to refer to the relatively stable personal and social factors that influence how individuals try to manage life crises and transitions. They refer to coping processes as cognitive and behavioural efforts individuals employ in specific stressful circumstances. The present study was limited to researching coping processes as researching coping resources was beyond the scope of the study due to time limits and budgetary constraints.

Moos and Schaefer (1993, p 243), use two main conceptual approaches to classify coping processes:

Focus of coping refers to a person’s orientation and activity in response to a stressor. An individual can approach the problem or avoid the problem in order to manage the emotions associated with the stress.
However, through practice wisdom, I believe the word *avoid*, is inappropriate and that the word *distraction* to be a more accurate reflection of the focus of coping strategies that is used by people in dealing with stress. As such, in this study I have used the words *approach* and *distraction* to refer to a person’s orientation and activity in response to stressors of loss.

*Method of coping refers to the cognitive or behavioural effort employed by people in managing stressful encounters.* (Moos and Schaefer 1993, p 243).

However, through practice wisdom, I believe some strategies involve a combination of cognitive and behavioural efforts. As such, in this study I have classified methods of coping into *cognitive*, *behavioural* and *cognitive/behavioural*.

Nolen Hoeksema (1999) further categorises coping strategies to problem-focused coping and emotion-focused coping. No attempt was made to separate strategies into these two methods, as I believe all strategies in the *Coping with Grief/Sadness Self-Assessment Scale* used in this study are utilised by respondents consciously or unconsciously to manage distressing emotions associated with grief. The adaptation of the method and focus of coping was discussed in Chapter 1 (1.12) discussing the development of the coping scale.

### 3.3 Coping with grief and loss in bereavement

Exline *et al* (1996) provide a broad overview of empirical research on bereavement. They draw on existing research to address three major clinical issues.
1. They provide an overview of how people typically respond to major losses.
2. They review the factors that have been shown to enhance vulnerability to the effects of loss.
3. They discuss the efficacy of various treatments.

There are wide differences in the strategies people use to cope with the emotional and practical consequences of a loss. Many of these strategies are dependent on the type of loss experienced, personality characteristics, age and gender of the griever. According to Exline et al (1996) controlled research has demonstrated the value of many different kinds of interventions to assist people cope with grief in bereavement. They say that there is “agreement among those treating the bereaved that an eclectic orientation is best because different approaches are most appropriate for different types of clients, for different symptoms exhibited by the same client, and for the same client at different points in time”. They also give examples that “guided mourning may be most useful in cases where mourning has been avoided, repressed, or delayed. In the case of a sudden, traumatic loss, available evidence suggests that the combination of exposure and anxiety management (e.g. relaxation training) works best. In those cases in which the client appears to be stuck in a state of chronic grief, they say a goal-oriented approach may be most appropriate (e.g. facilitating new social contacts and activities)”.


A common element running through most of these interventions is that they are structured to help the client face the reality of the loss and to promote processing of the loss. To assist the client face the reality of the loss and to promote processing of the loss, clinicians need to better
understand the nature of this loss. This leads us to a crucial aspect of this study - understanding losses in mental illness and how people cope with the grief associated with this loss.

3.4 Coping with grief and loss in mental illness.

Literature dealing specifically with coping with loss and grief in mental illness is sparse. Five key articles I cited were those of Stern et al (1999), Doornbos (1997), Eakes (1995), Bland (1993) and Karp (2001). Stern et al (1999, p. 354) say that “Coping with psychotic disorders can be understood in terms of specific strategies and styles that can be incorporated by carers to handle stress and solve problems, but it also has to do with the important task of making sense of psychotic experience, and with internal working-through of intense emotions”. Although it is acknowledged that stress of coping with the former may have an influence on the latter, the present study focuses only on the latter – the tasks of making sense of the experience and coping with the intense emotions of the loss.

The study of Doornbos (1997) posed two research questions: what are the common problems encountered by the caregivers of young adults with serious and persistent mental illnesses? What methods of coping do the caregivers of young adults with serious and persistent mental illness use to deal with these problems? Their sample consisted of 108 caregivers obtained by means of a non-probability sampling strategy.

Although respondents identified many problems, Doornbos says that 20 per cent of the caregivers wrote eloquently of their unending grief. The caregivers identified several coping mechanisms that they used as they faced the challenges inherent in serious mental illness, however it was
unclear if these coping mechanisms were identified as methods for coping with grief or the other problems of the disorder. Out of the methods identified (Doornbos (1997, p.24-25):

- 26 per cent assumed facilitative attitudes relative to the client and the mental illness itself
- 19 per cent relied on their faith
- 16 per cent identified the beneficial effect of increasing their knowledge base relative to mental illness
- 16 per cent found support groups to be a positive method of coping
- 12 per cent identified relying on their family and friends
- 7 per cent sought out professional assistance
- 6 per cent found it helpful to distance themselves from the client

However in the qualitative research project by Eakes (1995, p. 81) of 10 parents each individual was asked, “When a parent with a mentally ill child gets to feeling down about their situation, what could he/she do to feel better?” Responses were categorised as interpersonal (e.g. talking to others), emotional (e.g. crying), cognitive (e.g. thinking positively), or action-oriented (e.g. keeping busy). Eakes (1995) findings suggest that coping strategies most frequently cited were those labelled as cognitive (8 parents/13 citations). Six of the eight used action-oriented (19 citations) and interpersonal (11 citations) coping techniques. Interestingly, only three of those with chronic sorrow made reference to coping strategies categorized as emotional (3 citations) in nature.

Eakes found that the majority of the subjects in her study who evidenced chronic sorrow (five out of eight parents) described their grief-related feelings as less intense than at the time of their child’s diagnosis. This is
in contrast to the findings of Miller et al (1990), Atkinson (1994) and Solomon and Draine (1998). Eakes says that this apparent discrepancy in findings may be related to the length of time (average of 12 years) subjects in her study had been dealing with mental illness in their child. In Miller’s study, the patients had been diagnosed for a period of two years; the length of time since diagnosis for those participating in Atkinson’s study is not clear.

Bland (1993) gives 10 suggestions for long term coping with a diagnosis of schizophrenia. These suggestions, offered to both consumers and carers are:

1. Know as much about the illness as you can by becoming an expert in your own right
2. Be a good consumer of health services
3. Use a supportive network
4. Live in the present
5. Put the illness and disability in a box
6. Use language carefully
7. Maintain a sense of hopefulness
8. Learn some specific techniques for the management of stress
9. Develop a sense of humour
10. Reward yourself

Based on 60 detailed interviews with relatives of people with severe and chronic mental illness, Karp (2001) examines caregivers’ direct experiences with their family members and their interactions with the mental health system in contemporary America. Karp chronicles common changes that occur over time in relatives’ emotional reactions and sense of responsibility towards the ill family member. These
changes are linked with their evolving beliefs about the cause of the illness, their beliefs about a possible cure, and the extent to which the person affected and relatives have control over its course. Karp posits that throughout this process, relatives try to find a comfortable balance between their felt obligation to provide care for the person affected and their need to maintain sufficient distance for the purpose of self-preservation. Karp (2001, p 153), goes on to say that in the relatives support group, members espoused an illness ideology of sorts that provided them some guidance and comfort.

“… when members of the Family and Friends group at McLean’s hospital get together each week …...it is virtually mandatory during each meeting for the group to mention the Four Cs. "Like an indispensable ritual in a religious service, members recite in unison, “I didn’t cause it, I can’t cure it, and I can’t control it. All I can do is cope with it.”

Karp says that it implicitly suggests theories of mental illness that combine elements of science, therapy and spirituality. He says, that together these themes constitute a compelling cultural brew that provides comfort and a measure of direction to people who cannot escape asking, “what is the essential nature of mental illness? How and why do people become mentally ill? Might I somehow have contributed to a family member’s gross unhappiness? What is the right way to deal with a mentally ill person? What are the limits in my ability to help a family member in such awful pain? And the question most relevant to this study, “What do I need to do for myself in order to avoid being consumed by another person’s extraordinary emotional distress?”

In summary, although the above studies give some insight into coping strategies utilized by caregivers of the mentally ill, a literature search did
not reveal an appropriate instrument to measure coping strategies associated with the grief brought on by the loss of a child’s mental health. As such a scale was developed for use in this study as discussed in Chapter 1 (1.12) discussing Measurement Procedure.
CHAPTER 4: GRIEVING AND PSYCHOTIC DISORDERS IN A CROSS SECTION OF PARENTS IN WESTERN AUSTRALIA

In Chapter 4 I will discuss the findings of this study as they relate to grief. Firstly, I will discuss the findings of the profile of respondents and their children affected by a psychotic disorder. I will then discuss findings in relation to objective 1: To investigate the intensity of grief in a cross section of parents of individuals with psychotics disorders in Western Australia and determine if the results replicate international studies. I will also discuss the findings in relation to objective 2: To examine characteristics of the psychotic disorders of children, which may impact on the present grief reactions of parents. This includes the strength of the relationship between parents and children before and following onset of the disorder.

Following a literature search of empirical studies of grief in carers of the mentally ill, four key articles were identified. These are Miller et al (1990), Atkinson (1994) and Solomon and Draine (1996) Davis and Schultz (1998). Except for Davis and Schultz (1998), the studies used Miller et al’s MIV-TIG to measure grief.

In testing Objective 1 I have examined the intensity of grief in a cross section of parents of individuals with psychotics disorders in Western Australia. In addition, I have used Faschingbauer et al’s (1977) work to hypothesize the relationship between past behaviours and present feelings
related to grief (Parts 1 and 2 of MIV-TIG) as well as various types of grief adjustment patterns.

4.1 Profile of Respondents and their Children Affected.
Eighty-two biological parents of people affected by psychotic disorders responded by returning completed questionnaires. The response rate was 79.5%. In summary, they are predominantly:

- Aged 50-59 years (43.9%)
- Female (72%)
- Born in Australia (57.5%)
- Christian faith (67.1%)
- Highest level of formal schooling was secondary (62.5%)
- Did not have compounding factors of grief (95.1%)
- Child with psychotic disorder was a son (72%)
- Child with psychosis lived with parent (61%)
- Interacted with child at least once a day (70.7%)
- Had face-to-face interaction (90.2%)
- Child was aged 18-25 years at onset of psychosis (51.9%)
- Diagnosed 2-5 years ago (35.4%)
- Had only 1 hospitalisation at time of response (32.1%)
- Last hospitalisation was less than 1 year ago (51.3%)
- Child affected did not require assistance with personal hygiene, grooming, dressing etc. (81%)
- Parents reported having much emotional involvement with the child (98.8%)
- Parents reported having partial financial responsibility for the child (53.1%)
• Parents did not predict decrease in emotional involvement or any change in the assistance given in the future (67.5%)

• Their relationship with the child before the diagnosis of a psychotic disorder was as close as most of their relationships with others (45.1%)

• Their current relationship with the child with a psychotic disorder was closer than most relationships (46.3%)

• Parents reported being very upset about the illness at the time of diagnosis but eventually accepted or resigned to the illness (80.5%).

• Parents reported that they were coping “extremely, moderately or somewhat well” with their grief at present (69.6%)

4.2 The intensity of grief in the parents of the study.
As discussed in the literature review, grief in relatives of people with mental illness has been measured before. However, this study was conducted to determine if grief exists in a different cultural milieu – namely in a cross section of parents in Western Australia.

One of the measures of grief is based on how parents describe their feelings at the time that a diagnosis of a mental illness in their child is given to them. When parents were requested to identify some of the words that best describe their feelings at the time they found out about their child’s psychotic disorder and at the time of responding to the study, the following results emerged as summarised in Table 3 below:
Table 3: Description of Feelings at time of diagnosis and at time of study

<table>
<thead>
<tr>
<th>Description of feeling</th>
<th>At the time of diagnosis</th>
<th>At the time of the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angry</td>
<td>26.8%</td>
<td>11.0%</td>
</tr>
<tr>
<td>Hopeless</td>
<td>41.5%</td>
<td>13.4%</td>
</tr>
<tr>
<td>Frustrated</td>
<td>52.4%</td>
<td>39.0%</td>
</tr>
<tr>
<td>Sad</td>
<td>86.6%</td>
<td>72%</td>
</tr>
<tr>
<td>Depressed</td>
<td>51.2%</td>
<td>22%</td>
</tr>
<tr>
<td>Relieved</td>
<td>30.5%</td>
<td>24.4%</td>
</tr>
<tr>
<td>Disbelief</td>
<td>35.4%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Fearful</td>
<td>42.7%</td>
<td>22%</td>
</tr>
<tr>
<td>Numb</td>
<td>24.4%</td>
<td>4.9%</td>
</tr>
<tr>
<td>Resentful</td>
<td>11.0%</td>
<td>4.9%</td>
</tr>
<tr>
<td>Blamed</td>
<td>20.7%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Anxious</td>
<td>65.9%</td>
<td>46.3%</td>
</tr>
<tr>
<td>Guilty</td>
<td>37.8%</td>
<td>9.8%</td>
</tr>
<tr>
<td>Other feelings</td>
<td>20.7%</td>
<td>31.7%</td>
</tr>
</tbody>
</table>

Source: Survey of Parents in Grief Study, Western Australia, 2001. n=82

Table 3 shows a decrease of subjective grief related feelings from the time of diagnosis to the time of the study. From a practice wisdom perspective, some of these were expected. Examples of these are parents’ feelings of guilt where 37.8 per cent of parents reported feelings of guilt at the time of diagnosis. However, only 9.8 per cent of these parents reported that they felt guilty at the time of the study. Similarly,

---

3 For brevity, the remaining tables and figures referring to the survey data for this thesis will be entitled "Survey of Parents in Grief Study, W.A., 2001"
20.7 per cent of parents reported feeling blamed at the time of diagnosis. These feelings were reduced to 6.1 per cent at the time of the study.

From a practice wisdom perspective, such feelings in parents are often reduced by mass education that has been conducted by the Commonwealth Department of Health and Family Services, activities and educational sessions during Mental Health Week in October of each year and information and support groups run by ARAFMI, hospitals and clinics.

Feelings of frustration reported by parents decreased markedly from time of diagnosis (52.4 %) to the time of the present study (39.0%). However two out of five parents still experienced frustration.

