I am the author of the thesis entitled

Family Caregivers of the Mentally Ill and Adaptive Coping.

submitted for the degree of Doctor of Psychology.

This thesis may be made available for consultation, loan and limited copying in accordance with the Copyright Act 1968.

Full Name: BEVERLY EDITH ERATH (Please Print)
Signed: 
Date: 30.5.03
Signature Redacted by Library
Consultation of Thesis

Please sign this form to indicate that you have used this thesis in accordance with the Access to Thesis form signed by the author of this thesis.

<table>
<thead>
<tr>
<th>NAME (please print)</th>
<th>SIGNATURE</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>THOMAS PETERS</td>
<td>Signature Redacted by Library</td>
<td>12-9-03</td>
</tr>
</tbody>
</table>
FAMILY CAREGIVERS OF THE MENTALLY ILL

AND ADAPTIVE COPING

By

Beverly Edith Eramo
B.A. (Hons), B.Ed (Counselling), M.A.

Submitted in partial fulfilment of the requirements
for the degree of:

Doctor of Psychology (Clinical)

Deakin University
Australia
October 2002
I certify that the thesis entitled: Family Caregivers of the Mentally Ill and Adaptive Coping

submitted for the degree of Doctor of Psychology (Clinical)

is the result of my own work and that where reference is made to the work of others, due acknowledgment is given.

I also certify that any material in the portfolio which has been accepted for a degree or diploma by any other university or institution is identified in the text.

Full Name ....................................................... BEVERLY EDITH FRAMO (Please Print)

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

Date................................................................. 30-5-03
ACKNOWLEDGEMENTS

Completing this research has been a long journey, impinged upon by many of the stage of life issues that mature age student can encounter.

Throughout the study, my supervisor, Associate Professor Malcolm McMillan has provided encouragement, wisdom and humour as well as a keen critical analysis of the issues and I thank him for his contribution. I am also indebted to Professor Marita McCabe who provided supervision in Professor McMillan's absence; her assistance and support was much appreciated. Lina Riccardelli assisted with the statistical analysis of the data and I am grateful for her help.

I wish to thank the caregiver support groups, ARAFEMI workers and Maroondah Hospital staff who supported this study. My thanks are also extended to my fellow travellers on this journey, my classmates, Luke, Roger, Margaret and Eoin whose company and support enhanced the experience.

My family's support and encouragement were invaluable and the contribution of two special people must be acknowledged. My husband and best friend, Bob, has always supported my involvement in this study. He has foregone hours of my company in his retirement without resentment. Throughout the writing stage, he was a careful proof-reader and a tough critic. My daughter Madeleine has been a further source of support and practical assistance. Both have my love and gratitude.

Lastly, I wish to acknowledge the contribution of those courageous family caregivers who participated in this study. Their generosity in giving of their time and sharing their, at times painful, stories of their journey was appreciated and a humbling experience.
ABSTRACT

The issue investigated in this thesis concerned the adaptive coping strategies that caregivers of the mentally ill adopt at different stages of encounter with their family member's illness. Specifically, family caregivers' responses to the illness were investigated within the parameters of the Spaniol and Zipple (1994) 4-stage model of the evolution of caregivers' responses to mental illness. The accuracy of the model's representation of the experience of caregivers across all kinship relationships to the care-recipient was evaluated.

Spaniol and Zipple proposed four stages which they termed (1) Discovery/Denial, (2) Recognition/Acceptance, (3) Coping and (4) Personal/Political Advocacy. The first stage is characterised by persistent denial of mental illness and seeking answers from multiple sources. The second stage involves caregivers' expectations of professionals providing answers when the illness is recognised. At this stage caregivers experience guilt, embarrassment and blame. The cyclical nature of the illness impedes acceptance and caregivers experience a deep sense of loss and crisis of meaning as they gradually accept the reality of the situation. In the third stage coping replaces grieving and the issues encountered include loss of faith in professionals, disruption to family life and recurrent crises. Belief in family expertise grows and the focus of coping changes. The fourth stage proposes that caregivers become more assertive, self-blame decreases and the focus is upon changing the system. New meanings and values are integrated.

This study found that the model did not accurately describe the experience of all caregivers. Caregivers did not deny mental illness and adaptive coping occurred throughout all stages. Coping evolved as the issues encountered changed and was independent of resolution of grief. The issues encountered were more extensive than the model proposed and differed according to kinship relationship to the care recipient. The ways in which adaptive coping evolved were identified, as were the issues and their accompanying responses. Caregivers coped by adaptively responding to the requirements of care provision, maintaining a sense of self worth and generating positive affect.
# TABLE OF CONTENTS

**INTRODUCTION**

1

**CHAPTER 1**  
*Theoretical and Ethical Perspectives*  
1.1 Positive Psychology  
1.2 Competency Paradigm  
1.3 Stress, Appraisal and Coping Theory  
1.4 Adaptational Coping  
1.5 Methodological Issues  
1.6 Ethical Issues  
1.7 Summary  
6

**CHAPTER 2**  
*Caregivers and Care Provision*  
2.1 Definition  
2.2 Caregiver Characteristics  
2.3 Magnitude of the Caregiver Contribution  
2.4 Care Provision  
2.5 Summary  
20

**CHAPTER 3**  
*Sources of Caregiver Stress*  
3.1 Objective and Subjective Stressors  
3.2 Sources of Stress  
3.2.1 Situational Stressors  
3.2.2 Societal Stressors  
3.2.3 Intragenic Stressors  
3.3 Exceptionally Difficult Stressors  
3.3.1 Care Recipients Vulnerability  
3.3.2 Violence  
3.3.3 Substance Abuse and Dual Diagnosis  
3.3.4 Chronic Grief  
3.4 Summary  
27

**CHAPTER 4**  
*Ways of Coping and Determinants*  
4.1 Assessing Ways of Coping  
4.1.1 Problem Focussed Coping  
4.1.2 Emotion Focussed Coping  
4.1.3 Meaning Focussed Coping  
4.2 Determinants of Ways of Coping  
4.2.1 Type of Situation  
4.2.2 Amenability to Change  
4.2.3 Perceived Efficacy  
4.2.4 Coping Repertoire  
4.2.5 Matching Coping Response to Situational Requirements  
4.2.6 Stage of Encounter  
4.3 Summary  
41

**CHAPTER 5**  
*Coping Strategies for Caregivers*  
5.1 Goal Attainment Strategies  
5.2 Behaviour Management Strategies  
51
CHAPTER 5 (Continued)
5.3 Exceptionally Difficult Behaviour Management 53
5.4 Stigma Coping Strategies 53
5.5 Service System Strategies 54
5.6 Emotional Response Strategies 55
  5.6.1 Seeking Social Support 55
  5.6.2 Cognitive Strategies 57
  5.6.3 Meaning and Coping 58
    5.6.3.1 Definitions of Meaning 58
    5.6.3.2 Meanings and Goals 59
    5.6.3.3 Global Meaning 59
    5.6.3.4 Situational Meaning 60
    5.6.3.5 Positive Reappraisal 62
    5.6.3.6 Positive Affect 63
5.7 Summary 65

CHAPTER 6
Evolution of Caregiver Responses and Kinship Issues 66
6.1 Models of Evolution of Caregiver Responses 67
6.2 General and Kinship Specific Issues 71
  6.2.1 Parental Issues 72
  6.2.2 Spousal/Partner Issues 73
  6.2.3 Sibling and Adult Offspring Issues 74
6.3 Summary 76

CHAPTER 7
Current Study 77
7.1 Rationale 77
7.2 Aims of Current Study 77
7.3 Method 78
  7.3.1 Measures 78
    7.3.1.1 Demographics 78
    7.3.1.2 Ways of Coping Questionnaire 78
    7.3.1.3 Questionnaire Scoring 79
    7.3.1.4 Semi-Structured Interview 80
    7.3.1.5 Interview Credibility and Coding Reliability 83
  7.3.2 Hypothesis Testing 84
    7.3.2.1 Stage 1: Hypotheses about Discovery/Denial 84
    7.3.2.2 Stage 2: Hypotheses about Recognition/Acceptance 85
    7.3.2.3 Stage 3: Hypotheses about Coping 86
    7.3.2.4 Stage 4: Hypotheses about Personal/Political Advocacy 88
7.4 Participants 89
  7.4.1 Recruitment 89
  7.4.2 Participation 90
7.5 Procedure 91
  7.5.1 Ethics Approval 91
  7.5.2 Study Procedure 91

CHAPTER 8
Results 93
8.1 Data Screening 93
  8.1.1 Order of Presentation Effects 93
  8.1.2 Interview Credibility, Coding and Coder Reliability 94
8.2 Participant Demographics 94
  8.2.1 Gender 95
  8.2.2 Location 95
  8.2.3 Kinship 95
  8.2.4 Age 96
CHAPTER 8 (Continued)

8.2.5 Marital Status 96
8.2.6 Education 97
8.2.7 Employment 98
8.2.8 Extent and Duration of Care Provision 99

8.3 Care Recipient Demographics

8.3.1 Gender 100
8.3.2 Age 100
8.3.3 Co-Residency 101
8.3.4 Signs and Diagnosis 102
8.3.5 Current Condition 103
8.3.6 Hospitalisation 104

8.4 Testing the Hypotheses

8.4.1 Stage 1: Discovery/Denial Hypothesis 104
8.4.1.1 Discovery 105
8.4.1.2 Non-Recognition 105
8.4.1.3 Primary Appraisal 106
8.4.1.4 Causal Attribution 107
8.4.1.4a Causal Attribution: Parental Caregivers 107
8.4.1.4b Causal Attribution: Spouses/Partners 108
8.4.1.5 Denial/Failure to Recognise 108
8.4.1.6 Disorder Type and Recognition 109
8.4.1.7 Stage 1: Coping Responses 110
8.4.1.8 Summary regarding Stage 1 Hypotheses 111
8.4.1.9 Stage 1: The End 112

8.4.2 Stage 2: Recognition/Acceptance 112
8.4.2.1 Recognition 113
8.4.2.2 Initial Expectations of Professionals 113
8.4.2.3 Guilt, Embarrassment, Blame 114
8.4.2.4 Loss 116
8.4.2.5 Acceptance 116
8.4.2.6 Factors Impeding Acceptance 117
8.4.2.7 Crisis of Meaning 118
8.4.2.8 Stress Appraisal 120
8.4.2.9 Stage 2: Coping Responses 122
8.4.2.9a Stage 2: Coping Responses: Self-Controlling 124
8.4.2.9b Stage 2: Coping Responses: Planful Problem Solving: 125
8.4.2.9c Stage 2: Coping Responses: Seeking Social Support: 126
8.4.2.10 Summary regarding Stage 2 Hypotheses 126

8.5 Stage 3: Coping

8.5.1 Coping and Grief 128
8.5.2 Loss of Faith in Professionals 129
8.5.3 Disruption to Family Life 131
8.5.4 Recurrent Crises 133
8.5.5 Additional Issues
8.5.5.1 Stigma 135
8.5.5.2 Loss 135

8.5.6 Valuing the Support of Other Families 138
8.5.7 Current Focus of Concern and Goals 138
8.5.8 Improved Relationships with Professionals 139
8.5.9 Stress Appraisal 140
8.5.10 Stage 3: Coping Responses
8.5.10.1 Planful Problem Solving 141
8.5.10.2 Seeking Social Support 142
8.5.10.3 Self-Controlling Coping 148
8.5.10.4 Positive Affect and Reappraisal 149
8.5.10.4a Positive Affect 149
8.5.10.4b Positive Reappraisal 150

8.5.11 Summary of Hypotheses Regarding Stage 3 151
8.5.12 Stage 3: The End 152
CHAPTER 8 (Continued)
8.6 Stage 4: Personal and Political Advocacy 152
  8.6.1 Changes in Personal Appraisal and Assertiveness 153
  8.6.2 Decreased Self-Blame 153
  8.6.3 Coping Focus 154
  8.6.4 Collaborative Relationship with Professionals 154
  8.6.5 Political Advocacy 155
  8.6.6 New Meanings and Values 156
  8.6.7 Summary regarding Stage 4: Hypotheses 157

CHAPTER 9
Discussion 158
9.1 The Experience of a “Typical” Participant 158
9.2 The Spaniol and Zipple Model 159
9.3 Goodness of Fit 160
9.4 Stage 1: Discovery/Denial Differences 161
9.5 Stage 2: Recognition/Acceptance Differences 162
9.6 Stage 3: Coping Differences 165
9.7 Stage 4: Personal/Political Advocacy Differences 172
9.8 Limitations of Study 174
9.9 Summary of Issues 176

References 180

Appendices 192
LIST OF TABLES

Table 1:  
*Caregivers’ Mean Age, Standard Deviation and Range by Total Sample and by Interviewed Caregivers’ Kinship Group*  
96

Table 2:  
*Comparison of Educational Attainment Levels between Total Sample, Interviewees and General Australian Population*  
98

Table 3:  
*Extent and Duration of Care Provision by Total Sample and by Interviewed Caregivers’ Kinship Group*  
99

Table 4:  
*Care Recipient Gender by Total Sample and by Interviewees*  
100

Table 5:  
*Care Recipients Mean Age, Standard Deviation and Range*  
101

Table 6:  
*Goals at Stage 2 by Kinship Relationship*  
114

Table 7:  
*Mean Stress Appraisal Scores at Stage 2*  
120

Table 8:  
*Initial Relative Scores (Mean and Standard Deviations) on each of the eight Ways of Coping scale*  
122

Table 9:  
*Frequencies and Percentages of top three Ways of Coping at Stage 2*  
123

Table 10:  
*Goals at Stage 3 by Kinship Relationship to Care Recipient*  
139

Table 11:  
*Comparison of Mean Stress Appraisals at Stages 1 and 2 by Kinship Relationship*  
140

Table 12:  
*Comparison of Stage 2 (Initial) and Stage 3 (Current) Relative Scores (Mean and Standard Deviations) on each of the Ways of Coping scales*  
142

Table 13:  
*Comparison of Frequencies and Percentages of top three Ways of Coping at Stage 2 (Initial) and Stage 3 (Current) (N=60)*  
144
LIST OF APPENDICES

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Demographic Data Form</td>
<td>192</td>
</tr>
<tr>
<td>B</td>
<td>Folkman and Lazarus Ways of Coping Questionnaire</td>
<td>193</td>
</tr>
<tr>
<td>C</td>
<td>Interview Question Examples</td>
<td>194</td>
</tr>
<tr>
<td>D</td>
<td>Victorian Carer Association Newsletter Advertisement</td>
<td>195</td>
</tr>
<tr>
<td>E</td>
<td>Deakin University Student Notice Board Advertisement</td>
<td>196</td>
</tr>
<tr>
<td>F</td>
<td>Deakin University Ethics Committee Approval</td>
<td>197</td>
</tr>
<tr>
<td>G</td>
<td>Maroondah Hospital Ethics Committee Submission and Approval</td>
<td>198</td>
</tr>
<tr>
<td>H</td>
<td>Plain Language Statement</td>
<td>199</td>
</tr>
<tr>
<td>I</td>
<td>Participation Consent Form</td>
<td>200</td>
</tr>
<tr>
<td>J</td>
<td>Interview Appointment Form</td>
<td>201</td>
</tr>
<tr>
<td>K</td>
<td>Coder Reliability</td>
<td>202</td>
</tr>
<tr>
<td>L</td>
<td>Credibility of Content Statement</td>
<td>203</td>
</tr>
<tr>
<td>M</td>
<td>Correlations between Ways of Coping at Stage 2 and Caregiver/Care Recipient Demographics</td>
<td>204</td>
</tr>
<tr>
<td>N</td>
<td>Correlations between Ways of Coping at Stage 3 and Caregiver/Care Recipient Demographics</td>
<td>205</td>
</tr>
</tbody>
</table>
INTRODUCTION

It is primarily carers who are sustaining the fabric and operational effectiveness of mental health service systems across Australia (Mental Health Council of Australia and Carers Association of Australia Report 2000, p. 4).

Informal caregivers supporting family members with a mental illness have come to assume a central role in the provision of community based mental health services (Mental Health Council of Australia and Carers Association of Australia Report, 2000). Basing their calculations on American statistics, Andrews, Peters and Teeson (1994) proposed that in any twelve month period 2.9% of the population will experience a serious mental illness and require support to continue living in the community. Informal family caregivers are the major source of such support. The Association of Relatives and Friends of the Emotionally and Mentally Ill Report on the inaugural Statewide conference of Carers of the Mentally Ill (1995) claimed that family caregivers save State and Federal governments an estimated $8 billion per year in unpaid care. The extent of support provided by family caregivers and the financial implications of such support warrant investigation of those structures supportive of its continuation. The purpose of this study is to explicate the adaptive coping strategies that family caregivers adopt at different stages of their relative’s mental illness. This knowledge can assist health care professionals to work with family caregivers in ways that support their adaptive coping and sustain their health and well-being.
Over the past three decades there have been significant changes to the way in which mental health services are delivered and these changes have led to reliance upon family caregivers to provide services previously the province of the State. The changes to the way in which mental health services are delivered are linked to philosophical and economic considerations driving a move to de-institutionalisation as well as improved pharmacological treatments that make the option of return to the community more feasible for many patients. The guiding philosophy of de-institutionalisation with community care has been that of a humanitarian desire to reintegrate people with a physical or psychiatric disability into a caring community: “It is now considered better for peoples’ mental health to be treated in the community in familiar surroundings” (Sane, Australia, 1998). However, the community is often inadequately prepared to support them and families have been forced to take a more active role in their care (Rose, 1996).

The de-institutionalisation of the mentally ill has had major consequences for families who have assumed a central role in the care of family members. Lefley (1987) and Johnson (1990) claimed that family caregivers are expected to assume responsibilities for which they have received no formal training and which is stressful and burdensome. Until recent times neither professionals nor the mental health system have acknowledged the care provided by family caregivers. Twenty five years ago, critics of de-institutionalisation, for example, Doll (1976) and Scull (1981), expressed concern that shifting the burden of care to families of the mentally ill was simply a cheap alternative to the provision of hospital services. They noted that de-institutionalisation could have potentially damaging effects on both the patient and the family providing care. As Doll said, “Rather than removing treatment to a more civilised and benign setting it sends the problems home, which may have devastating
consequences for the patient, for his family and ultimately for the community mental health movement” (p. 185). Two and a half decades have passed since Doll first expressed these concerns. Rose (1996) argued that the burden of family care still exists and that there is a need to study caregivers’ experience of mental illness in the context of contemporary environments.

Providing support to a mentally ill relative or partner can be demanding and stressful. The literature abounds with examples of the difficulties that family caregivers have encountered (Cook 1988; Oldridge & Hughes, 1992; Winefield & Harvey, 1993). These difficulties are referred to in the literature as family burden (Hatfield & Lefley, 1987; Lefley, 1996). They can include the need to provide practical, financial and moral support as well as advocating with the mental health and/or legal system on behalf of their family member. Families must develop a range of adaptations to the objective problems posed by serious mental illness in their midst (Lefley & Wasow, 1994). The behaviours may be odd, bizarre, threatening or even violent (Johnson, 1990; Wasow, 1995). Caregivers may also need to cope with their own emotional responses to their relative’s illness and these can include anxiety, fear, anger, guilt and grief (Wasow, 1995). Despite the considerable burden that derives from caring for a mentally ill family member, Marsh, Lefley and Husted (1996) noted that there is a, “potential for families to demonstrate competence and mastery, to strengthen family bonds and to change in constructive and adaptive ways” (p. 119).

Interest in the adaptive coping responses that family caregivers employ to assist them in providing for the needs of a mentally ill family member was generated by Hatfield and Lefley’s (1987) seminal work: Families of the Mentally Ill. They noted, “Almost nowhere, however, do we find any substantial evidence of research on adaptive strategies used by families that reflect strength in the face of adversity”
Most studies in this field have focussed upon family deficits rather than upon those coping responses that enable the family to continue to provide care for the mentally ill member.

According to Rose (1996), studies of the coping behaviours of family caregivers of the mentally ill are sparse. There is a need for studies of caregivers’ coping responses and an understanding of the appraisals and meanings that they assign to the issues encountered in caregiving (Park & Folkman, 1997; Lazarus, 1999). Terkelsen (1987b) observed a paucity of research examining the meaning of mental illness to the family and Rose (1996) noted, “A promising area of research is a qualitative approach to investigating families’ perceptions of the illness experience, the meaning they attach to the personal situations, and the relationship of those meanings to their coping responses” (p. 73).

Two further aspects of coping behaviour that have recently received attention are those of “uplifts” or benefits derived from the caregiving role (Chesla, 1989), and the contribution of positive affect to coping (Folkman & Moskowitz, 2000). According to Chesla, positive aspects of the caregiving experience have virtually been ignored. However, the ability to find benefit in a difficult situation may well contribute to adaptive coping, as can caregivers’ ability to create pleasure and relief in the midst of ongoing stress.

Because adaptive coping strategies develop over time (Wasow, 1995, Terkelsen, 1987b), any study of their development requires a temporal orientation that considers the course of the illness as well as the factors that led to the adoption of those strategies. Knowledge of the existing strengths and adaptive coping strategies employed by family caregivers at different stages of the illness should contribute to improved service delivery.
Research into the adaptive coping strategies employed by family caregivers of the mentally ill can also contribute to the development and delivery of much needed supportive individual or group programs. Somerfield and McCrae (2000) suggested that, to be clinically relevant, coping research should seek realistic, targeted and modest goals. They proposed that the goals should be those of helping some of the people, some of the time, cultivating existing strengths, hastening the recovery from loss, and preserving and enhancing valued relationships (p. 624).

The issues encountered by family caregivers of the mentally ill differ from those of carers in general. The differences lie in the need to develop adaptive ways of coping with a fluctuating and stigmatised illness. Research that develops knowledge and understanding of how caregivers cope, their strengths and perceived sources of support in dealing with the multiplicity of stressors that accompany caring for a relative with mental illness is a vital step toward achieving the goals proposed by Somerfield and McCrae (2000). It is envisaged that the current study will contribute to the realisation of such goals.
CHAPTER 1

Theoretical and Ethical Perspective for a Study of Caregiving

Psychology should become the science and practice of the identification and promotion of adaptationally significant competencies (Masterpasqua, 1989, p. 1366).

This chapter considers the concepts, theories and ethics relevant to the study of family caregivers' adaptive coping. Three important concepts locate and direct this present research. They are those of the recently proposed field of psychological study termed "positive psychology" (Seligman & Csikszentmihalyi, 2000), the competency paradigm proposed by Hatfield and Lefley (1987), together with the conceptual analysis of stress and coping (Folkman and Lazarus, 1985) and White's (1985) identification of the key features of adaptation. Methodological issues and ethical considerations with particular relevance to the study of family processes are also discussed.

1.1 Positive Psychology
Kiely (1980) noted the need to account for strengths as well as weaknesses and courage and growth as well as failures in coping. The current focus upon psychopathology has meant that these aspects of coping have been neglected and are not well understood by professionals. The importance of such a focus was also noted by Hatfield and Lefley
(1987) who claimed that clinicians' ability to successfully work with caregivers may depend upon the ability to identify their strengths.

More recently, a number of psychologists have stressed the need for a new direction for the field of psychology in general. An emerging movement, that has been termed "positive psychology", has been identified by Seligman and Csikszentmihalyi (2000). They argued in favour of a changed focus for psychology with an emphasis upon positive subjective experience, traits, and institutions. They claimed that this shift in focus could begin to catalyse a change from preoccupation with repairing the worst things in life to building positive and preventative qualities. That is,

Whatever the personal origins of our conviction that the time has arrived for a positive psychology, our message is to remind our field that psychology is not just the study of pathology, weakness and damage; it is also the study of strength and virtue. Psychology is not just a branch of medicine concerned with illness or health, it is much larger. It is about work, education, insight, love, growth and play (Seligman & Csikszentmihalyi, 2000, p. 7).

Hatfield and Lefley's (1987) work and more recent studies of coping processes (Lazarus, 2000; Folkman, Chesney & Christopher-Richards, 1994; Folkman & Moskowitz, 2000) could be considered to be located within a framework of positive psychology. The findings of these studies and discussions of the future direction of coping research emphasise the need to recognise the relationship between positive affect, positive reappraisal and adaptational coping (Lazarus, 2000).

Positive psychology appears to offer a useful framework for researching the adaptive coping strategies of caregivers of the mentally ill. Adoption of a positive framework directs the researcher's attention to the recognition of the strengths, skills
and capabilities that family caregivers have developed rather than focussing upon pathology. This focus upon positive attributes can serve as a basis for the development of respectful, sensitive and supportive programs and interventions that build upon acknowledged strengths. Whilst the focus should be upon building on positive attributes, Lazarus (2000) warned against adopting a simplistic and “Pollyanna” like approach because it could fail to take into account both the positive and negative aspects of caregiving.

1.2 Competency Paradigm

Related to the notion of positive psychology is the competency paradigm when working with family caregivers. The concept was promoted more than a decade ago when Masterpasqua (1989) proposed that psychology in general should adopt a competency paradigm and focus upon the study of adaptationally significant strategies. Marsh, Lefley and Husted (1996) applied this concept to their study and work with family caregivers of the mentally ill. They proposed the need for a paradigmatic shift in professional practice with families of the mentally ill. This entailed a move from a disease based medical model, wherein family caregivers are viewed as pathological, pathogenic or dysfunctional, to a health based developmental model wherein they are considered to be competent or potentially competent. Adoption of a competence paradigm has many advantages for both caregivers and for the professionals who work with them:

The paradigm fosters the development of alliances between families and professionals; facilitates the identification, assessment and enhancement of the competencies that are relevant to coping with serious mental illness, encourages more precise theory and research
concerned with families; provides a blueprint for designing, implementing and evaluating professional services; improves the service system for people with mental illness, and promotes the empowerment of families (Marsh et al., 1996, pp. 1124-1125).

1.3 *Stress, Appraisal and Coping Theory*

Coping, according to Lazarus and Folkman (1984), refers to the, "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" (p. 141). An important feature of this definition is that coping is defined independently of its outcome; that is, all efforts to manage the demands of the situation are regarded as coping irrespective of whether or not they are successful. According to this model, whether or not coping behaviours are activated, and the type of behaviours activated, depends upon appraisal of the situation.

Stress is defined as a relationship between the person and the environment that is appraised as threatening or challenging (Folkman & Lazarus, 1988a). Central to this phenomenological model of stress and coping is the notion of coping as a mediator between a stressor and the outcome of exposure to that stressor. According to Folkman and Lazarus, the relationship between emotion and coping in stressful situations is bidirectional in that the emotion evoked by the stressor can affect selection of the coping response and the coping response in turn can affect the emotion experienced. The relationship of cognitive appraisal to stress has three components: primary appraisal, secondary appraisal, and reappraisal.

Primary appraisal is concerned with judgements or evaluations about the saliency of the encounter. Through the process of primary appraisal the person
evaluates whether an encounter is irrelevant, benign, positive or stressful (Folkman & Lazarus, 1985). Stressful appraisals are characterised as either threatening, challenging or causing harm or loss: “Threat refers to the potential for harm or loss, challenge refers to the potential for growth, mastery and gain and harm-loss refers to injury already done” (Folkman & Lazarus, p. 152). The issues encountered by family caregivers of the mentally ill could be appraised in terms of challenge but are more likely to be perceived as threatening or having the potential to cause harm and/or loss. This initial appraisal affects the choice of coping response.

Secondary appraisal is activated after primary appraisal indicates that a response is required. Secondary appraisal refers to the person’s evaluation of their coping resources and options. It addresses the question “What can I do?” (Folkman & Lazarus, 1985). To illustrate how the concepts of primary and secondary appraisal could be applied to the study of the coping responses of caregivers, consider the bizarre behaviour of the mentally ill family member. This behaviour may be perceived as either threatening or challenging (primary appraisal) and cause arousal that leads to consideration of coping options (secondary appraisal). Depending on the outcome, adoption of a coping response will in turn either increase or decrease the stress experienced and lead to reappraisal of the situation.

Reappraisal occurs subsequent to implementation of a coping response and consideration of the outcome of that response. It can either lead to the adoption of a different strategy, or to a changed focus of attention: “Coping when considered as a process, is characterised by dynamics and changes that are a function of continuous appraisals and reappraisals” (Folkman & Lazarus, 1988, p. 6).

Within the Folkman and Lazarus theory, coping is considered part of a dynamic, ongoing and changing process (Folkman & Lazarus, 1985; Lazarus, 1993) and this
approach implies a set of theoretical principles (Folkman & Lazarus, 1980). Firstly, observations and assessment of coping responses should be concerned with what a person *actually* thinks or does, not with what they usually do or should do. Secondly, what the individual thinks or does should be examined within a particular context. The coping strategy adopted is dependent upon the particular threat that is being responded to and can only be understood in this context (Folkman & Lazarus, 1985, Lazarus, 1993). Thirdly, what is attended to, and the threats themselves also change with time or with changing context (Lazarus & Folkman, 1984).

Several authors (Lazarus, 1993; Stone, Kennedy-Moore, Newman, Greenberg & Neale, 1992) have argued for the importance of adopting a transactional perspective in determining coping responses, whilst lamenting that existing coping measures are frequently based upon a dispositional or stylistic orientation. A dispositional or stylistic orientation assumes that people use the same coping strategies in all situations. Lazarus and Folkman (1984) noted that such approaches tend to, “grossly simplify complex patterns of coping into unidimensional schemes ... which have little explanatory and predictive value for what a person actually does in particular contexts” (p. 178). According to Pruchno and Resch (1989), viewing coping as a process raises the expectation that coping will change in response to the unfolding of the stressful situation.

The Lazarus and Folkman (1984) process model of stress, appraisal and coping is most relevant to the study of the changing behaviours and goals of caregivers in relation to the situations encountered in caring for a mentally ill family member. Mental illness is frequently a fluctuating disorder with periods of relative wellness interspersed with periods of crisis. Family caregivers of the mentally ill need to
develop adaptive responses to the multiplicity of challenges of the role and adaptational coping strategies may evolve over a period of years.

1.4 Adaptational Coping

According to Lazarus (1976) and Monat and Lazarus (1985), the concept of adaptation originated in biology and has been borrowed and changed somewhat by psychologists. Adaptation theory is based on evolutionary concepts and primarily the concept that living organisms will do what is necessary to struggle and survive (Hatfield, 1987). In this struggle certain behaviours develop that are defined as “coping mechanisms” and adaptive behaviour is conceptualised in terms of its appropriateness to the situation and effectiveness. Harvey (1966) extended this definition to include the attainment of goals: “In the ultimate sense, adaptability means the capacity to behave in ways maximally consonant with the attainment of goals” (p. 6).

Whether an adaptational coping response is to be regarded as either effective or ineffective depends on the person’s goals, the specific type of encounter, and the time frame adopted. For example, what is effective in the short term may be less useful in the long term and the use of denial illustrates this point. Initially, denial may protect the individual from being overwhelmed by a traumatic event but mitigate against finding ways of dealing with the event in the long term. There may be no universally effective coping process, though some might often be better or worse than others (Folkman & Lazarus, 1980; Lazarus & Folkman, 1985) and adaptive coping may more often be better than worse.

According to White (1985), “adaptation does not mean either a total triumph over the environment or total surrender to it, but rather a striving toward acceptable compromise” (p. 126). White described what he considered to be essential ingredients
in the production of adaptive coping responses: “Adaptive behaviour, in short, involves the management of at least three variables: securing adequate information, maintaining satisfactory internal conditions, and keeping up some degree of autonomy” (p. 133). The first of these variables, securing adequate information is an essential precursor to deciding upon a course of action and an obvious necessity for adaptive behaviour.

Strong unpleasant affects, such as anxiety, grief or shame, hamper the production of adaptive behaviours. Controlling such affects and maintaining a satisfying self-picture are necessary elements of adaptive coping (White, 1985). More than just maintaining control over negative affects, is the need to maintain, or even enhance, a sense of self worth or self-esteem. This may be particularly difficult for caregivers of the mentally ill whose efforts may not be valued by the care-recipient, (Newsom, 1999), society in general (Lefley, 1996), or mental health professionals (Human Rights and Equal Opportunity Commission, 1993).

The third aspect of adaptation, keeping up some degree of autonomy, is related to freedom of action, and in the case of family caregivers of the mentally ill this may mean having a repertoire and choice of responses to the multiple demands of caring: “Adaptive behaviour involves managing different things at once” (White, 1985, p. 130).

Felton and Revenson (1984) reported the independence of coping and psychological adjustment and cited a number of studies showing that adaptational coping did not account for changes in measures of well-being over time. However, Folkman and Lazarus (1988a) considered that the choice of outcome studied could be the problem, and subjective well-being and psychological adjustment may not be the most appropriate measures of adaptation. Possibly, assessment of whether a coping response is adaptive or maladaptive may depend upon the evaluation of the person
coping. McCrae and Costa (1986) made the point that how a person feels at the conclusion of a stressful event may be less important to them than whether they have learnt something from the experience, maintained social bonds or accomplished a significant task. Lazarus (1999) also stated a preference for understanding stress, emotion and adaptation by considering how the individual construes the situation.

1.5 Methodological Issues

According to Somerfield and McCrae (2000), “The study of human adaptational processes is in crisis: two decades of concentrated research have yielded relatively little of either clinical or theoretical value” (p. 620). In recent times, almost all areas of coping research have been the subject of scrutiny and criticism (Steed, 1998; Coyne & Racioppo 2000; Weber 1997; Lazarus 2000). For example, deRidder and Schreus (2001) claimed that therapists appear to be as little concerned with coping as researchers are with interventions, and stated that the implications of findings of coping research are often not apparent to clinicians. This gap between research findings and clinical practice was noted by Lazarus (1993) and Somerfield and McCrae (2000) also deplored the failure of previous studies to produce information of clinical relevance. Their evaluation of the current state of coping research is sufficient to bring despair to the heart of even the most optimistic researcher. Fortunately, they continued, “Despite the recent upsurge of criticism – or perhaps because of it and the creative solutions suggested by more constructive critics – there is renewed enthusiasm for research on adaptational processes” (p. 623). Here I consider some of these issues and discuss the practical and creative solutions offered in recent research.

Two key issues have emerged, they are, what should be studied and how should research be conducted? Lazarus (1993) noted a weakness in current conceptualisations
of coping as a process: "Coping process measures would be far more meaningful and useful if we knew more about the persons whose coping thoughts and actions in specific contexts are being studied" (p. 242). Insufficient attention has been given to the motivational aspects of coping, that is: "the general goals and situational intentions that mobilise and direct the choice of coping strategies employed" (p. 243).