From a practice wisdom perspective, I believe the cyclical nature of mental disorders poses many uncertainties for parents, and both parents and clinicians have difficulty at times differentiating behaviour related to symptoms and maladaptive behaviour that may be a result of attempts to cope with the disorder. Such difficulties may cause frustration. Feelings of frustration are also usually related to daily problems.

There was a marked decrease in feelings of hopelessness from 41.5 per cent at the time of diagnosis of the disorder to 13.4 per cent at the time of the study. Hopelessness in this instance may be considered as a broader concept and longer-term view of the situation.

There was no marked decrease in parents’ feelings of anxiety (65.9% to 46.3%) or fear (42.7% to 22.0%). Long periods of feelings of anxiety and fear have a major impact on people’s mental and physical health. Here
lies a further challenge for clinicians in exploring interventions that may reduce such feelings in parents.

The increase from “at the time of diagnosis” and “at the time of study” was only in “other feelings” where parents had listed the following “at the time of diagnosis”:

- “Hell on earth”
- “Waste, why, cause?”
- “Confused”
- “Ashamed and lonely”
- “What can I do to assist”
- “I need more knowledge”
- “Very worried”
- “Devastated”
- “Shock”
- “Dazed and panic stricken”
- “Grief”
- “Powerless”
- “I should have been more aware”
- “Thankful to find an answer”
- “Frightened of the changes that needed to be faced”

The feelings at the time of responding to the study, were:

- “Why?”
- “Acceptance, resignation”
- “Lonely”
- “Concern for the future”
- “Apprehension about future”
- “Feel encouraged at times”
- “At peace knowing that I have done as much as humanely possible”
- “Knowledgeable”
- “Hopeful”
- “Disappointment with health service”
- “Need to understand the illness”
- “More positive”
- “Satisfaction with changes to lifestyle after years of erratic behaviour”
- “Pleased that assistance is available”
• “Proud of the child’s achievements”

From practice wisdom, clinicians working with people experiencing grief in other situations of loss often hear the words as recalled in parents at the time of diagnosis - “hell on earth”, “shock”, “dazed and panic stricken”, “grief”, “powerlessness” and “devastated”.

The decrease of subjective grief related feelings from the time of diagnosis to the time of the study shown in Table 3 was validated with 69.6 per cent of parents responding that they were coping “extremely, moderately or somewhat well” with their grief (question 22, Appendix D).

Moving from the subjective expression of grief to more specific measurements of grief, the MIV-TIG developed by Miller et al (1990) is the only scale available to measure grief in relatives of the mentally ill. Using Part 1 of the MIV-TIG which was designed to assess a relative’s initial response to the loss of a person’s mental health, the current study attempted to assess the respondents mean scores of past behaviours related to grief reactions according to the length of time since diagnosis of a child’s mental illness. Figure 2 below gives the findings:
The results above indicate how parents in the current study recall their feelings and behaviours to have been at the time of the diagnosis. Using a 5 point Likert scale of 8 statements yielding a maximum score of 40, all parents except of those less than 1 year following diagnosis had a mean score of above 20 indicating over half the range. These results suggest high levels of grief in parents as they recall the time of diagnosis. The results also indicate that the highest level of mean scores were in parents who had a child diagnosed with a psychotic disorder within the past 2-5 years. Although there was a slight decrease of the mean score over time, even parents who had a child diagnosed over 20 years ago indicated a mean score of 21, suggesting high levels of grief.
Zisook and DeVaul (1985) in simplifying the staging of the grief process in bereavement, opted for a model of three partially overlapping but distinct stages:

(a) an initial period of shock, disbelief and denial;
(b) an intermediate acute mourning period of acute somatic and emotional discomfort and social withdrawal; and
(c) a culminating period of resolution.

However, they conclude that the expected time course for what would be accepted as “normal” bereavement is broadening through the years. In the present study there was no marked decrease in mean scores of parents’ recall of past behaviours related to grief, and as such no suggestion of a culminating period of resolution. I suggest that future researchers explore any triggers of grief and what could be done to lessen distress in parents of people with psychotic disorders. Suggested protocols for intervention will be discussed in Chapter 6, Implications for Practice.

The study also attempted to assess the respondents mean scores of present grief reactions (MIV-TIG Part 2) according to the length of time since diagnosis of a child’s mental illness. Figure 3 below gives the findings:
Using a 5-point Likert scale, if an individual scored 5 on each of the 16 variables, this would yield a maximum score of 80. All parents in the present study had a mean score of above 40. These results suggest high levels of present grief. The above results also indicate that the highest level of mean scores for present grief was in those who had a child diagnosed with a psychotic disorder within the past 1-2 years. From practice wisdom, I believe that this is a crucial time period when parents come to an understanding of psychotic disorders and the realisation that the diagnosis was not one of a “once only” episode.

Some feelings quoted by parents at the time of the study were “why”, “disappointment with health service”, “lonely”, and “apprehension about the future”.

**FIGURE 3: PRESENT FEELINGS OF GRIEF/TIME SINCE DIAGNOSIS**
(Source: Survey of Parents in Grief Study, W.A. 2001, n=78)
The study also indicates that the mean score for present grief is greater in parents of those diagnosed over 20 years ago. This is in contrast to the study of Solomon *et al* (1996) where they found that family members who had lived with mental illness in a relative for a longer period of time expressed less grief. In the present study, all of the parents in this group (length of time since diagnosis over 20 years) were aged 60 years and over. From practice wisdom, I believe that this is a time when parents are faced with their own mortality and concerns of who would care for their child when they are not around.

An interesting finding in the present study is that present feelings of grief increased with age in a cross section of male respondents and as such brings up further questions of the impact of age on grief in males. This is indicated in Figure 4 below:

**FIGURE 4: PRESENT LEVEL OF GRIEF (MEAN)/AGE OF RESPONDENT/GENDER**
(Source: Survey of Parents in Grief Study, W.A., 2001, n=80)
However, a note of caution for the above results in that the numbers of the older group of males aged 80-89 was small (n=2) and therefore the above findings could not be generalised. A longitudinal study would confirm if grief reactions increased with age in males of this population.

All other parent descriptors were weakly correlated with the parents’ present degree of grieving.

Finally, using Pearson product-moment correlation values, the study attempted to ascertain the relationship between the respondent’s present level of grieving and their subjective assessment of their level of coping. There was a positive correlation (r=0.325) significant at the 0.01 levels indicating that parents with higher levels of present grief indicated higher levels of difficulty coping with their grief. This indicates that the MIV-TIG is validated by the respondents’ own perception of coping level.

Further, to meet Objective 1 of the study, the method adopted by Fashingbauer et al (1977) in Table 4 below was used to provide information regarding a person’s progression through the various stages of grief by combining past behaviours (Part 1) and present feelings (Part 2) of the scale. High and low scores were above and below the 50th percentile, respectively on each part.
Table 4: Grief Reaction Groups of Fashingbauer et al (1977)

<table>
<thead>
<tr>
<th>Part 1 Past</th>
<th>Part 2 Present</th>
<th>Group Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>Low</td>
<td>Group 1: Absence of grief</td>
</tr>
<tr>
<td>Low</td>
<td>High</td>
<td>Group 2: Delayed grief</td>
</tr>
<tr>
<td>High</td>
<td>High</td>
<td>Group 3: Prolonged grief</td>
</tr>
<tr>
<td>High</td>
<td>Low</td>
<td>Group 4: Acute resolved grief</td>
</tr>
</tbody>
</table>

Respondents of the present study showed the following progression through the grief process:

![Figure 5: Grief Reaction Groups](source: Survey of Parents in Grief Study, W.A.,2001 n=82)
Therefore, using the method adopted by Fashingbauer et al (1977) parents’ progression through the various stages of grief in the present study indicate that 51.3% of parents were experiencing ‘delayed or prolonged grief’.

The Chi-square test for independence is used to explore the relationship between two categorical variables. In this instance, the research question that arose was: Is there an association between past behaviours related to grief reactions and present feelings of grief as reported by parents in the MIV-TIG? The results of the present study are indicated in Table 5 below:

Table 5: Relationship Between Level of Past Behaviours and Level of Present Grief

<table>
<thead>
<tr>
<th></th>
<th>Present Grief</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
</tr>
<tr>
<td>Past grief low</td>
<td>57.9%</td>
</tr>
<tr>
<td>Past grief high</td>
<td>42.1%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>N</td>
<td>38</td>
</tr>
</tbody>
</table>

(Source: Survey of Parents in Grief Study W.A 2001 n=78)

The Chi-square value was 4.106 with an associated significance level (p=0.043).

The results suggest that there is a strong association between past behaviours related to grief reactions and present feelings related to grief. As table 5 above further shows, 57.9 per cent of those with low grief now
had low grief in the past. Over two thirds (67.5 per cent) of those with high grief now had high grief in the past.

The above findings of parental grief are similar to the literature on Post Traumatic Stress Disorder (PTSD), that is, people with high initial distress following a traumatic incident are more at risk for developing symptoms of Post Traumatic Stress Disorder. Schnurr et al (2002) say that data from prospective studies have found that the intensity of an initial reaction to a traumatic event is predictive of the subsequent development of symptoms of Post Traumatic Stress Disorder.

Mohr and Regan-Kubinski (2001) in their qualitative study of parents’ experiences when their child becomes mentally ill, report that parents described sequelae of the process of seeking help, undergoing treatment, and the aftermath of treatment in words that illustrate that the sequelae do not give closure. They found that there were themes in the descriptions of sequelae that were consistent with post-traumatic stress. As discussed in the literature, while Regan-Kubinski (2001) found that families in their study experienced some of the symptoms of grief reactions, they also experienced the symptoms of trauma.

Table 5 has also brought up other questions in that 32.5 per cent of the present high grievers reported themselves to be low grievers in the past. Less than half (42.1 per cent) of those with high grief in the past had now moved to low grief.

Personal communication from Miller (2002) on the results of the present study suggests, “…the fact that scores for later grief were not that different suggest that a multivariable model would best predict the
occurrence of longstanding grief. Social support, coping skills in general, accurate information, the things we can change would seem to be natural choices for these”. Development of a multivariate model to analyse grief responses amongst parents was beyond the scope of this project/thesis.

**Conclusion**: There is measurable grief in parents of individuals with psychotic disorders in a cross section of parents in Western Australia. Although the scores in present feelings of grief was high in the respondents according to the MIV-TIG, the perception of the majority of respondents, as reported in the ‘Profile of Respondents Section” was that they were coping “extremely, moderately or somewhat well” with their grief (69.6%). However as demonstrated in Pearson product-moment correlation values (page 86), there was a significant positive correlation (r=0.325, p<0.01) indicating that parents with higher levels of present grief indicated higher levels of difficulty coping with their grief. Therefore the subjective statements and self-assessment of coping do not fully concur with the statistical analysis of feeling of grief. This paradox warrants further research.

It may suggest that a scale such as the adapted version of the Texas Revised Inventory of Grief, developed to measure grief in bereavement may not be able to capture crucial dimensions of grief of parents in the context of a child with a psychotic disorder. For example an item such as “I found a need to do things the way he/she used to do them” may be appropriate in grief in bereavement but may not be so in grief associated with loss of health through a psychotic disorder. A psychotic disorder is associated with major changes in personal characteristics. These changes may be present for quite some time in people who have a long prodrome
and when diagnosis and treatment have been delayed. Therefore it is unlikely that parents or relatives will find a need to do things the way a child used to do them. The findings of the study recommends that future researchers who may wish to develop a scale to measure grief in relatives of the mentally ill need to take into account the disabling effects of the particular disorder and the feelings of loss brought on by such a disability.

The method of having two different scales, the first with eight items and the other with 16 items causes difficulty in accurately measuring any change. In addition they are administered on two separate time points with the first being a retrospective self-assessment and the second a contemporary assessment of feelings. A longitudinal study requiring collection of factual information on a regular or continuing basis will allow measurement of any patterns of change.

The results of the study also reveal that the level of present grief was highest in parents whose children were diagnosed with a psychotic disorder within the last two years. Following a decline in mean score for present feelings after two years from diagnosis, there was an increase again in parents of children diagnosed over 20 years ago. All of these parents were of age 60 years and over suggesting that practitioners need to be aware of the special needs of parents at various stages of their child’s illness. All other parent descriptors were weakly correlated with the parents’ present degree of grieving.

When using the method adopted by Fashingbauer et al (1977) the study revealed a strong association between past behaviours related to grief reactions and present feelings related to grief in that respondents with
low initial grief revealed low grief in the present and respondents with high initial grief revealed high grief in the present. A multivariate statistical analysis is a possible avenue for further research in this area, but is beyond the scope of the present study.

4.3 Do the findings of the present study replicate international studies?

Having established that there is measurable grief in parents of individuals with psychotic disorders in a cross section of parents in Western Australia, the study examined if the results replicate international studies.

In the study of Miller et al (1990, p. 1321) they say “a test of the instrument with 58 family members of patients with schizophrenia or bipolar disorder revealed a surprisingly low level of initial grief but higher levels of present grief”. In the present study no attempt was made to differentiate between schizophrenia, bipolar disorder or any other psychotic disorder. The sample of relatives in Miller et al’s study consisted of parents, siblings and ‘others’ such as uncles, aunts, nephews and nieces whereas the sample in the present study consisted only of biological parents.