Both Lazarus (1993) and Folkman and Moskowitz (2000) suggested that information about the previously neglected role of positive affect on coping ability would enhance coping research. Folkman and Moskowitz claimed that positive affect can co-exist with distress and has important adaptational significance in coping:

A great deal more can be learned about coping that helps support positive affect by asking people to provide narratives about stressful events, including what happened, the emotions they experienced and what they thought and did as the situation unfolded (p. 652).

The over-reliance upon coping questionnaires has been criticised (e.g. Coyne & Racioppo, 2000), as has misuse of the Ways of Coping Questionnaire (Lazarus, 1999). This measure has been misused to study coping traits, although it was never intended to be used for this purpose. In the past, much coping research has relied upon the use of questionnaires and Coyne and Racioppo (2000) are particularly scathing in their criticism, claiming that such measures can yield only a superficial description of what actually occurs in coping. Folkman and Moskowitz (2000) also noted that, although quantitative research methods provide ease of comparisons within and between individuals, only qualitative research methods allow for the study of the micro-processes of coping. Lazarus (2000) acknowledged this point but claimed that questionnaires can have a place in coping research, particularly in the early stages, and
a combination of quantitative and qualitative data can enhance an understanding of how people cope.

Inconsistencies in researchers' definitions of the components of the coping process and the means of operationalising them have been reported. Siegel and Smith (1989) noted that unsuccessful coping efforts are sometimes reported as failures to cope and Peterson (1982) reported that variables treated as coping attempts in one study may be reported as outcomes in another, so that disentangling predictor and outcome variables in the literature is difficult. In an attempt to clarify this issue, Rudolph, Dennig and Weisz (1995) proposed a modified working definition of what they termed a "coping episode". The elements of a coping episode included a coping response, a goal underlying that response, and an outcome. In this manner, they also addressed concerns raised by Lazarus (1999) about acknowledging the motivational aspects of choice of coping response.

To ensure relevance to clinical practice, coping research needs to take into account these criticisms and attempt to address them. The combination of quantitative and qualitative measures, as suggested by Lazarus (2000), could address superficiality concerns in that quantitative measures may indicate broad and general trends in coping and qualitative data complement and deepen understanding of those responses. The role of quantitative measures may be in indicating what happens and when, whilst qualitative research may explicate the how and why of coping processes.

The use of longitudinal studies of coping that involve interviews at various stages of the care process or daily diary entries have been advocated (Tennen, Affleck, Armeli & Carney, 2000; Lazarus, 2000). In some cases, these studies have collected data over a period of years (Folkman, 1997; Stein, Folkman, Trabasso & Christopher-Richards, 1997) and rich and meaningful information of clinical relevance has been
produced (Lazarus, 2000). However, the practicality of applying this method to the study of caring for the mentally ill is unclear. Adaptive responses to mental illness in the family may only develop over a period of very many years (Hatfield & Lefley, 1987) and the onset of many mental disorders may be insidious and gradual; diagnosis only taking place after caregiving has functionally (although not necessarily consciously) commenced (Stephens & Zarit, 1989). These lengthy incubation periods may make it inherently difficult to access caregivers in the initial stages of their relative’s illness. Further, family caregivers may not initially recognise or identify themselves as such, and their initial responses to the illness may only be gathered retrospectively.

Retrospective research poses difficulties of accuracy of recall; caregivers may have forgotten how they initially responded to the illness, and coping questionnaires may function as an “aide memoir” prompting recollection of responses that could be further explicated at interview.

Finally, the important issue of clinical relevance of coping research (Somerfield & McCrae, 2000) could be addressed by ensuring that the information sought has direct links to the development of caregiver support programs or clinical practice.

1.6 Ethical Issues

Ethical issues with particular relevance to the study of family caregivers’ coping processes are considered here, and the means of addressing these issues discussed.

Larossa, Bennett and Gelles (1981) raised a number of ethical dilemmas specifically related to qualitative family research that included the difficulty of obtaining fully informed consent from participants and possible participant distress. They claimed that, even when family caregivers are appraised of the topic to be
discussed, sensitive and painful issues may be unexpectedly evoked in the course of
interview. Ensuring that participants are fully informed prior to deciding to take part in
qualitative family research presents particular difficulties, in that provision of a broad
outline of the type of questions to be asked at interview may be insufficient as issues
that impinge upon the privacy of others may emerge. Participants may, in the course of
interview, divulge information that they later regret and the option of reviewing their
contribution or withdrawing from the study at any stage could partially address these
issues.

The discussion of traumatic and sensitive issues can be emotionally distressing,
and may require the provision of post-interview de-briefing and/or support referral.
Again, the option of terminating the interview could partially address this issue and it
may be necessary to reiterate this option during the course of the interview. Debriefing
at the conclusion of the interview and provision of referral to appropriate caregiver
support agencies, if required, could further address continuing distress.

1.7 Summary

The theoretical and ethical perspectives relevant to the study of coping with mental
illness in the family have been discussed in this chapter. I have proposed that the
emerging field of study, designated as positive psychology, together with Hatfield and
Lefley’s paradigmatic shift in the way that family caregivers of the mentally ill are
viewed are most relevant in that they focus attention on adaptational coping strategies
rather than deficits. Knowledge and understanding of the ways of coping that family
caregivers have found to be useful would seem to be most relevant to the development
of supportive interventions. I have suggested that a process-oriented approach to
coping that is concerned with changes in responses as the situation unfolds (Folkman &
Lazarus, 1985) could combine with White's (1985) adaptational approach as an appropriate methodology.

I have noted and discussed relevant criticisms of coping research and considered ways in which these criticisms could be addressed. Ensuring the relevance of coping research to clinical practice was discussed as were suggestions that quantitative measures could be complemented by qualitative data about appraisals, goals, coping resources and options to enhance coping research.

The merits of longitudinal studies were considered, together with the practicality of their application to the study of family caregivers' adaptive responses. Ethical issues in qualitative family research, including the need to ensure confidentiality of both the caregiver and the care recipient were considered and possible responses to participant distress discussed.
CHAPTER 2

Family Caregivers and Care Provision

The family has become the replacement for the ward staff
(Hatfield and Lefley, 1987, p. 8).

2.1 Definition

What is a caregiver? In their search of the family caregiving literature, Schofield and Herrman (1993) found no universally accepted definition of who or what a caregiver is. They claimed that previous research has attempted to define caregivers only in terms of the tasks undertaken or the amount of time devoted to care provision. On the other hand, the Commonwealth Government's definition of a caregiver is solely concerned with determining eligibility for a Carer Benefit payment. Stringent financial and other criteria, including type of disability and degree of impairment, are applied before a person is designated a caregiver and becomes eligible for this benefit. Because the person requiring care must be over sixteen years of age, and because income and assets tests apply (Department of Social Security and Health and Family Services; 1997), many informal caregivers are excluded from surveys using such criteria. Narrow definitions of the caregiver role can mean that important information about the prevalence and contribution of caregivers can be missed (Schofield, 1998).

In an attempt to develop a more inclusive definition the Carers Association of Victoria (1999) offered the following, "A carer is someone providing unpaid care to someone with care/support needs" (Carers Association Victoria Brochure, 1999).
Whilst certainly broader than the Commonwealth Government's definition of a caregiver, this definition also has problems. For example, inclusion of the term "unpaid care" again excludes some caregivers of the mentally ill who may be in receipt of a Carer Benefit payment. The Carers' Association definition also makes no mention of kinship or relationship to the care recipient and makes no distinction between family and volunteer caregivers.

According to Schofield (1998), caring for a relative with a disability differs from other forms of caring in our society and that difference lies in three key aspects: responsibility, choice, and transgression of customary expectations. With respect to the first of these aspects, Schofield claimed that responsibility for the care recipient is central to the definition of a caregiver and rests upon the degree of responsibility. The degree of responsibility assumed by the caregiver is over and beyond that commonly associated with adult relationships. Where one person is limited in their physical or mental capabilities, as is the case in mental illness, there is a degree of necessary reliance on the caregiver. This is a point previously made by Twigg, Atkin and Perring (1990) who concluded that mental illness is often episodic in nature, and the care provided is frequently focused around responsibility rather than direct care tasks. For example, a mentally ill family member may not require feeding and bathing but the caregiver may need to assume responsibility for management of their finances.

According to Schofield (1998), choice is the second defining feature of family care provision. Although it may be assumed that the caregiver has freely decided, independent of legal requirements, to provide care, this may not be the case. The choice of whether or not to provide care to a family member can be restricted by societal expectations, bonds of affection and the practicality of obtaining alternative care outside of the family. According to Schofield (1998), "Carers' choice has been
further limited by trends in government policy over recent decades which have
promoted a shift from institutional to home-based care, in Australia, New Zealand and
elsewhere” (p. 9).

The practical difficulties of obtaining suitable accommodation and care for the
mentally ill outside of the family home may mean that co-residency is often more of a
necessity than a choice, despite previous recommendations (e.g. Dingman, 1974) that it
is best for adult patients to live away from home.

According to Schofield (1998), the third and final defining aspect of care-giving
is that of transgression of customary expectations and these are often related to stage of
life. Whilst it is normal to expect to provide extensive care to a child and it is often not
regarded as burdensome to do so, one seldom expects to have to continue providing
care to adult offspring. Similarly, a partner or spouse may reasonably expect to provide
care to their partner in old age, but rarely expects to assume that role early in the
marriage. As Schofield (1998) said, “The central concept of care-giving in the sense in
which we are using it is then not simply having responsibility for someone else, but
being responsible for that person beyond what might customarily be expected in that
relationship” (p. 10). Family caregivers can be related to the care recipient in a variety
of different kinship roles. They can be the parents or grandparents of adult offspring,
the spouse, partner, sibling, or even an in-law of a mentally ill family member. An
inclusive definition of who is a family caregiver is necessary to ensure that important
data is not excluded from any study. As noted, given the fluctuating nature of mental
illness, the degree of care-recipient impairment, caregiver tasks undertaken, or the
amount of time devoted to care provision may be less relevant to defining who is a
caregiver of the mentally ill. In the case of mental illness, care-giving is frequently
based upon assuming responsibility for the well-being of the family member. Including
all family members who self-identify as assuming responsibility for the provision of
care to a family member with a mental illness should yield broader and more relevant
research information.

2.2 Caregiver Characteristics

O’Brien (1998) reported that, when all types of disability and chronic illness are taken
into account, Australia has 1.5 million principal caregivers of people with severe or
profound disabilities. This figure includes parents providing care to physically or
intellectually disabled children, as well as spouses and adult children caring for elderly,
feeble or demented relatives, and also includes family caregivers of the mentally ill.
The figure translates into approximately one caregiver to every five Australian
households and represents a sizeable proportion of the population providing care-giving
services.

Under the auspices of the Victorian Health Promotion Foundation, Schofield
and Herman (1993) conducted a statewide survey of family caregivers. From an initial
survey sample that consisted of 98 respondents, approximately one third reported
providing care to a family member with a psychiatric or emotional problem of a severe
or moderate kind (p. 34). The survey identified both male and female caregivers but
women predominated, and this finding was considered to be hardly surprising as care
provision is usually considered to be a female role in Western societies. Lefley (1996)
reported the findings of an American survey conducted by the National Alliance for the
Mentally Ill. This survey found that the majority (73%) of mentally ill care recipients
were children of the care-givers, 69% were sons and 31% were daughters, and 42% of
the care recipients lived with their parents. These findings accorded with those
reported by O’Brien (1998) who claimed that the modern caregiver of a psychiatric
patient is most likely to be a parent, spouse or child, and, in the case of parental caregivers, mothers are usually the principal caregivers. O'Brien also reported considerable diversity in the age of caregivers, the duration of care provision and co-residency of care recipients.

Family caregivers and care recipients may or may not live together whilst maintaining the caregiver role. For example, Clarke and Drake (1994) noted that even when the mentally ill relative lives away from home family caregivers continue to provide financial and social support and devote time to their care. They claimed that emotional involvement may not decrease when co-residency ceases. A study by Carpentier, Lesage, Goulet, Lalonde and Renaud (1992) found psychological distress to be equally high for families living with or living apart from their mentally ill relative. Co-residency may be related to the kinship relationship of caregiver and care recipient. According to Wasow (1995) and Judge (1994), spouses or partners are more likely than parents to be living with the care recipient.

2.3 Magnitude of Caregiver Contribution

According to the Mental Health Council and Carers Association of Australia report (2000), an enormous contribution is made by Australian family caregivers of the mentally ill. This report claimed that, “Individual carers on average contribute 104 hours per week caring for a person with a mental illness” (p. 4).

The Mental Health Report (1997) cited in the final report of the Mental Health Council and Carers Association of Australia (2000, p. 2) showed that the annual government expenditure on mental health services provision was $2.07 billion. The major component of this sum was the salary of professional workers whose average duty time was less than 40 hours per week. In contrast, the 104 hours per week of
unpaid family care meant that caregivers were providing 2.5 times the average working week in care provision. Assuming these figures to be correct, they highlight the magnitude of the economic contribution of informal family care providers to the mental health system and the need to ensure their support.

2.4 Care Provision

Caregivers of the mentally ill often assume responsibility for a varied and diverse range of tasks (Hatfield & Lefley, 1987; Lefley, 1996). The stage of the illness and the degree of impairment often dictate the type and the amount of time devoted to care. For example, the provision of meals and accommodation with attendant household duties is one aspect of family care provision, although, as previously noted not all care recipients live at home (Schofield & Herrman, 1993).

Family caregivers may also be called upon to provide practical, financial and social support to their mentally ill relative. The family is often the only source of company and social support for people with a mental illness, and family caregivers frequently assume responsibility for their relative’s attendance at medical appointments and medication or treatment compliance, as well as for general health and safety issues. At times of crisis, it is often family caregivers who assume responsibility for obtaining treatment or admission to hospital. They may collaborate with mental health professionals to monitor progression of the illness and treatment response. Family caregivers can also be called upon to advocate on their relative’s behalf with the mental health system or the legal system. Many of these tasks are performed under stressful conditions and with little formal training (Mental Health Council and Carers Association of Australia Report, 2000). The requirements of care provision can change from day to day necessitating flexibility and a range of skills. At times of relative
stability, the amount of care required may lessen and, at times of exacerbation of symptoms, it can increase dramatically.

2.5 Summary

It is apparent from the Mental Health Council and Carers Association of Australia Report, (2000) that family caregivers make an enormous contribution to the delivery of mental health services in Australia. The type and amount of care that family caregivers provide varies in accordance with the demands of the situation. The report has even questioned the ability of the system to work without their contribution. Certainly the extent of their contribution highlights the need for health professionals to understand and support their work.

The lack of a common definition of who is a caregiver and the application of narrow criteria may have excluded some caregivers and their particular issues from inclusion in surveys. If some have been excluded, the extent and range of the types of issues or difficulties faced by family caregivers may be incorrectly estimated. Arriving at a consensual definition of who is to be considered a caregiver of the mentally ill is a critical issue in research in this field. However, allowing self-identification of family caregiver status may well add to the collection of useful information about this group.
CHAPTER 3

Sources of Caregiver Stress

The concerns and needs that face people with a mental illness, their friends and family are more than enough for anyone to deal with (Woolis, 1992, p. 193).

Many studies have reported high levels of stress in caregivers of the mentally ill (Lefley, 1996) and this chapter discusses the sources of that stress as a starting point for understanding the development of the adaptive coping strategies. The issues encountered in providing care can be the source of both chronic and acute stress and Lazarus (1999) considered,

Chronic stress arises from harmful or threatening, but stable conditions of life, and from the stressful roles people continually fulfil at work and in the family. Acute stress, conversely, is provoked by time limited, major or minor events that are harmful or threatening at a particular moment in life or for a relatively brief period (p. 144).

However, the distinction between chronic and acute stress may be somewhat blurred and one may lead to the other (Lazarus, 2000). This is particularly true of the experience of caring for a mentally ill relative where the fluctuating nature of mental illness exposes family caregivers to both chronic and acute stress. For example, chronic stress may derive from the on-going daily demands of care provision whilst acute stress may result from periods of symptom exacerbation.
3.1 **Objective and Subjective Stressors**

The objective burden of caring for a mentally ill family member is related to the management, treatment and control of the disorder whilst subjective burden refers to the caregiver’s experience of unpleasant or uncomfortable affects arising in response to the illness (Wasow, 1995; Griffin-Francell, Conn, & Gray, 1988).

The burden carried by families of the mentally ill can be varied and extensive and can include the need to provide practical support as well as coping with aberrant or even violent behaviours. Time constraints, relationship strains, financial difficulties and social isolation can all contribute to caregivers’ experience of situational stress.

The number and variety of objective problems and difficulties caused by mental illness are extensive. For example, Barrowclough and Tarrier (1992) listed some 50 distressing behaviours ranging in severity from mildly distressing restlessness and sleep disturbance, through to moderately distressful situations such as having a family member who talks to himself and is of odd appearance or manner and severe manifestations of distressing behaviours such as violence or suicidal intent. All family caregivers would have encountered some, if not the full range, of these distressing behaviours.

Research suggests that caring for a mentally ill family member at home can strain family relationships and disruptions to normal family social life, relationships and activities have been reported (Marsh, Lefley, Evans-Rhodes, Ansell, Doerzbacher, LaBabera & Paluzzi, 1996). Deveson (1991) reported that the strain of providing care can lead to the breakdown of marriages or relationships and Marsh et al. claimed, “the assault on the integrity of the family system presents many potential risks, including the risk of family disruption and stress, of failure to balance the needs of all family members, and of family disintegration” (p. 122).
Interactions with the mental health system, and at times with the criminal justice system, are further sources of stress (Marsh, et al., 1996). Such interactions may require of families the knowledge and confidence to make difficult decisions about their mentally ill family member and to act as advocates on their relative’s behalf at times of crisis (Deveson, 1991).

Subjective burden has been conceptualised as the emotional suffering that families experience in response to their relative’s illness and includes the painful and stressful emotions generated by the experience. Wasow (1995) noted that family caregivers commonly report experiencing a range of negative emotions that can include anxiety, sorrow, grief, fear and anger as a result of their relative’s disorder.

3.2 Sources of Stress

According to Lefley (1996), the stress that caregivers of the mentally ill experience can be of situational, societal, or iatrogenic origin, and all three can operate independently or collectively to contribute to the family caregiver’s ultimate experience of cumulative stress.

3.2.1 Situational Stressors

Situational stress derives from the daily experience of living with mental illness in the family and the issues encountered are often referred to as family burden and may be the most pervasive source of stress (Johnson, 1990; Cook, Lefley, Pickett & Cohler, 1994; Lefley, 1996; Reinhard, 1994). According to Marsh, et al., (1996), research findings supporting the notion have been so robust that “family burden” has come to define the family experience of mental illness. Whilst the term family burden is frequently encountered in professional discussions of caregiver issues, Harrison (2000) made the
point that the term may not be used by family caregivers themselves and may even be considered offensive by some. According to Rose (1996), it may be that what has been described as a burden could more accurately be described as a stressor.

3.2.2 Societal Stressors

Two major sources of societal stress encountered by family caregivers of the mentally ill are those of stigma and of service provision deficits. Stigma arises from a society's cultural attitudes toward the mentally ill and their families and may be either objectively or subjectively experienced. Within our culture mental illness is still stigmatised and the mentally ill are either feared, as in media portrayals of the dangerously insane, or ignored and neglected.

Borinstein (1992) and Philo (1994) considered the media to be the general public's primary source of information about mental illness and media portrayals influence public perceptions. Although community attitudes to mental illness appear to be changing with the advent of more educative and informative programs (Schizophrenia Fellowship, 1997; Sane, Australia, 1998), misunderstanding and fear are still apparent in media reporting of mental conditions and in the popular culture.

The stigma of mental illness can extend beyond the patient to include the entire family. McFarlane and Beels (1983) report that many families feel devalued by their association with mental illness and, “react with a sense of subjective defeat, as if the entire family has undergone a major change in its worth as a result of the illness” (p. 317). Lefley (1989) made the point that such evaluation of the family’s worth may be confirmed by society: “Social barriers are frequently erected against the relatives and households of negatively valued persons” (p. 557). Cultural expectations also play an important role in caregivers’ responses to mental illness. For example,
Kuipers, Leff and Lam (1992) found that the subjective belief that the whole family is devalued by the illness is most evident in the accounts of families whose ethnic background differs from that of the dominant culture. This belief may be prevalent in a multi-cultural society such as Australia, although Kuipers et al. reported that subjective stigma can be found in the accounts of caregivers from all backgrounds. Rose (1996) expressed concern that the impact of stigma on family members remains unclear and bears further consideration.

Service system deficits are a further source of stress and they can include a lack of services or difficulties in accessing appropriate care, as well as a lack of support for caregivers. Providing care to a mentally ill family member can be a thankless task; mental health professionals may not value the contribution and care recipients may not be appreciative of the help provided (Newsom, 1999). The Human Rights and Equal Opportunity report (1993) noted gaps in the provision of support and information to caregivers:

The parents, spouses and children of people with mental illness rarely have any specialist training or education in dealing with chronic mental illness, little or no knowledge of the side effects of psychotropic drugs, and no knowledge of how to calm or counsel a suicidal or potentially violent person. Caregivers are crying out for this basic information—frequently denied them on the basis of doctor-patient confidentiality (p. 456).

Current rhetoric in the mental health system promotes the notion of professionals and family caregivers working together and sharing management of the mentally ill. The ideal position is said to be one in which families are considered to be partners in the provision of a major support system that maintains people with a serious mental illness
in the community, or assists in re-integrating them within the community. However, a partnership between caregivers and professionals based upon mutual respect and shared goals, as envisaged by Hatfield and Lefley (1987) is often an unrealised ideal. In practice, it is not uncommon for families to encounter deviations from this ideal state (Deveson, 1991). Many caregivers have experienced a partnership with treating professionals that more closely resembles that described by Dr. Seuss (1995), the author of children’s books: “This is called teamwork. I furnish the brains. You furnish the muscles, the aches and the pains” (p. 8). The shift proposed by Hatfield and Lefley (1987) has been slow to translate into practice (Mental Health Council of Australia and Carers Association of Australia, 2000; Australian Psychological Society, 1998).

The Human Rights and Equal Opportunity report (1993) noted multiple criticisms of the treatment accorded to relatives and caregivers. As well as concerns about service deficits and the difficulties that caregivers encountered in obtaining information about their relative’s diagnosis, treatment and prognosis, complaints included those of disrespectful treatment by mental health professionals and disregard of caregivers’ observations and contribution.

3.2.3 Iatrogenic Stressors

Lefley (1996) referred to iatrogenic sources of caregiver stress; iatrogenic is a medical term that describes a secondary condition arising from professional treatment of a primary condition. Used in this context, the term refers to causal theories of mental illness that assign blame to family members and lead to deficits in clinicians’ recognition of caregiver issues.

Although no longer fashionable, models of family pathogenesis that blame parents or family members for causing or for maintaining the illness are still
encountered and their effect on family caregivers can be long lasting. Although many parents have overcome the belief that in some way they caused their relative’s illness, a residual sense of guilt often remains (Lefley, 1996).

Theories of family pathogenesis can lead to deficits in clinician training and limit professionals’ general knowledge about the extent of family burden. Such beliefs can lead to a failure to provide caregivers with the needed information and support that enables them to continue supporting their relative (Lefley, 1996; Lazarus, 2000). Recent attempts to provide such support are evident in programs such as the Bouverie Clinic, Fast Program (1997) and Government initiatives to explore innovations in the training of mental health professionals (Australian Psychological Society Bulletin, April, 1998). Two important principles emerged from initial consultations reported in this Bulletin: “Mental health professionals need to learn about and value the lived experience of consumers and carers” [and] “Mental health professionals should recognise and value the healing potential in relationships between consumers and service providers and carers and service providers” (p. 11). The Bulletin article expressed regret that these principles are not currently evident in the work of mental health professionals, and suggested that practical ways of changing this situation rely on greater involvement by consumers and caregivers in their education and training. Although such programs can contribute to a decrease in family caregivers’ burden of iatrogenic stress, the lasting effects of blame may persist as a source of stress.

3.3 Exceptionally Difficult Stressors

It is apparent that not all the stressors encountered by family caregivers are equally distressing and Barrowclough and Tarrier (1992) noted, some issues are more easily accommodated and adapted to than others. The previous sections of this chapter
considered the multiplicity of burdensome issues encountered in caring for a mentally ill family member. Here I discuss in greater depth those exceptionally difficult behaviours or situations that require the production of adaptive coping strategies under particularly stressful conditions. They include the objective burden of real or potential risk of harm to either caregiver or care recipient and the subjective burden of chronic grief.

3.3.1 Care Recipient Vulnerability

Concern for the ongoing safety of their mentally ill family member can be a significant source of stress to caregivers. For example, Freckleton, (1998) reported, “On occasions, the behaviour of persons when symptomatic with mental illness can render them vulnerable to serious exploitation” (p. 257). Care recipients with impaired judgement may be neglectful of their own health and safety, may take risks with money or when driving, or may even just disappear without informing anyone of their whereabouts (Deveson, 1991, McFadden, 1999). All these behaviours can cause considerable anguish about the safety and welfare of the family member. People with a mental illness may be duped out of money, lured into joining religious sects and/or sexually exploited. Further, mentally ill persons can behave in a provocative or aggressive manner leading to a risk of assault by members of the public or by members of the police force who may not be aware of their illness, and recent media accounts have highlighted this risk.

An area of vulnerability that has, to date, been under-researched is that of patients’ experience of violence or abuse within the mental health system, and the effect upon family caregivers. Kumar and Thomas (2001) claimed that the literature has concentrated on the mentally ill as perpetrators of violence and has neglected the
fact that they may also be the victims of violence. They cited research highlighting concern about the prevalence of physical and sexual abuse of patients by professionals. To date, it is not known to what extent family caregivers encounter and cope with issues of abuse or mistreatment of their relative within the mental health system.

Perhaps the issue that gives rise to the most fear, anxiety and grief for family caregivers is that of suicide. The Treatment Protocol Project (1997) of the World Health Organisation reported that up to 50% of individuals with schizophrenia will be clinically depressed in the first six months after an acute episode and during this period of time they have a particularly high risk of attempting or committing suicide. This project reported that the overall rate of suicide among individuals with schizophrenia is approximately 10% in the first five years following diagnosis (p. 374). Suicide is often linked to depression itself and this link has implications for the vulnerability of people with depressive disorders and other mental illness such as bi-polar disorder and personality disorders in which depression co-exists. Given the prevalence of suicidal risk in the mentally ill, family caregivers may need to develop adaptive ways of coping with actual and potential suicide attempts.

3.3.2 Violence

A further particularly stressful issue encountered in caring for a mentally ill family member is that of violence. This aspect of objective burden has been termed “risk” and it is considered to be one of the most difficult issues to deal with (O’Brien, 1998). Whilst the risk to caregivers may include verbal abuse, threats, temper outbursts and physical assault; at its most extreme it can also include risk of homicide. O’Brien reported examples of violence against family caregivers that culminated in homicide and discussed service delivery deficits that may have contributed to this outcome. He
claimed that there is a dearth of inquiry into the risk that caregivers face when looking after the mentally ill and even less into the coping strategies that caregivers employ to deal with such issues.

The prevalence of risk of harm to family caregivers is a source of conflicting research findings (Lefley, 1996) and may be masked by the failure of caregivers to report any but the most extreme examples. Torrey (1994) claimed that the vast majority of people with a mental illness are no more dangerous than other people in the general community and Link, Andrews and Cullen (1992) emphasised that the presence of psychotic symptoms, rather than mental illness per se, is the major determinant of violence.

Vadaddi, Soosai, Gillard and Adlard, (1997) conducted a study of the prevalence of abuse faced by the relatives of patients admitted to the psychiatric ward of a major Australian hospital and found that 32% of participants reported that they had been struck by the care recipient on at least one occasion, whilst 50% reported having been subjected to verbal abuse, threats and temper tantrums. The study found that caregivers that had experienced abuse reported an increased perception of burden and of living in fear of the patient.

Estroff, Zimmer, Lachicotte and Benoit (1994) reported a particular pattern of violence, largely directed at mothers who were primary caregivers and who were living with a psychotically ill family member. According to Staznickas, McNeil and Binder (1993), such patterns could be explained by the caregiver’s attempts to place limits on the behaviour of the ill family member, the amount of time spent in their company, and the caregiver’s availability as a target of violence. As middle-aged women make up a large proportion of caregivers (Schofield & Herrman, 1993) and because they are usually less capable of physically restraining their aggressive family member, they may
need to develop alternative coping strategies to manage violence and knowledge of
caregivers’ responses to violence has clinical relevance.

3.3.3 Substance Abuse and Dual Diagnosis

Dual diagnosis refers to the co-morbidity of any two conditions and is used here to
refer to the co-morbidity of mental illness and substance abuse. The Treatment
Protocol Project (1997) of the World Health Organisation reported that over 30% of
individuals with schizophrenia abuse substances such as alcohol and street drugs, and a
large proportion smoke marijuana and cigarettes. The Chief Executive Officer of
Youth and Substance Abuse addressed a community forum and estimated that 22% of
males and 16% of females in the 18-24 year age group have a substance abuse disorder.
(The Association of Relative’s and Friends of the Mentally Ill, Victorian branch
newsletter, June 2000). He described young people with mental illness and substance
abuse problems as core business for both drug and alcohol, and mental health services
and speculated that the number of young people suffering from mental illness may be
higher than reported because their symptoms may be masked by the use of drugs taken
in an attempt to quell symptoms. The combination of substance abuse and mental
illness raises particularly difficult issues for both caregivers and professionals in that
substance abuse may initially obscure underlying psychiatric disorders and cause
difficulties in diagnosis.

Obtaining suitable treatment for a person with the dual diagnosis of psychiatric
disorder and substance abuse presents additional difficulties. Brown, Ridgely, Pepper,
Levine and Ryglewicz (1989) claimed that, “Mental health personnel lack knowledge
about substance abuse, and substance abuse professionals lack knowledge of mental
illness” (p. 568). Despite a number of initiatives aimed at overcoming this problem,
the Treatment Protocol Project, (1997) reported that, "Individuals with schizophrenia and a co-morbid substance abuse problem can be shunted between agencies and frequently fall through the cracks" (p. 369).

As well as masking the early symptoms of mental illness, substance abuse can also exacerbate the condition and interfere with treatment compliance and hence increase the difficulty of care-giving. For example, Vaddadi et al. (1997) reported that the use of illegal substances, principally cannabis, and a poor relationship with the caregiver compounded the problem of violence. The ways in which caregivers cope with concurrent mental illness and substance abuse requires further investigation.

3.3.4 Chronic Grief

A number of practitioners, writers and researchers have considered grief to be central to the experience of caring for a relative or partner with a mental illness (Deveson, 1991; Woolis, 1992; Wasow, 1995; McFadden, 1999). Lafond (1994) wrote,

My experience as a mental health practitioner has taught me many lessons. Chief among these is the understanding that grief, with its attendant feelings of doubt, sadness, anger, guilt, fear, and shame, is an inevitable partner of mental illness (p. xi).

The grief experienced by family caregivers is commonly considered to be linked to the multiplicity of losses that accompany mental illness (Wasow, 1995). Kuipers (1991) identified two types of loss that family caregivers can experience: the loss of the person they knew and the loss of the hopes and aspirations they had for that person. The caregiver may, on a daily basis, witness and mourn their relative or partner's loss of health, employment and sense of self, as well as their own loss of the person they knew and loved. However grief may also derive from other losses that can accompany
mental illness such as the loss of social contacts, income and status in the community as a result of the illness (Lafond, 1994).

The grief experienced by family caregivers of the mentally ill has special qualities in being less amenable to resolution. As this grief arises in response to a chronic condition it may entail chronic mourning that differs from sudden or anticipatory grief, which can be time limited. Lefley (1996) referred to a “death-in-life” mourning process, the ongoing nature of which can preclude friends and family from finding closure, and Wasow (1995) noted,

Since afflicted members do not die or disappear when they develop SMI (serious mental illness), we face our loss every time we face our child, our parent, our spouse, our sibling, or our other SMI relative.

Our sorrow is strong and continuing. (pp. 103-104).

It is unclear just how family caregivers cope with their ongoing grief, however, Neimeyer (1998) proposed that all grieving involves a reconstruction of meaning. Investigation of whether family caregivers use this means of coping with chronic grief is warranted as this knowledge could inform the development of supportive grief counselling programs.

3.4 Summary

The study of adaptive coping strategies requires knowledge of the issues that the person is coping with (Lazarus, 1990). In this chapter I have briefly considered the multiplicity of potential sources of stress that family caregivers of the mentally ill can encounter.

Stress may derive from the daily experience of caring for a mentally ill family member, the caregiver’s perception and actual experiences of stigmatisation, and
service provision deficits. Additionally family caregivers may have, in the past, been blamed for causing or maintaining the illness, and their contribution to care unrecognised or devalued by mental health professionals. It is unclear if family caregivers continue to experience burden as a result of being implicated in the genesis or maintenance of the illness.

Studies of the burden of care show the likelihood that caregivers will encounter many of the above issues over the course of the illness (Lefley, 1989; Maurin & Boyd, 1990; Johnson 1990) and each may require the adoption of different ways of coping. Some of the components of family burden are exceptionally difficult to cope with. Extremely stressful components of objective burden that caregivers experience are those of the vulnerability of mentally ill family members, dual-diagnosis, the potential for suicide and the risk of violence. The subjective burden of chronic stress was also discussed in this chapter.
CHAPTER 4

Ways of Coping and Determinants

It is clear that we tend to speak of coping when we have in mind a fairly drastic change or problem that defies familiar ways of behaving, that requires the production of new behaviour, and very likely gives rise to uncomfortable affects like anxiety, despair, guilt, shame or grief, the relief of which forms part of needed adaptation under relatively difficult conditions (White, 1985, p. 123).

Lazarus and Folkman (1984) claimed that coping has at least two major functions: managing or solving the problem causing the distress, referred to as Problem-focussed coping, and the regulation of the emotions or distress caused by the problem, known as Emotion-focussed coping. These two distinct functions have been recognised by numerous researchers (Kahn, Wolfe, Quinn & Snoek, 1964, and Mechanic, 1962, both cited in Folkman 1984) and more recently, Lazarus (2000) has suggested that both functions may interact to affect outcome. For example, successful problem solving may lower emotional distress and lowered distress may affect the ability to solve the problem.

Hatfield and Lefley (1987) suggested that caregivers of the mentally ill develop ways of coping with both the practical issues and the emotional demands of the role, and their suggestion has received extensive endorsement from caregiver support organisations. A variety of publications intended for the use of caregivers of the
mentally ill suggest practical, skill-based solutions to the multitude of problems that may be encountered in providing care. They also emphasise the need to attend to the psychological distress that frequently accompanies the illness of a relative (Schizophrenia Fellowship, 1995; Sane Australia, 1998; Association of Relatives and Friends of the Mentally Ill, 1998).

4.1 Assessing Ways of Coping

The ways in which people cope have been measured by scales derived from the Ways of Coping Questionnaire (Folkman and Lazarus 1988b) and this measure contains items chosen as diverse and representative examples of potential coping responses rather than theoretically derived categories of coping. Factor analysis identified dimensions that may underlie endorsement of relevant items (Carver, Scheier & Weintraub, 1989) and eight sub-scales were identified. These included: Distancing (e.g. “I went on as if nothing had happened”) Escape-avoidance (e.g. “I wished the situation would go away or somehow be over with”) Positive Reappraisal (e.g. “I found new faith”) Confrontative Coping (e.g. “I stood my ground and fought for what I wanted”) Self-control Coping (e.g. “I tried to keep my feelings to myself”) Accepting Responsibility (e.g. “I criticized or lectured myself”) Planful Problem-solving (e.g. “I knew what had to be done, so I doubled my efforts to make things work”) or Seeking Social Support (e.g. “I talked to someone who could do something concrete about the problem”).

4.1.1 Problem-Focussed Coping

The Ways of Coping Questionnaire (WOCQ) scales concerned with Problem-focussed coping include Confrontive Coping, Self-control Coping, Planful Problem-solving, and
some items from the *Seeking Social Support* scale. Planning involves thinking about a problem and developing action strategies to deal with it whilst confrontive coping implies an aggressive element. *Seeking Social Support* has both Problem-focussed and Emotion-focussed elements in that it can include seeking information, advice or assistance, which is Problem-focussed coping and seeking emotional or moral support which is Emotion-focussed coping (Lazarus, 1991).

Problem-focussed coping strategies are particularly relevant when the encounter requires practical intervention or is amenable to change. For example, noticing that a mentally ill care recipient had ceased taking their medication and discussing how to achieve compliance with their treating medical officer would be considered to be Planful Problem Solving an element of Problem-focussed coping.

### 4.1.2 Emotion Focussed Coping

Emotion-focussed coping is directed at the regulation of the emotions and involves purely cognitive activities that do not directly alter the relationship with the environment but rather change the way that relationship is perceived (Folkman and Lazarus (1985). WOCQ scales measuring Emotion–focussed coping include such coping processes as *Distancing*, *Escape-avoidance*, *Positive Reappraisal*, and items concerned with emotional support from the *Seeking Social Support* scale. (Lazarus, 1991). Thus, one can try to control unpleasant affects by avoiding or distancing oneself, seeking the support of others or determining what is attended to by avoiding certain facts or their implications. One can also re-appraise the facts or their implications by denying their importance or relevance, or even by looking for positive benefits in the encounter.
According to Lazarus (1991), Positive reappraisal is not concerned with blocking a recurrent and threatening impulse from consciousness, but rather with altering the meaning of the encounter and this is a very powerful device for regulating stress and emotion. When this method succeeds, there is little or no reason to experience emotional distress because the harmful or threatening relationship has been made subjectively benign. For example, consider the situation in which a mentally ill care recipient is abusive and disparaging of the caregiver’s efforts who may legitimately feel angry but unwilling to display this emotion with its potentially negative consequences. If the behaviour can be excused because it is part of the illness or the care recipient is unable to make logical judgements, the provocation can be overlooked and anger need not be felt or expressed. Such coping strategies might be regarded as a healthy form of suppression or denial.

4.1.3 Meaning Focussed Coping

More recently, Park and Folkman (1997) and Park, Folkman and Bostrom (2001) have identified another way of coping that focuses on preventing the development of negative affects rather than dealing with them after they occur. Called “meaning focussed coping”, they describe it as different from problem focussed and emotion focussed coping. According to Park, Folkman and Bostrom (2001):

Meaning-focussed coping involves neither attempting to change the problematic situation nor attempting to directly alleviate the distress or palliate the negative emotions... Instead Meaning-focussed coping involves changing the appraised meaning of the situation to be more consistent with the person’s beliefs and goals (p. 482).
Although described as different from emotion focussed coping, meaning focussed coping is closely related to positive reappraisal, the cognitive aspect of emotion focussed coping. Park and Folkman (1997) and Park, Folkman and Bostrom (2001) believe that positive reappraisal differs sufficiently from other aspects of emotion focussed coping, such as seeking social support, to warrant consideration as a separate category of coping.

4.2 Determinants of Ways of Coping

Most people use nearly all forms of coping in stressful encounters, although the emphasis may be on one or another form according to the type of the encounter, the way it is appraised, and the particular person (Folkman & Lazarus, 1985). Men and women coping with a wide variety of real life issues were found to use both Problem and Emotion-focussed ways of coping in over 98% of the issues.

A variety of factors determine the ways that people cope with any given situation and some of the factors influencing ways of coping have included: type of situation, perceptions that the situation can be changed, efficacy of way of coping, coping repertoire, ability to match way of coping to requirements of the situation, and to the stage of encounter.

4.2.1 Type of Situation

The nature of the stressful situation can affect the choice of coping strategy and Folkman and Lazarus (1980) found family-related situations and those that related to health issues elicited more Emotion-focussed coping than did work related situations. Issues affecting the family, or health issues, cause more emotional distress than do work issues and hence require more Emotion-focussed coping.
Again, Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen (1986) reported that when the situation involved a threat to loved ones' well-being, participants reported using both more Confrontative and more Escape-avoidance coping, and fewer Problem solving and Distancing strategies.

4.2.2 Amenability to Change

Appraisal of the possibility of effecting change can be a factor influencing the adoption of a particular coping response. Folkman and Lazarus (1980) reported that participants in their study of coping used more Problem-focussed coping when the situation was appraised as changeable and more Emotion-focussed coping when the situation was appraised as not amenable to change. Subsequent research supported these findings (Folkman & Lazarus, 1984; Lazarus; 1993).

Family caregivers of relatives with dementia predominantly used Emotion-focussed coping (McKee, et al., 1997) and, as dementia is not amenable to positive change, the focus upon the need to relieve emotional distress could be expected. The perception of amenability to change may vary in the case of mental illness. Possibly family caregivers may initially consider their relative’s condition to be amenable to change and that appraisal may lead to a predominance of Problem-focussed coping in the initial stages of the illness and more Emotion-focussed coping as chronicity becomes apparent. Problem-focussed coping may be abandoned when it becomes apparent that goals are not attainable.

Park, Folkman and Bostrom (2001) found further support for the hypothesis that problem focussed coping is preferred when the situation is perceived as amenable to change. They also reported limited support for the use of emotion focussed coping when the situation could not be changed. However, meaning focussed coping was
found to be inversely related to caregivers’ depressed mood, regardless of the appraised controllability of the situation. They concluded that the use of this coping strategy was an adaptive response independent of whether the situation was amenable to change.

4.2.3 Perceived Efficacy

Several studies of dementia provided evidence that caregivers’ appraisals of coping efficacy affected predictions of caregiver stress and well-being. For example, Zautra and Wrabetz (1982) and McCrae and Costa (1986) found that, “active” coping efforts that were appraised as efficacious in dealing with a defined stressor were related to lowered reports of distress. Efficacious coping responses included seeking support, taking action, and expressing emotion. The efficacy of coping response appeared to interact with subsequent emotional state to lower stress, and presumably less Emotion-focused coping was required.

Appraisal of coping efficacy differs from self-efficacy appraisal in which the focus is upon the individual’s specific beliefs about their ability to control important life events. In contrast, appraisals of coping efficacy are liable to change over time in accordance with changes in the stressor, with practice, and with the development of new skills. Knowledge of how efficacy is appraised could assist in understanding its effect upon the person-environment relationship and influence on emotions and subsequent coping strategies (Lazarus & Folkman, 1984).

4.2.4 Coping Repertoire

A link between number and variety of coping responses and stress experienced has been posited. In a study examining the coping strategies of children who were hospitalised, Siegel (1983) found that children who were successfully coping with
hospital procedures reported using a greater number and variety of coping strategies than unsuccessful copers. Successful coping was measured by decreased physiological arousal and children with many different coping responses showed less arousal than those with a more restricted repertoire. The results have been interpreted in terms of flexibility in reaction to failure, if one strategy did not work then another would be tried. Seeman, Littman, Plummer, Thornton and Jefferies (1982) explicated this view:

In fact, there is no one right way. A particular solution may work with one person at one time but not with another person or not with the same person the next time around. Try one way, give it time and see what happens. If it seems to be working continue it. If it seems not to be working, try another tack (p. 51).

The ability of family caregivers to access a repertoire of coping responses may be a factor in successfully adapting to the fluctuating demands of mental illness.

4.2.5 Matching Coping Response to Situational Requirements

Siegel (1983) and Worchel, Copeland and Barker (1987) proposed an alternative explanation of coping efficacy to that of coping repertoire. They found that the presence of fewer, but more appropriate, strategies predicted successful coping and interpreted their findings in terms of the ability to match coping response to the requirements of the situation. However, these studies focussed upon a single event, possibly limiting their relevance to the study of family caregiver coping strategies. Caring for a mentally ill family member usually entails responding to a variety of different issues, over a long period of time.

Repertoire and appropriateness of coping response need not be mutually exclusive and caring for a mentally ill family member may well require an extensive
repertoire of coping responses that can be appropriately matched to the requirements of the particular situation. For example, coping with odd or unusual behaviours may require a different response to that needed to cope with treatment non-compliance.

4.2.6 Stage of Encounter

Central to the Folkman and Lazarus (1984) conception of coping as a process is the notion of change and the prediction that coping responses change and evolve over the duration of any stressful encounter (Folkman and Lazarus, 1980; Lazarus and Folkman, 1984). This contention was supported by the findings of a study of students’ ways of coping with an exam (Folkman and Lazarus, 1985). In the anticipatory stage, just prior to the exam, students tended to seek information from others and engaged in Problem-focussed coping. After the exam, and before grades were announced, the predominant style of coping was distancing, which made sense as nothing further could then be done to alter the outcome. When the outcome of the exam had been announced, Emotion-focussed forms of coping were emphasised. If the exam had been treated as a single stressful encounter the complexity of the strategies used at different stages would not have been discovered. Although this is a very different field, these findings suggest that the ways that family caregivers cope with their relative’s illness can best be understood in relation to the stage of encounter with the illness and the requirements of the situation.

4.3 Summary

In this chapter I have discussed a variety of ways of coping with the many different issues that family caregivers of the mentally ill can experience. Coping serves two functions: it may be directed toward altering the situation (Problem-focussed) or
toward controlling the emotional effects of the stressful situation (Emotion-focused). Commonly, both forms of coping are employed in most situations, however one or the other may predominate in different situations. The choice of coping strategy can be affected by the stage of the stressful encounter, amenability of the situation to change, repertoire of coping responses, and the ability to appropriately match coping response to requirements of the situation. All of these factors affect warrant consideration in relation to family caregivers' adaptive coping.
CHAPTER 5

Coping Strategies for Caregivers

Some strategies are experienced as more useful than others (Spaniol, 1987; p. 209).

Numerous publications offer practical advice to family caregivers on how to cope with the myriad of stressors that accompany mental illness (Seeman, Littman, Plummer, Thornton & Jeffries, 1982; Hatfield & Lefley, 1987; Woolis, 1992; Schizophrenia Fellowship, 1995; Perera, 1998). They offer practical suggestions and strategies for coping with the behaviours of care recipients, as well as ways in which caregivers can cope with their own health, and emotional responses to the situation.

Programs supportive of family caregivers have also been developed and Kavanagh (1998) reported, "Successful approaches have generally incorporated factors such as increasing tolerance of symptomatic behaviour, improving skills in resolving problems and fostering stress reduction" (p. 7). However, the effective elements of these programs is unknown and Kavanagh proposed, "This field still has many opportunities for sound psychological research and for therapy development" (p. 7). A logical starting point could be consultation with family caregivers about those aspects of support they have found to be helpful.

Many of the strategies suggested for coping with the stressors encountered by family caregivers would meet Folkman and Lazarus' (1984) criteria for Planful Problem Solving as they are aimed at actively seeking to change the situation.
Although most of them offer practical ways of coping, some of the professional guidance and advice offered may be difficult to implement. Consider the difficulty of implementing the following advice to caregivers in a potentially stressful encounter:


Do not become hostile or shout. Be honest. Acknowledge the ill person’s feelings. Accompany praise with smiles and other encouraging body language. And keep a positive attitude (Secunda, 1997, p. 119).

The extent to which caregivers actually use the suggested strategies and the situations in which they are employed is not known, however such knowledge could inform clinical practice and the development of supportive programs.

5.1 Goal Attainment Strategies

It has been proposed that Problem-focussed ways of coping may be abandoned in favour of Emotion-focussed coping when it appears that goals are not attainable. Alternatively, unattainable goals may be reappraised and more realistic goals adopted. Hatfield and Lefley (1987) claimed that redefining the problem in more useful terms is a basic approach to coping. Woolis (1992) acknowledged this point, “Most families need to pare down their hopes and expectations of what can reasonably be achieved by their relative” (p. 58). According to Taylor (1989), people coping with a difficult or stressful situation can attempt to regain control over the situation by shifting their focus from what cannot be controlled to what can be controlled and this shift of focus allows them to implement efficacious problem-solving strategies. Because of the fluctuating
nature of mental illness, caregivers’ goals may require frequent revision. For example, an initial goal of obtaining a cure or a return to prior levels of functioning for the mentally ill relative will doubtlessly need to be revised over time.

5.2 Behaviour Management Strategies
Family caregivers often need to develop strategies to cope with their relative’s difficult behaviours and Spaniol and Zipple (1994) suggest a variety of ways in which bizarre and odd behaviours can be managed. These include calmly and clearly setting limits, using distraction and gentle confrontation, amongst others and encouraging the development of self-management skills.

5.3 Exceptionally Difficult Behaviour Management
Lefley (1996) suggested several possible ways in which caregivers could manage violent or threatening behaviour, including seeking peer group support to learn ways of avoiding the violent situations, family therapy to improve communication, and referral to relevant treatment programs when substance abuse is involved. Involving the police to assist in restraining the violent family member was also suggested as a viable option. Adoption of such strategies may be dependent upon a number of factors. These factors could include access to group support, the availability of therapy sessions or treatment programs, as well as confidence in the ability of the police to assist.

5.4 Stigma Coping Strategies
Family caregivers may also need to develop adaptive ways of coping with the stigma attached to mental illness. Goffman (1963) cited in Minichiello, Aroni, Timewell and Alexander (1996) noted four ways in which people cope with stigma and termed these
Passing, Migration, Militant and Splitting. Passing refers to concealing the condition and passing as “normal” whilst Migration is concerned with avoiding or withdrawing from contact with those who may stigmatise. Adopting a Militant stance involves speaking out and refusing to be stigmatised and Secunda (1997) suggested that caregivers combat the stigma of mental illness by speaking out publicly about their relative’s condition or their experiences. She noted, “Some survivors have taken a more public stance, giving speeches and writing books about mental illness in their families” (p. 301) and this was the method adopted by Deveson (1991) and McFadden (1999). However individuals who publicly disclose or support their relative’s disclosures can risk further discrimination. Woolis (1992) suggested adoption of a safer strategy of limited and considered disclosure, which accords with Goffman’s notion of Migration. It is unclear if Goffman’s fourth way of coping with stigma, Splitting has relevance to coping with the stigma of mental illness. Splitting involves dividing those who are stigmatised into two opposing groups such as “good Jews” and “bad Jews”. According to Minichiello et al. (1996), Passing is by far the most common way of managing stigma.

Educative programs that address the issue of stigma can best be achieved through caregiver and consumer organisations and active participation in such organisations may be the most adaptive way of coping with the stigma of mental illness. (Lefley, 1996)

5.5 Service System Strategies

Adaptive ways of coping with the mental health system have been cited in the literature and these include developing personal and political advocacy skills (Woolis, 1992; Lefley, 1996; Spaniol & Zipple, 1994; Secunda, 1997). According to Woolis (1992),
family caregivers can develop skills that enable them to assertively insist upon the provision of information about their relative’s condition and recognition of their own role in treatment.

Collectively, and through caregiver support organisations, caregivers can petition for improvements to services. Individually, they can participate in programs to educate the community about mental health and act in an advisory capacity to regulatory bodies. Joining a caregiver support group or community organisation such as the Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI), Sane, or the Schizophrenia Fellowship may be a coping strategy that provides both social support and enables personal and political advocacy.

5.6 Emotional Response Strategies

As well as coping with the practical issues of caring for a mentally ill relative, caregivers often have to develop strategies to cope with their own emotional state. Coping with the emotional distress inherent in coping with mental illness and maintaining a sense of self worth may be central to the ability to continue providing care (White, 1985). The literature available to caregivers suggests a variety of ways in which this can be accomplished (Seeman, Litman, Plummer, Thornton & Jeffries, 1982; Hatfield & Lefley, 1987, Woolis, 1992; Perera, 1998). The strategies suggested include obtaining treatment for anxiety and depression, seeking social support, actively striving to generate positive affect and reappraising the situation positively.

5.6.1 Seeking Social Support

The literature concerned with coping strategies overwhelmingly recommends that caregivers seek the support of family, friends, and community organisations. As
previously noted, seeking social support has both Problem-focussed and Emotion-focussed elements and the two may interact. For example, Hatfield and Lefley’s (1987) suggestion that caregivers should join a peer support group for emotional support, direct problem solving help and to advocate for improved services covers Problem-focussed and Emotion-focussed elements. Solomon and Draine (1994) found social support to be a major factor contributing to adaptive coping in relatives of the mentally ill.

Seeking social support has also been recommended as a way of coping with the grief accompanying mental illness (Park & Folkman, 1997) and Lafond (1994) advised, “Don’t travel the sadness road alone” (p. 42), noting, “Humans are social animals with a basic need to relate to others and that social part does not dry up with grieving ... if anything it is more present” (p. 43). Terkelsen (1987a) also endorsed the value of social support:

The capacity to endure in the face of a tenacious problem depends on the existence of a community of fellow sufferers who affirm and protect one’s sense of worth even when the evidence of the moment is ambiguous or contrary; who share and keep alive a common interest in the midst of a wider society that does not care; who provide counsel and concrete assistance, and who foster a belief in the future when all others fail to do so (p. 149).

Although social support enjoys broad endorsement as a means of coping, it is unclear what kind of social support is most effective. Lloyd (1995) considered two different aspects of social support, which he referred to as perceived and enacted social support. Perceived social support is concerned with appraisals about the adequacy of the support available, and according to Cobb (1976), a perception of social support derives from
knowing one is a member of a socially coherent community and loved and esteemed. Enacted support refers to what individuals actually do to provide support. Intuitively, it appears that regardless of the actions of others, or the services provided, if they are not perceived as supportive they are unlikely to have a beneficial effect upon caregivers’ ability to cope.

House (1981) drew a distinction between expressive support and instrumental support that has parallels with WOCQ scale Seeking Social Support in that it has both Emotion-focused and Problem-focused elements. Instrumental support involves the provision of practical assistance and, when related to family care-giving, could encompass the provision of information about the illness, financial assistance, or the provision of practical assistance such as driving the family member to medical appointments. Expressive support involves spending time together and sharing or discussing problems, and it has been suggested that it is this form of social support that enables caregivers to cope with the emotional demands of care-giving. However, expressive and instrumental social support may interact to reduce emotional stress in caregivers.

5.6.2 Cognitive Strategies

A variety of cognitive strategies have been suggested to assist caregivers to cope with the emotional distress of caring for a mentally ill relative. For example, Hatfield and Lefley (1987) suggested that caregivers learn to distance themselves from situations they cannot or need not assume responsibility for, build a fulfilling life for themselves apart from their caregiver role, and develop a useful philosophy of life. They also suggested adopting a positive attitude and making lifestyle changes that include attending to physical, emotional and spiritual health.
5.6.3 Meaning and Coping

Lazarus and Folkman (1984) made the point that where there is little possibility of changing or eliminating the problem, the stressful impact can be buffered by responses that function to control the meaning of the problem. Park and Folkman (1997) proposed that the meanings that individuals attach to their situation and their experiences of care-giving are central to understanding the process of adaptive coping. According to Neimeyer (1998), finding meaning in what may appear to be a random and meaningless event is an adaptive way of coping with grief.

Terkelsen (1987a) observed that there were few formal studies of the meaning of mental illness to family members, and more recently Rose (1996) reiterated this observation. She suggested that qualitative research investigating caregivers’ perceptions of the illness experience, the meaning they attach to their personal situations and the relationship of those meanings to their coping experiences presents a promising approach.

5.6.3.1 Definitions of Meaning

Meaning has been accorded a multiplicity of different definitions in the literature (Park & Folkman, 1997):

Meaning within the coping process has been assessed in terms of re-evaluating an event as positive (e.g., Thompson 1985) answering the question of why an event occurred (e.g., Dolinger, 1986; Taylor 1983) or the question “Why me?” (e.g., Bulman & Wortman, 1977; Frazier & Schauben, 1994), enumerating ways in which life changed because of
the event (e.g., Collins, Taylor & Skokan 1990), and stating the extent to which one has "made sense of" or "found meaning in" the event (e.g., McIntosh, 1993; Silver, Boon & Stones 1983) (p.115).

All of the above definitions have relevance to understanding caregivers’ adaptive coping with the emotional distress of mental illness.

5.6.3.2 Meaning and Goals

Park and Folkman (1997) proposed that goals constitute a central element of a person’s meaning system and as previously noted are central to the understanding of adaptation Harvey (1966). Despite widespread acknowledgment that humans are goal oriented, goals are rarely considered in coping strategies research (Lazarus, 1991). Knowledge of the caregivers’ goals is an important first step in understanding the meanings they attached to the illness and in this sense is equated with appraisal that leads to adoption of a coping response.

Exploring the concept of meaning, Park and Folkman (1997) differentiated between two levels that they designated Global meaning and Situational meaning. Whilst conceptually different, these different aspects of meaning interact and form the basis of coping appraisals.

5.6.3.3 Global Meaning

Global meaning refers to peoples’ fundamental assumptions about the world and themselves (Park & Folkman, 1997). A number of researchers have proposed that people tend to assume that the world is an ordered and relatively predictable place with a just distribution of positive and negative events (Janoff-Bulman, 1992; Taylor & Brown, 1994). Encounters with traumatic and unpredictable events, such as mental
illness in the family, can shatter these assumptions (Janoff-Bulman, 1992) and people may come to believe that the world is no longer safe, fair and predictable (Wasow, 1995).

One way of coping with lost assumptions of fairness and predictability is to assign meaning to the traumatic event and Rothbaum, Weisz and Snyder (1982) stated that the search for meaning and understanding in any situation is related to the need to achieve a sense of control over the situation. Bulman and Wortman, (1977) claimed that, “Survivors reappraisal locate and create evidence of benevolence, meaning and self worth in the events that first challenged their shattered illusions” (p. 357).

According to Taylor, (1983) people also hold global beliefs about themselves; in general they see themselves as essentially good, moral and competent. Moreover, people often have illusory beliefs about their ability to control their destiny and events by engaging in “proper behaviours” (Janoff-Bulman, 1992). Mental illness in the family can challenge these basic beliefs. Woolis (1992) claimed that the injustice of seeing lives devastated by mental illness can shake even the most firmly held beliefs about religion, morality and the meaning of life: “It is indeed an incredible challenge to try to integrate the pain and suffering you see and feel with a more hopeful world view” (p. 122). However, maintenance of a positive world-view and sense of self worth may be essential components of coping with the challenges of mental illness. Global beliefs about commitment, loyalty, religion and the sanctity of marriage may well influence continuance of care provision.

5.6.3.4 Situational Meaning

Situational meaning refers to the interaction between global beliefs and goals and the circumstances of a particular person-environment. For example, when confronted with
a relative's diagnosis of mental illness, the initial and subsequent meaning of the event will be influenced by the caregiver's global system of beliefs and goals. Global meaning in terms of beliefs and goals regarding the relative, their relationship, perceptions of why such things occur and feelings of vulnerability will influence the caregiver's understanding of the situation.

Park and Folkman (1997) delineated three major components of Situational meaning, and the first is appraisal of meaning, the initial assessment of the personal significance of an event. This appraisal is usually rapid and is based upon prior knowledge and experience. Appraised Meaning has a motivational quality in that behaviours are likely to be motivated by the perceived threat to beliefs, goals or commitments. The second component refers to the Coping Processes in which people search for meaning if the event is appraised as stressful, and has parallels with Folkman and Lazarus (1984) concept of Secondary Appraisal. Beliefs about a just world, or about religion, can affect secondary appraisal processes in that they can form the basis of what can be done about the situation, and increase a sense of coping efficacy. The third component of Situational meaning refers to the meaning that people make of the event subsequent to its completion. Park and Folkman (1997) referred to this as Meaning of Outcome and related it to the concept of Positive Reappraisal.

Considering these concepts in relation to care provision, one's beliefs about a loving God and ordered universe may be threatened by the onset of illness (Appraised Meaning). This could lead to prayer for acceptance of God's will (Coping Process) and re-appraisal of the situation in terms of, "God intended I should be strengthened by adversity" (Meaning of Outcome).
5.6.3.5 Positive Reappraisal

Frankl (1963) wrote of the unique human capacity to, “transform a personal tragedy into a triumph, to turn one’s predicament into a human achievement” (p. 135). Positive reappraisal of the situation is one of the adaptive ways in which this may be accomplished.

According to Park and Folkman (1997), positive reappraisal allows threatening aspects of situations to be changed by altering either the Situational or Global meaning of the event, to ensure both agree. Distress is relieved or avoided by ensuring that Global and Situational meaning are congruent. Because global beliefs are relatively stable, Situational meaning is more commonly modified than Global meaning. The ways in which people modify Situational meaning include perceiving benefits in the stressful event, engaging in compensatory self-enhancement, or downward comparison with others, considering the bigger picture, developing a sense of humour about the event, or focussing upon events that reinforce existing beliefs or goals. An example of how caregivers may perceive benefits in the situation would be, “It wasn’t a good experience but I’ve learnt a lot from it”.

Compensatory self-enhancement is another related strategy. For example, “I’ve become a stronger person as a result of this experience.” A study by Marsh, Appleby, Dickens, Owens and Young (1993) found that many family caregivers used this strategy reporting that they had become better, stronger or more compassionate people as a result of coping with their relative’s illness.

A further way of coping by modifying the meaning of the situation involves making downward comparison with a real or hypothetical other: “At least, I’m better off than Betty” or “I’m not as badly off as most people in this situation”. Extending
this strategy to caring for a mentally ill relative could include, “My relative’s not
violent like Jack’s son”.

Adopting a “big picture” view of the situation is yet another meaning based
 coping strategy concerned with diminishing the importance of the situation in relation
to the general scheme of things. For example, “I’ll probably laugh about this in ten
years time” or “When you look at all that’s wrong with the world, this doesn’t rate”.

Further strategies concerned with altering the meaning of the situation include
developing a sense of humour about the event or situation and remembering or
focus upon events that reinforce existing beliefs or goals. For example, “Of course
I look after Joe, that’s what families are for”. Caregivers of the mentally ill may
employ any or all of the above ways of coping with the challenges of the illness: “The
essence of an adaptive resolution then is the modification of beliefs in a manner that
permits realistic coping and enjoyment of life” (Park & Folkman, 1997, p. 132).

5.6.3.6 Positive Affect

Maintaining positive affect has a significant adaptational function in the coping
process, and Folkman and Moskowitz (2000) claimed that neglect of this aspect of
coping has been a major deficit in theory and research. Their claim is based upon three
premises: firstly, that positive affect can co-occur with distress; secondly, that positive
affect in the context of stress has important adaptational significance of its own; and
thirdly, that meaning is central to coping that generates and sustains positive affect. In
support of their claim that positive affect has important adaptational significance of its
own they cited Lazarus, Kanner and Folkman’s (1980) proposal that, “positive
emotions may provide a psychological break or respite, support continued coping
efforts, and replenish resources that have been depleted by the stress” (p. 649). They
also cited Fredrickson’s (1998) review of evidence showing that positive emotions, “broaden the individual’s attentional focus and behavioural repertoire, and, as a consequence, build social, intellectual and physical resources (p. 649).

Lazarus (2000) explicated ways in which positive affect and distress can co-exist, noting that some emotions such as love or hope, are not unequivocally positive or negative, but rather mixed. They are experienced as positive when they are congruent with goals and negative when they are not. Similarly anger can be experienced as either positive or negative depending upon how it is used. Anger with a mental health system that frustrates care provision may be experienced as negative; however anger that motivates action to change the system may be experienced as positive.

The centrality of meaning to coping that sustains positive affect was deduced from a study of stress and coping in care-givers of people with AIDS (Folkman & Moskowitz (2000). Participants in this study reported that they coped by infusing ordinary events with positive meaning, thus generating positive affect. These care-givers created events that induced positive affect, such as planning a special meal or getting together with friends, or sought it in unplanned events such as noticing a beautiful flower. Folkman and Moskowitz cited research finding that positive and negative events tend to be moderately positively correlated. They hypothesised, “It may be that when a negative event occurs, the individual creates a positive event or interprets an otherwise ordinary event as positive as a way of offsetting the negative affective consequences of the negative event” (p. 651).

Although the experience of caring for a mentally ill relative is not exactly the same as that of caring for a person with AIDS, there are some similarities. Both involve coping with stressful conditions requiring the production of adaptive coping
strategies. It is possible that those caring for a mentally ill family member also cope by generating positive affect or by infusing ordinary events with positive meaning.

5.7 Summary

In this chapter, I have briefly considered professional advice to caregivers on ways of managing unwanted behaviours and ways of coping with issues such as stigma and service system deficits. It is unclear whether caregivers actually use these strategies and under what circumstances, or if they perceive such strategies to be efficacious in helping them to cope. An investigation of whether initial goals of cure are, over time, subsumed by more realistic goals of treatment and continuing provision of care is warranted.

Strategies to cope with the emotional distress caused by mental illness in the family were also discussed in terms of the meaning attributed to the illness and Positive Reappraisal. Ways of altering the meaning of the situation to reduce dissonance between Global and Situational meaning and maintain a sense of self-worth and security were discussed in relation to care provision. The contribution of positive affect was also discussed and the need to consider all these aspects of coping hypothesised.
CHAPTER 6

Evolution of Caregiver Responses and Kinship Issues

Strategies are not all that change. Over time the symptoms of the person with SMI keep changing, the mental health system changes and so do we and our loved ones. This is another reason that coping is a process and an individually crafted repertoire rather than one set of skills (Wasow, 1995, p. 128).

Wasow (1995) highlighted the fact that change on multiple levels is an inherent component of serious mental illness and as the situation evolves caregivers’ adaptive responses also need to evolve and change. Several researchers and clinicians have attempted to identify patterns of change and coping response generic to family caregivers’ evolving experience of coping. These models are either descriptive of the issues and responses at stages of encounter with the illness, or prescriptive of desired responses over time (Tessler, Killian & Gubbman, 1987). Such models could have an important role in identifying the support systems required at different stages of encounter and the adaptive skills that caregivers already possess.

Although stage of illness may be a major determinant of family caregivers’ coping responses it may not be the sole determinant. The caregivers’ kinship relationship to the care recipient may be a determinant of response because the issues encountered by parental caregivers may differ from those encountered by spousal and/or caregivers of other kinship relationship (Secunda, 1997). According to Lefley
(1996), "The relatives may represent very different populations" (p. 97). This chapter considers stage models of the evolution of caregiver response to mental illness and issues specific to kinship relationships.

6.1 Models of Evolution of Caregiver Responses

Tessler, Killian and Gubbman (1987) developed a nine-stage model of caregiver responses to mental illness. The model proposed that initially caregivers become aware that a problem exists but deny mental illness. This stage is followed by acceptance of the label of mental illness and faith in the mental health system to effect a cure. Subsequent stages involve recurrent crises, recognition of chronicity, and a loss of faith in mental health professionals. The model posits that these stages are then followed by development of a belief in the caregiver's expertise and concerns about the future.

Terkelsen (1987b) expanded upon the Tessler et al. (1987) model and reported, from clinical observation rather than research, that typically families go through ten phases in adapting to mental illness. The First Stage of response is normally one of ignoring what is happening and the Second Stage occurs when the severity of the condition triggers major concerns and leads to the first shock of recognition of the degree of problem. The major feature of this stage is the family's persistent and urgent help-seeking behaviour. Terkelsen refers to the Third Stage as "stalemate" because either the person being cared for, or the professional consulted, fails to recognise mental illness. The Fourth Stage involves containing the implications of the illness, denial of the severity of the illness, or alternative explanations of the symptoms such as laziness or drug abuse: "Typically at this stage of illness, family members approach
unusual behaviour as manifestations of temporary destabilisation rather than the first signs of an enduring condition” (p. 152).

The *Fifth Stage*, termed “transition to official patienthood”, occurs following some very compelling or disastrous event, such as a criminal assault or suicide attempt leading to a diagnosis of mental illness. The *Sixth and Seventh Stages* are concerned with a search for causes and a search for treatment and Terkelsen (1987b) claims that the search for causes is related to the notion that informed action is predicated on a detailed understanding of the cause of the condition. In the absence of definitive answers, the family is often thwarted in attempts to understand the cause of the condition. He referred to the *Eighth Stage* of this model as “the collapse of optimism”, because it becomes apparent that the mentally ill family member will not return to their prior level of functioning, and this leads to the *Ninth Stage*, termed “surrender of the dream”. This stage involves mourning the loss of potential and is considered to be a natural reaction to this development; the process resembling that following the death of a loved one. The *Tenth* and final stage of this model has been entitled “picking up the pieces” and involves the family compartmentalising the illness so they can get on with their life. At this stage, “the solution is very frequently for one member of the family (the primary care-giver) to specialise in looking after the welfare of the affected person while the rest of the family pursue other interests” (Terkelsen, 1987b, p. 165). The stage at which official transition to patienthood occurs may also represent the time of transition to official status as caregiver, as is the case for the purpose of eligibility for government caregiver benefits.