Part 1 of the MIV-TIG was designed to assess a relative’s initial response to the loss of a person’s mental health. Table 6 below gives a summary of Miller et al’s study and the present study listing the frequency of responses to the eight statements in Part 1 of the scale. To facilitate evaluating the responses the 5-point Likert scale was condensed to three points: completely or mostly true, neither true nor false, and completely or mostly false. The collapsing of the scale to three categories replicates the methodology adopted by Miller et al.
Table 6: Comparison of Study of Miller (1990) & Perera (2002)
Responses (by per cent)

**MIV-TIG - Part 1 (Past Behaviours)**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Completely or mostly true %</th>
<th>Neither True nor False %</th>
<th>Completely or mostly false %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>P</td>
<td>M</td>
</tr>
<tr>
<td>I found it hard to get along with certain people</td>
<td>16</td>
<td>38</td>
<td>14</td>
</tr>
<tr>
<td>I found it hard to work well when I became aware of his/her mental illness</td>
<td>35</td>
<td>67</td>
<td>22</td>
</tr>
<tr>
<td>I lost interest in other family members, friends and relatives</td>
<td>7</td>
<td>27</td>
<td>25</td>
</tr>
<tr>
<td>I found a need to do things the way he/she used to do them</td>
<td>7</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>I was unusually irritable</td>
<td>24</td>
<td>42</td>
<td>21</td>
</tr>
<tr>
<td>I couldn’t keep up with my usual activities for the first three months</td>
<td>28</td>
<td>56</td>
<td>11</td>
</tr>
<tr>
<td>I was angry with him/her for the changes that were taking place</td>
<td>26</td>
<td>20</td>
<td>22</td>
</tr>
<tr>
<td>I found it hard to sleep</td>
<td>41</td>
<td>70</td>
<td>21</td>
</tr>
</tbody>
</table>

(Miller n=58, Perera n=82)

The present study differed from the study of Miller et al in that only three of the eight statements had most responses in the *completely or mostly false* category whereas in Miller et al’s seven of the eight statements had most responses in the *completely or mostly false* category. However, similarly to Miller et al’s study, rarely did parents lose interest in other relationships or display signs of pathological grief, such as taking on traits of the person who became ill. In the present study a higher number of parents reported difficulty sleeping.
(Perera=70%, Miller et al=41%) and a higher number of parents found it hard to work well when they became aware of the child’s mental illness (Perera=67%, Miller et al=35%). When the mean scores of the category ‘completely or mostly true’ in the eight statements were compared, the present study had a considerably higher score (Perera=41.6, Miller et al=23).

Table 7 ranks from highest to lowest the statements of Past Behaviours as reported by respondents of Miller et al’s study. I have then compared it with the responses in the present study by colour coding the statements.

Table 7: **Comparison of the Study of Miller (1990) & Perera (2002),**

<table>
<thead>
<tr>
<th>MIV-TIG Part 1</th>
<th>STATEMENT</th>
<th>MILLER</th>
<th>STATEMENT</th>
<th>PERERA</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found it hard to sleep</td>
<td>41%</td>
<td>I found it hard to sleep</td>
<td>70%</td>
<td></td>
</tr>
<tr>
<td>I found it hard to work well when I became aware of his/her mental illness</td>
<td>35%</td>
<td>I found it hard to work well when I became aware of his/her mental illness</td>
<td>67%</td>
<td></td>
</tr>
<tr>
<td>I couldn’t keep up with my usual activities for the first three months</td>
<td>28%</td>
<td>I couldn’t keep up with my usual activities for the first three months</td>
<td>56%</td>
<td></td>
</tr>
<tr>
<td>I was angry with him/her for the changes that were taking place</td>
<td>26%</td>
<td>I was unusually irritable</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td>I was unusually irritable</td>
<td>24%</td>
<td>I found it hard to get along with certain people</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>I found it hard to get along with certain people</td>
<td>16%</td>
<td>I lost interest in other family members, friends and relatives</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>I lost interest in other family members, friends and relatives</td>
<td>7%</td>
<td>I was angry with him/her for the changes that were taking place</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>I found a need to do things the way he/she used to do them</td>
<td>7%</td>
<td>I found a need to do things the way he/she used to do them</td>
<td>13%</td>
<td></td>
</tr>
</tbody>
</table>

(Miller n=58, Perera n=82)
Although the present study had some similarities in the pattern as seen by the colour coding, the parents in the present study ranked the statement “I was angry with him/her for the changes that were taking place” lower than the relatives in Miller et al’s study.

Respondents of the present study were only biological parents of people affected by psychotic disorders, whereas Miller et al’s study included siblings, uncles, aunts, nephews and nieces whom they categorised as ‘others’.

From practice wisdom, I believe there is often more anger shown by siblings and other relatives than parents as psychotic disorders involve changes in personality and behaviour often seen as ‘bad’ rather than ‘mad’. Siblings often complain of being neglected by parents because of the time and concern shown towards the child affected by a psychotic disorder.

Further explanations may be that since the time of Miller et al’s study in 1990 there has been more understanding about psychosis as a biological disorder rather than the notion that family traits are etiological. Multiple Family Education groups were held regularly at the services where respondents were recruited. Share and Care Groups and education seminars about mental illness are also organised regularly by ARAFMI. The Federal Government’s community education programs have, I believe, had an impact in people treating mental illness as a biological disorder rather than purely a behavioural disorder.
Part 2 of the MIV-TIG was designed to assess the respondent’s present degree of grieving. Table 8 below gives a comparison of Miller et al’s and the present study:

**Table 8: Comparison of the Study of Miller (1990) & Perera (2002) Responses (by per cent)**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Completely or Mostly True %</th>
<th>Neither True nor False %</th>
<th>Completely or Mostly False %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>P</td>
<td>M</td>
</tr>
<tr>
<td>I cry when I think about how he/she used to be before the illness</td>
<td>36</td>
<td>27.5</td>
<td>28</td>
</tr>
<tr>
<td>I cry when I think about how he/she could have been if not for the illness</td>
<td>45</td>
<td>38</td>
<td>20</td>
</tr>
<tr>
<td>I get upset when I think about how he/she used to be before the illness</td>
<td>48</td>
<td>49</td>
<td>24</td>
</tr>
<tr>
<td>I get upset when I think about how he/she could have been if not for the illness</td>
<td>56</td>
<td>65.4</td>
<td>19</td>
</tr>
<tr>
<td>I very much miss the way he/she used to be</td>
<td>68</td>
<td>54</td>
<td>15</td>
</tr>
<tr>
<td>It is painful to recall memories of how he/she used to be</td>
<td>46</td>
<td>36</td>
<td>17</td>
</tr>
<tr>
<td>I am preoccupied with thoughts about how he/she used to be before the illness</td>
<td>11</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>I am preoccupied with thoughts about how he/she could have been if not for the illness</td>
<td>33</td>
<td>22.5</td>
<td>19</td>
</tr>
<tr>
<td>I hide tears when I think about him/her</td>
<td>27</td>
<td>27</td>
<td>25</td>
</tr>
<tr>
<td>No one will ever take the place that he/she used to have in my life</td>
<td>51</td>
<td>25</td>
<td>18</td>
</tr>
<tr>
<td>I can’t avoid thinking about how he/she was before the illness</td>
<td>37</td>
<td>25</td>
<td>26</td>
</tr>
<tr>
<td>I can’t avoid thinking about how he/she could have been if not for the illness</td>
<td>35</td>
<td>36</td>
<td>30</td>
</tr>
<tr>
<td>I feel it is unfair that he/she became mentally ill</td>
<td>51</td>
<td>62.2</td>
<td>28</td>
</tr>
<tr>
<td>Things and people around me still remind me of the way he/she used to be</td>
<td>21</td>
<td>19</td>
<td>32</td>
</tr>
<tr>
<td>Statement</td>
<td>Completely or Mostly True %</td>
<td>Neither True nor False %</td>
<td>Completely or Mostly False %</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>------------------------------</td>
<td>--------------------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td>I cannot accept his/her mental illness</td>
<td>14</td>
<td>14</td>
<td>57</td>
</tr>
<tr>
<td>At times I still feel the need to cry for him/her</td>
<td>47</td>
<td>54</td>
<td>30</td>
</tr>
</tbody>
</table>

(Miller n=58, Perera n=82)

In Miller et al’s study, 9 out of the 16 statements had most responses in the *completely or mostly true* category. However in the present study, only seven out of the 16 statements had most responses in the *completely or mostly true* category. Similarly to Miller et al’s study, certain items on Part 2 of MIV-TIG in the present study yielded extremely high scores. For example, 56 per cent (Miller et al) and 65 per cent (Perera) respondents found the statement “I get upset when I think about how he/she could have been if not for the illness” completely or mostly true. Over half the respondents found the following statements “completely or mostly true”

- **I feel it is unfair that he/she became mentally ill** (Miller *et al*=51%, Perera=62.2%)
- **I very much miss the way he/she used to be** (Miller *et al*=68%, Perera=54%)
- **At times I still feel the need to cry for him/her** (Miller *et al*=47%, Perera=54%).

In the present study slightly less than one third of people reported that “they still cried when they thought about how their relative used to be” and “that they were preoccupied with thoughts about how their relative could have been if not for the illness”.

97
When comparing the present study with Miller et al’s study in ranking statements in order of highest to lowest, many similarities emerged as shown in Table 9.

**Table 9: Comparison of the Study of Miller (1990) & Perera (2002)**

**Rank Order of “Completely or Mostly True” Category**

MIV-TIG Part 2 (Present Feelings)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Miller</th>
<th>Statement</th>
<th>Perera</th>
</tr>
</thead>
<tbody>
<tr>
<td>I very much miss the way he/she used to be</td>
<td>68%</td>
<td>I get upset when I think about how he/she could have been if not for the illness</td>
<td>65.4%</td>
</tr>
<tr>
<td>I get upset when I think about how he/she could have been if not for illness</td>
<td>56%</td>
<td>I feel it is unfair that he/she became mentally ill</td>
<td>62.2%</td>
</tr>
<tr>
<td>No one will ever take the place that he/she used to have in my life</td>
<td>51%</td>
<td>I very much miss the way he/she used to be</td>
<td>54%</td>
</tr>
<tr>
<td>I feel it is unfair that he/she became mentally ill</td>
<td>51%</td>
<td>At times I still feel the need to cry for him/her</td>
<td>54%</td>
</tr>
<tr>
<td>I get upset when I think about how he/she used to be before the illness</td>
<td>48%</td>
<td>I get upset when I think about how he/she used to be before the illness</td>
<td>49%</td>
</tr>
<tr>
<td>At times I still feel the need to cry for him/her</td>
<td>47%</td>
<td>I cry when I think about how he/she could have been if not for the illness</td>
<td>38%</td>
</tr>
<tr>
<td>It is painful to recall memories of how he/she used to be</td>
<td>46%</td>
<td>It is painful to recall memories of how he/she used to be</td>
<td>36%</td>
</tr>
<tr>
<td>I cry when I think about how he/she could have been if not for the illness</td>
<td>45%</td>
<td>I can’t avoid thinking about how he/she could have been if not for the illness</td>
<td>36%</td>
</tr>
<tr>
<td>I can’t avoid thinking about how he/she was before the illness</td>
<td>37%</td>
<td>I cry when I think about how he/she used to be before the illness</td>
<td>27.5%</td>
</tr>
<tr>
<td>I cry when I think about how he/she used to be before the illness</td>
<td>36%</td>
<td>I hide tears when I think about him/her</td>
<td>27%</td>
</tr>
<tr>
<td>I can’t avoid thinking how he/she could have been if not for the illness</td>
<td>35%</td>
<td>No one will ever take the place that he/she used to have in my life.</td>
<td>25%</td>
</tr>
<tr>
<td>STATEMENT</td>
<td>MILLER</td>
<td>STATEMENT</td>
<td>PERERA</td>
</tr>
<tr>
<td>------------------------------------------------------------</td>
<td>--------</td>
<td>------------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>I am preoccupied with thoughts about how he/she could have been if not for the illness</td>
<td>33%</td>
<td>I can’t avoid thinking how he/she could have been if not for the illness.</td>
<td>25%</td>
</tr>
<tr>
<td>I hide tears when I think about him/her</td>
<td>27%</td>
<td>I am preoccupied with thoughts about how he/she could have been if not for the illness</td>
<td>22.5%</td>
</tr>
<tr>
<td>Things and people around me still remind me of the way he/she used to be.</td>
<td>21%</td>
<td>Things and people around me still remind me of the way he/she used to be.</td>
<td>19%</td>
</tr>
<tr>
<td>I cannot accept his/her mental illness</td>
<td>14%</td>
<td>I cannot accept his/her mental illness</td>
<td>14%</td>
</tr>
<tr>
<td>I am preoccupied with thoughts about how he/she used to be before the illness</td>
<td>11%</td>
<td>I am preoccupied with thoughts about how he/she used to be before the illness</td>
<td>9%</td>
</tr>
</tbody>
</table>

(Miller n=58, Perera n=82)

The results of the present study had many similarities to the study of Miller *et al*, as seen in the colour coding above. For example, the statement, “I get upset when I think about how he/she could have been if not for the illness” ranked first in the present study and second in Miller *et al*’s. The statement, “It is painful to recall memories of how he/she used to be” ranked seventh in both studies.

The statements, “Things and people around me still remind me of the way he/she used to be”, “I cannot accept his/her mental illness” and “I am preoccupied with thoughts about how he/she used to be before the illness” ranked fourteenth, fifteenth and sixteenth respectively in both studies.

One difference between the two studies that was apparent was that the respondents in Miller *et al*’s study ranked the statement “no one will ever take the place that he/she used to have in my life” third (51%) whereas...
the respondents in the present study ranked the statement eleventh (25%).

When the percentages of mean scores of the category completely or mostly true in the 16 statements of Table 9 were compared, Miller et al’s study had a slightly higher score than the present study. (M=39.12, P=35.18).

Comparison of the present study with that of Atkinson (1994) was limited. It was unclear from her paper how she arrived at a conclusion that increase of mean score of 23.8 from initial grief to mean score of 53.8 on present grief represented increase of grief. By following Miller et al’s method of scoring the two parts of the MIV-TIG scale, Parts 1 and 2 does show increases in scores. This is because Part 1 with 8 statements yields a maximum score of 40 and Part 2 with 16 statements yields a maximum score of 80.

Comparison of the present study with that of Solomon et al (1998) was not possible as their study begins with the assumption that there is measurable grief in parents of the mentally ill but does not give scores of the two scales that could be compared with the present study. As their study utilised multiple regression analysis, there was no discussion of the MIV-TIG as a dependent variable. However their study found that family members who had lived with mental illness in a relative for a longer period of time expressed less grief.

**Conclusion:**

The initial response of grief in Miller et al’s study is similar in pattern to the present study, however the magnitude of initial grief in respondents
was higher in the present study. The responses of present grief in the two studies were similar, although Miller et al’s study showed a slightly higher score than the present study. The differences in the two studies may be explained by the fact that Miller et al’s study included siblings and other relatives whereas the respondents of the present study were limited to biological parents. There are also other factors such as cultural differences between the two populations that may explain these differences.