Although the above models of the evolution of caregiver responses are detailed they may not easily translate into appropriate professional response to caregiver needs at any given stage. Neither do they consider social developments that have seen
caregivers responding to the need to improve the mental health system. Spaniol and Zipple (1994) incorporated these issues in their abbreviated, four-stage, version of the evolution of caregiver responses to the mental illness of a family member. Including many of the stage-related issues proposed by Tessler et al. (1987) and Terkelsen (1987b), this model also emphasised the development of caregivers' political and personal advocacy skills. Their inclusion of this further stage is doubtlessly related to advances in the recognition of caregiver issues and the advocacy of caregiver support groups.

According to the Spaniol and Zipple (1994) model, the four main stages of caregiver adaptation to mental illness include a stage of Discovery-Denial, followed by a stage in which Recognition-Acceptance predominates and these two stages approximate the first five stages of Terkelsen's model. The two subsequent stages are concerned with Coping and adjusting to the multiple demands of the illness and the development of Personal and Political Advocacy.

In the early stages of the illness, families may not recognise the symptoms of mental illness and can attribute their relative's behaviour to other sources such as drugs, stress, or bad company. Their coping responses are directed toward obtaining information about the cause of their relative's behaviour. According to Spaniol and Zipple (1994), during the initial stage of Discovery-Denial the information available to the family about the illness is often confusing and unsatisfactory and no clear-cut diagnosis may be available. The lack of diagnosis can give rise to anxiety and anger at a perceived lack of professional competence. Possibly, coping responses at this stage of the illness are motivated by a need to reduce uncomfortable emotional affect leading to a predominance of emotion-focussed coping, although some individuals continue with problem-focussed coping responses, seeking alternative cures and treatments.
During the second stage, termed Recognition/Acceptance, gradual recognition of mental illness occurs, and at this stage some professionals may blame family members for causing the illness. Despite the cyclical nature of the illness, gradually the family recognises its chronicity, and acceptance of the illness leads to deep feelings of loss and the grieving process commences. This stage also leads to a crisis in meaning and issues of purpose of life become important in that values and global beliefs may change.

The third stage of Spaniol and Zipple’s (1994) model, termed Coping, approximates the Tessler et al. (1987) ninth and Terkelsen (1987b) tenth stage and is concerned with skills acquisition and adaptively meeting the demands of caring for a mentally ill family member. At this stage coping begins to take the place of grieving and as belief in family expertise grows so does anger toward professionals and the inadequacy of the mental health system. This anger is resolved as caregivers identify helpful professionals, recognise the limits of professional support and value their own contribution.

Spaniol and Zipple (1994) extended the model to include a further stage which they termed Personal and Political Advocacy and, in the final stage, caregivers may become more assertive in ensuring their own and their relative’s rights to information and treatment are respected. They may also become politically involved in attempting to change or modify the mental health system and lessen the stigma of mental illness.

Although Terkelsen (1987b) recognised that the evolution of caregiver responses is not linear, all stage or phase models of the evolution of mental illness and caregiver responses convey the impression of linearity. Clearly mental illness does not always progress in a linear fashion and adaptive coping responses are probably affected by a variety of factors additional to stage of illness. Skills acquisition may be one such
factor and Spaniol and Jung (1987) suggested that, "When the skills required to complete a specific task have not been acquired, individuals may find themselves stuck with behaviours that are no longer useful" (p. 90).

There is no direct evidence of how accurately stage models of the evolution of caregiver responses reflect the experience of caregivers of different kinship relationship to the care recipient. Possibly they principally address the experience of parental caregivers. However, such models have the potential to make an important contribution to service system planning and to the training of mental health professionals. Their accuracy in describing the issues caregivers encounter and how they respond to different stages of the illness warrants further investigation.

6.2 General and Specific Kinship Issues

The term "family caregiver" when applied to caregivers of the mentally ill, tends to evoke a vision of parents, or more usually, a mother, caring for a mentally ill adult child. Although this is the most common configuration (Skinner, Steinwachs & Kasper, 1992), family caregivers may be related to the care recipient in a number of different ways. They can be spouses or partners, siblings caring for a brother or sister, or adult children caring for a mentally ill parent. Manion (1996) reported estimates that 35-40% of people hospitalised with a psychiatric disorder are discharged to live with spouses. The literature suggests that caregivers of different kinship relationships share many issues in common but also encounter issues specific to their particular kinship group.

Among the issues common to all caregivers, Gubbman, Tessler and Willis (1987) found no differences between parental and spousal caregivers' assessment of the most troublesome behaviours. Both groups found odd or bizarre behaviours, angry
outbursts, failure to contribute domestically, and failure to socialise with friends, equally distressing. Judge (1994) noted that, spouses, parents and siblings might all share in common the grief of loss of the person they knew to mental illness. Despite the commonality of these problems, some issues appear to be specific to particular caregiver kinship relationships. There may be an interaction between type of illness, stage of life demands and the requirements of providing care to a mentally ill family member that differ according to kinship relationship. For example, Lefley (1996) noted that the concerns of elderly parents caring for an adult child with schizophrenia may differ from those of a young wife caring for a partner suffering from bi-polar disorder.

6.2.1 Parental Issues

The issues that appear to be almost exclusive to parental caregivers are those of guilt, chronic grief and concern about future care provision. Wasow (1995) noted that parents may experience chronic grief over the loss of their child to mental illness, and this grief can be exacerbated with each failure to achieve developmental milestones such as completion of education, development of career, marriage, and the production of grandchildren. The guilt that parents experience may also be related to professional blame or their own beliefs about their role in the aetiology or maintenance of the illness. Spouses and caregivers of other kinship relationships are less likely to assume such causal responsibility.

The ageing parents of mentally ill adult children may also be concerned about what will happen to their offspring when they die or when they are no longer able to continue looking after them (Lefley, 1987). This issue may be less relevant to spousal caregivers, sibling or offspring caregivers, who, because of their age, relative to that of the care recipient, may reasonably expect to outlive their mentally ill relative.
6.2.2 Spousal/Partner Issues

Lefley (1996) reported that support groups for caregivers of affective disorders (depression and bi-polar disorder) are predominantly composed of spouses, possibly reflecting the later onset of these disorders and the lower marriage rates for persons with schizophrenia. There are a number of issues that appear to be specific to spousal caregivers and these include financial concerns, the loss of companionship and intimacy, and single parenting. Some of these issues may be specific to the type of mental illness, for example, profligacy and overspending are behaviours typical of manic states that would most adversely affect spousal caregivers.

According to Lefley (1996), spousal caregivers are usually younger than parental caregivers and are likely to have the role of parent as well as spouse with competing demands on their time. Mental illness can affect parenting ability and spousal caregivers can find themselves in a role similar to that of single parents, with the additional burden of caring for their ill partner.

The ability of a mentally ill partner to work and contribute to the family’s income can be adversely affected, placing an additional burden of financial and time constraints upon the well spouse or partner, who may be required to become the main breadwinner in the family. According to Lefley (1996), spouses may also find their career prospects hampered by the demands of caring for a mentally ill partner. Female caregivers can be most affected in that, “Wives may have to become the financial mainstay while continuing to fulfill homemaking and childrearing responsibilities, while husbands typically look elsewhere for substitute caregivers to fulfil these roles” (p.105). The need to compensate for loss of income is unlikely to be an issue of similar importance to caregivers in other kinship relationships who are less likely to be
dependent upon the financial contribution of their care recipient. However, the time constraints imposed by multiple roles may be relevant to all kinship groups.

Spousal caregivers are often faced with the difficult decision of whether to remain in the marriage and they may be ambivalent about leaving or remaining in the relationship and agonise over the decision. Extended family members may also hold strong views about the decision to remain or leave (Wasow, 1995) leading to family conflict and limiting the support for non-compliant spouses. Judge (1994) reports that the partner who leaves often experiences residual guilt about the decision. Despite higher than normal divorce rates of patients with bi-polar disorder, a large minority remains married (Hafner, 1986).

Isolation from support may also be an issue more relevant to spouses than to caregivers of other kinship relationships. There can be a lack of caregiver support groups relevant to spouses needs. Caregiver support groups are often biased toward the needs of parental caregivers, and, “well spouses also tend to hide their dilemmas from family and friends” (Lefley, 1996, p. 105). Time constraints deriving from the need to supplement the family income and assume the bulk of the parenting role may also be factors limiting spousal caregivers’ participation in support groups.

6.2.3 Sibling and Adult Offspring Issues

The issues specific to sibling and adult offspring as caregivers of the mentally ill have received scant attention in the literature as the focus has been upon their role in the family as children or siblings rather than as caregivers. However, two issues, specific to these caregivers that have been noted are those of conflict with spouses or partners about their care-giving role and concerns about genetic transmission of the illness (Secunda, 1997).
Gerace, Camilleri and Ayers (1993) noted three different patterns of sibling response to the illness of schizophrenia and labelled these patterns: collaborative, crisis oriented and detached. Crisis oriented siblings tended to only become involved when the situation demanded intervention, whilst detached siblings distanced themselves from the situation and, in some cases, from other family members as well. Siblings who became caregivers of a mentally ill brother or sister would most likely fit the collaborative pattern in that they are engaged in ongoing active involvement with their ill sibling as well as with other family members and mental health providers. Secunda (1997) reported finding a similar, but not identical, pattern of sibling involvement. In a study of sibling and offspring responses to mental illness she found that 48% of the offspring of a mentally ill parent and 37% of siblings were closely involved with their ill relative, providing emotional and care-taking support.

Both Secunda (1997) and Lefley (1996) noted that offspring and siblings of the mentally ill frequently express fear that they may also become ill. This is not an issue of personal concern to parental or spousal caregivers, although they may fear genetic transmission of the illness to their children. Wasow (1995) reported that all participants in a study of siblings expressed genetic fears for themselves and/or for their children and in some cases this led to a decision to avoid having children.

Secunda (1997) reported that offspring and/or siblings often perceive that they have limited choice about whether to provide care to a mentally ill relative as the needs of the situation and their love and loyalty to their relative can bias their decision. The role of caregiver may be inherited upon the death of a parent, or when a parent is no longer able to continue providing care, and can be assumed at a stage of life when they are also involved with their own marriage and family demands. This can lead to conflicting requirements of providing care to their mentally ill kin whilst attending to
the needs of their family. Conflict can be exacerbated when spouses or partners are antagonistic to their partner providing care and Secunda reported increased stress in caregivers experiencing such conflict.

6.3 Summary

In this chapter I have considered stage models of the evolution of caregiver responses to the mental illness of a family member. Although all models incorporate roughly similar aspects of the evolution of caregivers’ responses to the illness, the model proposed by Spaniol and Zipple (1994) differs in its focus upon coping skills, and the development of caregiver responses concerned with personal or political advocacy. I have suggested that stage models could contribute to planned provision of caregiver support at different stages of the illness and the need to ascertain if they accord with the experience of all caregivers.

Differences in the issues encountered by parental, spousal and other caregivers were considered. These differences included stage of life issues and the associated demands of family life, caregiver’s age and the type of mental illness, and it was proposed that caregivers of different kinship relationships may respond differently to the illness. The relevance of a stage-model of the evolution of caregivers’ responses to mental illness to caregivers of different kinship relationships requires further investigation.
CHAPTER 7

Rationale, Aims and Method

7.1 Rationale

Economic constraints placed upon mental health services together with the prevailing philosophy of community care have firmly established the continuing need for family caregivers to provide support to psychiatrically ill family members. The inevitability of the situation highlights the need to understand and support those processes that enhance the family’s ability to care for their mentally ill family member.

The provision of support to family caregivers not only enables continuation of community care but also has major implications for the maintenance of their well being and for lowering the burden of care. The design of relevant support structures requires knowledge of the issues family caregivers encounter at different stages of the illness, their goals, adaptive coping responses and appraisal of the efficacy of support available. This knowledge also has implications for the training of mental health professionals, as noted in the Australian Psychological Society Bulletin (1998):

“Mental health professionals need to learn about and value the lived experience of consumers and carers” (p. 11).

7.2 Aims of Current Study

The current study aimed to obtain knowledge of how the adaptive coping strategies adopted by family caregivers of the mentally ill evolve over time. It investigated these ways of coping within the framework of positive psychology as proposed by Seligman
and Csikszentmihalyi (2000) and within the competency paradigm proposed by Hatfield and Lefley (1987).

The study also evaluated the relevance of the Spaniol and Zipple (1994) stage model of the evolution of family caregiver responses to caregivers across kinship relationship groups. Caregivers' coping responses are evaluated at each stage of this model using Folkman and Lazarus' (1985) conceptual analysis of coping and White's (1985) analysis of adaptation.

7.3 Method

Family caregivers' adaptive responses to the different stages of mental illness are studied using a combination of quantitative and qualitative data. The information obtained from questionnaire responses is complemented by semi-structured interview data.

7.3.1 Measures

7.3.1.1 Demographics

Demographic data that enables examination of the relationship between coping responses and caregivers' gender, age, geographic location, kinship, marital status, education, employment, extent and duration of care provision was obtained. Similarly, information about care recipients' age, gender, co-residency, current condition and history of hospitalisation was obtained. (See Appendix A)

7.3.1.2 Ways of Coping Questionnaire

Caregivers' coping strategies were measured using the Ways of Coping Questionnaire (WOCQ), revised version, developed by Folkman and Lazarus (1988). This self-
questionnaire consists of 66 items that assess the thoughts and actions used by individuals to cope with stressful encounters. The questionnaire consists of brief descriptions of coping responses that are endorsed on a four point scale ranging from “not used at all” to “used a great deal”. The scale yields eight subscales (Folkman & Lazarus 1988) and these are as follows: Confrontive Coping, Distancing, Self-controlling, Accepting Responsibility, Escape-Avoidance, Seeking Social Support, Purposeful Problem Solving and Positive Reappraisal.

According to Folkman and Lazarus (1988), the internal consistency of the subscales, measured by Cronbach’s alpha, ranges from .61 to .79 in the derivation sample, and is regarded as more satisfactory than most of the measures of coping process. Test-retest reliability has not been reported in the literature, and research on the reliability of this scale has been restricted to the question of internal consistency (Parker & Endler, 1996). Test-retest reliability is difficult to apply to this scale because it measures situation specific responses. However, Folkman and Lazarus (1988) report that face validity and construct validity are acceptable to the extent that the findings are consistent with theoretical predictions. A copy of the version of the Folkman and Lazarus (1988) Ways of Coping Questionnaire used in the current study is shown in Appendix B.

7.3.1.3 Questionnaire Scoring

Responses to the Folkman and Lazarus (1988) Ways of Coping Questionnaire were examined for order of presentation effects and scored in accordance with the instructions accompanying this measure. Two methods of scoring this questionnaire have been proposed. Raw scores can be used to determine the frequency of use of the behaviours described by each of the eight scales. Alternatively, relative scores of
coping strategies, that is the degree to which each subscale was used relative to all others, can be obtained and are derived by:

(a) calculating the average item score for the items on a given scale by dividing the sum of the ratings on the scale by the number of items on that scale,

(b) calculating the sum of the average item scores across all eight scales, and

(c) dividing the average item score for a given scale by the sum of the average item scores across all eight scales.

This method controls for the unequal number of items within each scale and for individual differences in response rates (Folkman & Lazarus, 1988). Relative scores can reveal relationships among the scales that are not apparent using the raw score technique (Vitaliano, Maiuro, Russo & Becker; 1987) and this is the scoring technique employed in the current study.

7.3.1.4 Semi-Structured Interview

Interviewees were asked to recount their experience of coping with the mental illness of their family member and questions relevant to the four stages of the Spaniol and Zipple model were asked, if the information was not spontaneously generated. The questions asked sought to determine the issues encountered at different stages and caregivers’ appraisals, goals, supports and coping responses to those issues.

Questions relevant to Stage 1 included the opening interview question, “How did this illness begin and what did you do?” This question elicited information about caregivers’ initial Discovery that something was wrong and their responses to this first stage of the Spaniol and Zipple model. Their initial appraisal of the situation was
obtained by asking “What made this situation stressful?” if the information was not spontaneously provided. Folkman and Lazarus' (1988) suggested this question because, “Asking the individual to identify what made the situation stressful elicits the individual’s primary appraisal of what was at stake” (p. 14). This question was repeated, as appropriate, throughout all stages of the encounter, as was the question “How did you feel about that?” or “How did that affect you?” This question elicited information about caregivers’ affective response to the issues discussed, if this information was not spontaneously reported.

Information about caregivers’ initial causal attribution was obtained by asking “What did you think caused this?” if the information was not spontaneously offered, as was the question “What did you know about this illness then?” This question sought information about caregivers’ knowledge of and denial of the illness. The question “What did you do about this?” generated information about information seeking responses.

Questions relevant to Stage 2 Recognition/Acceptance included “What did you want to achieve at this stage?” This question was repeated at Stage 3 and provided information about what motivated caregivers’ responses at the second and third stage (initial and current). It is based upon Cochran and Tesser’s (1996) definition of a goal as, “a source of motivation, an incentive to action” (p. 2). It also elicited information about expectations of cure or treatment, whilst the question “How did you feel about this?” provided information about caregivers’ experience of guilt or embarrassment and experience of loss. Information about the effect of the cyclical nature of the illness was obtained by asking, “Did you think he/she was cured?” if this information was not spontaneously generated. The question “What has this illness meant to you?” provided
information about the crisis of meaning that the model claims occurs and the further question "and now?" sought information about how that meaning may change.

At Stage 3 the question "How did you feel about this?" was repeated, if necessary, to obtain information about the resolution of grieving predicted by the model. Additionally caregivers were asked about the issues they encountered at this stage, to obtain information about disruption to family life and recurrent crises and their responses to these issues. Questions appropriate to obtaining this information, such as "What happened then?" and "What did you do about that?" were asked. The question "What did you/didn't you find helpful?" provided information about the loss of faith in professionals, as predicted by the model, and established if current working relationships with professionals had improved. It also provided information about whether the support of other caregivers was valued. The question "What do you want to achieve now?" established the current focus of caregiver's coping.

Questions relevant to Stage 4 of the Spaniol and Zipple model included "How have you been able to help your relative?" Responses to this question provided information about caregivers' recognition of their role, whilst the appropriate use of the question "What did you do about this?" provided information about assertive behaviours. Caregivers who reported initial self-blame or professional blame for causing the illness were asked if they still felt that way. The focus of coping was gauged by asking, "What do you want to achieve now?" and the question "What have you done about this?" in response to complaints about service system deficits, obtained information about personal/political advocacy. Questions such as, "What do you mean when you say?" allowed ambiguous or unclear responses to be clarified.

All interviewees were asked to indicate on a ten point scale, where 1 = not at all stressful and 10 = extremely stressful, their appraisal of how stressful they considered
the situation to be initially, that is when they first discovered that their relative was mentally ill, and currently.

The final question, "Do you have anything more you want to say about coping, or is there anything you want to ask me?" was included to enable interviewees to raise additional issues or address remaining questions and this question concluded the interview. Appendix C contains a copy of the information about interview questions that was provided to participants prior to interview.

7.3.1.5 Interview Credibility, and Coding Reliability
Prior to analysis of the data obtained at interview, a stratified random sample of interviews was evaluated for credibility of content.

The semi-structured interview data was analysed using QSR NUD*IST, a computer software package designed for use with qualitative data that assists in coding, indexing, searching text and theorising about such data: “QSR stands for Qualitative Solutions and Research, a software development company in Melbourne, Australia, developing software and working with researchers in over forty countries. NUD*IST stands for Non-numerical Unstructured Data Indexing, Searching and Theorising” (QSR NUD*IST User Guide, 1997, p. 2).

Coder reliability was determined by comparing the researcher's classification of coping responses with that of an independent coder. Agreement between my coding and that of an independent coder was calculated.
7.3.2 Hypothesis Testing

The following hypotheses tested the accuracy of individual aspects of the four stages of the Spaniol and Zipple (1994) model of the evolution of caregivers’ responses to mental illness against caregivers’ experiences and adaptive responses.

7.3.2.1 Stage 1 Hypotheses about Discovery/Denial

According to Spaniol and Zipple (1994), family caregivers first deny mental illness and may not believe their relative’s changed behaviours to be serious. They do this because their relative’s behaviour differs from media portrayals of mental illness, or because they attribute changes to alcohol, drugs, laziness or bad friends. This denial is persistent.

The relationship with the family member deteriorates and caregivers become frustrated and seek answers from multiple sources. The following hypotheses tested these aspects of the Discovery/Denial stage against caregivers’ reported experiences.

**Hypothesis 1.1 Changed behaviours are not initially attributed to mental illness and mental illness is persistently denied.**

This hypothesis was confirmed if interviewees’ narratives or responses to the question “What did you think caused these changes?” indicated they sensed the behaviours were caused by mental illness but persistently attributed them to other causes.

**Hypothesis 1.2 Because of denial relative’s behaviours are not initially a cause of serious concern.**

This hypothesis was confirmed if interviewees who denied mental illness indicated that they did not initially appraise the situation to be threatening.

To test Spaniol and Zipple’s proposal that coping begins at Stage 3, evidence about the kinds of coping used at this early stage was obtained.
7.3.2.2 Stage 2 Hypotheses about Recognition/Acceptance

Spaniol and Zipple's model proposed that at Stage 2 awareness of mental illness develops, and does so gradually. At this time, family caregivers seek answers from professionals. They may experience guilt, embarrassment and self-blame or be blamed by mental health professionals and experience a deep sense of loss that includes loss of future potential of the family member. Variability in the manifestations of the illness militates against acceptance of the chronicity of the illness and the loss. When these are accepted, grieving commences allowing the creation of new hopes and expectations. At this stage caregivers can experience a crisis of meaning, questioning themselves, their relationships, work or the meaning of life. The following hypotheses tested the accuracy of this description of the evolution of caregivers' responses.

*Hypothesis 2.1 Recognition of mental illness is gradual.*

This hypothesis was confirmed if interviewees accounts showed gradual recognition of the illness.

*Hypothesis 2.2 Acceptance of the diagnosis of mental illness and the implications of the diagnosis are impeded by the fluctuating nature of the illness.*

This hypothesis was confirmed if interviewee's narratives indicated that the fluctuating nature of the illness impeded acceptance of the diagnosis and of its implications.

*Hypothesis 2.3 Mental health professionals are expected to have answers.*

This hypothesis was confirmed if, in response to the question, "What did you want to achieve at this stage?" interviewees indicated that they expected that professionals would accurately diagnose, cure, or treat the illness.
Hypothesis 2.4 Caregivers experience guilt, embarrassment or blame.

This hypothesis was confirmed if, in response to the question "How did you feel when you learnt this?" interviewees indicated that they experienced guilt, embarrassment, self or professional blame.

Hypothesis 2.5 Caregivers experience a deep sense of loss of the person known.

This hypothesis was confirmed if, in response to the question, "What did you feel then?" interviewees indicated grief related to loss of the family member and/or their potential.

Hypothesis 2.6 A crisis of meaning is experienced.

This hypothesis was confirmed if interviewees' narratives or responses to the question "What has this illness meant to you?" indicated that a crisis of meaning was experienced.

Evidence about adaptive coping in Stage 2, Recognition/Acceptance, was obtained from caregivers' responses to the Ways of Coping Questionnaire and interviewee narratives.

7.3.2.3 Stage 3 Hypotheses about Coping

According to the model, coping commences at Stage 3 and replaces grieving.

Caregivers cope with disruption to family life, recurrent crises, persistence of the illness and loss of faith in professionals. They question professional competency and experience anger, hopelessness and despair. As belief in their own expertise grows, they come to accept the limits of what they can do about the illness and value the support of other families. The focus is now upon managing symptoms and improving the family member's functioning. Reliable mental health professionals are identified and a closer working relationship established with them. The following hypotheses
tested the accuracy of this description of the issues encountered at this stage against caregivers' reported experiences.

**Hypothesis 3.1** *Coping replaces grieving.*

This hypothesis was confirmed if responses to the Ways of Coping Questionnaire and interviewees' narratives indicated that coping occurs only after grieving has ceased.

**Hypothesis 3.2** *A loss of faith in mental health professionals occurs.*

This hypothesis was confirmed if interviewees' narratives indicated a loss of faith in mental health professionals at this stage.

**Hypothesis 3.3.** *Disruption to family life and recurrent crises occur.*

This hypothesis was confirmed if interviewees' narratives or responses to the question "What else happened at this stage?" indicated that disruption to family life and recurrent crises occurred at this stage.

**Hypothesis 3.4** *The support of other families is valued.*

This hypothesis was confirmed if responses to the question "What helps you to cope now?" indicated that the support of other families was valued.

**Hypothesis 3.5** *The focus of coping at this stage is symptom management, improving care recipient function and improving community services.*

This hypothesis was confirmed if interviewees' responses to the question, "What do you want to achieve now?" indicated that symptom management, improved care recipient function and improved community services are the focus of current coping.

**Hypothesis 3.6** *Working relationships with mental health professionals are established.*

This hypothesis was confirmed if interviewees' narrative accounts indicate that they have now established working relationships with mental health professionals.
In addition, caregivers’ responses to the Ways of Coping Questionnaire (Current) and interviewee narratives provided information about their adaptive coping responses to the various issues encountered at this stage.

7.3.2.4 Stage 4 Hypotheses about Personal/Political Advocacy

The model proposes that the way caregivers feel about themselves changes at Stage 4. With development of a new awareness of their role in the recovery process the assertiveness of caregivers increases and self-blame decreases. Their focus is upon changes they consider necessary and collaborative roles based upon equality with professionals are established. An interest in the training of professionals may develop and, with increased political advocacy, many partake in united efforts to change the system. New meanings and values are integrated. The following hypotheses tested these aspects of the final stage of the model.

Hypothesis 4.1 Caregivers self-concept changes and they become more assertive.

This hypothesis was confirmed if interviewees’ narratives indicated they now recognise the importance of their role and their narratives or responses to the question “What did you do about this?” indicated the adoption of assertive behaviours.

Hypothesis 4.2 Self-blame decreases.

This hypothesis was confirmed if those interviewees who initially reported self blame now report, either spontaneously or in response to the probe question “... and now?” decreased self-blame.

Hypothesis 4.3 Changes considered necessary become the focus of coping.

This hypothesis was confirmed if interviewees’ responses to the question “What do you want to achieve now?” indicated a focus on changes considered necessary.

Hypothesis 4.4 New collaborative roles with professionals are established.
This hypothesis was confirmed if interviewees' narratives indicated that collaborative roles, based upon equality, have been established with professionals.

_Hypothesis 4.5 Political advocacy to change the system becomes important._

This hypothesis was confirmed if interviewee's narratives indicated that caregivers engaged in political advocacy activities aimed at changing the system.

_Hypothesis 4.6 New meanings and values are now integrated._

This hypothesis was confirmed if interviewees' narratives or responses to the question "What has this illness meant to you?" indicated integration of new meanings or values.

### 7.4 Participants

#### 7.4.1 Recruitment

Participants in the study were recruited using a variety of methods including placing an advertisement in the Victorian Carer Association's Newsletter inviting family caregivers to participate (Appendix D) and six caregivers volunteered in response to this advertisement. An advertisement inviting participation was also posted on Deakin University student notice boards (Appendix E) and two caregivers volunteered. I attended four caregiver support group meetings to talk about the study and to invite participation. Two of these meetings were conducted in Victorian rural centres and two in the metropolitan area of Melbourne and twenty-four caregivers agreed to participate. In addition, I attended the 1998 Carers Conference held at Melbourne University, where I distributed information about participation in the study and three caregivers volunteered.

I also addressed an umbrella meeting of caregiver support group representatives that was conducted at Maroondah Hospital in Victoria to speak about the aims of the study and to invite participation. Support group representatives who attended agreed to
promote the study to members of their group and to distribute copies of the questionnaire to those of their members who expressed a willingness to participate. In total 30 questionnaires were distributed to these representatives and 21 (70%) were completed and returned. This response rate accords with questionnaire response rates reported by Moser (1966). A further three caregivers who were not members of any support group, but had learnt about the study through friends or relatives, contacted me and volunteered to participate.

7.4.2 Participation

In total, 61 caregivers completed the Ways of Coping Questionnaire and forty-eight of them indicated that they were willing to be interviewed.

Subsequent to completing the questionnaire and interview, one participant withdrew from the study when her son became concerned that she may have disclosed sensitive information that could identify him. All data provided by this participant was deleted from the study leaving a total of 60 respondents in the total sample.

Forty-eight of the 61 participants consented to be interviewed, leaving 47 when the above caregiver's data was deleted. Four of the remaining 60 participants declined to be interviewed citing time constraints and I was unable to ascertain why the remaining nine declined to be interviewed. Despite negotiating several appointments, two respondents failed to attend and a further two could not be contacted at the address or telephone number that they provided. The total sample of interviewees consisted of 43 caregivers who were clearly not selected randomly.
7.5 Procedure

7.5.1 Ethics Approval

Approval to conduct the study was sought and obtained from the Deakin University Ethics Committee (Appendix F). Ethics approval was also obtained from the Maroondah Hospital Ethics Committee and this enabled access to caregiver support organisations affiliated with this hospital. Approval was granted subject to minor procedural changes to meet their requirements (Appendix G).

7.5.2 Study Procedure

Prior to participation, each caregiver was provided with a Plain Language Statement that outlined the aims of the study and the limits of participation (Appendix H). All participants were requested to provide written consent (Appendix I) to their participation in the study. Participants were requested to complete the Ways of Coping Questionnaire twice, the first time according to their initial responses on learning that their family member was mentally ill and the second time according to their current responses. To control for order of presentation half received the Initial measure first and half received the Current measure first. Participants were also requested to provide demographic data about themselves and about the relative to whom they were providing care. Those participants who were also willing to be interviewed were requested to provide contact details that would enable an appointment to be made, (Appendix J) and to return that information together with their completed questionnaires in the stamped and self-addressed envelope provided. I obtained contact information verbally at support group meetings I attended, and from callers who telephoned to volunteer. Those participants who were willing to be interviewed nominated a time and place suitable to them. I personally conducted all of the
interviews, the majority of which (69%) were conducted in the participant’s home. The remainder were conducted in my office or at a private location nominated by the participant.

Interview responses were recorded in note form and supplementary notes taken. The duration of the interview was determined by the respondent and ranged from approximately 40 minutes to 75 minutes. Prior to commencement of the interview approximately 10-15 minutes was allowed to effect introductions and to establish a comfortable relationship. Subsequent to completion of the interview, a further 10-15 minutes de-briefing period was allowed to enable response to any residual questions and to provide further information or referral if required.

Although all participants were provided with written information about the purpose and methodology of the study and their right to withdraw at any stage, this information was verbally repeated at the commencement of interview, as there was a time lapse between completion of the questionnaires and date of interview. None of the participants decided to withdraw at this stage.

Four caregivers became emotionally distressed when discussing sensitive issues and although offered the option of terminating the interview all decided to continue. A list of community support agencies was made available to any participant who was not already in contact with such an agency; only one participant accepted this offer.

Consent forms and interview transcripts were separated to ensure anonymity of participation. All traces of other identifying information, such as the care recipient’s or treating medical officer’s name were omitted or altered in the published data.
CHAPTER 8

Results

8.1 Data Screening

All variables were examined for accuracy of data entry, the extent and distribution of missing values and the nature of their distribution. Missing values comprised less than 1% of the total data and were random across variables and stage of encounter with mental illness. No evidence of systematic omissions was found and missing data were therefore replaced with group means. No univariate outliers were present and after examination for skewness and kurtosis and an inspection of residual plots all variables were judged to be normally distributed.

8.1.1 Order of Presentation Effects

In order to control for order effects, the order of presentation of the WOCQ questionnaires (initial/current) was counterbalanced. A one way ANOVA was nevertheless conducted to test the hypothesis that counterbalancing had controlled for order effects. A significant difference was found for one scale only: "Seeking Social Support" and this difference was found in both the Initial $F(1, 58) = 5.238, p < .05$ and Current presentations of the questionnaire $F(1, 58) = 5.514, p < .05$. Participants who completed the questionnaires according to their Initial response to the illness first scored significant higher ($M = 15.72, SD = 7.56$) on Seeking Social Support than those in the counterbalanced condition ($M = 11.72, SD = 5.86$).
8.1.2 Interview Credibility, Coding and Coder Reliability

Prior to analysis of the data obtained at interview, a stratified random sample of interview transcripts, comprised of four transcripts (approximately 10% of the total interview sample) was evaluated for credibility of content. All identifying features of the transcripts were omitted or changed before they were evaluated. The transcripts, which included two interviews with Parental Caregivers, one interview each with a Spousal Caregivers, and a respondent from the Other Caregiver group, were read and evaluated by two family support workers from ARAFEMI (The Association of Relatives and Friends of the Emotionally and Mentally Ill). They concluded that the content of these transcripts was representative of the issues they encountered in their work with family caregivers of the mentally ill (Appendix L).

All the interview data was transcribed, converted to plain text, and entered into QSR NUD*IST. I examined the transcripts and coded them by kinship relationship (Parental, Spousal or Other), the four stages of the Spaniol and Zipple model, (Discovery/Denial, Recognition/Acceptance, Coping, Personal/Political Advocacy), Issue and Coping Response (Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving and Positive Reappraisal).

A random selection of 50 coping responses was coded by an independent coder and the agreement between that coding and mine was calculated. Ninety-eight percent concurrence was achieved (Appendix K).

8.2 Participant Demographics

Demographic data for the total sample of 60 participants who completed questionnaires and the 43 of these participants who were interviewed is as follows:
8.2.1 Gender

The total sample of respondents who completed the questionnaires \( N = 60 \) consisted of 47 females and 13 males and the sample of interviewees \( n = 43 \) consisted of 32 females and 11 males. The gender composition of the interviewees varied slightly from that of the total sample in the higher participation of males, however females predominated in both groups, according with Schofield and Hermann’s (1993) findings of the predominance of female caregivers.

8.2.2 Location

The majority of the total sample, 68\% \( (n = 41) \) resided in urban areas of Victoria and 32\% \( (n = 19) \) resided in rural areas. Of the 43 caregivers who were interviewed, 70\% \( (n = 30) \) resided in urban areas of Victoria and 30\% \( (n = 13) \) resided in rural areas.

8.2.3 Kinship

The most common kinship relationship to the care recipient reported by interviewees was that of parent/child. Sixty percent of the interviewees \( (n = 26) \), were Parents, 20 of them mothers and 6 fathers. The predominance of Parents in the sample tended to confirm that caregivers are most likely to be a parent, spouse or child, and, in the case of parental caregivers, mothers are the most likely care provider (O’Brien, 1998).

Spouses/Partners made up 28\% \( (n = 12) \) of the total population of interviewees. This group consisted of ten wives or partners of the care recipient and two husbands.

The small group designated “Other” caregivers consisted of five caregivers, three of whom were caring for a mentally ill mother. They comprised one son, one
daughter and her partner. The other two caregivers in this group consisted of a sister and her partner who were providing care to a mentally ill sibling.

8.2.4 Age

Table 1 shows the mean age of the total sample and that of interviewees by kinship relationship group.

Table 1:

| Caregivers Mean Age, Standard Deviation and Range by Total Sample and by Interviewed Caregivers Kinship Group |
|-------------------------------------------------|----------------|----------------|----------------|
| Group                                           | Mean Age   | Standard Deviation | Range         |
| Total Sample                                    | 55.47     | 12.10             | 28 – 78 years |
| Interviewed Caregivers                         |            |                  |                |
| Parental \((n = 26)\)                           | 63.27     | 8.58              | 40 – 78 years  |
| Spousal \((n = 12)\)                            | 49.08     | 11.30             | 28 – 68 years  |
| Other \((n = 5)\)                               | 37.60     | 10.36             | 32 – 56 years  |

From the above table it can be seen that respondents in the Parental group were older than those in either the Spousal or Other groups. These findings accord with Lefley (1996) who reported that Spousal caregivers tend to be younger than Parental caregivers. A wide range of caregiver ages is reported in both the total sample and across the three kinship groups and this accords with O’Brien (1998) who reported considerable diversity in caregiver age.

8.2.5 Marital Status

The majority of total sample respondents \((n = 42)\) were married, 15 were divorced, widowed or separated, and the remaining three were single.
The percentage of Parental interviewees who were married 62% (n = 16) was less than that of the total sample. Thirty-eight percent of this group were separated, divorced or widowed - figures may have been affected by stage of life issues that include the likelihood of spousal mortality in this older age group.

The majority of Spousal caregivers, 92% (n = 11) were either married or living in a committed relationship with the care recipient. One respondent was unmarried and no longer living with the care recipient, although continuing to provide care. Four of the five Other caregivers (80%) were married.

8.2.6 Education
Twenty-five percent (n = 15) of the total sample held tertiary qualifications and 18% (n = 11) had post-graduate qualifications. Fifty-seven percent of the total sample had completed secondary education.

A slightly higher percentage of interviewees 26% (n = 11) reported holding tertiary qualifications and 23% (n = 10) had post-graduate qualifications. The remaining 51% of interviewees (n = 22) reported having completed secondary schooling.

The educational achievements reported in both the total and interviewed sample are higher than those of the Australian adult community (Australian Bureau of Statistics, 1999). Table 2 compares the educational attainment of the total study population, the interviewees and the Australian general public.
Table 2:

*Comparison of Educational Attainment Levels between Total Sample, Interviewees and General Australian Population*

<table>
<thead>
<tr>
<th>Educational Level</th>
<th>Total Sample</th>
<th>Interviewees</th>
<th>Australians Aged 15–64yrs*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Percent</td>
<td>n</td>
</tr>
<tr>
<td>Primary</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Secondary and Trade</td>
<td>34</td>
<td>57%</td>
<td>22</td>
</tr>
<tr>
<td>Tertiary</td>
<td>15</td>
<td>25%</td>
<td>11</td>
</tr>
<tr>
<td>Post-Graduate</td>
<td>11</td>
<td>18%</td>
<td>10</td>
</tr>
</tbody>
</table>

Note: The age range of the total sample (28 - 78 years) differs from that reported in the Australian Bureau of Statistics sample (15-64 years). It can be seen that participants in this study had higher levels of educational achievement than those of the general population, and these levels may affect their choice of coping strategies. The higher educational achievements of participants may also affect the extent to which these participants represent caregivers in general.

8.2.7 Employment

Forty-five percent (n = 27) of the total sample was in paid employment, 57% of whom were employed full time and 48% were employed part-time. More than half of the total sample was not in paid employment (n = 33). Those not in paid employment tended to be retirees or wives engaged in home duties.

Fewer Parental interviewees were in paid employment, only seven were in paid employment and the majority of these were employed part-time. The lower employment rate of this group may again be related to age and stage of life issues. In contrast, the majority of Spousal interviewees were in paid employment: half of them
were engaged in full-time and half in part-time employment. Three of the five Other caregiver group interviewees were in full-time employment and the remainder were unemployed. The higher rates of employment in these kinship groups suggest the possibility of greater time constraints when combined with their care-giving duties.

8.2.8 Extent and Duration of Care Provision

The following table shows the type of care provision (full-time/part-time) and the mean years' duration of care provision.

Table 3:

**Extent and Duration of Care Provision by Total Sample and by Interviewed Caregiver Kinship Group**

<table>
<thead>
<tr>
<th>Sample</th>
<th>Extent of Care Provision</th>
<th>Duration of Care Provision (years) Mean and SD</th>
<th>Range (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Sample</strong></td>
<td>Full Time 35%</td>
<td>Mean: 11.55 SD: 8.73</td>
<td>6mths – 38 years</td>
</tr>
<tr>
<td>(N = 60)</td>
<td>Part Time 63%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N/Avail 2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Interviewed Caregivers:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental ((n = 26))</td>
<td>Full Time 19%</td>
<td>Mean: 14.93 SD: 9.07</td>
<td>9mths – 38 years</td>
</tr>
<tr>
<td></td>
<td>Part Time 81%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spousal ((n = 12))</td>
<td>Full Time 50%</td>
<td>Mean: 13.06 SD: 9.78</td>
<td>7mths – 30 years</td>
</tr>
<tr>
<td></td>
<td>Part Time 50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other ((n = 5))</td>
<td>Full Time 40%</td>
<td>Mean: 5.96 SD: 5.89</td>
<td>8mths – 14 years</td>
</tr>
<tr>
<td></td>
<td>Part Time 60%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The majority of respondents in both the total sample and the interviewed sample were providing part-time care to their mentally ill relative, perhaps indicative of the different
care needs of the mentally ill from those of the physically disabled. The mean duration of care provision by Parental and Spousal caregivers was longer than that of Other caregivers, however, as also noted by O'Brien (1998), there was considerable diversity in the duration of care provision.

8.3 Care Recipient Demographics

8.3.1 Gender

Table 4 shows care recipients' gender by kinship relationship to the caregiver.

Table 4:

<table>
<thead>
<tr>
<th>Care Recipient Gender by Total Sample and by Interviewees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample Group</td>
</tr>
<tr>
<td>---------------</td>
</tr>
<tr>
<td>Total Sample ((N = 60))</td>
</tr>
<tr>
<td>Interviewed Sample ((n=43))</td>
</tr>
<tr>
<td>Parental ((n = 26))</td>
</tr>
<tr>
<td>Spousal ((n = 12))</td>
</tr>
<tr>
<td>Other ((n = 5))</td>
</tr>
</tbody>
</table>

From the above table it can be seen that the majority of care-recipients were male, findings similar to those reported in the American survey cited by Lefley (1996) wherein the majority of care recipients were also males. The only group in which female care recipients predominated was in the Other caregiver group, and it is possible that this anomaly is a function of the restricted sample size of this group.
8.3.2 Age

Table 5 shows the mean of age of care recipients in the total sample and in the interviewed sample by caregiver kinship relationship.

Table 5:

*Care Recipients Mean Age, Standard Deviation and Range*

<table>
<thead>
<tr>
<th>Total Sample</th>
<th>Mean Age</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Sample (N = 60)</td>
<td>38.73</td>
<td>12.45</td>
<td>6 - 73 years</td>
</tr>
<tr>
<td>interviewees (n = 43)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental (n = 26)</td>
<td>34.54</td>
<td>6.38</td>
<td>16 - 42 years</td>
</tr>
<tr>
<td>Spousal (n = 12)</td>
<td>48.58</td>
<td>10.97</td>
<td>26 - 68 years</td>
</tr>
<tr>
<td>Other (n = 5)</td>
<td>49.00</td>
<td>18.68</td>
<td>30 - 73 years</td>
</tr>
</tbody>
</table>

The above table indicates considerable diversity in the ages of care recipients. They ranged from teenage to elderly care recipients. As may be expected, recipients of parental care were younger than those being cared for by spouses or other caregivers.

8.3.3 Co-Residency

The majority, 65% (n = 39) of care recipients in the total sample resided with their caregiver, (85% full time and 15% part-time).

Forty-two percent (n = 11) of parental care recipients lived with their parents and most of them (73%) lived with them full-time, whilst 27% lived with their parents part-time. The majority of Parental care recipients 58% (n = 15) lived away from home. In contrast, the majority of Spousal care recipients (92%) resided with their partner full-time and only one part-time. Five of the Other caregivers were providing care to three care recipients, two of whom resided full-time with their relative and one
lived independently. Despite the limited sample size, this accords with the findings of Skinner, Steinwachs and Kasper (1992) who reported similar parental co-residency figures in an American sample. Full-time co-residency was highest for Spousal caregiver recipients and this accords with Wasow (1995) and Judge (1994) who claimed that spouses or partners were more likely to be co-resident.

8.3.4 Signs and Diagnosis

The mean length of time since care recipients in the total sample first showed signs of mental illness was 18.46 years (SD = 18.11; range 2 to 60 years). This was 16.79 years (SD = 7.75; range 4 – 30 years) for Parental care recipients and 14.42 years (SD = 11.24) for Spousal care recipients. No meaningful figures could be provided for care recipients in the Other group, because those caring for a parent were not aware of when their relative first showed signs of mental illness or first received a diagnosis.

Mean years since care recipients were first diagnosed with mental illness was 16.87 (SD = 21.13; range 3 – 29 years) in the total sample. Five percent (n = 3) of the caregivers in the total sample said they did not know if their relative had received a diagnosis. In the interview sample, the mean time since Parental care recipients had been diagnosed was 16.29 years (SD = 18.26; range 3 to 29 years) and Spousal care recipients 14.42 years (SD = 11.24; range .5 to 35 years). One Parental caregiver reported that she had never been advised of her daughter’s diagnosis.

Of the 43 caregivers who were interviewed, 29 reported that they were caring for a relative who had been diagnosed with schizophrenia. The majority of Parental caregivers (92%) and Other caregivers (80%) were providing care to a relative with schizophrenia, and only one Spousal caregiver was caring for a partner who had been diagnosed with schizophrenia.
Of the total sample of interviewees, nine were caring for a relative with a diagnosis of bi-polar disorder and the majority of them were Spousal caregivers \((n = 8)\). One Parental caregiver and none of the Other caregiver group reported caring for a relative with this disorder.

Two Spousal caregivers were providing care to a relative suffering from severe depression, none of the Parental or Other caregivers reported caring for a relative with this disorder. Two interviewees, (one each Parental and Other caregiver) reported that they did not know their relative’s diagnosis.

8.3.5 Current Condition

Participants considered the majority of care recipients in both the total and interviewed sample to be in a stable or mostly stable condition. Eighty-five percent of the total sample care recipients were considered to be in a stable or mostly stable current condition, in comparison with 88% of Parental care recipients, 67% of Spousal care recipients and 60% of Other care recipients in the interview sample.

Caregivers reported that 8% of the total sample care recipients were mostly unstable and 5% were not currently stable. Information about the current condition of one care recipient was not known. Four percent of Parental care recipients were mostly unstable and a further 8% unstable. Seventeen percent of Spousal care recipients were mostly unstable, as were 20% of Other care recipients, and 8% of Spousal care recipients were currently unstable.
8.3.6 Hospitalisation

The majority of care recipients in both the total sample and interview sample had been hospitalised for their illness at some time (Total sample = 92%, Parental Care Recipients = 92%, Spousal Care Recipients = 100%, Other Care Recipients = 60%).

The mean number of years since care recipients were last hospitalised was 11.95 years for the total sample ($SD = 26.85$). Parental caregivers reported 11.39 years ($SD = 26.28$), Spousal caregivers 3.39 years ($SD = 3.73$) and Other caregivers 3.63 years ($SD = 4.54$). Eight percent of the total sample had never been hospitalised.

8.4 Testing the Hypotheses

Throughout the remainder of this chapter the qualitative and/or quantitative data are reported in relation to the hypotheses derived from each of the four stages of Spaniol and Zipple's model.

8.4.1 Stage 1: Discovery/Denial Hypotheses

The qualitative data relevant to the first or Discovery/Denial stage of the Spaniol and Zipple (1994) model were those obtained from interviewees' narrative accounts of their experience of mental illness. The opening question of the interview, “How did your relative’s illness begin and what did you do?” invited interviewees to discuss their initial response to the illness. Their responses are reported in relation to their initial recognition of their relative’s changed behaviours, their primary appraisal of the situation, their causal attributions, and their initial coping responses and their failures to recognise mental illness.
8.4.1.1 Discovery

Because of prior knowledge, not all caregivers could be said to have discovered that their relative had a mental illness. Discovery was precluded for those interviewees (19%, n = 8) who had had an initial experience of mental illness that precluded discovery. This group consisted of three caregivers who were caring for a mentally ill parent or parent-in-law, one sibling and her partner caring for her brother, and three spouses. All had prior knowledge of the family member’s illness or professional experience of mental illness. Thus, in responding to inquiry about how he discovered his mother’s illness, a son replied, “It’s just something I’ve lived with all my life” (R. 29). Similarly, a daughter responded, “I don’t remember my mother being any other way” (R. 56) and her partner added, “In all the time I’ve known her, I’ve never known her to be any different” (R. 57).

Two of these caregivers who were employed in the mental health system said that they were familiar with the signs and symptoms of mental illness. For example, a sister caring for her brother said, “I’m not a psychologist or anything like that but I’ve been working in mental health long enough to recognise that he was mentally ill” (R. 46) and her partner, who was assisting in caring for his brother-in-law accepted this diagnosis. Two wives caring for their mentally ill spouse told of being aware of their husbands’ illness when they married: “I knew [husband] wasn’t well when I first met him” (R. 24) and, “I knew he had a mental illness when I married him” (R. 59).

8.4.1.2 Non-Recognition

Thirty-five (81%) of caregivers did eventually “discover” the mental illness of their relative but said that they did not initially recognise that their relative was mentally ill.
This group comprised 100% \((n = 26)\) of Parental, 75\% \((n = 9)\) of Spousal and none of the Other caregiver group. Although a diverse range of unusual changes in behaviour was reported, the key factor was that the changes were out of character rather than that they were recognisable as symptoms of mental illness. For example, a wife said “He wasn’t the same person he used to be ... he was angry and argumentative all the time” (R. 30), and a father reported, “He used to be a really popular outgoing sort of kid ... Then over a period of time he became withdrawn and gradually he dropped out of everything” (R. 34). These caregivers told of first noticing withdrawal, preoccupation with strange ideas or schemes, odd, bizarre or angry and aggressive behaviours. Thus, a father said, “Back then she stopped eating for a week or more and she couldn’t say why” (R. 32). One mother said, “It began with him becoming pretty depressed and he wasn’t sleeping. He’d be up all night playing music, if you can call it that” (R. 38). Another mother reported, “He said a lot of things that didn’t make too much sense” (R. 21), but this did not cause her to contemplate mental illness.

8.4.1.3 Primary Appraisal

Most of the interviewees (91\%, \(n = 39\)) reported that their primary appraisal of the situation was that it was one of threat but it was not mental illness that posed the threat so much as their own confusion about what was happening: “I was worried out of my mind. I had no idea what was going on” (R. 02), or to the perceived threat to their relative’s well being or survival: “I was afraid I was going to lose her” (R. 36). One interviewee, the partner of a daughter caring for her mother, perceived initial marital conflict over his mother-in-law’s illness as a threat to his marriage: “I used to think if
we didn’t make it, you know, didn’t stick it out, it’d be because of her [mother-in-law]” (R. 57).

The remaining 9% of interviewees \((n = 4)\) initially appraised the situation as challenging rather than threatening. For example a wife who was aware of her husband’s illness when they married said: “I really thought we could get past it, or we could find a cure or something” (R. 24). Similarly, a son caring for his mother reported, “I reckoned we’d make it, we’d get over it, and we have” (R. 29).

8.4.1.4 Causal Attribution

Most interviewees sought a cause for the changed behaviour and the attribution varied slightly by the type of relationship.

8.4.1.4a Causal Attribution: Parental Caregivers

Twenty-five of the twenty-six Parents interviewed reported that they initially attributed their relative’s changed behaviours to a variety of causes other than mental illness. Nine Parents said that they initially considered their relative’s behaviour to be a response to stressful life events. For example, one mother said, “We put it down to the stress of competition” (R. 21). Another mother attributed her son’s behaviours to the shock of learning he was adopted: “He got a bad shock and he never got over it” (R. 58). A father reported, “About that time he split up with his girlfriend and we put it down to that” (R. 34). Seven Parental caregivers attributed the changes they observed to normal developmental issues: “At first we thought it was just part of growing up” (R. 01). Four initially believed the changes resulted from substance abuse. Their responses included, “I wondered if he was using some drug. We knew he’d been using marijuana” (R. 49), “To tell you the truth, we both thought he might be on drugs or
something like that. We couldn't think what else it might be” (R. 8). Only one Parent said she had contemplated the possibility that the symptoms she observed could indicate mental illness: “I thought it could have been drugs or alcohol or even mental illness” (R. 55).

8.4.1.4b Causal Attribution: Spouses/Partners

These caregivers saw relationship strains as a causal factor in addition to stressful life events such as work pressures, home renovations, adoption of a child, or post-operative stress. For example, one wife said, “I thought it must have been something I'd done” (R. 48), and a husband reported, “I used to wonder if I caused it” (R. 26). Unlike Parental caregivers, none of the Spousal/Partner caregivers initially attributed their partner’s symptoms to substance abuse.

8.4.1.5 Denial/Failure to Recognise

Nineteen percent of the caregivers (n = 8) who discovered but did not recognise mental illness spontaneously offered explanations of why this had happened. For example, a mother explained, “There's no history of mental illness in my family, so I wouldn't have known what to look for” (R. 21). Another mother, caring for a daughter with an intellectual disability said, “I didn't know you could be retarded and have a mental condition too” (R. 35). A mother caring for two mentally ill sons said, “Despite [brother’s] schizophrenia we just didn't make the connection. It never occurred to us it could happen twice. Something like lightning not striking twice in the same place” (R. 23).
8.4.1.6 Disorder Type and Recognition

The type of mental illness had an effect on the ease with which the problem was recognised. Here depression occupies a rather special place. For example, a husband spoke of his wife’s prior experience of postnatal depression: “I don’t think of that as the same thing [mental illness] because she came good [improved] and things were all right for some years” (R. 45). Similarly, two wives dismissed prior experiences: “I’d been told he had a nervous breakdown when he was about twenty. We just thought he was a bit sensitive” (R. 20) and, “He had been depressed once before, but that was a long time ago. When I think back to then, it seems that it built up over a period of time and then he got better. It’s the sort of thing that you tend to forget, to put it out of your mind” (R. 48). A mother spoke of her son’s previous depression when his marriage ended: “I didn’t think of it in terms of him being ill. I don’t think you could call it mental illness what happened to him back then” (R. 28).

The behaviours of relatives with bi-polar disorder posed another set of problems. Nine of the twelve Spousal or Partner caregivers (75% of this group) caring for a relative who was subsequently diagnosed with bi-polar disorder told of becoming aware of their partner’s increased irritability, hostility or excessive spending and engagement in bizarre or imprudent schemes. For example, a wife said, “It got to the point where he wasn’t sleeping and he came up with these wild idea about moving back to [country of origin] because he had this idea that he could start a financial advisory service there and get people to invest in Australian shares. The trouble was, he didn’t know anything about Australian shares and he hadn’t been home in twenty years or more” (R. 60).

The remaining three Spouses were caring for a partner with depression ($n = 2$) or schizophrenia ($n = 1$). Two husbands told of the onset of depression and their wife’s
withdrawal following childbirth. The wife caring for a husband with schizophrenia had prior knowledge of the illness.

8.4.1.7 Stage 1: Coping Responses

The coping responses that caregivers reported at this stage were related to their appraisal of the situation, their causal attribution and their goals. It was apparent from interviewee's narratives that their principal goal was to obtain information about why their relative was behaving differently, and what could be done about it. As one caregiver put it, "Our main concerns at that time were around finding out what was wrong with him" (R. 55).

Eighty-one percent of caregivers (n =35), told of attempting to discover the cause of their family member's behaviours by consulting with relatives, friends, employers and/or medical practitioners.

The local general practitioner was consulted by 63% of caregivers, (n = 27) who reported mixed success in obtaining the information they required. Twenty-five interviewees said they received a referral for psychiatric assessment and nine reported that their general practitioner did not initially recognise mental illness. For example, a husband whose wife was subsequently diagnosed with bi-polar disorder said, "I talked to the doctor about it. Anyway he didn't seem terribly concerned" (R. 26). A mother whose son was later diagnosed with schizophrenia said, "We took him to our local GP but he couldn't say what it was" (R. 27). Another mother reported, "There wasn't any diagnosis at that stage but he was put into hospital for a week or so. At first they said he was suffering from stress and then he was sent home but he still wasn't right" (R. 43). "We took him to the doctor and got him tested but I don't remember anyone ever saying what it was, or what was causing it. There just wasn't any diagnosis. It
was really confusing” (R. 02). As one mother noted, “We didn’t know what was going on and it was beginning to sink in that nobody else knew either” (R. 01).

Nine of the 27 caregivers who consulted a general practitioner did not receive immediate specialist referral and they told that their relative’s condition deteriorated, treatment provided proved ineffectual and they were eventually referred for psychiatric assessment. Two said they sought specialist referral: “We were the ones that told the doctor we wanted a referral to a psychiatrist” (R. 27), and “I got in touch with this psychiatrist that I used to know when he was a GP and he saw [son] and had him admitted to a private hospital” (R. 02). A further two caregivers said they sought emergency hospital care that led to psychiatric assessment of their relative and the remaining five caregivers reported that their relative’s behaviour led to police intervention that resulted in psychiatric assessment. All reported accepting the diagnosis of mental illness.

8.4.1.8 Summary regarding Stage 1 Hypotheses

From interviewees’ narratives it is apparent that Discovery/Denial is not a stage encountered by all caregivers. It is not a stage relevant, of course, to those with prior knowledge or professional knowledge of the illness. However, for the majority, what was discovered was not mental illness but changes in behaviour not obviously related to illness. Consequently, although the changes in the relatives’ behaviours were not initially attributed to mental illness, it could not be said that mental illness was denied.

Nor was the hypothesis confirmed that caregivers would not initially consider their relative’s changed behaviours to be serious. The majority did appraise these changes as threatening, primarily because of the confusion that they generated.

Consequently, when most of the interviewees attributed the initial signs to factors other
than mental illness this does not seem to have been due to denial. Other factors that militate against denial are to be seen in the caregivers seeking information, in their considering the feasibility of various alternate causal explanations and in their not being provided with a diagnosis of mental illness by a medical practitioner or psychiatrist. Denial of mental illness first requires knowledge of it.

It is also apparent that the commencement of adaptive coping can be seen in the information seeking responses reported by these caregivers.

8.4.1.9 Stage 1: The End

Obtaining an official psychiatric diagnosis of mental illness seems to have marked the end of this first stage and the transition to the next. A mother said: “The psychiatrist thought that he had body dysmorphic disorder. That was the first real indication that he had some mental problem” (R. 01).

8.4.2 Stage 2: Recognition/Acceptance

Here quantitative and qualitative data relevant to the Spaniol and Zipple model’s second stage in the evolution of caregiver coping responses is reported. According to the model, recognition of major mental illness develops gradually, together with an expectation that professionals will have answers. Caregivers may be blamed for causing the illness or blame themselves, experiencing guilt, embarrassment or blame and the cyclical nature of the illness impedes acceptance. Acceptance leads to profound feelings of loss of the person known and their future potential, and caregivers experience a crisis of meaning.
8.4.2.1 Recognition

The majority of interviewees, 74% \( (n = 32) \), said that their recognition of mental illness had been a very slow process that evolved over a long period of time and was linked to diagnosis. For example, a father told, “After that first time [first episode] nothing much happened for quite a while and he sort of settled down. We still didn’t think that he had a mental illness, more like drugs or something” (R. 08). A mother stated, “I don’t know who said it but there was this sort of gradual dawning that this is mental illness, serious mental illness” (R. 25). Recognition of mental was dependent upon official diagnosis and we have seen that it was diagnosis that marked transition from the first stage of Discovery/Denial to that of Recognition/Acceptance.

Otherwise, recognition was “sudden” or already known for only 26% of interviewees \( (n = 11) \). This group included two Spouses with prior knowledge of the illness, three caring for a parent or parent-in-law with long standing mental illness, one Spousal and two Other caregivers (a sibling and her partner) whose professional training enabled early identification. It also included three Parents for whom recognition was sudden. For example, the mother of a son missing for some years related, “We got this call from the police one night. They said they had him out at [psychiatric hospital] and we went out there and we were told he had schizophrenia and that was it” (R. 22).

8.4.2.2 Initial Expectations of Professionals

In response to a question about what they hoped to achieve after receiving an initial diagnosis of mental illness, interviewees reported goals indicative of their expectations of mental health professionals at this stage. Table 6 shows interviewees’ initial goals by kinship relationship to the care recipient.
Table 6:

Goals at Stage 2 by Kinship Relationship

<table>
<thead>
<tr>
<th>Goals*</th>
<th>Parents $n = 26$</th>
<th>Spouses $n = 12$</th>
<th>Other $n = 5$</th>
<th>% of Total $N = 43$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cure</td>
<td>8</td>
<td>3</td>
<td>-</td>
<td>26</td>
</tr>
<tr>
<td>Treatment</td>
<td>7</td>
<td>3</td>
<td>-</td>
<td>23</td>
</tr>
<tr>
<td>Care/Safety/Control</td>
<td>6</td>
<td>1</td>
<td>4</td>
<td>26</td>
</tr>
<tr>
<td>Knowledge</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>30</td>
</tr>
<tr>
<td>Conceal</td>
<td>2</td>
<td>3</td>
<td>-</td>
<td>12</td>
</tr>
<tr>
<td>Support Partner</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>02</td>
</tr>
<tr>
<td>Maintain relationship</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>02</td>
</tr>
<tr>
<td>Financial security</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>02</td>
</tr>
<tr>
<td>Self-care</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>07</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>-</td>
<td>1</td>
<td>07</td>
</tr>
</tbody>
</table>

*Note: 37% of Interviewees nominated more than one goal.

From Table 6 it can be seen that the goals most frequently nominated by caregivers at the time of recognising their relative’s illness were those of obtaining treatment or cure for the care recipient and knowledge about the illness for themselves. Responses related to these goals included: “I suppose back then we thought we’d find a cure or the right treatment for him” (R. 01) “I wanted to make sure he was safe” and “I wanted a clear idea of what was happening. I really needed to know what I was dealing with” (R. 21). These responses implied an expectation that professionals would provide treatment, cure and/or information.

8.4.2.3 Guilt, Embarrassment, Blame

The guilt that interviewees spoke of was related to self-blame and was evident in the narratives of 15% of Parents ($n = 4$), and 17% of Spouses ($n = 2$). One mother said, “I
thought maybe I just didn’t look after him well enough. I was sure it was something that I’d done, or maybe something I hadn’t done” (R. 28). A further two mothers expressed concern about their failure to initially recognise the symptoms of mental illness: “We didn’t pick up that it wasn’t quite right. We should have!” (R. 23) and, “We’ve always wondered if there was something we should have noticed and if it would have made a difference if we had” (R. 38). Two Spousal/Partner caregivers (a husband and a partner) told of initial feelings of guilt: “I know it doesn’t make much sense but I thought in some way it might be my fault” (R. 37).

Shame and embarrassment were experienced by 28% of interviewees (n = 12) when their family member’s illness was recognised and they told of fearing that the family would be stigmatised if the illness became known in the community. This group consisted of one Parental, nine Spousal and two Other caregivers. The majority of interviewees who were concerned with the possibility of being stigmatised (n = 12) appraised it in terms of threat to themself or their family’s social standing. One partner said, “I’m ashamed to say that I felt embarrassed by him. In some odd way I thought that it reflected on me” (R. 39).

Mental health professionals had blamed 16% (n = 7) of those interviewed (5 Parental and 2 Spousal caregivers) for causing or maintaining the illness. One mother said, “He [treating doctor] told us that parents are always to blame” (R. 22). A wife accused by her husband’s therapist of co-dependency told, “I think it was put to me that I was supportive of his illness, that I was encouraging him to be sick, because ... I’m not sure why I was supposed to be doing that. Perhaps because I wanted to be in control” (R. 40).
8.4.2.4 Loss

Forty-two percent of interviewees ($n=18$), 17 Parents and 1 Spouse, told of grieving the loss of the person they once knew and/or their relative’s lost potential. A mother said, “Well I felt, I do feel sad when I look at [son]. I think of everything that could have been” (R. 22). Another mother reported, “I think the hardest thing I’ve had to cope with is the grief. At first it feels like you’re grieving, like your heart’s breaking all the time, and then it gets less, and then when you think you’re over it something else comes up and you’re right back where you started” (R. 21). Only 7% of interviewees ($n=3$) directly related their experience of stress to grief at this stage. For example, a mother told, “It broke my heart to see him like that” (R. 02), and another said, “It was just so sad” (R. 35). A wife whose husband engaged in sexual affairs when he was ill told of the loss of the person she had known and trusted: “To this day I don’t trust him. I never will trust him again (R. 20).

8.4.2.5 Acceptance

Interviewees differentiated two aspects of acceptance; acceptance of the diagnosis of mental illness and acceptance of the implications of the diagnosis. We have seen that the medical diagnosis was readily accepted at the end of Stage 1, but acceptance of the implications of the diagnosis was slower and impeded by the cyclical nature of the illness, lack of knowledge and changes in the diagnoses.

None of the caregivers interviewed ($n=43$) reported that they disputed the initial professional diagnosis that their relative had a mental illness. One mother even told of her relief when her son’s illness was recognised: “You’ll probably think that I’m a bit strange, I know it sounds odd, but I felt better about that. I’m not saying I was happy that [son] was sick ... I didn’t feel like it was my fault any more” (R. 25).
Acceptance of the diagnosis of mental illness was independent of diagnosis of a specific mental illness. Thirty-three per cent of interviewees \((n = 14)\) said that there was a gap of one to five years between the first signs of mental illness and their receiving a specific diagnosis of type of mental illness. Another \(12\% (n = 3)\) reported five or more years before they received a specific diagnosis and a further \(8\% (n = 2)\) said that at no time had they received a firm diagnosis. For example, a father said, “Well we knew it was mental illness but nobody said exactly what it was and the psychiatrist wouldn’t talk to us” (R. 54). A mother reported, “We saw this woman psychiatrist out at [psychiatric hospital] and she said that she didn’t want to diagnose anything for twelve months because labels stick and we should wait and see” (R. 27). A daughter who was aware of her mother’s long-standing mental illness but not of the specific diagnosis reported, “Do you know, I didn’t know until a few years ago. I think one of the doctors just dropped it into the conversation, like – your mother’s disorder – and I said – What’s that? – and he said – Bi-polar disorder” (R. 56).

8.4.2.6 Factors Impeding Acceptance

Interviewees reported that although the fluctuating nature of the illness impeded acceptance, what further complicated and impeded acceptance was the lack of information about its implications and the changes in diagnoses.

Eighty-four percent of interviewees \((n = 36)\), told of how the fluctuating nature of their family member’s illness had impeded their acceptance of the illness. For example, one mother told of her expectation of cure: “After that first episode, when he came out of [psychiatric hospital] we thought he was cured but he wasn’t. It’s just gone on from there” (R. 27). Another related her experience of the fluctuating nature of the illness: “He was really good for about three years; we thought he was over it, and
then he had another breakdown” (R. 19). And another mother said, “For me, probably one of the most difficult issues for me has been just accepting what has happened; that is accepting it’s not going to get better” (R. 22).

Forty-two percent of interviewees (n = 18) said that their relative had received multiple diagnoses and this had affected their acceptance of the illness. For example, a son caring for his mother said, “They’ve come up with a dozen different ideas since then [initial diagnosis]. I used to think they’d find out what was wrong with her and we’d be home and hosed but it doesn’t happen like that does it?” A mother told of how professional disagreement about diagnosis affected acceptance: “I remember the therapist said, ‘And who said he had schizophrenia anyway?’... We were even more confused” (R. 22).

Acceptance of the full implications of mental illness was also hindered by caregivers’ lack of knowledge about the illness, its treatment and prognosis. In total 56% of interviewees (13 Parental, 7 Spousal and 2 Other caregivers) said that mental health professionals had failed to provide them with information about the illness. One wife angrily told of the effects of this lack of information provision: “He [husband’s psychiatrist] took this attitude that I didn’t need to know” and, “I didn’t even know that he needed to take his medication, his lithium, all the time, always” (R. 20). A mother said, “Nobody talked to us, yet we were the ones that had to look after her. I know it has something to do with confidentiality, but ...” (R. 41).

8.4.2.7 Crisis of Meaning

It was clear from interviewees’ responses that most had experienced a crisis of meaning. The majority of interviewees, 63% (n = 27) said that acceptance of their
family member’s illness caused them to question themselves, their relationships, values and beliefs.

In response to the question about what the illness has meant to them, two Parents (5% of interviewees) spoke of existential loss. Their responses included: “I’m not sure there is any meaning to life at all. Maybe it’s just all one big random event. You either get lucky or you don’t” (R. 23) and “What meaning? There isn’t any! That’s what it’s meant. It’s meant that I live my life without meaning” (R. 33).

Sixteen percent of interviewees ($n = 7$), six Parents and one Spouse, said that, as a result of the illness, they had lost belief in a fair and just world. The responses of two mothers illustrate this: “I get pretty down sometimes, it doesn’t seem fair” (R. 58) and “I suppose if you want to be philosophical about it, it’s meant that you can’t count on a fair shake in life. It’s meant life isn’t fair, people don’t get what they deserve” (R. 21).