4.4 Characteristics of the psychotic disorder in children that may impact on the grief of parents.

Miller et al (1990) attempted to ascertain the relationship between the respondents’ present level of grieving (as assessed by Part 2 scores) and various characteristics of the disorder such as number of hospitalisations, age at onset of mental illness, duration of illness and time since last hospitalisation. They found that all such descriptors were weakly correlated with the relatives’ present degrees of grieving. Neither was there a correlation between the present level of grieving of relatives and family members who lived with the affected members and those who did not.

The parents in the study of Atkinson (1994) reported that the frequency of thinking about “How their child could have been if not for the disease” was higher during an acute exacerbation of the disease.

The respondents of Solomon et al’s (1996) study included parents, siblings, spouses and adult children of people with either schizophrenia or major affective disorder. Their study found that lesser grief was associated with parents who had their relative living with them. They
suggest that if the relationship between living with the ill relative and expressed grief was supported in future research, an explanation might be that family members experience less grief in sustained relationships with their ill relative.

A further suggestion they offer is that family members had greater opportunity to understand the course of mental illness in their relative. Thus, exacerbations of symptoms are more easily set in the context of the course of illness.

However, they also offer an alternative explanation in that a third, unmeasured factor explains both living with the ill relative and lower levels of expressed grief. Solomon et al (1996) also found that “more years of illness” in a child was associated with less grief in parents.

The present study attempted to find out if firstly, the results replicate the study of Miller et al (1990) in relation to grief and characteristics of the disorder in children.

The present study differed from that of Miller et al (1990) in relation to two characteristics of the disorder of their child. Significant positive correlations were found in parents’ present level of grieving and the following characteristics of the disorder as shown in Table 10:

- Where frequent assistance was required by the child in personal care (personal care was defined as assistance with personal hygiene, grooming, dressing etc)
- Late onset of psychotic disorder in child,
Table 10: Correlation Analysis of Characteristics of the Disorder of Children and Present Level of Grieving of Parents

<table>
<thead>
<tr>
<th>Characteristic of Disorder</th>
<th>n</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance with personal care</td>
<td>77</td>
<td>.258</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Age of onset of psychotic disorder in child</td>
<td>77</td>
<td>.232</td>
<td>&lt;0.05</td>
</tr>
</tbody>
</table>

(Source: Survey of Parents in Grief Study, W.A.2001 n=82)

The above result indicates that grief scores were higher in parents whose children required frequent assistance with personal hygiene, grooming and dressing. Practice wisdom suggests that children who require assistance with personal hygiene, grooming and dressing would have predominantly negative symptoms. This could be one explanation and would be confirmed by future research by the use of a scale such as the Life Skills Profile (Rosen et al 1989), which assesses behavioural deficits in people with schizophrenia.

Secondly, results also indicate that parents of children who were older at age of onset had higher levels of grief compared to those who were younger at onset. Both of these variables were weakly correlated with the relatives’ present level of grief in the study of Miller et al (1990). From practice wisdom, I believe that the loss becomes much more tangible for a parent with late onset as parental expectations of children being independent are much higher when children have moved through adolescent milestones. This could be one explanation, but further research is warranted.

Further this study attempted to replicate a key component of the study by Atkinson (1994). She found that the statement “How their child could
have been if not for the disease” was higher during an acute exacerbation of the disease. It is unclear from Atkinson’s study how she defined ‘acute exacerbation of the disease’. In the absence of any specific measure of ‘acute exacerbation’, ‘time since last hospitalisation’ was the only indicator in the data set of the present study that could be compared to that of Atkinson’s. The results of the present study are shown in Table 11 below.

Table 11: Frequency of Thinking “How their Child could have been if not for the Disorder” at Times of Exacerbation

<table>
<thead>
<tr>
<th>Last Hospitalisation</th>
<th>&lt; 1 year ago</th>
<th>&gt; 1 year ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely false</td>
<td>16.7%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Mostly false</td>
<td>14.3%</td>
<td>19.4%</td>
</tr>
<tr>
<td>Neither true nor false</td>
<td>33.3%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Mostly true</td>
<td>23.8%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Completely true</td>
<td>11.9%</td>
<td>11.1%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

N=78    X²=1.109    df=4    p>.05

Source: Survey of Parents in Grief Study, W.A. 2001, n=82

Results suggest that there was no significant correlation between these two variables.

The present study also attempted to find out if it replicates the study of Solomon et al (1996) where they found that lesser grief was associated with parents who had their relative living with them. In the present study there was no significant correlation between these two variables (r=0, p=0.10).
Conclusion: The present study differed from the study of Miller et al (1990), in that it found a significant positive correlation between parents’ present feelings of grief and the frequency of assistance they give their child in personal hygiene, grooming and dressing. To the best of my knowledge, these findings have not been reported before.

To the best of my knowledge, the findings that higher levels of grief was associated in parents whose children were older at onset of the disorder has not been previously reported.

The present study differed to that of Solomon et al (1996) in that higher grief was not associated with more years of illness.

4.5 Changes in relationship between parents and children following onset of disorder.

Questions 17 and 18 of the first questionnaire (Appendix D) requested parents to indicate their relationship with the son/daughter before onset of the disorder and at the time of the study. Using Pearson’s product-moment correlation coefficient, the present study attempted to ascertain if there was a relationship between the parents perceived relationship with their child before the illness and their relationship with the child at the time of the study. There was a strong positive correlation between these two variables (r=.459, n=82, p<.0005) indicating that high levels of perceived closeness before the illness was associated with high levels of perceived closeness at the time of the study. These results suggest that the disorder did not affect the relationship between parent and child. This is also consistent with the Psychodynamic and Attachment Theories that, attachment problems and hence problematic bonds between people
may carry over into adjustment to bereavement. The results of the present study suggest that attachment problems and problematic bonds may have carried over into parents’ grief when a child developed a psychotic disorder.

**Conclusion:** The results of this study suggest that the disorder did not have an effect on the relationship between parents and their child who was unwell. To the best of my knowledge, no previous study reports such findings.
CHAPTER 5: COPING WITH GRIEF

In Chapter 5 I will discuss the findings of this study as they relate to coping with grief. Firstly, I will discuss objective 3: To identify specific coping strategies that parents consider as being most helpful to them in dealing this grief. Secondly, I will discuss objective 4: To examine the relationship between intensity of grief and coping patterns of parents. Thirdly, I will discuss objective 5: To identify gender differences in grieving and coping strategies used.

Coping processes have been classified using two main concepts. The first concept emphasises the method of coping – whether a person uses predominantly a cognitive, behavioural or a combination of both methods to cope with the grief reaction. The second concept emphasises the focus - whether a person approaches the problem or distracts him or herself from it. A full discussion of coping was included in Chapter 3 of this thesis. In addition Chapter 1 (1.12) also outlines the development of a scale for coping that has been utilized in this study and also indicates the categorisation of each strategy. However, the scale requested respondents to indicate which strategies, if any, they have ever used and does not necessarily request them to indicate how frequently these strategies were used. Therefore a different pattern of results may emerge in Tables 12 to 21 if respondents were asked how frequently they used the strategies, whether they still used them and if so, how effective they consider them to be.
5.1 Specific coping strategies that parents consider as being most helpful to them in dealing with their grief.

Thirty-six different coping strategies were offered to respondents in the *Coping with Grief/Sadness – Self-Assessment Scale*. Data was analysed to ascertain the strategies that parents found to be most useful. Table 12 below ranks them in order of most useful to least useful (highlighted column).

**Table 12: Coping Strategies Considered as Most Helpful by Parents**

<table>
<thead>
<tr>
<th>COPING STRATEGIES</th>
<th>Behaviour Used By %</th>
<th>% Found to be Useful</th>
<th>% Not Useful or Harmful</th>
<th>% Found to be Harmful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gaining knowledge about the mental illness affecting my child by reading</td>
<td>78</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Believing that my child is getting the best medical care possible</td>
<td>78</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing my experiences with others in similar situation</td>
<td>56</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being involved in social activities with friends</td>
<td>45</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being involved in information &amp; support groups run for families by Hospitals and Clinics</td>
<td>44</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussing my sadness/grief with a member of the treating team in my own home</td>
<td>43</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working (outside employment)</td>
<td>38</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finding time for myself</td>
<td>61</td>
<td>98</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Physical activities</td>
<td>59</td>
<td>98</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Reading about how other people in my situation cope</td>
<td>50</td>
<td>98</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Building a close relationship with my spouse</td>
<td>50</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Discussing my sadness/grief with a member of the treating team in the clinic or hospital</td>
<td>49</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Being able to get away from the home care tasks and responsibilities for some relief</td>
<td>49</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Relying on my spiritual belief</td>
<td>46</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>COPING STRATEGIES</td>
<td>Behaviour Used By</td>
<td>% Found to be Useful</td>
<td>% Not Useful or Harmful</td>
<td>% Found to be Harmful</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>----------------------</td>
<td>-------------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>Developing myself as a person</td>
<td>43</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Discussing my sadness/grief with an appropriate health professional who is not a member of the treating team</td>
<td>42</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Becoming self reliant and independent</td>
<td>39</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Building a closer relationship with people</td>
<td>37</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Going out with my spouse on a regular basis</td>
<td>37</td>
<td>97</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Talking over personal feelings and concerns with someone other than a professional counsellor</td>
<td>60</td>
<td>96</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Doing things together as a family</td>
<td>56</td>
<td>96</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Entertaining friends in our home</td>
<td>33</td>
<td>96</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Being involved in hobbies (e.g. art, music)</td>
<td>49</td>
<td>95</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Talking over personal feelings and concerns with my spouse</td>
<td>69</td>
<td>93</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Telling myself that I have many things to be thankful for</td>
<td>65</td>
<td>92</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Believing that things will always work out</td>
<td>62</td>
<td>92</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Being involved in Care &amp; Share groups of the Association of Friends &amp; Relatives of the Mentally Ill (ARAFMI)</td>
<td>33</td>
<td>92</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Encouraging child with mental illness to be independent</td>
<td>76</td>
<td>91</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Assisting others in similar situations</td>
<td>27</td>
<td>90</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Being sure prescribed medication is being taken by child as required</td>
<td>67</td>
<td>89</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Investing myself in my children</td>
<td>39</td>
<td>88</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Being able to explain our family situation to relatives, friends and neighbours so they may understand</td>
<td>72</td>
<td>79</td>
<td>14</td>
<td>7</td>
</tr>
</tbody>
</table>
COPING STRATEGIES

<table>
<thead>
<tr>
<th>Behaviour Used By %</th>
<th>% Found to be Useful</th>
<th>% Not Useful or Harmful</th>
<th>% Found to be Harmful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crying more than usual</td>
<td>56</td>
<td>75</td>
<td>18</td>
</tr>
<tr>
<td>Sleeping more than usual</td>
<td>22</td>
<td>72</td>
<td>17</td>
</tr>
<tr>
<td>Allowing myself to get angry</td>
<td>54</td>
<td>50</td>
<td>14</td>
</tr>
<tr>
<td>Eating more than usual</td>
<td>29</td>
<td>29</td>
<td>13</td>
</tr>
</tbody>
</table>

(Source: Survey of Parents in Grief Study, W.A.2001 n=82)

Firstly, the 36 strategies above were classified to ‘cognitive,’ ‘behavioural’ or a combination of ‘cognitive-behavioural’ methods. They were then classified as either an ‘approach’ or ‘distraction’ focus. As discussed in the development of the scale, the following six basic types of coping processes were identified:

1. Cognitive-approach
2. Cognitive-distraction
3. Behavioural-approach
4. Behavioural-distraction
5. Cognitive/behavioural-approach

In the present study, the two most frequently used strategies were:

1. Gaining knowledge about the mental illness affecting my child by reading.
2. Believing that my child is getting the best medical care possible.

Seventy-eight (78%) of respondents used the two strategies. All respondents using them (100%) found them to be useful strategies.
Neither of these strategies was found to be harmful. Using the method discussed in the development of the coping scale, both of these strategies are categorised as *Cognitive-Approach* strategies.

Although the following two strategies were utilised by less than half of the respondents, all using them (100%) found them to be useful strategies.

1. Working (outside employment).
2. Being involved in social activities with friends.

Both strategies are categorised as *Behavioural-Distraction* strategies.

Similarly the following two strategies used by fewer respondents (56% and 43% respectively) was found to be helpful and not harmful:

1. Sharing my experiences with others in similar situations.
2. Discussing my sadness/grief with a member of the treating team in my own home.

Both the above strategies were categorised as *Cognitive/Behavioural-Approach* strategies.

When respondents were requested to cite the three most useful strategies from the list of 36 strategies offered or from the strategies they identified, the following 3 were the most frequently cited:

1. Talking over personal feelings and concerns with my spouse.
2. Relying on my spiritual belief.
3. Gaining knowledge about the mental illness affecting my child by reading

The first and third strategies were categorised as **Cognitive-Approach** strategies, while the second was categorised as a **Cognitive/Behavioural-Approach** strategy.

In the three most harmful categories, the following were the most frequently cited:

1. Allowing myself to get angry
2. Being able to explain our family situation to relatives, friends and neighbours so they may understand
3. Eating more than usual

The first strategy was categorised as a **Behavioural-Approach** strategy, the second a **Cognitive/Behavioural-Approach** strategy and the third a **Behavioural-Distraction** strategy.