Fourteen percent of interviewees ($n = 6$) all of whom were Parents spoke of initially experiencing a crisis of confidence and a loss of sense of self. One mother reported, “You can become very lost in this illness” (R. 44). Another mother said that initially she interpreted her son’s illness as a reflection of her parenting ability: “It seemed to mean that I was a failure as a mother” (R. 01).

A further 7 percent of interviewees ($n = 3$) all Parents, said the illness had caused them to question their faith. One mother said, “I know this, it’s lessened our faith. I don’t know how you reconcile the two. You’d like to think about a good and a loving God, what the church says, but, well this, it doesn’t fit does it?” (R. 22). Acceptance of their partner’s illness precipitated a crisis of decision for 16% of interviewees ($n = 7$). These interviewees, all wives or partners, spoke of grappling with the difficult decision of whether or not to remain in the relationship. For example,
one wife said, "I wouldn’t walk out on him when he’s so sick, not that I haven’t thought of it" (R. 48). Another reported, "It also made me question what I want in a partner" and "I keep thinking that I really want a partner more like my Dad; someone strong you can rely on. I have to decide whether to stay or go" (R. 39). At time of interview, three remained undecided and the remainder had decided to stay.

8.4.2.8 Stress Appraisal

The majority of interviewees, 95% \((n = 41)\) said that they considered this time to be particularly stressful. They rated their appraisal of stress on a scale of 1-10 where 1 represented not at all stressful and 10 represented extremely stressful and Table 7 shows their initial mean stress appraisals.

Table 7:

**Mean Stress Appraisal Scores at Stage 2**

<table>
<thead>
<tr>
<th>Interviewed Sample</th>
<th>((N = 43))</th>
<th>Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental ((n = 26))</td>
<td></td>
<td>9.48</td>
</tr>
<tr>
<td>Spouses ((n = 12))</td>
<td></td>
<td>8.66</td>
</tr>
<tr>
<td>Other ((n = 5))</td>
<td></td>
<td>6.7</td>
</tr>
</tbody>
</table>

All Parental caregivers \((n = 26)\) said that when they first became aware that their son or daughter was mentally ill they considered the situation to be extremely stressful. Their comments included: "It would have to be the most stressful thing that’s ever happened to us so far" (R. 30). Another added: "It might be thirty years ago but I can still recall how dreadful it was" (R. 52), and "It was probably the most stressful situation I’ve ever encountered" (R. 55) and "The world was collapsing around me" (R. 25).
The majority of Spousal caregivers, 83% \((n = 10)\), also reported high levels of stress at this stage, although slightly lower than those reported by Parental caregivers. Their responses included: “I was worried about him, but I had so much to worry about then. I was worried about what people might think and how we’d manage and ... you name it” (R. 20). Two wives (16%), with prior knowledge of their husband’s illness didn’t consider the situation to be particularly stressful initially. One wife reported, “I don’t think it was so stressful initially” and added, “I was more optimistic then” (R. 24).

The lowest initial stress appraisal scores were reported by interviewees caring for a parent or sibling. A daughter caring for her mentally ill mother explained, “I didn’t think of it as stressful then. Now I think about it that can’t be right. I really don’t know what to tell you” (R. 56).

Interviewees attributed their stress at this stage to lack of information about the illness, receiving changing diagnoses, blame, grief and fear of being stigmatised.

Twenty-six percent of interviewees \((n = 11)\) attributed the stress they experienced to their lack of knowledge about the illness and what they should be doing. For example one mother said, “I think, not knowing what to do but feeling like I should do something. That was stressful.” (R. 28). Another mother said, “It was stressful all right because we just didn’t have a clue what was going on” and “Things have changed, it’s different now, but then, nobody told us anything” (R. 19).

Twenty-six percent of interviewees \((n = 11)\) related their stress to concern for the welfare and safety of their family member. A mother reported, “Clearly he wasn’t safe” (R. 01), and a wife said, “He could have, you know, died that is” (R. 30).
8.4.2.9 Stage 2: Coping Responses

Quantitative data on caregivers' coping responses to the demands on caregivers at this stage are presented in Table 8. This table shows caregivers' mean scores and standard deviations on each of the eight Ways of Coping scales at initial recognition of mental illness and interviewees' narrative accounts of the coping strategies they adopted at this stage compliment these data.

Table 8:

*Initial Relative Scores (Means and Standard Deviation) at Stage 2 on each of the eight Ways of Coping scales*

<table>
<thead>
<tr>
<th>Way of Coping</th>
<th>M</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive Coping</td>
<td>13.00</td>
<td>3.82</td>
<td>60</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>13.88</td>
<td>4.30</td>
<td>60</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>10.24</td>
<td>4.95</td>
<td>60</td>
</tr>
<tr>
<td>Distancing</td>
<td>10.92</td>
<td>5.29</td>
<td>60</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>15.65</td>
<td>3.99</td>
<td>60</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>13.72</td>
<td>7.00</td>
<td>60</td>
</tr>
<tr>
<td>Escape/Avoidance</td>
<td>12.66</td>
<td>4.87</td>
<td>60</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>9.92</td>
<td>4.42</td>
<td>60</td>
</tr>
</tbody>
</table>

It can be seen that all caregivers used all eight ways of coping after they became aware of their family member's mental illness. To examine the initial importance of each of the eight scales, participants' three highest scores were coded and the frequencies for each of the three choices were added together to establish the total frequency with which each scale was highly endorsed. A percentage was then calculated to determine what percentage of participants chose a particular way of coping in any of their top three choices and Table 9 shows participants' selections.
Table 9:

*Frequencies and percentages of top three Ways of Coping at Stage 2*

<table>
<thead>
<tr>
<th>Way of Coping</th>
<th>Frequency</th>
<th>Percentage</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive Coping</td>
<td>20</td>
<td>33.33</td>
<td>60</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>32</td>
<td>53.33</td>
<td>60</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>13</td>
<td>21.66</td>
<td>60</td>
</tr>
<tr>
<td>Distancing</td>
<td>12</td>
<td>20.00</td>
<td>60</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>36</td>
<td>60.00</td>
<td>60</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>31</td>
<td>51.66</td>
<td>60</td>
</tr>
<tr>
<td>Escape/Avoidance</td>
<td>24</td>
<td>40.00</td>
<td>60</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>12</td>
<td>20.00</td>
<td>60</td>
</tr>
</tbody>
</table>

| Total:                    | 180       |            | 300|

From Table 9 it can be seen that Self Controlling coping, was the most frequently nominated strategy of the three most favoured ways of coping at Stage 2 being endorsed by 60 percent of respondents. Planful Problem Solving was the second most frequently chosen strategy being nominated by 53% of respondents, and Seeking Social Support the third, chosen by 52% of participants.

The relationship between the eight Ways of Coping and Caregiver/Care Recipient demographics at this stage is shown in Appendix M but interviewee’s accounts of their use of the three principal ways of coping at Stage 2 (Self-Controlling, Planful Problem Solving and Seeking Social Support) are reported here. It should be noted that 7% (n = 3) of interviewees defined coping in the vernacular sense; that is coping was equated with mastery of the situation, or with the ability to maintain equilibrium, and these caregivers spoke of their initial responses to the illness in terms of failure to cope. For example, one mother reported, “I got depressed, really
depressed. For a while there I couldn’t go to work. I could hardly get out of bed. I had to get treatment, medical treatment. Would you call that coping? Having to take antidepressants all the time? I don’t call that coping” (R. 23).

8.4.2.9a Stage 2 Coping Responses: Self-Controlling

The self-controlling behaviours that interviewees reported included hiding feelings from others and not letting them intrude, not acting hastily, and leaving things open.

Interviewee reports of initially concealing feelings from others were related to fear of negative evaluation and stigma, protecting the careee from further stress and according priority to the careee’s concerns. Forty-four percent of interviewees (n = 19) reported that initially they concealed their distress about the illness from others. For example, one mother said, “I didn’t let on that I’d been affected by it [diagnosis]. He was down enough already without me adding to it” (R. 28). A son caring for his mother said, “Anyway, there wasn’t much point dwelling on me. She was the one needing attention” (R. 29). A wife with prior knowledge of her husband’s illness said, “I didn’t let it affect me too much. I managed to keep optimistic for a long time” (R. 24).

Forty percent of interviewees (n = 17) related concealment of distress to fear of being stigmatised, and nine of these interviewees were wives. One wife reported, “I suppose I just wanted it to pass and to keep it quiet. I wanted to play it down. I think I’d gone in to protective mode, like putting my head in the sand. I suppose I was trying to protect both of us” (R. 20). One father told of controlling his anger over the psychiatrist’s dismissive treatment of him: “We weren’t going to argue with him. It was more important getting [son] back on his feet” (R. 54).
Deciding not to act hastily and to leave things open initially was related to a lack of knowledge about what should be done. Forty-two percent of interviewees ($n = 18$) said that initially they lacked knowledge about how they should respond. According to one wife, "I didn't know what to do or what I was supposed to do" (R. 20). One father reported, "I thought we had to find out more before we raced into doing anything" (R. 51).

Self-controlling coping had a weak negative correlation with the caregiver's employment status ($r = -0.26$), (Appendix M.), suggesting that caregivers engaged in full time employment use this way of coping slightly more frequently than others.

8.4.2.9b Stage 2 Coping Responses: Planful Problem Solving

The focus of the problem solving responses that interviewees reported at this stage of encounter with mental illness was upon obtaining treatment for the care recipient and obtaining knowledge about the illness for themselves.

Thirty-five percent of interviewees reported actively seeking information about their family member's condition, and 16% ($n = 7$) said that at this stage they consulted more than one doctor seeking a cure for the illness. Their responses included: "I asked, I asked people, I quizzed the doctors, the hospital, I got the ear of a couple of friends that are medicos. I didn't just let it go" and, "I read, I read everything I could get my hands on" (R. 21). A father, frustrated at the lack of information provision, reported, "I did my own research into it. I read books and pamphlets on it" (R. 32).

A further 9% ($n = 4$), of interviewees, consisting of two wives, one parent and one sibling, reported drawing on their past experience of mental illness at this stage. One mother related, "Actually this is my second time around. This is my second son with mental illness" adding, "I knew what was in store for us" (R. 23).
Extent of care provision had a weak positive correlation \( (r = .30) \), with Problem Solving, (Appendix M.), suggesting that part time caregivers use this way of coping more frequently than full time caregivers.

8.4.2.9c Stage 2: Coping Responses: Seeking Social Support

The support provided by partners, family members, friends and work colleagues was cited as the major initial source of assistance by 81% of interviewees \( (n = 35) \), 22 Parental, 10 Spousal and 3 Other caregivers. Families provided 93% of all initial social support and the support they provided was of both a practical and emotional nature. For example, a wife said, "The main source of support was my family. They helped out from time to time with money and food and with support" (R. 36) and another stated, "I don't know what I would have done without her [mother]. She's been a rock" (R. 60).

There was a weak negative correlation, (Appendix M), between Seeking Social Support and the years since diagnosis, \( (r = -.31) \), the years since the first signs of mental illness, \( (r = -.36) \), care recipient's age \( (r = -.30) \).

8.4.2.10 Summary regarding Stage 2 Hypotheses

Although recognition of mental illness was sudden for some caregivers, it was gradual for the majority. Nevertheless, what happened provided only partial support for Spaniol and Zipple's model: the gradual recognition of mental illness and its acceptance was more determined by the inability of caregivers to obtain a firm diagnosis than by overcoming denial. Recognition and acceptance was virtually immediate and independent of the type of mental illness once the diagnosis was made.
Acceptance of the implications of the illness was another matter, almost a separate process, and was much more gradual, being not only on the fluctuating nature of the illness but also on the lack of information about it and its prognosis, and the changes in diagnosis.

Once recognition occurred, the expectations of caregivers were as Spaniol and Zipple proposed: professionals were expected to have the answers about treatment, cure and prognosis. Also, in accord with Spaniol and Zipple's model, the majority of caregivers confirmed that they experienced blame or self-blame linked to feelings of guilt and embarrassment, which were linked to fear of stigmatisation. In these respects the hypotheses were confirmed.

However, a deep sense of loss of the person they had once known was reported by 42% of interviewees, all of whom, except one, were Parental caregivers, so that the hypothesis was only partially confirmed. Similarly, although the majority of caregivers did experience a crisis of meaning, the relationship to the care recipient affected the experience and the issues involved. The Parental caregivers were most affected, and in several different ways, the issues were very different for the Spousal/partner caregivers and none of the Other caregivers even reported experiencing the crisis.

Stress appraisals showed that the point at which caregivers first recognised that their relative had a mental illness was extremely stressful. Responses to the Ways of Coping questionnaire and interviewees' narratives showed that adaptive coping continued throughout this stage of encounter with mental illness and was focussed upon their stated goals of managing their emotional responses to the illness, obtaining treatment for the family member and information for themselves.
8.5 Stage 3: Coping

According to the Spaniol and Zipple model, coping begins at this stage when grieving ends. The issues that caregivers have to cope with include a loss of faith in professionals, inadequate care provision, disruption to family life, recurrent crises and feelings of pessimism and despair with which they cope by accepting the limits of what they can accomplish, valuing their own expertise and the support of other caregivers. The focus of coping is upon symptom management, improving their relative's functioning, inpatient care and community services, and finding professionals they can work with.

Quantitative and qualitative data relevant to this stage in the evolution of caregiver responses to mental illness is reported here.

8.5.1 Coping and Grief

It was apparent from interviewees' narratives that grieving and coping were quite independent processes and that coping was not dependent on the resolution of grief, rather the two processes occurred concurrently.

The grief that interviewees reported appeared to be chronic. None of the interviewees who spoke of grieving the loss of their family member said that they no longer grieved. Responding to a question about how they currently felt about their relative's illness, 21% of interviewees (n = 9), six Parents and three Spouses told of their continuing sadness. As one mother said, "I still grieve. I feel worst, absolutely the saddest when I get an occasional glimpse of what she used to be. It reminds you of what you've lost" (R. 44). Another mother commented, "You know, I think the worst thing of all was the sadness. It still is, it never goes away" (R. 02). Yet another commented, "It just still upsets me; I imagine it always will. It's not something you get
over” (R. 21). All of those who spoke of continuing grief were also concurrently coping with a range of other issues that they encountered.

8.5.2 Loss of Faith in Professionals

Interviewees told of a loss of faith in mental health professionals and related it to their dissatisfaction with changing diagnoses. Inadequate or inappropriate treatments, poor communication with professionals and even the abuse of their relative whilst in the care of the mental health system were further sources of dissatisfaction. They also told of service system deficits that affected their faith in the ability of the system to adequately provide care.

Changing diagnoses affected caregivers’ confidence in mental health professionals. Following the first diagnosis, 72% of interviewees (n = 31) reported receiving at least one more diagnosis and these changing diagnoses affected caregivers’ confidence in mental health professionals. One mother said, “Initially I put my trust in the medical system. That was a bad mistake. I thought their powers of diagnosis were better than they were. He’s had multiple diagnoses over the years” (R. 55). A husband angrily reported, “No wonder I’ve got no respect for them. First it’s panic attacks and then post-natal depression and then its schizophrenia and manic depression, and now? Now it’s schizo-affective and she’s still sick, no better at all thanks to their treatment. In fact, she’s worse than ever” (R. 26).

Dissatisfaction with inappropriate or inadequate treatment received by their family member was expressed by 40% of interviewees (n = 17), 11 Parental, five Spousal and one Other caregiver. For example a mother related, “He [psychiatrist] was using deep sleep therapy and he put her in to hospital and put her to sleep for hours on end” and, “I didn’t know it was an outdated treatment”
A wife cited lack of treatment continuity as a source of dissatisfaction: “You’d start off on a new treatment and you’d think to yourself – this time they’ve got it right – and then they’re gone [treating doctor] and you start all over again with someone else” (R. 24). An inappropriate early release from hospital prior to recovery also caused a loss of faith in treating professionals: “If you do get him in to hospital, he’s out again before he’s properly treated. That’s been our experience; you’re on your own” (R. 43).

Being treated with disrespect by mental health professionals was recalled by another 16% of interviewees \( (n = 7) \), six Parents and one Spouse. For example, one mother said, “He [caseworker] talks to me like I’m an idiot or something, so I don’t have much to do with him” (R. 58).

Finally, 7% of interviewees \( (n = 3) \), 2 Parents and 1 Spouse, reported that their relative had been abused whilst in care and expressed extreme anger and loss of faith in mental health professionals. A mother reported her daughter had been sexually abused whilst in care and a husband reported the abuse of his wife: “Back then, back when she was in [clinic] the psychiatrist interfered with her. I feel pretty bad about that because when she told me, at first I didn’t believe her” (R. 26). A mother reported being informed that her daughter was in hospital after an “accident”: “I talked to the doctor and he was being what I’d call caggy. He was being very careful about what he said to me, but I got the impression that he didn’t think it was an accident either but he wasn’t going to do anything about it” (R. 35).

A different category of issue was provided by the service system deficits reported by 49% of interviewees \( (n = 21) \). This group comprised 12 Parental, 7 Spousal and 2 Other caregivers and the deficits they spoke of included both a lack of services and difficulty in accessing them. One wife living in a country area reported, “The biggest problem here [rural area] is that the services aren’t available unless you
move in to town” (R. 24). A husband complained of limited services: “Try ringing the emergency number on a Saturday night, see if you get an answer. There’s no answer. They don’t even answer the phone” (R. 26). All who experienced these deficits expressed anger and frustration, except one who expressed resignation. Lack of and inaccessibility of services were appraised as a challenge by 79% of those who encountered this issue, and a threat by the remaining 21%. Although both urban and rural caregivers reported service system deficits, this issue was more prevalent in the narratives of rural caregivers who made up 24% of those reporting deficits.

8.5.3 Disruption to Family Life

The narrative accounts of interviewees confirmed that an extensive number and variety of situational stressors disrupted family life but it is unclear if these only occurred at this stage. These included care-recipients’ difficult and/or potentially harmful behaviours as well as strained or broken family relationships. All interviewees (n = 43), across all kinship groups, therefore reported coping with more than one disruptive behaviour.

Coping with distressing, demanding or odd behaviours was reported by 79% of interviewees, (n = 34), 21 Parental, 10 Spousal and 3 Other caregivers who had encountered withdrawal, sleep disturbance, irritability, verbal abuse, excessive spending, and promiscuity and told of the anger, frustration, irritation and embarrassment they experienced. Most of these behaviours were appraised as challenging, however excessive spending and promiscuity were appraised as threatening to financial security or to the marital relationship. One story vividly illustrates the disruptive nature of these behaviours: “Just the other week the dog attacked the chook, [chicken] right? and [brother-in-law] puts the chook in the house
and the dog outside. Can you make any sense of that? Then there's the racket he makes. The stereo's going full pelt, the dog's yapping and the chook's shit ting everywhere in the house. There's chaos and the neighbours complained and that sort of thing happens all the time" (R. 47).

Behaviours that were potentially harmful to the care recipient and disruptive to family life were reported by 60% (n = 26) of interviewees, comprising 15 Parental, 6 Spousal and 5 Other caregivers. They told of coping with their relative's careless or unsafe behaviours, such as erratic driving, smoking in bed and treatment non-compliance and said they experienced fear, anxiety and anger. The majority of interviewees appraised these behaviours as threatening to the care recipient's well being and only two caregivers regarded them as challenging.

Treatment non-compliance was the most frequently reported disruptive issue that caregivers encountered and was reported by 47% (n = 20) of all interviewees and was the cause of confrontations and arguments. One wife's report illustrates this point: "He didn't want to take it [medication] and we ended up having terrible blues about it" (R. 48).

Forty-four percent of interviewees (n = 19), 15 Parents and four Spouses, all wives, said that their relative's irritability or verbal abuse had disrupted family life. For example, a father said: “He's either not talking to you or when he does you wish he wouldn't bother. He's got a mouthful of abuse for you” (R. 51). A wife reported, "He was angry and argumentative all the time. You couldn't look sideways at him but he'd pick a fight" (R. 30).

Disruption to marriages and family relationships was reported by 44% (n = 19) of interviewees, 9 Parental, 6 Spousal and 4 Other caregivers, all of whom told of the strain the illness had placed on their relationships. For example, a son caring for his
mentally ill mother reported, “You mightn’t think so but I was married once. You
know [laughs] you could say that Mum put paid to that” (R. 29). A mother reported, “It
meant the end of my marriage” (R. 21). Family relationships were affected when some
family members withdrew or absented themselves and one mother’s comments about
her eldest son were typical: “We never see him. He doesn’t want anything more to do
with us. He made that clear” (R. 06). A father added, “It’s broke up the family. Yes it
has! It’s affected the boys, they both left home early. They weren’t sticking around”
(R. 26).

8.5.4 Recurrent Crises

The recurrent crises that interviewees spoke of were linked to fluctuations in the illness
and care recipient behaviours such as absconding, substance abuse, suicide threats or
attempts, and aggressive behaviours such as property destruction or actual physical
assault. These behaviours were appraised as threatening by the majority of caregivers,
with the exception of property destruction which was appraised as challenging by seven
of those coping with this issue.

Seventy-nine percent of interviewees (n = 34), 22 Parental, ten Spousal and two
Other caregivers, described recurring psychotic episodes necessitating additional
treatment or hospitalisation. One wife said, “It all runs together; hospital, home, back
to care of the G.P., psychiatrists. We’ve had years of it” (R.20).

Thirty percent of interviewees (n = 13) nine Parental, three Spousal and one
Other caregiver, reported recurrent crises related to their relative’s disappearance. A
mother said, “He’d disappear for days at a time. I didn’t know where he was” (R. 58)
and another related, “He could have been dead for all we knew” (R. 01).
Thirty three percent of interviewees \((n = 14)\), 12 Parents and 2 Spouses, (both wives), spoke of the care recipient’s substance abuse. Parents told of the use of illegal substances, alcohol or both, whilst the two wives told of alcohol abuse. A mother related, “We had any number of confrontations about his drinking and bringing drugs in the house and they all turned nasty” (R. 43).

Forty four percent of interviewees \((n = 19)\), 11 Parental, 7 Spousal and 1 Other caregiver, spoke of coping with suicide attempts, threats or potential. All, except one, said these issues caused them to feel anxious and fearful and two reported also feeling angry. For example, “It was terrifying, I was sure he’d end up killing himself” (R. 39).

Nineteen percent of interviewees, \((n = 8)\), all Parents, reported recurrent crises related to property destruction. One mother reported, “He’d get frustrated and wreck ... he’s wrecked things; deliberately destroyed things around the place when he’s in that mood” (R. 21).

Twenty-six percent of interviewees, \((n = 11)\), nine Parents and two Spouses, (both wives) said they had been physically assaulted by their relative and the severity of that assault ranged from relatively minor [face slapping] to severe and life threatening, necessitating hospitalisation of the caregiver. In accordance with the severity of the assault, they told of experiencing a range of emotions from anger to extreme fear and in one case developing Post-Traumatic Stress Disorder. For example, one mother told, “She’d hit me if I went in to her room” (R. 52). A further 9\% \((n = 4)\), two Parental and two Other caregivers, said that their relative had assaulted another family member, acquaintance or other person. A son reported, “I used to pay the old bat next door to keep an eye on her of a day but that didn’t work out too good. She said Mum hit her” (R. 29).
8.5.5 Additional Issues

Interviewees reported encountering issues that appeared to be additional to those proposed by the Spaniol and Zipple model; experiencing and losses other than loss of the person known.

8.5.5.1 Stigma

Although 28% \((n = 12)\) of interviewees indicated that they continued to fear that they could be stigmatised if their relative's illness became known in the community, 12% \((n = 5)\) said that they had actually been stigmatised. These caregivers also appraised the stigmatisation in terms of harm/loss that had been suffered by the whole family.

For example, a mother reported, "[Older son] was going out with this girl and her parents put a stop to that. They stopped it when they found out about the ... about [brother's] schizophrenia" (R. 19).

8.5.5.2 Loss

Interviewees reported encountering more issues than those proposed in the Spaniol and Zipple model. These included losses other than loss of the person once known. Some form of loss was experienced by every one of the interviewees \((n = 43)\) and these losses were invariably appraised in terms of harm/loss. Eighty-eight percent \((n = 38)\) of caregivers responding to the question, "What has this illness meant to you?" defined the illness in terms of loss. For example, "I suppose that's one thing it has meant is multiple losses; but you have to work your way through that" (R. 21). The losses reported were extensive and affected many areas of caregivers' lives as well as the continuing experience of loss of the person once known.
The responses of two interviewees illustrate this point: “It’s affected just about everything in my life ever since” (R. 29) and, “No husband, no job, no money, no friends and every few months my only child tries to kill me” (R. 33). Loss of sense of self worth and confidence was an issue reported by 9% of interviewees (n = 4), one Parent and three Spouses. For example, one wife reported, “You can become very lost in this illness” (R. 44).

Financial loss was reported by 19% of interviewees (n = 8), four Parental, three Spousal and one Other caregiver. These losses derived from either the caregivers’ or care-recipient’s loss of career, their relative’s excessive spending or, in one case, from the expense of replacing property destroyed by the care-recipient. Reflecting upon her partner’s excessive spending, one wife said, “Keeping my head above water; that’s one thing. It’s cost us over the years; of course it’s cost us. We’ve lost money” (R. 26). Another wife reported, “We were going to have a trip back to England and maybe go up to Queensland to visit [son] for a bit. That’s all off now. It won’t happen because the money’s not there any more; it’s all gone” (R. 30). A father told of the expense of repairing the damage his son caused to the family home: “It cost over $14,000 to fix up the place after him” (R. 08). Speaking of the loss of career, a son claimed, “If this hadn’t happened, I’d still be there [Army] now” (R. 29). A mother reported, “It got so I couldn’t sleep and I couldn’t keep my mind on the job. I’ve had to give up work” (R. 33).

Thirty five percent of those interviewed (n = 15), 11 Parental and four Spousal caregivers, reported the loss as that of their own physical and mental health. Thirty five percent of those interviewed (n = 15), 11 Parents and four Spouses, reported loss of physical and mental health as a result of the illness. They claimed that the stress of caring for their relative had had a detrimental effect upon their physical and mental
well being. Their responses included: “I think it’s affected both [husband’s] and my health. I wouldn’t be surprised if it hasn’t shortened our lives” (R. 27).

Another mother reported, “I’m tired. It wears you out” (R. 02). Clinically significant conditions were reported. Loss of mental health included reports of anxiety and depression: “My nerves are shot and I had to ... I got ... the doctor gave me sleeping pills and something for the depression” (R. 33). In the most extreme example, one wife reported developing post-traumatic stress disorder following severe assault.

The loss of future children or grandchildren was mentioned by 7% of interviewees (n = 7), two Parental and one Other caregiver, a son caring for his mentally ill mother. A mother described how her well daughter’s decision not to have children because of her sister’s illness meant: “I’ll never have grandchildren and that saddens me” (R. 52). A male caring for his mother regretfully discussed his decision to remain childless: “That’s what eternal life is, passing your dreams on to your kids. That’s the meaning of life, not all this other stuff people go on about. It’s about future generations. The rest, well, who knows” (R. 29).

Fourteen per cent of interviewees (n = 6), four Parental, one Spousal and one Other caregiver, claimed that they had lost part of their life to the illness and told of losses related to their emotional response to the illness or the demands of care provision. For example, one mother related, “It’s meant that I’ve spent, you could say wasted, years being angry about how unfair it all is” (R. 01). According to another mother, “It meant that a big chunk of my life was lost to sadness and grief” (R. 21). One father told of how providing care had affected his retirement: “We’re not free like we thought we would be” (R. 41).

Five percent of interviewees (n = 2), told of their experience of dislocation when the illness necessitated leaving their home. A mother who had relocated to a
country town to remove her daughter from an unsafe environment said, “It’s meant I’m a prisoner, a homeless displaced person. I’d prefer to be here [Melbourne] but I can’t take the risk” (R. 06). The second, a wife, told of leaving the family farm and relocating in a rural city to ensure access to services: “It’s gone now and we’ll probably never go back there now. It makes me sad just thinking about it” (R. 24).

8.5.6 Valuing the Support of Other Families

Interviewees’ responses to the question “What helps you to cope now” indicated that the support of other caregivers was valued by some but not all caregivers. Thirty-seven percent of interviewees (n = 16) said that a caregiver support group was now their main source of social support: “It’s been the main support in my life” (R. 02) and, “You could say they’ve been a life saver for me” (R. 21). The support of other caregivers was more frequently reported as valued by Parents. Fifty-four percent of Parents mentioned this source of support in comparison to 17% of Spouses and none of the Other caregivers.

8.5.7 Current Focus of Concern and Goals

The current focus of interviewees concerns are reported in Table 10 which shows their goals by kinship relationship to the care recipient.
Table 10:

Goals at Stage 3 by Kinship Relationship to Care Recipient

<table>
<thead>
<tr>
<th>Goals</th>
<th>Parents n = 26</th>
<th>Spouses n = 12</th>
<th>Other n = 5</th>
<th>% of Total N = 43</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cure</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>02</td>
</tr>
<tr>
<td>Treatment/Care</td>
<td>9</td>
<td>2</td>
<td>-</td>
<td>26</td>
</tr>
<tr>
<td>Future Care</td>
<td>3</td>
<td>2</td>
<td>-</td>
<td>12</td>
</tr>
<tr>
<td>Coping</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Accommodation</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>05</td>
</tr>
<tr>
<td>Improve System</td>
<td>7</td>
<td>1</td>
<td>-</td>
<td>19</td>
</tr>
<tr>
<td>Maintain relationship with care recipient</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>05</td>
</tr>
<tr>
<td>Self-care</td>
<td>11</td>
<td>11</td>
<td>2</td>
<td>56</td>
</tr>
<tr>
<td>Improve relationship with Professionals</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>05</td>
</tr>
</tbody>
</table>

*Note: 26% of Interviewees nominated more than one goal.

It can be seen from Table 10 that, as compared with the data in Table 6, the current goals differ from those initially reported in that caregivers now recognise their own needs as well as those of the care recipient. They also show a concern with improving the mental health system, an issue that Spaniol and Zipple locate in their fourth stage, and with improving relationships with professionals.

8.5.8 Improved Relationships with Professionals

Fifty-three percent (n = 23) of those interviewed told of improved or more satisfactory relationships with treating professionals. For example, one wife said, “Now we’ve got a pretty good doctor here. He’s good, he listens and he does what he can. He’s been really helpful” (R. 24). Three of those who told of improved relationships with
professionals qualified their remarks. One mother told, “Some of them will talk to you but that’s not true of all of them” (R. 27). A father said, “We still don’t have the sort of relationship we would like to have with his psychiatrist yet. We’d like to get some improvement there, but in the main things are a lot better than they were” (R. 54).

Another wife said, “I’ve found that having a good social worker or caseworker’s most important. They’re not all the same you know, they vary” and added “Another thing, you want to be on good terms with the CAT team [Crisis Assessment and Treatment team] too, so they’ll be there when you need them” (R. 36).

8.5.9 Stress Appraisal

Interviewees of all kinship relationships reported decreased appraisals of stress over time and Table 11 shows their current mean stress appraisals in Stage 3.

Table 11:

Comparison of Mean Stress Appraisals at Initial Recognition and Currently by Kinship Relationship.

<table>
<thead>
<tr>
<th>Interviewed Sample (N = 43)</th>
<th>Mean Score Stage 2.</th>
<th>Mean Score Stage 3.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents (n = 26)</td>
<td>9.48</td>
<td>6.75</td>
</tr>
<tr>
<td>Spouses (n= 12)</td>
<td>8.66</td>
<td>6.75</td>
</tr>
<tr>
<td>Other (n = 5)</td>
<td>6.70</td>
<td>5.90</td>
</tr>
</tbody>
</table>

A paired sample t-test showed a statistically significant difference between Stage 2 stress appraisals, when caregivers first recognised their family member’s illness and Stage 3, current stress appraisals, t (31) = 4.78, p < .01. This indicated that all interviewees appraised the situation as significantly less stressful now than when first recognised.
A one-way, between-groups, ANOVA tested for differences in the Stage 2 and Stage 3 stress appraisals of caregivers of different kinship relationships. A statistically significant difference at the .05 level was found between groups at Stage 2, \( F(2, 41.24) = 21.75, p < .05 \). Post-hoc comparisons using the Student Newman-Keuls test indicated that the mean initial stress score of Other caregivers, \( M = 4.75, SD = 3.30 \) was significantly lower than that of Parental caregivers \( M = 9.69, SD = .68 \) and Spousal caregivers \( M = 8.63, SD = 1.46 \) at Stage 2. Although Other caregivers initially appraised the situation to be significantly less stressful than either Parental or Spousal caregivers that appraisal changed over time and no significant differences in current stress appraisals were found between groups at Stage 3.

8.5.10 Stage 3: Coping Responses

Quantitative data comparing the Means and Standard Deviations of caregivers’ Relative scores on each of the eight Ways of Coping scales across time is shown in Table 12. High scores are indicative of high utilisation of that way of coping.
Table 12:

Comparison of Stage 2 (Initial) and Stage 3 (Current) Relative Scores (Mean and Standard Deviations) on each of the Ways of Coping Scales

<table>
<thead>
<tr>
<th>Way of Coping</th>
<th>M</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive Coping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>13.00</td>
<td>3.82</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>10.92</td>
<td>3.10</td>
<td>60</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>13.88</td>
<td>4.30</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>16.34</td>
<td>3.79</td>
<td>60</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>10.24</td>
<td>4.95</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>9.03</td>
<td>3.73</td>
<td>60</td>
</tr>
<tr>
<td>Distancing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>10.92</td>
<td>5.29</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>12.04</td>
<td>3.75</td>
<td>60</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>15.65</td>
<td>3.99</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>15.44</td>
<td>3.64</td>
<td>60</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>13.72</td>
<td>7.00</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>14.86</td>
<td>5.66</td>
<td>60</td>
</tr>
<tr>
<td>Escape/Avoidance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>12.66</td>
<td>4.87</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>8.92</td>
<td>3.69</td>
<td>60</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>9.92</td>
<td>4.42</td>
<td>60</td>
</tr>
<tr>
<td>Current</td>
<td>12.43</td>
<td>4.52</td>
<td>60</td>
</tr>
</tbody>
</table>
It can be seen that caregivers continued to use all of the eight ways of coping both initially and currently. The scores were examined to determine if a statistically significant change in coping changes over time. Repeated measures MANOVA, with time (initial and current) as the within-subjects variable revealed a significant difference between Ways of Coping scale scores at Stage 2 and Stage 3 (Wilks = 0.459, $F(7,53) = 8.932$, $p < 0.01$, Effect size 0.541).

Individual univariate tests showed a significant decrease in Confrontive Coping scores $F(1, 59) = 13.99$, $p < 0.01$, Effect size = 0.19 and in the Escape/Avoidance scores $F(1, 59) = 45.81$, $p < 0.01$, Effect Size = 0.44 over time. These tests also revealed a significant increase in Planful Problem Solving, $F(1, 59) = 24.19$, $p < 0.01$, Effect Size = 0.29, and in Positive Reappraisal, $F(1, 59) = 20.56$, $p < 0.01$, Effect size = 0.26. Accepting Responsibility, Distancing, Self-Controlling, Seeking Social Support did not change significantly over time. The results appear to indicate that caregivers develop problem solving skills and cognitive strategies that lead to less confrontation and avoidance.

The three most frequently favoured Ways of Coping scores were coded and the frequencies for each of the three choices were added together to establish the total frequency with which each scale was endorsed. A percentage was then calculated to determine what percentage of participants chose a particular way of coping in any of their top three choices and is shown in Table 13.
Table 13:

Comparison of Frequencies and Percentages of Top three Ways of Coping at Stage 2 (Initial) and Stage 3 (Current) (N = 60)

<table>
<thead>
<tr>
<th>Way of Coping</th>
<th>Initial</th>
<th>Current</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percentage</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>20</td>
<td>33.33</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>32</td>
<td>53.33</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>13</td>
<td>21.66</td>
</tr>
<tr>
<td>Distancing</td>
<td>12</td>
<td>20.00</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>36</td>
<td>60.00</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>31</td>
<td>51.66</td>
</tr>
<tr>
<td>Escape/Avoidance</td>
<td>24</td>
<td>40.00</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>12</td>
<td>20.00</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>180</strong></td>
<td><strong>300</strong></td>
</tr>
</tbody>
</table>

From Table 13 it can be seen that there was a change in the three most favoured ways of coping between Stage 2 and Stage 3. Accepting Responsibility, Confrontive Coping and Escape/Avoidance decreased over time whilst Planful Problem Solving, Distancing, Seeking Social Support and Positive Reappraisal increased. Initially only 53% of caregivers chose Planful Problem Solving in their top three coping strategies and currently 76% of caregivers selected this way of coping. Seeking Social Support was the second most frequently chosen current strategy, being nominated by 63% of respondents, and Self-Controlling the third remained the same over time and was chosen by 60% of participants.

The relationship between Ways of Coping at Stage 3 and the demographic data for Caregivers and Care Recipients is shown in Appendix N.
Here data derived from interviewees’ narrative accounts of their adaptive coping strategies is reported in relation to the three most favoured ways of coping identified at this stage by the Ways of Coping Questionnaire: Planful Problem Solving, Seeking Social Support and Self-Controlling Coping.

8.5.10.1 Planful Problem Solving

Interviewees reported using a variety of different problem solving strategies to cope with the difficult and distressing issues they encountered.

Twelve percent of interviewees (n = 5) told of planning activities to engage care recipients who were withdrawn. For example, one mother reported arranging for a volunteer worker to visit: “We’ve got son on to that [Visitor Scheme] and that’s been another positive” (R. 22). This mother also spoke of obtaining a pet for her son: “He loves Oscar [the cat]. Even when he doesn’t want to be with us he’ll spend time with Oscar” (R. 22).

Nineteen percent of interviewees (n = 8) said they had planned and implemented responses designed to change odd and distressing behaviours. One wife reported, “His caseworker, she told us that we have to help him by setting limits and by being consistent and by not putting up with whatever. It would have been better for all of us if we’d done that from the start” (R. 36).

Seven percent of interviewees, all of them Spouses (n = 3), two wives and one husband, said they had coped with their partner’s excessive spending by assuming control of the family finances. The husband said, “I took over the money side and we’ve managed somehow” (R. 26). Another wife found employment to ensure the family’s financial stability.
Fourteen percent of interviewees (n = 8) used problem solving strategies to cope with their relative’s absconding. The strategies included conducting a search and advising the police of their disappearance. One mother told, “I tried locking him in, locking him in his room; it didn’t work though” and added, “I got smart to him, I figured out, I got to know where to go look for him” (R. 58).

Substance abuse was less successfully coped with by using problem solving strategies. One mother relocated to a country town to limit her daughter’s access to drugs: “Now we stay up in [country town] because she’s safer there” (R. 06). Five Parents told of unsuccessfully setting limits. For example, a mother told, “I tried to set limits, someone suggested I should do that. I told her she couldn’t stay if she kept on smoking [marijuana] so she moved out but that didn’t work and she came back. I couldn’t just turn her away” (R. 44). Only two interviewees, both wives, said they had been successful in limiting their husband’s consumption of alcohol.

Twenty one percent of interviewees (n = 9) used problem solving strategies that included obtaining additional treatment and vigilance to cope with actual or potential suicide. Seven Parents and two Spouses (both wives) sought treatment: “We got him to hospital and they pumped his stomach out” (R. 21). Three interviewees, two Parents and one Spouse (a husband) said they coped with the threat of suicide by maintaining vigilance. For example, one Spouse (a husband) reported, “We didn’t leave her on her own ever” (R. 45). A father said, “We still watch him pretty careful. It’s hard to say if he’s going to try that again. He gets a bit sick of us checking up on him all the time but he’s brought it on himself” (R. 51).

All interviewees who reported encountering aggressive behaviours used problem solving strategies that included seeking emergency services intervention, obtaining an intervention order, relocating the care-recipient, securing the home,
restraining and seeking additional treatment. One mother told, “We’ve had times when we had to call the police or the CAT team. Once or twice we had to get out of the house in the middle of the night” and added, “After we talked to his caseworker we helped him get somewhere else to live” (R. 27). Another mother said, “He wouldn’t go so we went to Court and got an order to restrain him, for whatever good that does. When he’s like that he pays no attention to it at all” (R. 43).

Planful Problem Solving at this stage was correlated with caregiver’s educational level, \( r = .33 \), suggesting that caregivers who are better educated are more likely to use this way of coping. (Appendix N)

8.5.10.2 Seeking Social Support

Responses to the question, “What helps you to cope now?” indicated that social support remained an important source of support throughout all stages of encounter with mental illness and increased over time. Seventy-nine percent of interviewees \( n = 34 \) nominated social support as currently helpful to their coping, however the source providing that support changed over time. The support provided by families decreased from 93% of total support reported initially to 82% currently and 37% of interviewees \( n = 16 \), now cited a caregiver support group as their main source of social support.

Seeking social Support again had a weak correlation with the three demographic variables reported at Stage 2; age of care recipient, \( r = -.26 \), recency of diagnosis \( r = -.31 \), and recency of signs of illness, \( r = -.26 \). The results suggest that those caring for a younger care recipient with recent signs of illness and recent diagnosis are more likely to seek social support. (Appendix N)
8.5.10.3 Self-Controlling Coping

The self-controlling coping behaviours that interviewees reported currently using were related to coping with unwanted negative feelings of grief, despair and continuing fear of stigma. They told of coping with stigma by keeping their feelings to themselves and of keeping their feelings from interfering with their ability to provide care. Negative feelings were controlled by maintaining a positive attitude, and by obtaining treatment for themselves.

Twenty-one percent of interviewees (n = 9) 5 Parents and 4 Spouses, said they were still concerned about the possibility of stigmatisation and coped by concealing their feelings. Two of these, a wife and a mother doubted that talking about their feelings would help. For example, one wife said, “I’m glad I didn’t tell anyone the whole story. At least I could keep my pride and not have people feeling sorry for me” (R.20). A parent added, “Anyway sometimes it doesn’t help that much talking about it, you just get bogged down in self pity” (R. 19).

Twenty-three percent of interviewees (n = 10), six Parents and four Spouses told of obtaining medication or seeking counselling to assist in controlling their feelings of anxiety and depression. A mother told, “I’m still taking anti-depressants and I’ve just got this new one” (R. 52).

Seventy-two percent of interviewees (n = 31), 20 Parental, 8 Spousal and three Other caregivers spoke of keeping their feelings from interfering with their ability to provide care by maintaining a positive attitude and a sense of humour to counteract feelings of despair. For example, a mother said, “I try not to be negative, not to focus on it [illness]” and added, “I try to focus on the positive. I look for something positive everyday” (R. 22). A father reported, “I look for ways to be happy and to rejoice in the world as it is. Every day I remind myself that it’s OK to whistle on the way to a
funeral” (R. 49). A mother spoke of the need to maintain a sense of humour: “You’ve
got to laugh at it, otherwise you’d go mad” (R. 19). Another mother added,
“Sometimes that’s all you’ve got left is a sense of humour” (R. 27).

Self-controlling coping had a weak negative correlation with care recipient’s
current condition, \( r = -0.27 \), indicating that the more stable the care recipient the more
likely the caregiver to engage in self controlling coping. (Appendix N)

From interviewees’ accounts of their adaptive coping strategies at Stage 3 it
appeared that two further coping strategies, Positive Re-appraisal, and generating
Positive Affect had an important bearing upon controlling negative feelings and data
relevant to these strategies are reported here.

8.5.10.4 Positive Affect and Positive Reappraisal

From accounts of the adaptive coping strategies used at Stage 3 it appeared that two
further coping strategies, generating Positive Affect and Positive Re-appraisal were
important in controlling negative feelings. Data relevant to these strategies are
reported here.

8.5.10.4a Positive Affect

Forty percent of interviewees \( n = 17 \) deliberately engaged in activities that generated
positive affect such as exercise or sporting activities, “The only relief I got was on the
tennis court” (R. 28), or listening to music “I call it Mozart at midnight” (R. 06). Four
interviewees said that their employment generated positive affect: “I don’t take mental
health days off. I go in to work for my mental health days” (R. 01), and “It’s like stress
relief for me to get in to work … It’s as good as a holiday” (R. 24). The remainder
spoke of reading, watching television, listening to the radio, gardening, shopping,
dining out and playing bingo. Most told of engaging in more than one of these activities.

8.5.10.4b Positive Reappraisal

There appeared to be a connection between controlling feelings of grief and despair and positive reappraisal. Eighty eight percent ($n = 38$) of the interviewees who told of coping with loss paired their narrative with an account of one or more benefits derived from the situation. The benefits discussed included improved relationships, deepened faith, and enjoyment of the caregiver role.

Sixteen percent of interviewees ($n = 7$), 6 Parents and one Spouse said that the family had become closer as a result of the illness. For example, one father told of an improved relationship with his sons: “There’ve been some positive benefits in the way they relate to us. It’s brought us closer together as a family” (R. 34).

Twenty-six percent of interviewees ($n = 11$), four Parental, six Spousal and one Other caregiver, spoke of uplifts in the relationship. For example, a wife said, “He’s such a sweet, nice man when he’s not ill” (R. 40). A mother added, “I like having him here when he’s well” and, “I think I’ve relied on him for company” (R. 28).

Five percent of interviewees ($n = 2$) said that their faith had increased as a result of the illness. One mother said: “My faith has been deepened by our experience of mental illness” (R. 50).

Nineteen percent of interviewees ($n = 8$) positively reappraised the situation by comparing their situation to that of others. For example, “We’ve been lucky, [son] never got up to some of the tricks you hear about” (R. 34). Another father said, “There are plenty of people out there that got a worse deal than we did” (R. 50).
Sixteen percent of interviewees \((n = 7)\) told of finding enjoyment in their caregiver role and in working with other caregivers. For example, one mother said, "I'd have to say, I've got a lot of satisfaction out of helping other people" (R. 21). An elderly mother spoke of the benefits of providing care: "You could say it's given me a reason to go on living" (R. 35).

8.5.11 *Summary Regarding Hypotheses about Stage 3*

Data relevant to this stage did not confirm the hypothesis of Spaniol and Zipple that coping replaces grieving. For many caregivers there was no resolution to grief, and coping and grieving occurred concurrently. The majority, but not all of interviewees' responses confirmed that caregivers lose faith in professionals and some of the reasons why that occurred were identified: changing diagnosis, inappropriate or inadequate treatments, lack of continuity of services, disrespect shown to caregivers and the abuse of care recipients. Whether these reasons confirm what Spaniol and Zipple had in mind is unclear.

The majority of interviewees' narratives confirmed the hypothesis that they experience disruption to family life and encounter recurrent crises but two additional issues were identified: stigma and loss beyond that of the person once known. The hypothesis that caregivers value the support of other caregivers received some support, principally from Parental rather than Spousal or Other caregivers. The goals that interviewees identified at this stage confirmed the hypothesis that symptom management, care recipient function, such as socialising, and improving community services are the focus of coping. A further focus was that of self-care. The majority, but not all, of interviewees' narratives confirmed the hypothesis that improved working
relationships with professionals are established but in some cases they did not change or even deteriorated.

Stress decreased and caregivers used more Planful Problem Solving and Positive Re-appraisal at this stage. Planful Problem Solving was related to coping with symptom management, disruption to family life and recurrent crises, whilst Positive Reappraisal was related to meeting the goal of self-care. The cognitive strategies used included seeking benefits in the situation and downward comparison. Additionally, caregivers actively generated positive affect by engaging in pleasing activities.

8.5.12 Stage 3: The End

The most frequently reported benefit from encounter with mental illness was that of personal growth and development of confidence and assertiveness. Although the model predicts these developments in Stage 4, in this sample they occurred at Stage 3 and appeared to mark transition to Stage 4.

8.6 Stage 4: Personal and Political Advocacy

According to the Spaniol and Zipple model, caregivers change in Stage 4. They develop a new awareness of their role and become more assertive and engage in political and personal advocacy. They blame themselves less, their goals become more focussed on making necessary changes and they negotiate more collaborative and equal roles with professionals. New global meanings and values are integrated or deepened, whilst political advocacy becomes important for many. Data relevant to these issues is reported here and is derived from interviewees’ narrative accounts of their current concerns and adaptive coping strategies.
8.6.1 Changes in Personal Appraisal and Assertiveness

Ninety-three percent of interviewees (n = 40) 25 Parental, 12 Spousal and two Other caregivers reported that they had changed for the better as a result of their relative’s illness. One mother related, “I have changed though, I had to. I suppose you could say that I’ve grown as a result of this sickness” (R. 24). Interviewees told of becoming stronger, more assertive, more independent and developing personal advocacy skills. One mother said, “You sort of learn how to stand up for yourself and how to manage” (R. 58). Relating how she was stronger as a result of the illness, a mother claimed, “I feel like I’ve been given the strength to deal with it” and another added, “It’s like steel being forged in the fire” (R. 35). A daughter caring for her mother said, “It’s meant I’ve become a very independent person. With the sort of family background I’ve got, I’ve had to be…” (R. 56). They also spoke of becoming more compassionate and tolerant. One mother said, “These days I’m more tolerant of people’s foibles. Another reported “I think I’m more sensitive to the needs of others” (R. 55). These interviewees related their changed sense of self to their ability to deal confidently and assertively with professionals and the mental health system when they considered it appropriate.

8.6.2 Decreased Self-Blame

Despite their familiarity with current theories of the aetiology of mental illness, three interviewees (all Parents) reported lingering guilt about their possible role in the aetiology of the illness. For example, one mother related, “I know they’d howl me down at [support] group but I can’t help but wonder if this wouldn’t have happened if I’d left [violent husband]” (R. 02). The remainder of those who initially blamed themselves (n = 3) no longer did so and a mother said, “There was this young doctor in
the hospital and I talked to him. He told me, he said – Why do you feel so guilty? It’s not your fault – That really made me think about what I was doing” (R. 28).

8.6.3 Coping Focus

Although interviewees reported that their current goals were focussed upon continuing to provide care and taking care of themselves, 16% ($n = 7$) also nominated a goal of changing and improving the mental health system. A mother said, “Well, it’s also meant that I’m committed to doing something about mental illness” (R. 01). Responding to the question, “What do you want to achieve now?” another replied, “Just one thing, improving the system. I’m putting all my efforts into that now” (R. 43).

8.6.4 Collaborative Relationship with Professionals

Although 53% of interviewees told of improved relationships with professionals, only 14% ($n = 6$) spoke of a collaborative relationship. One mother told, “I think that forming an alliance with the treatment team has helped him and me” (R. 01). Another spoke of the benefits of continuity of care in that it allowed a collaborative relationship to be established. She said that her son had the same caseworker for six years and remarked, “We’ve been lucky there” (R. 19).

Nine percent of interviewees ($n = 4$), two Parental and two Other caregivers told of experiencing the opposite of a collaborative relationship with treating professionals and spoke of actively avoiding contact with them. One mother said, “It’s meant I’ve become very cynical. I’ve lost all faith, all trust in professionals and I’ve spent the last, I don’t know how many years avoiding them or if I have to fighting them” (R. 06).
8.6.5 Political Advocacy

Fifty-six percent of the caregivers interviewed, \( n = 24 \), 22 Parents and 2 Spouses, were or had been a member of a caregiver support group, and 8 of them, all Parents, spoke of their membership as a form of indirect participation in political advocacy. Speaking about the benefits of caregiver support groups, one mother said, “They understand, they know how it is and they try to do something about it” (R. 43).

Nineteen percent of interviewees \( n = 8 \), 7 Parents and one Spouse, said that they were directly involved in political advocacy on behalf of the mentally ill. They told of engaging in a variety of political activities that included petitioning the government for better services, leading caregiver support groups and assisting in organising conferences as well as developing a web site to inform the public and caregivers about mental health issues. For example, one mother reported, “I’ve taken up a position on the [committee]. I’ve become much more political about these issues” (R. 21). Another mother added: “I can’t make it go away for [son] but I can do something about making it better for others; even if it’s only a little bit” (R. 01). A father said, “I don’t waste my time and energy any more. Now I channel it into action. I’m involved with a group that’s trying to change the system” (R. 33).

Seven percent of interviewees \( n = 3 \) said that they regarded their participation in the current study as a way of advocating on behalf of the mentally ill. For example, one mother said, “I don’t mind telling you about my experiences, as long as it gets the message out there” (R. 21).

A further 7% of interviewees \( n = 3 \) were employed in the mental health system and said that they advocated on behalf of the mentally ill in their workplace.
8.6.6 New Meanings and Values

Ninety-one percent of interviewees ($n = 39$) 24 Parental, 10 Spousal and 5 Other caregivers, told of examining and re-assessing their global values. For example one wife said, “It’s meant a complete re-evaluation of our life and values and in many ways that’s not a bad thing” (R. 40). A father claimed, “Sometimes it takes something like this to make you sit down and work out what’s important and what isn’t” (R. 34).

One interviewee’s summation of the meaning of the illness in her life encapsulated this re-evaluation:

It’s been like the menopause, it’s the defining thing in my life.
I’ve let go of all that crap about how you look and gone back to basics. My career isn’t the most important thing in my life any more. I’m not prepared to put the same time in to it. I’ve learnt to work smarter, not harder. Money doesn’t have the same importance either. Financially, I’m learning that I’m only responsible for myself and I don’t need a lot of money, only enough to live.
That’s a weight off my shoulders. It’s been a huge gift, I don’t know if I would ever have made a commitment to anyone if this hadn’t happened”. She added, “This experience has given me more than it’s taken from me. I like the person I’ve become. Now, I’m aware of my own mortality, I wasn’t before. I never gave it a second thought. Now I value what I’ve got and I enjoy it” (R. 37).

Interviewees appeared to assess their sense of self worth against their re-evaluated global belief system. Forty-seven percent of interviewees ($n = 20$) spoke of reassessing the value of loyalty and commitment and linked this assessment to their sense of self-worth. A mother speaking of her caregiver role said: “I think you should be able to count on your family when you need them” (R. 35). A son caring for his mother told,
"You could say I’m overly loyal where Mum is concerned but I couldn’t just dump her like that" (R. 29). A husband added, “The way I see it, you don’t walk out on your commitments” (R. 26).

8.6.7 Summary Regarding Stage 4: Hypotheses

The data derived from interviewees’ narrative accounts partially confirmed the hypothesis that caregivers change and become more assertive at this stage. The majority of interviewees reported personal growth that translated into more confident and assertive ways of dealing with professionals. The hypothesis that self blame decreases was confirmed by some caregivers and disconfirmed by others, as was the hypothesis that the focus of coping changes toward changing the system. The hypothesis that caregivers, at this stage, establish collaborative relationships with treating professionals received slight support. Despite relationships with professionals improving, few spoke of establishing a collaborative relationship. If participation in a caregiver support group was included, the majority of interviewees were involved in some form of personal or political advocacy, partially confirming the hypothesis that political advocacy becomes important. The majority of interviewees reported experiences confirming the hypothesis that new beliefs and values are integrated. This appeared to be achieved by re-evaluating global beliefs and evaluating their situational responses against these values. This way of coping served the important adaptive function of maintaining self-esteem and self worth.
CHAPTER 9

Discussion

I begin the discussion by evaluating how well the Spaniol and Zipple model of the evolution of caregiver responses approximates the experience of a “typical” participant in the present study. I then discuss the individual components of each stage of the model and their relevance to caregivers across kinship relationship groups.

9.1 The experience of a “typical” participant

To the extent that any of my interviewees could be designated as “typical”, the most frequently encountered participant in this study was a mature-aged (40 yrs +), secondary level educated, married mother, living in an urban area and no longer in paid employment. She was providing part-time care to a son with schizophrenia, who no longer resided at home.

According to her narrative, initially she was puzzled and distressed by her son’s changed behaviours. She considered the changes to be serious and threatening and did attribute them to causes other than mental illness, but she did not deny mental illness because she simply had no knowledge of it. She sought information about what could be happening to her son from multiple sources, the most important of which was the family general practitioner who eventually referred them to a psychiatrist.

Recognition of mental illness was gradual, not because of denial – the diagnosis was not disputed once it was made – but because it took some time before the referral was made. Acceptance of the implications of the illness was hampered by lack of
knowledge, by changing diagnoses and fluctuations in the illness. She experienced negative feelings of guilt and shame and her beliefs about herself and the world in general were challenged. She grieved the loss of the child she knew and her hopes for his future and this grief was never completely resolved. She found this to be an extremely stressful time and coped by controlling her own feelings, obtaining treatment for her son, information about the illness and support from family members.

Despite chronic grieving and a loss of faith in professionals for failing to provide information or adequate treatment and treating her with disrespect, she continued to cope with the multitude of issues arising from the illness. She experienced numerous losses, but that of the person known was the most grievous. Family life continued to be disrupted by her son’s recurrent hospitalisations as well as his distressing and difficult behaviours. Eventually she recognised the need for caring for herself as well as caring for her son and actively engaged in activities that provided relief from the stress of caring. She came to view herself in a more positive light. Her appraisal of stress decreased and she found ways of coping with the multiplicity of issues accompanying the illness. Although the family continued to provide support, a caregiver support group became a major source of support. Her relationship with treating professionals improved but did not approximate one of equal partnership and she now seeks to change the system through the advocacy of her caregiver support group.

9.2 The Spaniol and Zipple Model

Spaniol and Zipple do not identify an individual family caregiver, but rather speak of the family’s evolving responses to mental illness. However, it appears unlikely that all members of the family respond in the same manner to their family member’s illness
and the model is only meaningful if applied to the responses of the designated family caregivers.

According to their model, the "typical" response to mental illness in the family is initial denial of the seriousness of the condition and an attribution of the changes to substance abuse, laziness or bad friends. When tensions increase, answers are sought through any possible sources and denial of mental illness is persistent. Recognition is gradual, leading to feelings of guilt, embarrassment and self-blame or professional blame. The fluctuating nature of the illness impedes acceptance. When the chronicity of the illness is accepted, a deep sense of loss of the person once known and their future potential is experienced, as is a crisis of meaning. Coping begins to replace grieving and the issues coped with include disruption to family life and recurrent crises, pessimism and despair. There is a loss of faith in professionals, and a belief in their own expertise develops. The support of other families is valued and the focus becomes management of symptoms and improving functioning of the family member. Reliable professionals are eventually identified and the family's role in the recovery process recognised, leading to personal advocacy and assertiveness. Family caregivers now feel differently about themselves, blaming themselves less and focussing upon necessary changes. Collaborative roles, based on equality are negotiated with professionals and political advocacy to change the system becomes important. New meanings and values are integrated into their belief system.

9.3 Goodness of Fit

Comparison of the two accounts of the evolution of family caregiver's responses to mental illness reveals significant differences between those predicted by the Spaniol and Zipple model and those of the "typical" caregiver identified by this study. The
most important of these differences concerned whether mental illness was denied when the changed behaviours were perceived, and whether those changes were judged to be serious. Adaptive coping was also present in the initial information seeking responses, occurred throughout all stages, and did not replace grieving. Acceptance seemed to be of two kinds: acceptance of mental illness as such and acceptance of its implications. The latter was impeded by more than the fluctuating nature of the illness. The losses that caregivers experience are more extensive than loss of the person known, and the focus of coping changed to include self-care as well as managing the symptoms of the recipient and improving his functioning. Although improved roles with treating professionals were reported, these were not roles of collaborative equality.

The differences between the Spaniol and Zipple model and what I found are now discussed in more detail. The ways in which caregivers experiences varied from those predicted by the model are discussed and related to the hypotheses generated about the components of each of the stages.

9.4 Stage 1: Discovery/Denial Differences

Firstly, this stage was not relevant to all caregivers and the experience of those to whom it did apply was different from that expected. Those with prior knowledge of mental illness, spouses who were aware of their partner’s illness when they married and adult offspring caring for a mentally ill parent, did not experience this stage. The majority of those who could be said to have “discovered” their relative’s illness told of being most concerned about the changed behaviours, but did not attribute the changes to mental illness. This causal attribution did not appear to be denial of mental illness so much as a lack of familiarity with its symptoms. For example, a number of Parental caregivers attributed the changes to drug abuse and, in fact, 33% of care recipients
were using illegal substances, a rate that accords with the Treatment Protocol Project (1997) of the World Health Organisation findings. It is possible that this concurrent substance abuse could account for the number of general practitioners who also initially failed to recognise the symptoms of mental illness.

The hypothesis that caregivers would seek answers from multiple sources received some confirmation, but, rather than confirming that denial was taking place, this seeking of information seemed to be an essential component of adaptive coping (White, 1985).

9.5 Stage 2: Recognition/Acceptance Differences

The narrative accounts of interviewees did not confirm the hypothesis that recognition of mental illness was universally gradual in the way proposed by Spaniol and Zipple. Although it was gradual for the majority of interviewees, this was because of the delay in an official diagnosis being made. Of course, the Recognition part of Stage 2 was not relevant to those with prior knowledge of their relative’s illness (Spousal and Other Caregivers).

The hypothesis that caregivers would expect mental health professionals to have answers was partially supported by interviewees’ accounts of their goals at this stage. The majority told of goals that focussed upon obtaining treatment and cure for the care recipient and ensuring their safety. Presumably the expectation was that mental health professionals would provide this care and treatment. At this stage, few caregivers appeared to recognise the need to care for themselves.

The hypothesis that caregivers would experience guilt, embarrassment or blame at this stage was only partially confirmed. Guilt and blame or self-blame were most apparent in the narratives of Parental caregivers and nineteen percent of them
reported having been blamed by professionals for causing the illness. The older age of Parents in the interview sample and the commencement of the illness in an era when such causal attribution was fashionable may explain this finding. Spousal caregivers who were blamed encountered more recent theories of co-dependency or high expressed emotion.

Experience of shame and embarrassment was reported by 75% of Spousal caregivers and appeared to be related to a concern that they or their family would be stigmatised if the existence of the illness became generally known.

The hypothesis that caregivers would experience a deep sense of loss of the person known and their future potential, was again only partially confirmed, and then only by Parental caregivers. It was absent from the narratives of Spouses and Other caregivers, particularly those caring for a parent who reported they had never known the care recipient to be any different. Experience of the loss of the person known may have been related to type of mental illness because the majority of Spousal caregivers were, as Lefley (1996) also found, caring for a partner with bi-polar disorder, and it is possible that the personality of people with this disorder remains more intact than in schizophrenia, with consequent less grief for the person lost.

The hypothesis that the fluctuating nature of the illness would impede acceptance of its chronicity and accompanying loss received partial support. Interviewees’ indicated that although they accepted the professional diagnosis of major mental illness, acceptance of the implications of the illness was slower and was impeded by several factors, including its fluctuating nature. Lack of knowledge about mental illness, its treatment and prognosis; together with the failure of professionals to communicate relevant information impeded acceptance, as did multiple and changing diagnoses. From interviewees’ narratives, it appears that acceptance of chronicity and
loss would be nigh on impossible, without knowledge of the implications of the diagnosis.

Parental and Spousal caregivers’ narratives partially supported the hypothesis that caregivers would experience a crisis of meaning at this stage. None of the Other caregivers reported experiencing such a crisis of meaning, possibly because of their more distant relationship to the care recipient (two were in-laws) or their prior knowledge. The crisis of meaning precipitated by the illness differed for Parental and Spousal caregivers. Parents questioned their existential beliefs, as (Janoff-Bulman, 1992, Taylor & Brown, 1994, Wasow, 1995) found occurred following traumatic events, and beliefs about their self-worth, particularly in relation to their parenting ability. Spousal caregivers questioned their beliefs about commitment to marriage or relationship.

The majority of Parental and Spousal interviewees appraised this stage when they first recognised mental illness, as extremely stressful. The lower stress appraisals of Other caregivers at this stage may be related to the timing of their appraisals. The group with prior knowledge of the illness indicated that their stress appraisals were related to the time when they first became responsible for the care of their relative.

Caregivers’ responses to the Ways of Coping questionnaire and interviewee’s narratives indicated that all of the eight modes of coping were used initially and currently. This finding accords with that of Folkman and Lazarus (1985) who reported that the majority of men and women coping with a stressful event used both problem-focused and emotion-focused coping in over 98% of the occasions. Family caregivers may possess a repertoire of adaptive coping skills permitting flexibility of response, a finding in accordance with White (1985), Seeman, Litman, Plummer,
Thornton and Jefferies (1982) and Siegel (1983) who claimed that the ability to access a repertoire of coping responses was a major factor in adaptive coping.

The three most favoured coping responses at this stage were Self-Controlling Coping, Planful Problem Solving and Seeking Social Support. Interviewees explicated how and why these ways of coping were used. Self-controlling coping appeared to be related to the priority accorded to goals of treatment and cure, and caregivers appeared to be controlling their own feelings in order to achieve these goals. This way of coping was also related to fears of stigmatisation, because interviewees implied they initially believed the illness would pass and could be concealed until it did. Planful Problem Solving was also about obtaining treatment for the care recipient and information about the illness and its treatment.

Social Support was provided mainly by other family members and was, as Lloyd (1995) suggested, perceived as a major source of support, and was both emotional and practical in accordance with House’s (1981) concept of support. Family support also seems to have both Problem-focussed and Emotion-focussed elements as Lazarus, (1991) noted. According to Solomon and Draine (1994), seeking social support is a major factor contributing to adaptive coping in relatives of the mentally ill, and participants in the current study used this way of coping and perceived it as useful. Social support may also have assisted, as Park and Folkman, 1997, and Lafond, 1994 found, in coping with the grief experienced by many caregivers.

9.6 Stage 3: Coping Differences

According to the Spaniol and Zipple (1994) model, coping does not commence until Stage 3, and after grieving has ceased. However, caregivers’ narratives and responses to the Ways of Coping Questionnaire show that coping commenced in Stage 1 and
continued until the present. Similarly, grieving, at least for Parental caregivers, appears to be chronic, as Lafond (1994), Lefley (1996) and Wasow (1995) also found. In these respects, the hypothesis that coping takes the place of grieving was not supported.

The hypothesis that caregivers lose faith in professionals was confirmed. All interviewees reported this loss of faith and identified the reasons. Inappropriate and inadequate treatment, changing diagnoses, poor communication, service system deficits and abuse of the care recipient were identified. The list of complaints was a sad indictment of the mental health system and confirmed the need for improved services that the Australian Psychological Society, (1998); the Mental Health Council of Australia, (2000) and National Standards for Mental Health Services, (2000) have called for. Despite the implementation of educative programs such as the Bouverie Centre's Family Sensitive Training program (1997) it was apparent from caregivers' narratives that further improvements are required.

Seven percent of interviewees reported that their relative had been abused whilst in the care of mental health services. These findings add weight to the call by Kumar and Thomas, (2001) for further investigation of the subject, even though they provided no indication of the prevalence of abuse of the mentally ill.

The hypothesis that the illness would disrupt family life was confirmed, and interviewees' narrative accounts indicated that the issues causing this disruption were many. All of the interviewees told of coping with a variety of situational stressors, and all had encountered more than one of them. The number and variety of these confirmed Barrowclough and Tarrier's (1992) account of caregivers encountering multiple distressing behaviours and the types of stressors accorded with those reported by researchers into family burden (eg. Johnson, 1990; Cook, Lefley, Pickett & Cohler, 1994; Lefley, 1996; Reinhard, 1994). Absconding is an additional stressor reported by
caregivers in the current study that should be added to the already extensive list. It should be noted that Harrison (2000) claimed that caregivers rarely referred to the issues encountered as burden, and Rose (1996) considered they could better be described as stressors. Some support for these views was found in the observation that none of the interviewees spoke of burden.

The issues causing disruption to family life were identified from interviewees’ narratives and included the care-recipient’s behaviours, moods and treatment non-compliance. They also included the responses of other family members to the illness and confirmed reports of relationship strains, (Deveson, 1991; Marsh et al., 1996; Secunda, 1997). The only situational stressor exclusive to any kinship group was unfaithfulness, and only one wife reported it. It is unclear if this behaviour should even be attributed to the mental illness, however the wife clearly did so. It is also unclear if the low incidence of report of this stressor reflects its rare occurrence or the reluctance of caregivers to discuss such issues. I favour the latter explanation because the majority of spouses in the current study were caring for a partner with bi-polar disorder, and unfaithfulness can be symptomatic of this disorder. Excessive spending, which can also be a symptom of bi-polar disorder was reported by a quarter of all spouses and only one parent. It appeared that differences in the extent to which some stressors were encountered reflects differences in the type of mental illness.