When requested to list up to three coping strategies that they had used which were not listed in the **Coping with Grief/Sadness – Self-Assessment scale**, there were approximately 67 different strategies listed. This illustrates the idiosyncratic nature of coping as supported by the study of Stroebe et al (1993). Stroebe et al’s coping strategies ranged from acceptance and disbelief, emotional control, rationalisation, faith, avoidance, being busy/active distraction, involvement with others, expression and exposure to indulgence.
5.1.1 Method of coping

The *method* of coping explores if a person uses primarily a cognitive, behavioural or a combination of both methods to cope with the grief. An analysis of methods of coping of the 36 strategies in the scale showed cognitive methods were the most frequently used as shown in Table 13 and Figure 6 below:

Table 13: Frequently used Methods of Coping Grouped into Categories

<table>
<thead>
<tr>
<th>Method</th>
<th>Frequency</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>50</td>
<td>62.5</td>
</tr>
<tr>
<td>Behavioural</td>
<td>7</td>
<td>8.8</td>
</tr>
<tr>
<td>Cognitive-behavioural</td>
<td>23</td>
<td>28.8</td>
</tr>
<tr>
<td></td>
<td>80</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Source: Survey of Parents in Grief Study, W.A. 2001 n=80
However, a qualitative research study by Eakes (1995) found a similar result when identifying coping mechanisms used by parent to deal with the recurring feelings associated with chronic sorrow in parents of chronically mentally ill individuals. Their responses were categorised as interpersonal, emotional, cognitive or action-oriented. Coping strategies most frequently cited were those labelled as cognitive. This is also consistent with the findings of Hainsworth et al (1994) that cognitive strategies were among the most prevalent styles of coping with chronic sorrow used by parents of individuals diagnosed with chronic or life-threatening conditions.
5.1.2 Focus of coping

The focus of coping explores if a person ‘approaches’ the problem or ‘distracts’ him or herself from it. An analysis of the 36 strategies in the scale showed that an ‘approach’ focus was the most frequently used as shown in Table 14 and Figure 7 below:

Table 14: Frequently used Focuses of Coping Grouped into Categories

<table>
<thead>
<tr>
<th>Focus</th>
<th>Frequency</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approach</td>
<td>58</td>
<td>73.4</td>
</tr>
<tr>
<td>Distraction</td>
<td>21</td>
<td>26.6</td>
</tr>
<tr>
<td></td>
<td>79</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: Survey of Parents in Grief Study, W.A.2001 n=79

**Figure 7: Focus of Coping Grouped**

Source: Survey of Parents in Grief Study, W.A.2001, n=79
Out of the 36 strategies listed in the Coping with Grief/Sadness – Self-Assessment Scale, there were 13 strategies that some parents subjectively found to be ‘harmful’. The right hand column of Table 10 indicates 13 strategies that respondents had used but subjectively found to be ‘harmful’. Out of these 13 strategies, six have been categorised as ‘distraction’ and six as ‘approach’. The ‘distraction’ strategies are:

1. Physical activities.
2. Telling myself that I have many things to be thankful for.
3. Believing that things will always work out.
4. Investing myself in my children.
5. Sleeping more than usual
6. Eating more than usual

The ‘approach’ strategies are:

1. Doing things together as a family
2. Talking over personal feelings and concerns with my spouse
3. Encouraging child with mental illness to be independent
4. Being sure prescribed medication is being taken by child as required
5. Being able to explain our family situation to relatives, friends and neighbors so they may understand
6. Allowing myself to get angry

The above shows that there was a mixture of ‘distraction’ and ‘approach’ focuses that were cited as most harmful by parents in this study. Although the following 2 strategies were less frequently used, they were found to be the most ‘harmful’:

1. Sleeping more than usual (11%)
2. Eating more than usual (58%)
Both are classified as ‘Behavioral-Distraction’ strategies. Horowitz’s Trauma model as cited in Nolen-Hoeksema and Larson’s study *Coping with Loss* (1999, p. 14) say,

“People oscillate between denial and intrusive thoughts, remaining with the intrusive thoughts as they work through the loss, but when these thoughts are too overwhelming and painful, they retreat into denial”.

Remaining with intrusive thoughts could be understood as an ‘approach’ focus. Whilst some of the strategies offered in this study are not categorized as ‘denial’, they are suggested as ‘distraction’ where respondents take some ‘time out’ from thinking about the loss or intrusive thoughts of the loss. Stroebe *et al* (1993) say that if the bereaved are fortunate, they will be able to regulate, or ‘dose’ the amount of feeling they can bear and divert the rest, using defensive operations of the most mature as well as of the most regressive nature.

Interestingly, when parents were requested to list three coping strategies they had used, but not listed in the *Coping with Grief/Sadness – Self-Assessment* scale as suggested by Stroebe *et al* (1993) they listed many coping strategies that could be classified as mature or regressive in nature. Some of the common mature responses were:

- “Taking care of myself by having a massage, aromatherapy and being with mother nature”
- “Simplifying lifestyle, lowering expectations and avoiding stressful encounters”
- “Writing, reflection, acceptance”
- “Sexual intimacy”
The most common regressive responses were:

- “Self-blame”
- “Blaming others”
- “Displaying hopelessness and anxiety”
- “Smoking,”
- “Consuming alcohol”

**Conclusion**: In identifying specific coping strategies that parents consider as being most helpful to them in dealing with their grief, cognitive strategies were most frequently used by parents and subjectively found to be more helpful. Although behavioral strategies were less frequently used, those who used them said that they were helpful. Strategies that involved both a cognitive and a behavioral method were also less frequently used than purely cognitive methods. However, the subjective experience of those who used them was that they were helpful. These findings have been supported in past studies.

An **approach** focus was most frequently used by respondents and also subjectively found to be most helpful. The most harmful strategies cited by respondents were a mixture of **approach** and **distraction** focuses, suggesting that griever need to oscillate between these two focuses in order to manage intrusive thoughts or work through the loss.

The idiosyncratic nature of coping was highlighted in this study with parents listing many strategies that were not listed in the **Coping with Grief/Sadness – Self-Assessment Scale**. As supported in the study of
Stroebe et al (1993) some of these could be classified as mature and some as regressive in nature.

5.2 The relationship between intensity of grief and coping patterns of respondents.
Spaniol (1987) and Eakes (1995) have identified coping mechanisms used by caregivers of those with serious and persistent mental illnesses. Spaniol and Jung (1987, p. 85) suggest that individual adjustment is the manner in which the person deals with different life situations whether these are inner directed and/or outer-directed psychological processes.

Hatfield (1987, p. 76) identify several researchers (Hirschowitz 1976; Lazarus, Averill and Opton, 1974; Mechanic 1974; White 1974) “who believe that mental health professionals have been too preoccupied with the way people feel and not concerned enough about what they do”.

Caplan (1964) identifies several characteristics of effective coping. Although he considered intrapsychic coping to be important, he also considered knowledge and information, the availability of a helping network, and a well-developed problem-solving capacity to be equally important.

The coping strategies in the Coping with Grief/Sadness – Self-Assessment Scale were categorised into method of coping and focus of coping offering respondents a choice ranging from purely cognitive (intrapsychic), a combination of cognitive and behavioural and purely behavioural. The strategies also offered respondents a choice of ‘approach’ focussed or ‘distraction’ focussed strategies. By doing so, the
study attempted to identify if the method or focus of coping utilised had a relationship to the level of grief experienced by respondents.

In results of Objective 3 the method of coping utilised by respondents reveals that on a spectrum of coping, respondents cited helpful methods to range from predominantly **cognitive** (62.5%) **cognitive/behavioural** (28.8%) to predominantly **behavioural** (8.8%).

Firstly, by looking at the extremes of this spectrum (e.g. cognitive and behavioural only) analysis of data show that there were significant differences in the present level of grief between respondents who used predominantly cognitive *methods* and those who used predominantly behavioural *methods* of coping. To assess if respondents were using predominantly cognitive or behavioural methods of coping, each persons responses to the 36 coping strategies were analysed. First, the responses categorised as cognitive methods were added and then the responses categorised as behavioural were added. If a respondent used more cognitive methods they were categorised as a ‘cognitive respondent’. Similarly, if a respondent used predominantly behavioural methods they were categorised as a ‘behavioural respondent’. The results of the present study are shown in Table 15:
Table 15: Level of Present Grief and Method of Coping
Chi-square test for Independence

<table>
<thead>
<tr>
<th></th>
<th>Cognitive</th>
<th>Behavioural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Grief</td>
<td>43.8%</td>
<td>85.7%</td>
</tr>
<tr>
<td>High Grief</td>
<td>56.3%</td>
<td>14.3%</td>
</tr>
<tr>
<td>N</td>
<td>48</td>
<td>7</td>
</tr>
</tbody>
</table>

Chi square = 4.305, d.f.=1, p<.05
Source: Survey of Parents in Grief Study, W.A.2001 n=55

The above results indicate that most respondents who adopted predominantly cognitive coping strategies reported high levels of present grief. By way of contrast, most respondents who adopted predominantly behavioural strategies reported low levels of present grief. Note though that the sample size was small (n=55).

Interestingly, Parks and Pilisuk (1991) in their examination of gender and psychological costs of care giving found an increased level of depression in those who used cognitive styles of coping, despite its positive connotation. Parks and Pilisuk (1991) findings are consistent with the results of this study as seen in Table 15 above.

Secondly, by looking at the focus of coping between ‘approach’ and ‘distraction’, analysis of data did not show significant differences in respondents who utilised an approach or a distraction focus as shown in Table 16 below:
**Table 16: Level of Present Grief and Focus of Coping**

<table>
<thead>
<tr>
<th></th>
<th>Approach</th>
<th>Distraction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Grief</td>
<td>51.8%</td>
<td>42.9%</td>
</tr>
<tr>
<td>High Grief</td>
<td>48.2%</td>
<td>57.1%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>N</td>
<td>56</td>
<td>21</td>
</tr>
</tbody>
</table>

Chi square=.487, d.f.=1, p>.10

Source: Survey of Parents in Grief Study, W.A. 2001, n=77

Hatfield (1987, p. 72) suggests that defence mechanisms such as denial or diversion of attention were traditionally viewed as pathological or maladaptive but these she says can serve a positive function in allowing persons not to be overcome by stress. This view is supported in the present study where there was no significant difference in the present level of grief in respondents who utilised a focus of distraction, which has traditionally been viewed as pathological or maladaptive.

The study of Stroebe et al (1993) researched different dimensions of coping with emotional pain in bereavement. Stroebe et al (1993, p. 30) say that, “The human thrust towards homeostasis places the bereaved in an enormous conflict between very powerful and opposing forces. Faced with intense emotional anguish, a primary task of the bereaved is to shut off pain. On the other hand, the disruptive changes that are the psychological and material reality of the survivor demand attention”. They say that, “Throughout the grieving process, adaptation operates in highly idiosyncratic ways to allow the survivor to face reality while simultaneously protecting them against too great an onslaught of affect”.

122
Many of the researchers in the area caution that defensive strategies may cause trouble in the long run if they make no provision for learning anything new about the source of the loss. There lies the challenge for clinicians working with families of the mentally ill. Implications for practice of these findings will be discussed in Chapter 6.

**Conclusion:** In examining the relationship between intensity of grief and coping patterns of parents in the present study, findings suggest that there was a significant relationship between the intensity of grief and coping methods in that parents using predominantly behavioural methods of coping showed less intensity in their grief than parents using predominantly cognitive methods. These findings have been supported in other studies in coping with stressful events.

There was no significant relationship between parents using mainly an approach focus or parents using mainly distraction focus of coping. This has been supported in the research of Stroebe *et al* (1999) who say that adaptation operates in highly idiosyncratic ways to allow the survivor to face reality while simultaneously protecting against too great an onslaught of affect.

**5.3 Gender differences in grieving and coping strategies.**

Several researchers have suggested that men and women experience grief associated with the death of a child differently. Sidmore (1999-2000) found that women experienced higher levels of grief than men. Other researchers suggest that mothers and fathers grieve at different times, express grief in different ways, or cope with loss differently (Bohannon, 1990). From practice wisdom, I believe that these differences can sometimes cause communication difficulties and may result in marital
problems. Doka and Martin (1998) say that the bereaved male is frequently seen as impaired by an apparent inability both to express feelings and to seek social support. They say that masculine grief is different, but not deficient. They used the term ‘masculine’ to emphasise that the pattern is gender-related and not gender-specific.

Davis and Schutz (1998) in their study on *Grief, Parenting and Schizophrenia* found that, contrary to trends in the literature, mothers and fathers did not significantly differ in intrusive thinking, avoidance behaviour and distress related to recall of diagnosis. However, their study found that contact hours with the child with mental illness did significantly interact with gender, to influence mothers’ and fathers’ intensity of intrusive thinking. Mothers in the upper category of contact hours reported greater intensity of intrusive thinking, whereas the reverse occurred for fathers.

Objective 5 therefore has two components: the first being to identify gender differences in grieving and the second being to identify gender differences in coping processes (method and focus).

An analysis of gender differences in grief in the present study is shown in Table 17:
Table 17: Gender Differences in Grief/Present Feelings of Grief (grouped)

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Grief</td>
<td>39.1%</td>
<td>52.6%</td>
</tr>
<tr>
<td>High Grief</td>
<td>60.9%</td>
<td>47.4%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>N</td>
<td>23</td>
<td>57</td>
</tr>
</tbody>
</table>

Chi square= .716, d.f.=1, p>.05

Source: Survey of Parents in Grief Study, W.A. 2001 n=80

Although more males expressed high levels of grief as shown in the table above, the differences are insufficient to be statistically significant. Similarly, although Davis and Shultz (1998) study used the *Experience of Stress Scale* to measure distress due to reminders of the loss and the present study used the MIV-TIG to measure grief, the present study supports Davis and Shultz’ (1998) findings that mothers and fathers did not significantly differ in distress related to recall of diagnosis. If future research confirms the absence of gender-related differences in grieving, greater attention should be paid to the influence of variables such as personality factors or attachment to the child.

Implications for practice on these findings will be discussed in Chapter 6.

An analysis of gender differences in coping processes in the present study was limited to the method and focus of coping only and the findings of the method are shown in Table 18 below:
Table 18: Gender Differences in Method of coping (1)

<table>
<thead>
<tr>
<th>Method</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>56.5%</td>
<td>64.9%</td>
</tr>
<tr>
<td>Behavioural</td>
<td>0.0</td>
<td>12.3%</td>
</tr>
<tr>
<td>Cognitive-Behavioural</td>
<td>43.5%</td>
<td>22.8%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>N</td>
<td>23</td>
<td>57</td>
</tr>
</tbody>
</table>

Chi-square=5.445, d.f. = 2, p>.05

Source: Survey of Parents in Grief Study, W.A. 2001, n=80

In the present study, a higher percentage of women used cognitive methods of coping. More men than women used cognitive-behavioural methods of coping. However the differences are insufficient to be statistically significant.

The study further attempted to analyse the data limiting the analysis to only cognitive and behavioural methods, thus excluding those who predominantly used combinations of cognitive-behavioural methods. The results are shown in Table 19:

Table 19: Gender Differences in Method of coping (2)

<table>
<thead>
<tr>
<th>Method</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>100%</td>
<td>84.1%</td>
</tr>
<tr>
<td>Behavioural</td>
<td>0.0</td>
<td>15.9%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>N</td>
<td>13</td>
<td>44</td>
</tr>
</tbody>
</table>

Chi-square=2.358, d.f. = 1, p>.10

Source: Survey of Parents in Grief Study, W.A. 2001 n=57
Although a slightly higher percentage of men used **cognitive** methods and a small percentage of women used **behavioural** methods of coping, there were no significant differences in coping methods utilised by men and women.

The study then attempted to find any significant gender differences in the focus of coping utilised by men and women. These findings are shown in Table 20 below:

<table>
<thead>
<tr>
<th>Focus</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approach</td>
<td>82.6%</td>
<td>69.6%</td>
</tr>
<tr>
<td>Distraction</td>
<td>17.4</td>
<td>30.4%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>N</td>
<td>23</td>
<td>56</td>
</tr>
</tbody>
</table>

Chi-square=1.404, d.f.=1, p>.05

Source: Survey of Parents in Grief Study, W.A. 2001 n=79

The above results show no significant differences in the focus of coping utilised by fathers or mothers.

Doka and Martin (1998) identified some studies that have found that men and women chose different strategies to adapt to loss in bereavement. They cite the study of Osterweis *et al* (1984), which found that men used self-help groups less often than women. They also cite a suggestion of Rando (1986, pp. 5-44) that following the loss of a child, men may see themselves as needing to be providers, protectors, and problem-solvers, making it difficult for them to accept and receive help. They say that this
may be one possible reason for their reluctance to attend support groups: Doka and Martin (1998) cites other studies that also found men to be more private, intellectual and introspective in their grief.

In terms of implications for clinical practice and wider policy development, Doka and Martin’s (1998) review of the literature and subsequent suggestions are important issues and this study attempted to find if the results support their suggestions. Table 21 below shows gender differences in coping strategies.

**Table 21: Gender Differences In Coping Strategies**
Coping With Grief/Sadness - Self Assessment

<table>
<thead>
<tr>
<th>COPING STRATEGIES</th>
<th>% of Mothers Using Strategy</th>
<th>% of Fathers Using Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sleeping more than usual</td>
<td>23.7</td>
<td>17.4%</td>
</tr>
<tr>
<td>2. Eating more than usual</td>
<td>30.5</td>
<td>26.1</td>
</tr>
<tr>
<td>3. Crying more than usual</td>
<td>71.2</td>
<td>17.4</td>
</tr>
<tr>
<td>4. Allowing myself to get angry</td>
<td>55.9%</td>
<td>47.8</td>
</tr>
<tr>
<td>5. Relying on my spiritual belief</td>
<td>45.8</td>
<td>47.8</td>
</tr>
<tr>
<td>6. Finding time for myself</td>
<td>64.4</td>
<td>52.2</td>
</tr>
<tr>
<td>7. Working (outside employment)</td>
<td>45.8</td>
<td>17.4</td>
</tr>
<tr>
<td>8. Becoming self reliant and independent</td>
<td>45.8</td>
<td>21.7</td>
</tr>
<tr>
<td>9. Being able to get away from the home care tasks and responsibilities for some relief</td>
<td>59.3</td>
<td>21.7</td>
</tr>
<tr>
<td>COPING STRATEGIES</td>
<td>% of Mothers Using Strategy</td>
<td>% of Fathers Using Strategy</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>----------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>10. Telling myself that I have many things I should be thankful for</td>
<td>72.9</td>
<td>43.5</td>
</tr>
<tr>
<td>11. Being involved in hobbies (eg. art, music)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Physical activities</td>
<td>61.0</td>
<td>52.2</td>
</tr>
<tr>
<td>13. Being involved in social activities with friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Building close relationships with people</td>
<td>44.1</td>
<td>17.4</td>
</tr>
<tr>
<td>15. Believing that things will always work out</td>
<td>64.4</td>
<td>56.5</td>
</tr>
<tr>
<td>16. Developing myself as a person</td>
<td>49.2</td>
<td>26.1</td>
</tr>
<tr>
<td>17. Building a closer relationship with my spouse</td>
<td>45.8</td>
<td>60.9</td>
</tr>
<tr>
<td>18. Investing myself in my children</td>
<td>40.7</td>
<td>34.8</td>
</tr>
<tr>
<td>19. Doing things together as a family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Going out with my spouse on a regular basis</td>
<td>61.0</td>
<td>43.5</td>
</tr>
<tr>
<td>21. Talking over personal feelings and concerns with my spouse</td>
<td>64.4</td>
<td>82.6</td>
</tr>
<tr>
<td>22. Talking over personal feelings and concerns with someone other than a professional counsellor</td>
<td>64.4</td>
<td>47.8</td>
</tr>
<tr>
<td>23. Entertaining friends in our home</td>
<td>39.0</td>
<td>17.4</td>
</tr>
<tr>
<td>COPING STRATEGIES</td>
<td>% of Mothers Using Strategy</td>
<td>% of Fathers Using Strategy</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------</td>
<td>-----------------------------</td>
<td>----------------------------</td>
</tr>
<tr>
<td>24. Encouraging child with mental illness to be independent</td>
<td>76.3</td>
<td>73.9</td>
</tr>
<tr>
<td>25. Being able to explain our family situation to relatives, friends and neighbours so they may understand</td>
<td>74.6</td>
<td>65.2</td>
</tr>
<tr>
<td>26. Gaining knowledge about the mental illness affecting my child by reading</td>
<td>81.4</td>
<td>73.9</td>
</tr>
<tr>
<td>27. Being sure prescribed medication is being taken by child as required</td>
<td>67.8</td>
<td>65.2</td>
</tr>
<tr>
<td>28. Believing that my child is getting the best medical care possible</td>
<td>74.6</td>
<td>87.0</td>
</tr>
<tr>
<td>29. Reading about how other people in my situation cope</td>
<td>54.2</td>
<td>39.1</td>
</tr>
<tr>
<td>30. Sharing my experiences with others in similar situation</td>
<td>57.6</td>
<td>52.2</td>
</tr>
<tr>
<td>31. Being involved in Care &amp; Share groups of ARAFMI.</td>
<td>40.7</td>
<td>13.0</td>
</tr>
<tr>
<td>32. Being involved in information &amp; support groups run for families by Hospitals and Clinics</td>
<td>40.7</td>
<td>56.5</td>
</tr>
<tr>
<td>33. Assisting others in similar situation</td>
<td>30.5</td>
<td>17.4</td>
</tr>
<tr>
<td>34. Discussing my sadness/grief with a member of the treating team <strong>in my own home</strong></td>
<td>45.8</td>
<td>34.8</td>
</tr>
<tr>
<td>35. Discussing my sadness/grief with a member of the treating team <strong>in the clinic or hospital</strong></td>
<td>47.5</td>
<td>52.2</td>
</tr>
</tbody>
</table>
Some important results have emerged from this study. Firstly, fathers used the strategies listed in the scale less frequently than mothers but the differences were not significant. However, out of the 36 strategies listed there were eight strategies (highlighted in Table 21) that were significant in that less than half of the fathers responding utilised them. These are, in rank order from least utilised:

1. Crying more than usual
2. Being able to get away from the home care tasks and responsibilities for some relief
3. Being involved in social activities with friends
4. Becoming self reliant and independent
5. Working (outside employment)
6. Building close relationships with people
7. Being involved in Care and Share Groups of ARAFMI.
8. Entertaining friends in our home

From a practice wisdom point of view, some of these were expected. For example only 17.4 per cent of men used the strategy ‘crying more than usual’ compared to 71.2 per cent of women. Only 13 per cent of men used Care & Share groups compared to 40.7 per cent of women.
However some of the assumptions of clinicians in the practice setting were challenged with only 17.4 per cent men using ‘Working (outside employment)’ compared to 45.8 per cent of women.

These results are also in contrast to McBride (1996, p.85) (quoting book of Staudachar (1991), Men and Grief), that, “two of the six typical ways that men cope with their grief is “to become immersed in activity, for example to return to work quickly” and “to express anger instead of sadness, yearning or despair””. In this study 47.8 per cent of men “allowed myself to get angry” compared to 55.9 per cent of women. Similarly the strategy “Being able to get away from the home care tasks and responsibilities for some relief” was only used by 21.7 per cent of men compared to 59.3 per cent of women. The focus of both strategies were categorised as ‘distraction’.

The second significant aspect in the results of this study is that out of the 36 strategies offered, men used only five strategies more frequently than women. These are highlighted as in Table 21. These are, in rank order from mostly utilised were:

1. Believing that my child is getting the best medical care possible.
2. Talking over personal feelings and concerns with my spouse.
4. Being involved in information and support Groups run for families by hospitals and clinics.
5. Discussing my sadness/grief with a member of the treating team in the clinic or hospital.

The above results show that for the sample of men in the present study, “building closer relationships with their spouse” and “talking over
personal feelings and concerns with my spouse” were important strategies that were utilised by more men than women. The results also suggest that although men used self-help groups less frequently, they used information and support groups more frequently. This suggests that men find gathering information more useful than self-help through sharing experiences.

The fact that there was no significant differences in the intensity of grief in fathers and mothers, and no significant differences in the process of coping utilised but that there were significant differences in coping strategies used suggest that fathers, like mothers grieve as intensely but may use different strategies to cope with their grief. Further although the strategies may be different, the process of grieving is not. These findings also reflect the idiosyncratic nature of coping.

**Conclusion:** In identifying gender differences in grieving and coping strategies, the present study found no significant differences in grief in mothers and fathers. Neither were there any significant gender differences in the methods of coping nor the focus of coping. However there were significant differences in the frequency of some of the strategies used by mothers and fathers supporting Doka & Martin’s (1998) suggestion that the masculine pattern of grieving may be different but not deficient.
CHAPTER 6: IMPLICATIONS FOR PRACTICE

As suggested by Klein and Bloom (1995) in the *Bridges of practice Wisdom*, this study attempted to challenge pre-existing scientific knowledge that there is measurable grief in parents of the mentally ill. The findings of this study suggest that this grief, while it has some similarities with grief in bereavement, also has some differences. Objective 6 of this study considered the implications of the research findings for practice principles, in a way that will also reflect practice wisdom. However, these are offered as practice principles only, and each situation needs to be considered individually.

The ‘person in environment’ has been an important concept of the social work profession since its inception (Wood 1996). With an understanding of how environmental factors influence human functioning, social workers can make a valuable contribution in mental health settings. Instead of seeing the psychological phenomena and social phenomena as an ‘either/or’ dichotomy, we need to integrate these levels of human activity by seeing the individual in his/her context in a systemic way. Therefore, social work practice in mental health settings fall into the following broad areas:

1. clinical
2. community development, and
3. supervision, education and quality improvement.

This report recommends that social workers in mental health settings apply the results of this study in all of the above three areas.
6.1 Clinical

There is measurable grief in parents of people with psychotic disorders. In contrast to traditional assumption, this grief does not necessarily decrease in intensity over time. A longitudinal study may show that it is cyclical in nature. Social workers need to be aware of this grief and offer a variety of strategies to parents to cope with this loss. These may be individual counselling, psycho-educational groups, regular family meetings with treating teams and referral to self-help groups of ARAFMI.

Individual Counselling

The following are some key aspects, compatible with the results of this study, that I have found helpful:

- Making sure the parent has ‘permission’ to grieve. This is particularly important as in mental illness, the exact nature of the loss is sometimes difficult to define as the child with the disorder is still alive and a healthy partial self exists in all people with psychotic disorders.

- Assisting parents to accept and express all the various feelings of grief. As quoted by a parent in this study, “I feel ashamed and lonely”. Some other feelings that have been named by parents are “sense of betrayal”, “questioning one’s own judgement and sanity”, “powerlessness/loosing control of yourself”, “sense of isolation”. Often simply naming the feeling or experience helps normalise unacceptable feelings such as anger. Anger sometimes camouflages the more disruptive feeling of fear.

- Evaluating family members’ ideas about what caused the disorder and their belief about what influence the course or outcome of illness. Beliefs that evoke blame, shame or guilt may block the
grieving process. Theories of aetiology implicating parents to the disorder may still be around.

- Encouraging expression of feelings in a private place that is comfortable and non-threatening. The results of this study showed that while mothers used their own homes for discussion of sadness and grief with clinicians, fathers used clinics or hospital settings.

- Being especially aware of parents of children who have required an admission to hospital or intervention involving involuntary status. Findings of this study were consistent with post-traumatic stress disorder, although it is unclear if these findings are particularly related to parents who experienced a specific kind of trauma associated with their child’s mental disorder.

- The time period of 1-2 years following the first episode or diagnosis may be a particularly vulnerable time for parents. In this study, the grief score was highest in parents in the period of 1-2 years following diagnosis. This is a crucial time when parents may realise that the symptoms were not purely related to illicit drug use or that is was a ‘once-only’ episode.

- As social workers, being aware of the specific concerns of parents throughout their life span. For example, the mean grief scores of parents over the age of 60 years increased. The issues that may cause them grief at this time may be different to those of a younger age. Fifty-three per cent (53.1%) of parents in this study reported having partial financial responsibility for the child. Parents may need assistance to make provision for their child when they are no longer able to assist them. This could be in assisting in preparation of wills, trust accounts, application for an Administration Order. Clinicians need to discuss supported
accommodation available for their child. Some of the West Australian services offering Independent Living Programs such as Wesley Supported Accommodation program or Fremantle Housing Association combined with psycho-social support through programs offered by Ruah Inreach, Homecare Services, Perth Home Care and Southern Cross Care are invaluable in assisting clients gain independence from parents and developing a sense of purpose in their life.

- Counselling individually, group counselling and disseminating information may need to be repeated from time to time. The cyclical nature of mental illness means that parents would be coping quite well at certain times but not at other times. This may cause frustration for parents as shown in the results of this study. At times when a child is going through a relapse, anxiety may be higher and retention of information about services and mental illness may be partial.

- Being aware that parents of children who need assistance with personal care may be particularly vulnerable. Such people may need assistance through referral to an agency that receives funding through the Home and Community Care program to provide them with home support.

- Noting that parents of children with a late onset psychotic disorder were particularly vulnerable in this study. It may be necessary to explore the exact nature of the loss in these situations.

- Assessing the level of assistance given by parents to their children. Is this congruent with family life cycle assumptions of the changing roles? Explore if some of the assistance provided can be given through an independent living program provided by mental health services or local government services or other
agency receiving funding through the Home and Community Care program.

- The results of this study were consistent with psychodynamic and attachment theories in that, attachment problems and hence problematic bonds between people may carry over into adjustment to the loss. Social workers need to be eclectic in their intervention and apply broad approaches to counselling as the situation calls. Counselling need to be person-centred with a focus on the ‘here-and-now’ but also psychodynamic as social workers relationship with the parent strengthens. Within a psychodynamic model social workers could assist parents focus on the influence of past events on present experience and behaviour.

- Cognitive-behavioural approaches to counselling may be especially useful for parents. A focus of learning new ways of thinking and behaving is important for parents who may never have experienced the disruption that is brought on by symptoms of psychotic disorders. Hallucinations and paranoid thoughts may result in major changes in their child’s behaviour and thus personality. The results of the study showed parents who used highly behavioural coping strategies had lower levels of present grief. A psycho-educational approach through individual or group therapy will be helpful for parents to understand the symptoms of the disorder, understand these symptoms in the context of the disorder and explore different strategies to deal with the grief brought on by these changes. Parents need to be encouraged to try different strategies of coping and find the strategy that best suits them.
• Results of the study showed that parents oscillated between taking ‘time out’ or distraction from the loss and approaching the problems involved with the loss. Both focuses are important at different times. Social workers need to understand this and assist parents to distract themselves or take ‘time out’ when overwhelmed with grief. However, parents could also be assisted at times to approach the problem and find strategies to deal with the problem. Therefore, counselling needs to encompass validating the parents’ experience of loss and grief. It also needs to encompass revision of the implications of this loss from time to time and facilitate the dampening of the intrusive processes at times when they are overwhelmed with grief. However, if a parent is in a prolonged distraction phase, the clinician could gently dismantle the defence processes by exploring the loss and its associated meaning.

• Respecting the strengths and resources of parents and the direction in which they wish to apply them. Discovering strengths requires a process of cooperative exploration between parents and clinician. ‘Expert’ clinicians do not have the last word on what parents need.

• Results of the study showed that there were no differences in the intensity of grief in mothers and fathers. Therefore clinicians should be aware that fathers may be experiencing intense grief though they may not emotionally display this grief. As such both fathers and mothers need to be given every opportunity to participate in counselling and information and support groups. Social workers need to be aware of this and offer fathers assistance. The needs of parents in fulltime employment need to be taken into account and if ongoing counselling sessions are
required, be flexible and offer appointments at lunchtime or late in the afternoon.

- The end task of the grieving process in bereavement is reinvestment of energy in other relationships. This may be impossible for parents in this situation. Adaptation rather than acceptance may be a more appropriate explanation in such losses where parents invest energy in learning new ways of relating to a partially healthy child.

Family Counselling
In addition to individual counselling, it is also useful to identify social work practice issues for families. The results of the present study highlight the following implications for practice:

- Provide clarity to parents that, although the illness may affect each parent differently, it continues to influence all family relations with equal power. As suggested by Ackerman (1966), “conflict between the minds of family members and conflict within the minds of any one-member stand in reciprocal relation to one another”. Do the mother and father of the child affected have the same belief of the aetiology of the disorder and what might influence the course or outcome of illness? Parents who have vast differences in their views may experience conflict and marital disharmony causing a secondary loss. These beliefs need to be explored within a couple-counselling situation where differences may be brought to the forefront for discussion. Parents could be encouraged to set individual goals and joint goals to cope with their grief and also to strengthen the couple relationship.

- As suggested by the results of this study, although there were no significant differences in the methods and focus of coping between
mothers and father, some of the strategies that fathers used more frequently were different to those used by mothers. For example, fathers placed a higher emphasis on strengthening relationships with their spouse whether it is by building a closer relationship or discussing personal issues with the spouse. Social workers need to be aware of the idiosyncratic nature of coping.

Psycho-educational Groups

- Information and support to parents through multiple family groups have been an effective strategy to assist parents. The results of the study showed that fathers used information and support groups much more frequently than mothers. Such groups give parents the opportunity to meet others in similar situations, understand that some situations are not unique to them and thus separate the disorder from the person. Groups have also prevented social isolation caused by stigma of mental illness. Parents need to be given information on new medication, their effects and side effects. The information given to parents needs to be updated to keep abreast of current research and findings. The Breakthrough series of lectures run annually by ARAFMI and Casson Homes together with information and support groups run by hospitals and clinics are examples of these. The groups need to be evaluated so that issues that are deemed important to parents are presented and those that are not removed.

- Being aware that groups are unable to deal with worries that families feel are too private or intimate to be aired. Therefore careful assessment and explanations of the aims and purposes of a group is necessary before referring parents to information and support groups.
• Being aware that some parents do not wish to identify with other families of mentally ill individuals and being respectful of their wishes.
• Being aware that groups are sometimes best being run in the evenings enabling working parents to attend.
• Facilitating groups in a way that enables families to develop a sense of empowerment with professionals identified as one potential resource.

Self-help groups
The final category of clinical intervention relates to self-help groups. The study suggests that clinicians need to inform parents of the services available through ARAFMI. The support of others is invaluable in dealing with grief. Self-help groups provide a forum for parents to discuss specific issues related to mental illness without experiencing stigma. The mutual support groups run by ARAFMI bring together people coping with similar problems. The caring and sharing experience assists in making difficult situations more tolerable and in perspective. As parents with similar experiences facilitate groups, it assists in empowering their role of “helper” as well as gaining assistance for themselves.

Assessing resources and risk factors - the development of a checklist.
This research project has highlighted the importance of certain elements in predicting outcome of grief in parents of the mentally ill. It is suggested that careful assessment of these factors will help clinicians and parents develop a care plan, which may pinpoint potential roadblocks or resources. Therefore, the development of a checklist is recommended with the following seven central topics:
1. Symptoms of high initial grief reactions (changes in sleep patterns or appetite, keeping up with activities, feelings of anger, irritability, changes in mood, concentration levels etc)

2. The nature of the lost relationship with the child diagnosed with a psychotic disorder i.e. what this particular relationship and its loss mean to this particular parent.

3. Circumstances surrounding the duration of the untreated psychosis, diagnosis, admissions to hospital (whether these required involuntary treatment or police assistance).

4. Parents’ personal reaction to the loss, prior history of losses, their beliefs about mental illness and any past experiences of mental illness in family members or themselves.

5. External influences such as other stressors, perceived support.

6. Predominant coping style with past losses and with present circumstances as well as emotion-regulation processes.

7. Considering the secondary losses (e.g. strain on marital relationship, relationships with other children).

6.2 Community Development

The second area of social work practice discussed in this thesis relates to community development. Community development refers to the process of facilitating the community’s awareness of the factors and forces that affect its health and quality of life, helping to empower the community with the skills needed to take control over and improve those conditions (Hawe et al 1990). Again, these social work practice issues have been identified from my experience with this research project, as well as my extensive literature review and discussions of these matters in my professional practice.
• Social workers need to participate in the development of community programs and policies relevant to addressing issues specific to parents.

• Support peak bodies and organisation such as ARAFMI and W.A. Association of Mental Health (WAAMH). Such organisations promote the ‘voice’ of carers and consumers. Such participation will avoid decrease of prevalence of models that focus on pathology and weaknesses only.

• The mental health subcommittee of the West Australian branch of the Australian Association of Social Workers is currently writing a submission for the review of the Mental Health Act (WA) 1996. Legislation that has a detrimental effect on families need to be brought to the attention of legislators and policy makers by grass-root level practitioners.

• Advocate for health research funding priorities to recognise the impact of psychotic disorders, treatment and services on families.

• Protect services for carers of the mentally ill from cutback in health and welfare spending by Federal and State Governments.

6.3 Supervision, Education and Quality Improvement

Social Workers need to advocate and be involved in a structured approach to mental health specific training in undergraduate social work courses, continued provision for professional development and further education for social workers. The 1990s have brought many changes to mental health care in Western Australia. The Mental Health Act 1996 of Western Australia was passed by both Houses of Parliament on 13 November 1996 and proclaimed. This brought significant changes to practice from the previous Act of 1962. Delivery of community based mental health services has increased following closure of Heathcote
Hospital and reduction of beds at Graylands Hospital. Some specific issues relating to supervision, education and quality improvement that have been highlighted as a result of this study are:

- In providing professional supervision to students or new graduates encourage them to consider interventions that take into account the special needs of parents.
- When conducting performance development, encourage social workers to include the needs of families in their goals.
- When evaluating performance management, assist social workers to identify any difficulties they may experience in working with families and assist them in setting goals to overcome these difficulties.
- Teach students and new graduates to use diagrammatic assessment of family relationship and community interactions through tools such as genograms and ecological maps. Often in medical records clinicians are overwhelmed with data. The use of diagrammatic assessments assists data to be ordered, selected and arranged to reduce confusion and overload. Importantly, such diagrams also encourage clinicians to “think systems’ and consider a client in his/her total life space over time.
- Ensure that staff development programs in mental health settings include education on family sensitive practice.
- Advocate and promote changes to the curricula of social work courses in tertiary institutions to include family sensitive practice.
- Evaluate programs and services regularly to ensure they continue to meet the needs of consumers and carers.
SUMMARY

Grief in parents of the mentally ill has been an under-recognised area of practice in mental health settings. Often this grief has been seen as pathological resulting in healthy expression of grief being seriously inhibited. With the trends in reducing hospital beds and funding cutbacks on rehabilitation programs for the mentally ill, parents have to cope with increased objective burdens. The subjective burden of loss and grief is increased in such situations.

This study, An Investigation of the Relationship Between Intensity of Grief and Coping Patterns of Parents of Individuals Affected by Psychotic Disorders, attempts to contribute to the knowledge of loss and grief in this special area of mental illness. The practice wisdom of 10 years experience within the mental health service and contributions from other clinicians who work at a ‘grass-root’ level has greatly assisted in developing research questions. Results of the study indicate that there is measurable grief in a sample of parents of people with psychotic disorders in Western Australia, which has similarities to international studies. The results have implications for social work practice, and development of policy in mental health settings and also future research in the area of loss and grief.

It is hoped that the contribution this study has made will assist social workers to work towards assisting parents to reach a point, as one parent in this study has said, “I am at peace knowing that I have done as much as humanely possible”.
APPENDIX A - INFORMATION SHEET

AN INVESTIGATION OF THE RELATIONSHIP BETWEEN INTENSITY OF GRIEF AND COPING PATTERNS OF PARENTS OF INDIVIDUALS AFFECTED BY A PSYCHIATRIC DISORDER

The Directorate of Mental Health Services of the Fremantle Hospital and Health Service employ me as a Senior Social Worker. I am enrolled with the Curtin University of Technology to study towards a Master of Social Work Degree (by Research) and I invite you to participate in this research. The Human Research Ethics Committees of the Fremantle Hospital and Health Service and Curtin University of Technology have approved this study.

Nature and purpose of the study
The research I am conducting will examine the relationship between intensity of grief and coping patterns of parents when a child develops a psychiatric disorder.

What your participation will involve
If you agree to participate in this study please contact me on the telephone number given at the end of this letter. I will explain the project to you. Once you have signed the consent form, you will receive 3 questionnaires that you will need to fill and return to me within 2 weeks. The questionnaires will take less than 1 hour to complete. You will need to answer them by ticking the appropriate box. A stamped envelope will be enclosed with the questionnaire so that you may return them to me. I will call you on the telephone number given in the consent form to find out if you have any concerns about the questionnaire.

When the consent form has been returned to me, six people will be selected randomly and invited to participate in a face-to-face interview. You have the right to decline to be interviewed. If you agree to be interviewed, I will ask you some questions about your experiences and thoughts about having a child with a diagnosis of a psychiatric disorder and about the coping strategies you have utilised. The face-to-face interviews will be tape recorded.

Addressing concerns that you may have as a consequence of participation.
They key worker of your son/daughter, family counsellor from the Association of Relatives and Friends of the Mentally Ill (ARAFMI) or I agree to be available to you should you have any questions or concerns by being involved in the study.
I guarantee that confidentiality will be maintained during this study. Your name will not be required in the questionnaires. Personal details will not be reported in any manner.

This study calls for your voluntary participation and should you wish to withdraw at anytime, it will not prejudice your son’s/daughter’s future treatment at this hospital.

I hope that the results will be helpful for parents who have had a child with a diagnosis of a psychiatric disorder and those professionals who work with you to alleviate the grief you experience and promote effective coping.

I hope your participation will be rewarding knowing that you are essential participants in research that aims to promote parents’ wellbeing. If you require any further information, you are welcome to call me at Fremantle Hospital and Health Service (Tel 9432 3410).

If you have any concerns regarding the way this study is being conducted, you may call the Chairman of the Ethics Committee on Tel 9431 2929.

Yours sincerely,

Kanthi Perera
Senior Social Worker/Community Liaison Officer
Early Intervention in Psychosis Program

**CONTACT NUMBERS**

<table>
<thead>
<tr>
<th>Name</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kanthi Perera</td>
<td>9432 3410</td>
</tr>
<tr>
<td>Association of Relatives</td>
<td>9319 8799</td>
</tr>
<tr>
<td>and Friends of the</td>
<td>9228 0577</td>
</tr>
<tr>
<td>Mentally Ill</td>
<td>9402 7022</td>
</tr>
<tr>
<td>Fremantle office</td>
<td>9250 7611</td>
</tr>
<tr>
<td>Perth office</td>
<td></td>
</tr>
<tr>
<td>Hillarys office</td>
<td></td>
</tr>
<tr>
<td>Midland office</td>
<td></td>
</tr>
<tr>
<td>Outside Perth Metro –</td>
<td>1800 811 747</td>
</tr>
<tr>
<td>Freecall</td>
<td></td>
</tr>
</tbody>
</table>
AN INVESTIGATION OF THE RELATIONSHIP BETWEEN
INTENSITY OF GRIEF AND COPING PATTERNS OF PARENTS OF
INDIVIDUALS AFFECTED BY A PSYCHOTIC DISORDER

Kanthi Perera is a senior social worker employed by the Directorate of Mental Health Services of the Fremantle Hospital & Health Service. She is enrolled with the Curtin University of Technology to study towards a Master of Social Work Degree (by Research). She is seeking parents of people affected by a psychotic disorder to participate in her research. The Human Research Ethics Committee of the Fremantle Hospital & Health Service has approved the study.

Nature and purpose of the study
The research she is conducting will examine the relationship between intensity of grief and coping patterns of parents when a child develops a psychotic disorder.

What your participation will involve
Your participation will involve filling in two questionnaires, which will take less than 1 hour to complete. You will need to answer them by ticking the appropriate box. Your name will not be required in the questionnaires. You will need to return them to Kanthi within 2 weeks of receiving.

She will also require six people to participate in a face-to-face interview where she will ask you some questions about your experiences and thoughts about having a child with a diagnosis of a psychotic disorder and about the coping strategies you have utilised. She will use a tape recorder for these 6 interviews. She guarantees that confidentiality will be maintained and that personal details will not be reported in any manner.

She hopes that the results of the study will be helpful for parents who have had a child diagnosed with a psychotic disorder and those professionals who work with them to alleviate the grief they experience and promote effective coping. She also hopes that it will assist Mental Health Services to allocate resources seen as most helpful for carers in coping with grief.

IF YOUR ARE INTERESTED IN PARTICIPATING PLEASE CONTACT
KANTHI PERERA – TELEPHONE NO. 9432 3410
APPENDIX C - CONSENT FORM

AN INVESTIGATION OF THE RELATIONSHIP BETWEEN
INTENSITY OF GRIEF AND COPING PATTERNS OF PARENTS OF
INDIVIDUALS AFFECTED BY PSYCHIATRIC DISORDERS

Parent’s name:.............................................

Address: ........................................................................................................

Telephone No: ...............................

1. I agree entirely voluntarily to take part in the study of the relationship between intensity of grief and coping patterns of parents of individuals affected by psychiatric disorders.

2. I understand and accept the nature of the study, which has been explained, to my satisfaction by Kanthi Perera.

3. If I have any further questions regarding the study I may contact Kanthi Perera on Tel 9432 3410.

4. I understand that I will not be referred to by name in any report concerning this study.

5. I understand that I am able to withdraw from the study without any consequences.

6. I have been given and read a copy of this Consent Form and Information Sheet.

7. I am over 18 years of age.

Signature by Parent

Signed..........................................

Date: .................................
Thank you for completing this questionnaire. The information provided by you will assist us to enhance our services and make it more relevant to your needs. All information is confidential.

First of all we would like to ask you some questions about yourself. The answers will assist us to ascertain if there is a relationship between the intensity of grief and some personal background of parents.

1. What is your age: ......................
2. What is your gender: Male Female
3. What is your country of birth: ..............................................

**Please indicate your answers for the following questions by ticking only one box.**

4. Your religion:
   - Christian
   - Islam
   - Buddhist
   - Hinduism
   - Judaism
   - Other ...........................................................................................................
   - No Religion

5. Please indicate the highest level of formal schooling you have completed
   - Primary
   - Secondary
   - Tertiary
   - Post-graduate

6. Has anyone in your immediate family died within the last 6 months?
   - Yes
   - No

7. The person who has a mental illness is my (check one only):
   - Son
   - Daughter

8. Does this person live with you?
   - Yes
   - No
9. How much interaction do you have with this person (check only one)?

☐ At least once a day
☐ 4 – 6 times / week
☐ 2 – 3 times/week
☐ Once weekly
☐ Once every 2 weeks
☐ Once per month or less

10. How do you usually interact with this person (check only one)?

☐ By telephone
☐ Face-to-face
☐ By mail

*The next few questions are about your son/daughter who is unwell. Your responses will help us establish whether the intensity of grief is related to the duration and severity of a child’s illness.*

11. How old was this person when he/she became ill or was diagnosed as having a mental illness? _____ years

12. This person became ill or was diagnosed as having a mental illness:

☐ Within the past 3 months
☐ 3 – 6 months ago
☐ 6 – 9 months ago
☐ 9 – 12 months ago
☐ 1 – 2 years ago
☐ 2 – 5 years ago
☐ 5 – 10 years ago
☐ 10 – 20 years ago
☐ More than 20 years ago

13. How many hospitalisations has this person had since diagnosis? __________

14. When was his/her last hospitalisation (check only one)?

☐ Within the past 3 months
☐ 3 – 6 months ago
☐ 6 – 9 months ago
☐ 9 – 12 months ago
☐ 1 – 2 years ago
☐ 2 – 5 years ago
☐ 5 – 10 years ago
☐ 10 – 20 years ago
☐ More than 20 years ago
15. What type of assistance/care do you provide for your son/daughter?

15(a) Personal care (check only one)
- I assist frequently with personal hygiene, grooming, dressing, etc.
- I assist sometimes with personal hygiene, grooming, dressing etc.
- I do not assist with personal hygiene, grooming, dressing etc.

15(b) Emotional care (check only one)
- I have much emotional involvement with this person, for example, I care very much what happens to him/her
- I am somewhat detached emotionally from this person, for example, I care what happens to him/her sometimes
- I am very detached emotionally from this person, for example, I don’t really care what happens to him/her

15(c) Financial assistance (check only one)
- I am totally responsible for financial matters
- I have partial financial responsibility
- I have no financial responsibility for this person

16. Compared to the amount of assistance/care given to my son/daughter now (as indicated in the previous question), how in your opinion is this likely to change in the future (check only one)?

- I will give more assistance or be more responsible in the future
- I will give less assistance or be less responsible in the future
- My assistance or care for this person will not change

The next two questions relate to the nature of your relationship with your son/daughter who is unwell. Your responses will assist us establish if there is a relationship between the extent of grief and nature of a relationship.

17. Looking back to the time before my son/daughter became ill, I would guess that my relationship in general with him/her was:

- Closer than any relationship I’ve had before or since
- Closer than most relationships I’ve had with other people
- About as close as most of my relationships with others
- Not as close as most of my relationships
- Not very close at all
18. My current relationship with this person is:

- [ ] Closer than any relationship I’ve had before or since
- [ ] Closer than most relationships I’ve had with other people
- [ ] About as close as most of my relationships with others
- [ ] Not as close as most of my relationships
- [ ] Not very close at all

The next three questions relate to your feelings. Your answers will assist us establish the pattern of grief experienced by parents in relation to having a child diagnosed with a mental illness.

19. When I first became aware of my son/daughter’s mental illness (check only one):

- [ ] I had a difficult time accepting this information and still find it hard to accept
- [ ] I was very upset but eventually got over it, that is, I eventually accepted his/her illness

20. Please tick the boxes of as many words below that best described your feelings when you first found out about your son/daughter’s illness.

- [ ] Angry
- [ ] Hopeless
- [ ] Frustrated
- [ ] Sad
- [ ] Depressed
- [ ] Relieved
- [ ] Disbelief
- [ ] Fear
- [ ] Numb
- [ ] Resentful
- [ ] Blamed
- [ ] Anxious
- [ ] Guilty
- [ ] other (list) __________________________
21. Please tick the boxes of as many words that best describe your feeling **right now about your son’s/daughter’s illness.**

- Angry
- Hopeless
- Frustrated
- Sad
- Depressed
- Relieved
- Disbelief
- Fear
- Numb
- Resentful
- Blamed
- Anxious
- Guilty
- other (list) __________________________

Next, we would like to ask you how you are coping with your grief at present so that we may ascertain if there has been any change in your feelings of grief now as compared to the past.

22. Please tick the box that best indicates your opinion.

- Extremely well
- Moderately well
- Somewhat well
- Unsure
- With some difficulty
- With moderate difficulty
- With extreme difficulty

*Thank you for completing this questionnaire*
APPENDIX E-1 – MIV-TIG PART 1
PAST BEHAVIOUR RELATED TO GRIEF EXPERIENCE

Think back to around the time that you first became aware that your son/daughter was suffering from a mental illness. Answer all of these items about your feelings and actions at that time by indicating whether each item is completely true, mostly true, neither true nor false, mostly false or completely false. Check the best answer.

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I found it hard to get along with certain people</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I found it hard to work well when I became aware of his/her mental illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I lost interest in other family members, friends and relatives</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I found a need to do things the way he/she used to do them</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I was unusually irritable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I couldn’t keep up with my normal activities for the first three months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I was angry with him/her for the changes that were taking place</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I found it hard to sleep</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX E-2 MIV-TIG - PART 2
PRESENT FEELINGS RELATED TO GRIEF EXPERIENCE

Now answer all of the following items by checking how you *presently* feel about your relative who is unwell.

<table>
<thead>
<tr>
<th>Please do not look back at Part 1</th>
<th>COMP. TRUE</th>
<th>MOSTLY TRUE</th>
<th>NEITHER TRUE NOR FALSE</th>
<th>MOSTLY FALSE</th>
<th>COMP. FALSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a I cry when I think about how he/she used to be before the illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b I cry when I think about how he/she could have been</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a I get upset when I think about how he/she used to be before the illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2b I get upset when I think about how he/she could have been</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 I very much miss the way he/she used to be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 It is painful to recall memories of how he/she used to be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6a I am preoccupied about thoughts about how he/she used to be before the illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6b I am preoccupied about thoughts about how he/she could have been if not for the illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 I hide tears when I think about him/her</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 No one will ever take the place that he/she used to have in my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9a I can’t avoid thinking about how he/she was before the illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9b I can’t avoid thinking about how he/she could have been</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 I feel it is unfair that he/she became mentally ill</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Things and people around me still remind me of the way he/she used to be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 I cannot accept his/her mental illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 At times I still feel the need to cry for him/her</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
There is extensive literature on coping strategies which people use to deal with grief and sadness. Listed below are some of these. We would like to know which strategies, if any, you have used to cope with your grief or sadness in relation to your son/daughter having a mental illness?

**Question 1** - Please indicate by placing a tick in the first column if you have ever used any of these strategies. We would then like you to indicate your opinion as to their usefulness/harmfulness by ticking the most appropriate column.

<table>
<thead>
<tr>
<th>COPYING STRATEGIES</th>
<th></th>
<th>Useful</th>
<th></th>
<th>Harmful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sleeping more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Eating more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Crying more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Allowing myself to get angry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Relying on my spiritual belief</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Finding time for myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Working (outside employment)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Becoming self reliant and independent</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Being able to get away from the home care tasks and responsibilities for some relief</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Telling myself that I have many things I should be thankful for</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Being involved in hobbies (eg. art, music)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Physical activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Being involved in social activities with friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Building close relationships with people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Believing that things will always work out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Developing myself as a person</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPYING STRATEGIES</td>
<td>Tick yes if ever used</td>
<td>Useful</td>
<td>Harmful</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>----------------------</td>
<td>--------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>17. Building a closer relationship with my spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Investing myself in my children</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Doing things together as a family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Going out with my spouse on a regular basis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Talking over personal feelings and concerns with my spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Talking over personal feelings and concerns with someone other than a professional counsellor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Entertaining friends in our home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Encouraging child with mental illness to be independent</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Being able to explain our family situation to relatives, friends and neighbours so they may understand</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Gaining knowledge about the mental illness affecting my child by reading</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Being sure prescribed medication is being taken by child as required</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Believing that my child is getting the best medical care possible</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Reading about how other people in my situation cope</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Sharing my experiences with others in similar situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. Being involved in Care &amp; Share groups of the Association of Friends &amp; Relatives of the Mentally Ill (ARAFMI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Being involved in Information &amp; Support groups run for families by Hospitals and Clinics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Assisting others in similar situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. Discussing my sadness/grief with a member of the treating team in my own home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Discussing my sadness/grief with a member of the treating team in the clinic or hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Discussing my sadness/grief with an appropriate health professional who is not a member of the treating team</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
We would also like to know of the strategies that you have used but we have not listed. This would help us to let others know of these strategies.

**Question 2** – Please list below 3 strategies that you have used but we have not listed above.

<table>
<thead>
<tr>
<th>COPING STRATEGIES Please specify</th>
<th>Useful</th>
<th>Harmful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Tick yes if ever used</td>
<td>Extremely useful</td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Now we would like to have your opinion about those strategies that you found most useful or harmful in coping with your sadness/grief.

**Question 3a**
Please list the 3 coping strategies that you found most useful either out of the ones we have listed or you identified in Question 2

1. ______________________________
2. ______________________________
3. ______________________________

**Question 3b**
Please list the 3 coping strategies you found most harmful either out of the ones we have listed or you identified in Question 2

1. ______________________________
2. ______________________________
3. ______________________________
BIBLIOGRAPHY


Australian Association of Social Workers, September 1999, *The Development of Competency Standards for Mental Health Social Workers – Final Report*


Bruce, E J and Schultz, C L (2001) Nonfinite Loss and Grief, A Psychoeducational Approach, Maclennan and Petty, Australia


Commonwealth Department of Health & Aged Care (1999), *Achieving the Balance. A Resource Kit for Australian Media Professionals for the Reporting & Portrayal of Suicide and Mental Illness*

Coghlan, R, Lawrence, D, Holman, D and Jablensky, A (2001) *A Duty to Care: Physical Illness in People with Mental Illness*, Department of Public Health & Department of Psychiatry and Behavioural Science, University of Western Australia


Doornbos, M M (1997) The Problems and Coping Methods of Caregivers of Young Adults with Mental Illness, *Journal of Psychosocial Nursing & Mental Health Services*, September 35(9), 22-26


Early Psychosis Prevention and Intervention Centre (EPPIC) (1997), *Information Leaflets: What is Psychosis?* Melbourne


Kumar, R (1996) Research Methodology, A Step-By-Step Guide For Beginners, Longman, Australia


National Standards for Mental Health Services (1997) Mental Health Branch, Commonwealth Department of Health and Family Services, Canberra


Report of the Ministerial Taskforce on Mental Health of Western Australia, Volume 2, March 1996, Government Publisher, Western Australia


Smith, G, McCavanagh, D, Williams, T, Lipscombe, P (1996) *Making a Commitment: The Mental Health Plan for Western Australia*, Health Department of Western Australia, Perth


Tarrier, N and Barowclough, C (1990) Family Intervention. Special Issue: Behavioural Treatment of Chronic Psychiatric Illness. *Behaviour Modification*


Worthington, R C (1994) Models Of Linear And Cyclical Grief, Different Approaches To Different Experiences, *Clinical Paediatrics*, May, 297-300