The hypothesis that caregivers would experience recurrent crises was confirmed. All interviewees told of recurrent crises and, whilst most reported crises related to fluctuations in the illness, other issues were identified. Caregivers’ narratives identified issues of suicidal intent, as noted by the Treatment Protocol Project, (1997) of the World Health Organisation; aggressive and assaultive behaviours, (Vaddadi et al. 1977) and substance abuse (Brown et al. 1989). The type of substance
abused differed, Spousal caregivers reporting alcohol abuse and Parental caregivers reporting other illegal substances. In contrast, Other caregivers did not report any substance abuse. Accounts of violence approximated those reported by Vaddadi et al., and Parental caregivers reported more assaultive and aggressive behaviours than Spousal caregivers. Possibly Spousal caregivers would be less inclined to remain in an assaultive relationship and this may have been a factor considered when deciding whether to continue the relationship. In summary, the issues encountered at Stage 3 were extensive and varied.

Two additional issues that do not exactly accord with disruption to family life or recurrent crises were identified: Stigma and Loss. Stigmatisation was found in the accounts of caregivers of different backgrounds, as noted by Kuipers, Leff and Lam (1992). Additionally the current study found confirmation of McFarlane and Beels’ (1983) contention that families coping with mental illness feel devalued and act as if they have been devalued by concealing the illness. Interviewees who reported fearing the stigma of mental illness invariably appraised it in terms of threat and those who had experienced being stigmatised appraised it in terms of harm/loss. Their responses indicated that they believed that the family had been, or could be, harmed or devalued in the eyes of the general community as a result of the illness and the expected harm was a loss of status. Those who had experienced actual stigmatisation confirmed Lefley’s (1989) contention that families of the mentally ill are devalued and social barriers are erected against them.

The second issue identified from interviewee’s narratives was that of loss, and the losses experienced were extensive. All interviewees of all kinship relationships reported some form of loss as a result of the illness and many reported several losses. Loss appeared to be one of the defining themes of the encounter with mental illness.
Interviewees of all kinship relationships reported decreased stress appraisals at Stage 3; however the decrease was less for Other caregivers than for Parental and Spousal caregivers. This may be explained by their lower initial stress appraisals and their initial reported optimism.

Although care-recipient issues remained important, interviewees’ goals changed in accordance with Taylor’s (1989) contention that a shift to what can be attained is required and the adoption of more modest goals (Hatfield & Lefley, 1987; Woolis, 1992). The shift was from seeking a cure to include a focus upon self-care and this appeared to be related to their recognition of the value of their caregiving role.

Caregivers’ responses to the Ways of Coping questionnaire at Stage 3 and interviewees’ narratives of their coping responses confirmed change consistent with adaptive coping. Currently and initially, respondents used all eight of the ways of coping scales however, multivariate analysis of variance confirmed significant changes in caregivers coping responses between the time when they initially became aware that their family member had a mental illness and currently. These findings support Folkman and Lazarus’ (1985) conceptualisation of coping as a process with inevitable change. A comparison of initial and current responses indicated that ways of coping change over time and more Planful Problem Solving coping was used. Adaptive coping appeared to develop over time as suggested by Wasow (1995) and Terkelsen (1987b).

The use of Confrontive Coping and Escape/Avoidance decreased over time. Initially, but not currently, their use accorded with Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen’s (1986) finding that a threat to loved ones’ well-being elicited more of these ways of coping. Changes in the use of these ways of coping may be related to caregivers’ decreased experience of stress over time and the development of adaptive problem solving skills.
Folkman and Lazarus (1980) reported that when a situation is appraised as not amenable to change more Emotion-focussed coping is used. However, responses to the Ways of Coping questionnaire indicated that although one Emotion-focussed way of coping Escape/Avoidance decreased, another, Positive Reappraisal, increased. The results suggest that over time caregivers come to cope with emotional distress by finding meaning in the situation, as proposed by Park and Folkman (1997). This interpretation would also accord with Spaniol and Zipple's (1994) contention that as families come to accept the illness they seek to find meaning in the situation.

The three most favoured ways of coping at this stage remained Planful Problem Solving, Seeking Social Support and Self-Controlling coping; however their application varied according to the issues encountered.

Problem solving coping directed at changing the behaviours was the predominant response to situational stressors and, as reported by Folkman and Lazarus (1984), was most frequently used when the encounter required practical intervention in the management of difficult behaviours and fluctuations in the illness. The strategies used included setting limits, seeking additional treatment, maintaining vigilance, although obtaining training in self-management skills for the care recipient, as suggested by Spaniol and Zipple (1994), was not reported.

Treatment non-compliance was the stressor most likely to evoke confrontive coping, however, this was frequently, but not always, assertive confrontation rather than aggressive confrontation, and met with a measure of success.

In answer to O'Brien's (1998) concern regarding how caregivers manage violence, they told of setting limits, removing access to weapons, seeking Police or crisis service intervention, relocating the care recipient and obtaining legal orders
banning contact. The most successful strategy appeared to be finding alternative accommodation for the care-recipient.

Less success was reported in coping with substance abuse issues. As reported by the Treatment Protocol Project, (1997) of the World Health Organisation and Brown et al. (1989) these care recipients tend to fall through the cracks and Parental caregivers were resigned to being unable to change the situation.

Almost fifty percent of interviewees reported service system deficits, confirming the Report of the National Inquiry into the Human Rights of People with Mental Illness (1993) finding that service gaps exist. The issue of inaccessibility or lack of services was more prevalent in the accounts of rural caregivers the majority of whom directed their efforts to managing the problem rather than changing the system. Their coping strategies included relocating or travelling to obtain treatment.

Urban caregivers expressed concern about unsatisfactory or inappropriate treatments and engaged in confrontive coping and problem solving responses aimed at changing the system. Differences between urban and rural responses may have been related to access to support groups that campaigned for change.

The source of social support changed over time and the majority of Parental caregivers now sought support from a caregiver support. The support provided by families decreased slightly, possibly because aging parents of caregivers may have been less able to continue providing support. Although Hatfield and Lefley (1987) recommended participation in a support group, only two Spousal caregivers and none of the Other caregivers were members. Possibly these groups are less relevant to Spouses, as Lefley (1996) suggested or non-participation may reflect a desire to conceal the illness.
Self-Controlling behaviour was related to maintaining a positive attitude and ensuring that negative feelings did not interfere with care provision. It was also related to concealing the illness for fear of being stigmatised and equated with Goffman’s (1963) notion of “Passing”, that is concealing the illness and passing as “normal” and Minichello, et al.’s (1996) observation that “Passing” is the most frequently means of coping with stigma. In the case of Spousal caregivers such behaviour could be considered adaptive in that, as Harvey (1966) claimed, adaptability means the capacity to behave in ways maximally consonant with goal attainment and this strategy enabled attaining the goal of ensuring the partner continued working between bouts of illness. Although it may seem contradictory, maintaining a positive attitude toward the illness appeared to coexist with attempts to conceal it. This strategy, which may be pragmatic and based on the realisation that mental illness is not universally accepted, warrants further investigation.

Rose (1996) expressed concern about how stigma affected caregivers. It affected them in two different ways; the loss of friendships and broken family relationships and the alienation and isolation caused by concealing the illness.

Positive Affect was created by actively engaging in a variety of pleasurable activities similar to those reported by Folkman and Moskowitz (2000) and coexisted with negative affect as acknowledged in the father’s statement, “It’s OK to whistle on the way to a funeral”. Chesla’s (1989) finding that uplifts or benefits assist coping found support and the benefits included enjoyment of the company of the care recipient or that of other caregivers. Park and Folkman’s (1997) proposal that meaning is found in the use of downward comparisons was also supported in that interviewees reported positive comparison of their situation against that of hypothetical others, and seeking comfort in religious beliefs that make the suffering meaningful.
9.7 Stage 4: Personal/Political Advocacy Differences

The majority of interviewees of all kinship relationships supported the hypotheses that the way carers feel about themselves changes and they become more assertive. Park and Folkman (1997) designated this meaning focussed way of coping “compensatory self-enhancement” and these findings concur with those reported by Marsh et al. (1993). This way of coping has important adaptational qualities in restoring a sense of self worth (White, 1985). Caregivers’ sense of self worth can be challenged by societal attitudes (Lefley, 1996) and the care-recipient’s lack of appreciation of the care provided (Newsom, 1999). Caregivers appeared to maintain a sense of self worth by finding congruence between their global beliefs about commitment and their actions in providing care to their mentally ill relative as proposed by Park and Folkman (1997).

The hypothesis that caregivers experience decreased self blame at this stage received mixed support. None of the Spousal caregivers who had initially been blamed for maintaining the illness spoke of continuing self-blame, however some Parental caregivers reported residual guilt, as Lefley (1989) also found.

The hypothesis that necessary changes would become the focus of coping, was partially supported although only seven percent of interviewees were directly engaged in political advocacy, the majority regarding their support group as the means of effecting such changes.

Similarly, the hypothesis that at this stage collaborative and equal relationships with mental health professionals are established received slight support. The majority of interviewees reported improved relationships, but only 14% spoke of collaborative relationships, supporting the Australian Psychological Society’s (1998) call for improved training of mental health professionals.
The hypothesis that, at this fourth stage, new meanings and values are integrated received support from the majority of interviewees (91%) across all kinship relationships. From interviewees' narratives, it appeared that integration was achieved by re-evaluating global beliefs about values and self and finding congruence between these global beliefs and their situational response of care provision, in accordance with Park and Folkman (1997) proposed meaning-based coping strategies. Rose (1996) expressed interest in understanding the meaning caregivers attach to their personal situation and this finding of enhanced self-worth when global and situation meaning are congruent contributes to such understanding. This way of coping may also assist in coping with chronic grief in that Neimeyer (1998) suggested that finding meaning in what appears to be a random and meaningless event is an adaptive way of coping with grief.

9.8 Limitations of Study

The semi-structured interviews with family caregivers provided a rich source of information about their experiences of encounter with mental illness; however some caution is warranted. A significant factor is the lack of opportunity for independent verification of the events and responses reported. This problem is not unique to qualitative methods, as responses to the Ways of Coping Questionnaire also cannot be verified.

Both qualitative and quantitative data were based upon participants' recollection of how they responded to events that occurred in the past when they initially became aware of their relative's mental illness. In some cases, that event occurred a long time ago, even up to thirty years previously, and the possibility that aspects had been forgotten or that memory of the event had been distorted over time
should be considered. This is a problem common to all retrospective studies. Asking people what they had for dinner two days ago can elicit distorted recollections. In the case of research into the development of mental illness it is unavoidable in that commencement of the illness is often only recognised in retrospect. Some evidence of the validity of caregivers’ recollection of the issues they encountered and their responses can be found in the congruence between their narratives and those reported in the literature.

Sample bias is a further issue warranting consideration. Participants in the current study volunteered. There is a possibility that caregivers who were more confident or considered themselves to have mastered coping skills may have self-selected and those who were less confident of their abilities may have avoided participation. Some evidence of such bias is apparent in the fact that participants reported higher educational levels than those of the general community and it was my observation that most participants were articulate and appeared to be functioning well in their caregiver role. Although these factors need to be taken into account in interpreting the findings, the study was concerned with understanding adaptive coping strategies and obtaining a sample of caregivers who were able to report a variety of successful ways of coping could be advantageous.

A further limitation is the lack of analysis of the effects of cultural expectations on caregivers’ responses. The size and composition of the sample precluded examination of this variable and this may limit generalisation of the findings across different ethnic populations.

Another issue for consideration in interpreting the findings is that some respondents stated that they regarded their participation in the study as a means of bringing service system deficits and mental health issues to the attention of mental
health professionals and policy makers. This motive doubtlessly influenced the choice of issues discussed and the way in which they discussed them. For example, it is possible that caregivers wishing to obtain better services in the community may have exaggerated the lack or inaccessibility of services. However, there was no evidence of systematic distortion in the narratives obtained and the accounts given accorded with the findings of previous research (Andrews, Peters & Tecson, 1994).

9.9 Summary of Issues

The Spaniol and Zipple (1994) model implies that the stages are sequential. However, a well-defined sequence does not seem to have marked the experience of the participants in this study. For example, adaptive coping, grieving and disruption to family life occurred throughout the illness. Although a progression was evident in interviewee's narratives and questionnaire responses, it was difficult to allot the issues and responses to particular stages, other than the first one.

Nor does the Spaniol and Zipple model match very well the experience of caregivers of any kinship relationships studied here, but to the extent that it does, it more closely approximates that of Parental caregivers. Lefley (1996) had already suggested that caregivers of different kinship relationship to the care recipient may represent entirely different populations and some support for her suggestion was found here. Not all the stages of the Spaniol and Zipple model and the issues encountered in them were relevant to all caregivers across all kinship relationships and the discrepancies limit its application to planning service delivery.

Finally, as it stands, the model is largely descriptive and, except for the movement from Stage 2 to Stage 3, lacks a dynamic that determines the movement from one stage to another. Spaniol and Zipple propose that it is the resolution of
grieving in Stage 2 that leads to the coping of Stage 3. In that interviewees coped adaptively in all stages whilst also experiencing grief at all stages, the present findings did not support their proposal. What Spaniol and Zipple appear to be referring to as coping in their Stage 3 is *mastery* rather than what Folkman and Lazarus (1984) mean by coping. That the difference is important may be illustrated by the finding by Siegel and Smith (1989) that unsuccessful attempts to change situations may be reported as failures to cope with the consequence that interviewees’ reported lack of success in managing their depression without the assistance of medication was classed by them as a failure.

According to Coyne and Racioppo (2000), questionnaires can provide only superficial understanding of coping processes. This study found that the Ways of Coping questionnaire provided only a broad indication of how caregivers’ ways of coping evolved. A more in depth understanding of why the adoption of a particular strategy occurred and how it was implemented required a qualitative methodology. Coping questionnaires, used on their own, can provide only a superficial understanding of coping processes.

Two issues with the scales of the Ways of Coping questionnaire emerged when considered in relation to interviewees’ narratives. First, the Confrontive coping scale makes no provision for assertive confrontation and Confrontive coping is only seen in terms of aggressive efforts to alter the situation. Interviewee’s accounts of coping indicated that they also used assertive confrontation and the Ways of Coping questionnaire missed such efforts. The second issue concerns the classification of the use of medication to control depression or anxiety as Escape/Avoidance coping. The issue caused a difference of opinion between coders, in that one considered this to represent Planful Problem Solving whilst the other designated it Escape/Avoidance.
coping. Obtaining treatment for the care recipient was classified as Planful Problem Solving, but obtaining treatment for the caregiver as Escape/Avoidance coping.

Finally, several findings were relevant to the concerns expressed by Somerfield and McCrae (2000), Lazarus, 1993) and deRideer and Schreus (2001) about the relevance of studies of coping behaviours to clinical practice. Interviewee’s narratives identified issues and concerns about their treatment by mental health professionals. These issues could be addressed by inviting caregiver participation in the development of a “best practice” model of response to mental illness that serves the dual function of training mental health professionals and informing service delivery.

The study also identified service system deficits that need to be addressed at a policy level. These include the provision of emergency and after-hours services in rural areas and continuity of care provision. Again, caregiver participation in policy development may serve to identify and target areas requiring priority changes.

Perhaps the most important aspect about translating the findings to clinical practice is the need for a change of focus. A shift is needed from a deficit model to one that identifies and builds upon the adaptive coping skills that families already possess, as proposed by Hatfield and Lefley (1987). This would include enhancing and supporting those behaviours and individuals that caregivers have identified as supportive of their caregiving role. For example, finding ways to include supportive family members in therapy or activities may enhance support for the caregiver. Similarly, encouraging participation in activities that generate positive affect and activities that confirm the worth of the caregiving role should be considered.
The provision of creative and alternative modes of caregiver support that acknowledge the need of some caregivers to conceal the illness and time and distance constraints that limit participation in support groups could be developed and may include computer based peer support amongst others.
REFERENCES


APPENDIX A

Demographic Data Form
FAMILY CARER STUDY

To begin, this section asks you to provide some information about yourself. Please place a tick beside the answers that best describe you or fill in the information requested.

(1) Are you? Male ...... Female ......

(2) Which age group are you in?

20 yrs or less ...... 21 – 30 yrs ...... 31 – 40 yrs ...... 41 – 50 years ......
51 – 60 yrs ...... 61 – 70 yrs ...... 70 or more years ......

(3) Do you provide full-time care? ...... Part-time care? ......

(4) How long have you been providing care? .......... yrs .......... months

(5) Are you single? ....... Married or living together ...... Separated ......
Divorced ......

(6) Are you in paid employment? Yes ...... No ......

if yes – Full-Time ...... Part-Time ......

(7) What is the highest level of schooling that you completed?

Primary, year ...... Secondary, year ...... Tertiary ...... Post-graduate ......

Please continue over page
Would you now please give some information about your family member-

(1) Are they: Male ...... Female ......

(2) Which age group do they belong to?
   20 yrs or less ...... 21 – 30 yrs ...... 31 – 40 yrs ...... 41 – 50 years ......
   51 – 60 yrs ...... 61 – 70 yrs ...... 70 or more years ......

(3) Do they live with you? Yes ...... No ......
   If yes – Full-Time ...... Part-Time ......

(4) When did they first show signs of mental illness? ...... yrs ago ...... months ago

(5) When were they first diagnosed? ...... yrs ago ...... months ago

(6) How would you rate their condition right now?
   (a) Stable (Rational, not psychotic) ......
   (b) Mostly Stable ......
   (c) Mostly Unstable ......
   (d) Completely Unstable (Psychotic) ......

(7) Have they ever been hospitalised for this illness? Yes ...... No ......
   If yes –

(8) When were they last hospitalised? ...... years ago ...... months ago
APPENDIX B

Folkman and Lazarus Ways of Coping Questionnaire
WAYS OF COPING SCALE

INSTRUCTIONS: Below are some ways that people have coped with difficult situations. Thinking back to when your family member first became mentally ill, would you please indicate (by circling the appropriate number) the extent to which you used each of these ways of coping at that time.

Key: 0 = Does not Apply/Not used    1 = Used Somewhat    2 = Used Quite a Bit    3 = Used a Great Deal

1. I just concentrated on what I had to do next, the next step  0 1 2 3
2. I tried to analyze the problem in order to understand it better  0 1 2 3
3. I turned to work or another activity to get my mind off things  0 1 2 3
4. I felt that time would have made a difference
the only thing was to wait  0 1 2 4
5. I bargained or compromised to get something positive from the situation  0 1 2 3
6. I did something that I didn't think would work but at least I was doing something  0 1 2 3
7. I tried to get the person responsible to change his or her mind  0 1 2 3
8. I talked to someone to find out more about the situation  0 1 2 3
9. I criticized or lectured myself  0 1 2 3
10. I tried not to burn my bridges, but leave things open somewhat  0 1 2 3
11. I hoped for a miracle  0 1 2 3
12. I went along with fate, sometimes I just have bad luck  0 1 2 3
13. I went on as if nothing had happened  0 1 2 3
14. I tried to keep my feelings to myself  0 1 2 3
15. I looked for the silver lining, so to speak: tried to look on the bright side of things  0 1 2 3
16. I slept more than usual  0 1 2 3
17. I expressed anger to the person/s who caused the problem  0 1 2 3
18. I accepted sympathy and understanding from someone  0 1 2 3
19. I told myself things that helped me feel better  0 1 2 3
20. I was inspired to do something creative about the problem  0 1 2 3
21. I tried to forget the whole thing  0 1 2 3
22. I got professional help  0 1 2 3
23. I changed or grew as a person  0 1 2 3
Key: 0 = Does not Apply/Not used  1 = Used Somewhat  2 = Used Quite a Bit  3 = Used a Great Deal

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>24.</td>
<td>I waited to see what would happen before doing anything</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25.</td>
<td>I apologised or did something to make up</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26.</td>
<td>I made a plan of action and followed it</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27.</td>
<td>I accepted the next best thing to what I wanted</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28.</td>
<td>I let my feelings out somehow</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29.</td>
<td>I realised that I had brought the problem on myself</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30.</td>
<td>I came out of the experience better than I went in</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31.</td>
<td>I talked to someone who could do something concrete about the problem</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32.</td>
<td>I tried to get away from it for a while by resting or taking a vacation</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33.</td>
<td>I tried to make myself feel better by eating, smoking, drinking, or using drugs or medication, etc.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>34.</td>
<td>I took a big chance or did something very risky to solve the problem</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35.</td>
<td>I tried not to act too hastily or follow my first hunch</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36.</td>
<td>I found new faith</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37.</td>
<td>I maintained my pride and kept a stiff upper lip</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>38.</td>
<td>I rediscovered what is important in life</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>39.</td>
<td>I changed something so things would turn out all right</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>40.</td>
<td>I generally avoided being with people</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>41.</td>
<td>I didn’t let it get to me, refused to think about it too much</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>42.</td>
<td>I asked advice from a relative or friend I respected</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>43.</td>
<td>I kept others from knowing how bad things were</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>44.</td>
<td>I made light of the situation, refused to get too serious about it</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>45.</td>
<td>I talked to someone about how I was feeling</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>46.</td>
<td>I stood my ground and fought for what I wanted</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>47.</td>
<td>I took it out on other people</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>48.</td>
<td>I drew on my past experiences, I was in a similar situation before</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>49.</td>
<td>I knew what had to be done, so I doubled my efforts to make things work</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>0 = Does not Apply/Not used</td>
<td>1 = Used Somewhat</td>
<td>2 = Used Quite a Bit</td>
<td>3 = Used a Great Deal</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------</td>
<td>-------------------</td>
<td>---------------------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td>50.</td>
<td>I refused to believe that it had happened</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>51.</td>
<td>I promised myself that things would be different next time</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>52.</td>
<td>I came up with a couple of different solutions to the problem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>53.</td>
<td>I accepted the situation since nothing could be done</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>54.</td>
<td>I tried to keep my feelings about the problem from interfering with other things too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>55.</td>
<td>I wished that I could change what had happened or how I felt</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>56.</td>
<td>I changed something about myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>57.</td>
<td>I daydreamed or imagined a better time or place than the one I was in</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>58.</td>
<td>I wished the situation would go away or somehow be over with</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>59.</td>
<td>I had fantasies about how things may turn out</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>60.</td>
<td>I prayed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>61.</td>
<td>I prepared myself for the worst</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>62.</td>
<td>I went over in my mind what I would say or do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>63.</td>
<td>I thought about how a person I admire would handle the situation and used that as a model</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>64.</td>
<td>I tried to see things from the other person's point of view</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>65.</td>
<td>I reminded myself how much worse things could be</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>66.</td>
<td>I jogged or exercised</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
APPENDIX C

Interview Question Examples
Sample Interview Questions:

Listed below is a general outline of the type of questions you may be asked at interview.

(1) How did this illness begin and what did you do?

(2) Was it stressful?

(3) If so, what was it that made it stressful?

(4) Can you estimate, on a scale of 1-10, how stressful it was initially/now?

(5) What did you want to achieve initially/now?

(6) What helped you cope initially/now?

(7) What has this illness meant to you?

(8) Is there anything else about coping that you would like to add?

You may be asked additional questions about the issues you encountered and what you did to cope. You are not obliged to answer any of the questions or to talk about issues you do not wish to discuss.
APPENDIX D

Victorian Carer Association Newsletter Advertisement
Dear Madam,

I would be grateful if you would include the following article in the next edition of the Victorian Carer magazine. As suggested, I have limited the text to 200 or less words.

**CARER RESEARCH**

*Are you providing full or part-time care to a family member with a mental illness?*

Beverly Eramo is a Clinical Psychologist who is completing doctoral studies at Deakin University, Burwood Campus. She is researching the ways that carers cope at different stages of mental illness.

In recent years programs have been developed to provide support to carers. This research can enhance the delivery of current and new programs. Your participation can make a valuable contribution to this field.

Beverly Eramo is looking for carers who:

- Have a family member with a diagnosis of Schizophrenia or Bi-Polar (Manic/Depressive) Disorder who has experienced more than one acute episode.

- Have provided care (full or part-time) for two or more years.

You will be asked to complete a questionnaire about how you coped at different stages of the illness and your stress levels; and to participate in an interview arranged at a time and place to suit you. Your confidentiality will be protected at all times.

**Contact:** For an information package about the research or participation call Beverly Eramo, on her private practice phone number: 9899 0607 or the School of Psychology, Deakin University, Burwood Campus.

Sincerely,

Beverly Eramo
Clinical Psychologist
APPENDIX E

Deakin University Student Notice Board Advertisement
ARE YOU CARING FOR SOMEONE WITH A SERIOUS MENTAL ILLNESS?
Or
DO YOU KNOW SOMEONE PROVIDING CARE?

Beverly Eramo, Doctoral Student, Clinical Psychology, Deakin University, is conducting a study of carer coping strategies under the supervision of Professor Malcolm Macmillan. Would you, or they, consider participating in this study?

IF SO

Please ring or contact
Professor Malcolm Macmillan
Psychology Department
Building W
Deakin Campus
Ph. 9244 6846

You will be provided with full information about the study to enable you to decide if you wish to participate.
APPENDIX F

*Deakin University Ethics Committee Approval*
MEMORANDUM

TO: Ms Beverley Eramo  
Psychology 
Burwood

FROM: Secretary, Deakin University Ethics Committee (DUEC)

DATE: 24 September 1999

SUBJECT: PROJECT: EC 20-99  (Please quote this project number in future communication.)
FAMILY CAREGIVERS OF THE MENTALLY ILL AND ADAPTIVE COPING

The above human research project was again considered at DUEC Meeting 5/99 held on 20 September 1999, given proposed modification(s) to the project as previously approved. The Ethics Committee decision is as follows.

THAT APPROVAL BE GIVEN FOR MS BEVERLEY ERAMO, UNDER THE SUPERVISION OF PROFS MALCOLM MACMILLAN & MARITA MCCABE, PSYCHOLOGY, TO UNDERTAKE THIS PROJECT, AS AMENDED, FROM 21 AUGUST 1999 TO 30 JUNE 2000.

Standard on-going ethical clearance has been given for the above project as modified, the conditions of which are listed on the accompanying page.

In arriving at its decision, the Committee noted your undated letter received to hand 1 September 1999 with accompanying documentation. The Committee noted the modification to the project in the light of the involvement of Maroondah Hospital, also given appropriate approval by the Hospital.

Please contact me if you have any queries about on-going ethical clearance. I can be contacted on (03) 9251 7123 (x17123). The project number should be quoted in any communication.

Keith Wilkins  
Secretary, DUEC  
Email: keithwil@deakin.edu.au
APPENDIX G

Maroondah Hospital Ethics Committee Submission and Approval
Ms Beverly Eramo  
46 Sunhill Road  
GLEN IRIS VIC 3146

Dear Ms Eramo

Project Title: *Family Caregivers of the Mentally Ill and Adaptive Coping*

Your project has now been approved by the Hospital's Management Executive Committee.

The Committee requires you to preserve the confidentiality of information about research subjects and of records. Information that is obtained for your research that is confidential or personal must not be used for purposes other than those specified in the approved protocol.

As you will appreciate the Committee has a duty to monitor all research projects and will request written reports on a regular basis to ensure research is conducted in accordance with NHMRC and Hospital requirements. The Committee is also to be notified in writing at the earliest convenience when the project is completed or abandoned.

You are expected to comply with the final approved protocol/subject information and should any of the following situations arise the Ethics Committee must be informed in writing at the earliest convenience:

- Adverse effects on research subjects.
- Proposed changes in the proposal/protocol.
- Unforeseen events that might affect continued ethical acceptability of the project.
- Changes in researchers.

You are also required to distribute to each of your subjects/participants, a copy of the *Information Pertaining to Participating in a Research Project* leaflet. A copy of this leaflet accompanies this letter.
Where necessary, contact should be made with the Chief Health Information Manager regarding access to records. The Ethics Committee is also to be notified in writing when the project is completed or abandoned.

When your research has completed, you are required to submit the following to the Hospital’s Ethics Committee:
- a final report;
- implications for further research (if relevant);
- recommendations for alterations to Current Clinical Practice (if relevant).

If the project is abandoned, the Committee is to be informed, in writing, of the reasons.

The Committee wishes you success with your project and looks forward to receiving your report on the outcome in due course.

In the meantime, would you please sign and return the enclosed letter as your acceptance of the conditions indicated. Once you have forwarded the signed Acceptance of Conditions of Maroondah Hospital Ethics Committee form, you may commence your Research Project.

Yours sincerely,

Paul Crockett
Convener/Secretary, Ethics Committee
INFORMATION PERTAINING TO PARTICIPATING IN A RESEARCH PROJECT

This information sheet is to be given to each person who participates in a research project that has been approved by the Ethics Committee at Maroondah Hospital.

The research project in which you have agreed to participate, like all research projects conducted at or involving Maroondah Hospital, has been approved by the Hospital's Ethics Committee.

The Ethics Committee reviews all proposals for research involving the Hospital, and it has the power to approve or reject research proposals. The Committee monitors the progress of each approved research project for the life of the project.

The Ethics Committee is composed of doctors, nurses, paramedical staff, a layman and a laywoman, a lawyer and a religious representative, and functions in line with National Health and Medical Research Council (NHMRC) guidelines.

The prime responsibilities of the Committee are to ensure that each proposed research project is well prepared, that it is ethically sound, and that the rights and safety of people who participate in research are upheld.

The Ethics Committee encourages comments, both positive and negative, from people who are participating in projects it has approved. Your comments, especially those relating to your treatment in the project, the information you have been given and your feelings regarding the project, are welcomed.

All comments are treated in the strictest confidence, and unless you state otherwise, your personal details will be kept confidential. Written comments should be forwarded to:

The Convenor/Secretary, Ethics Committee
Maroondah Hospital, PO Box 135, RINGWOOD EAST VIC 3135

or you may telephone the Convenor/Secretary of the Ethics Committee, on 9871 3333, pager 088, Monday to Friday during business hours.

To assist the Committee in addressing your comments, you need to provide the following information – the name of the research project in which you are participating and the name of the researcher with whom you have been dealing. Your name and address should only be included if you wish to be identified, or if you wish the Committee to be able to contact you.

If you have any concerns or queries, it is also advisable that you inform, and if you wish, discuss, the issues with the person who is conducting the research in which you are participating.

Chairman, Ethics Committee
Aug '98

Davey Drive, Victoria Australia

PO. Box 135
Ringwood East Victoria 3135 Australia

Tel (03) 9871 3333
Fax (03) 9879 1570
APPENDIX H

Plain Language Statement
Family Caregivers of the Mentally Ill and Adaptive Coping

My name is Beverly Eramo and I am enrolled in a Doctorate of Clinical Psychology degree at Deakin University, Burwood Campus. As part of my degree I am undertaking a research project under the supervision of Professor Malcolm Macmillan and Professor Marita McCabe to investigate what people do to cope with the stress of caring for a mentally ill family member. I am interested in understanding how ways of coping change over the course of the illness and which strategies have been useful at different times. I would like to invite you to participate in this research.

To gather information, I will ask you to complete a questionnaire about how you coped over two separate stages of the illness: (1) When your family member first became ill or was diagnosed with a mental illness, and, (2) Your ways of coping now. You will be asked to complete these questionnaires prior to an interview. It is estimated that it will take about 45 minutes to complete them. At interview, the researcher will ask what you intended to achieve when you used any particular strategy, and how successful this coping strategy was. You will also be asked about your appraisal of the situation over the two stages, for example: “Did you believe the situation to be hopeless?” You will be asked to estimate, on a 10-point scale how stressful you found each stage of the illness and why. A copy of the questionnaires and interview questions will be provided prior to interview. The researcher will contact you to establish a mutually acceptable time to interview you regarding your responses. It is estimated that the interview will take a further 45 minutes to one hour, although extra time may be required should you wish to discuss any issues arising from the research.

Your responses will be recorded on the questionnaires and in note format. With your consent, a portion of the interview may be taped and then transcribed. No names are recorded on the tape and, once, transcribed, the tape will be returned to you or destroyed. Your name and address will not be released to any other person. Some transcriptions of the taped interviews will be checked by another researcher to ensure that they have been correctly sorted. These interview responses will be identifiable by code only, not by name. All information will be stored in a locked cabinet at the University for a period of six years from publication and then destroyed.

All information collected from the interview and questionnaires will be treated as confidential, however, you should note that I have a duty of care to ensure your safety. If you inform me that you, or others, are in danger of harm I must inform the relevant person to offer help. Should you, at any time during the interview or later, experience uncomfortable or distressing feelings, you will be provided with a list of referrals to support agencies in your area for use. If you, at any stage throughout the time of the study, wish to cease participating in the project, you are free to do so. This refusal will in no way affect the ongoing clinical
care of your relative. A summary of my findings will be provided to the Psychology Department and will be made available to anyone interested in the outcome of the research.

If you choose to participate, or have any queries, please contact me on my private practice phone number listed below and I will send you copies of the questionnaires and arrange an interview at a time and place of mutual convenience.

Thank you for your interest in this research.

Beverly Eramo  
Box Hill Counselling  
46 Hamilton Street  
Mont Albert 3127  
Ph: 9899 0607

Professor: Prof. M. Macmillan  
Department of Psychology  
Deakin University  
221 Burwood Highway  
Burwood Ph: 9244 6846

Should you have any concerns about the conduct of this research project, please contact:

(1) The Secretary, Ethics Committee, Research Services, Deakin University, 221 Burwood Highway, BURWOOD VIC 3125. Tel (03) 9251 7123 (International +61 3 9251 7123).

(2) The Secretary of the Ethics Committee at Maroondah Hospital, if your relative is receiving care from the Maroondah Hospital Area Mental Health Service.
APPENDIX I

Participation Consent Form
DEAKIN UNIVERSITY ETHICS COMMITTEE
CONSENT FORM:

I, ________________________________

Hereby consent to be a subject of a human research study to be undertaken
by Beverly Eramo, Student, Doctor of Clinical Psychology Degree, Deakin University
and I understand that the purpose of the research is to determine the coping strategies used by family caregivers
at different stages of mental illness and their success in achieving carer aims. The results may be used to
enhance or develop carer support programs.

I acknowledge

1. That the aims, methods, and anticipated benefits, and possible risks/hazards of the research study, have
   been explained to me.

2. That I voluntarily and freely give my consent to my participation in such research study.

3. I understand that aggregated results will be used for research purposes and may be reported in scientific
   and academic journals.

4. Individual results will not be released to any person except at my request and on my authorisation.

5. That I am free to withdraw my consent at any time during the study, in which event my participation
   in the research study will immediately cease and any information obtained from me will not be used.

Signature: ____________________________ Date: ____________________________
APPENDIX J

Interview Appointment Form
Family Caregivers and Adaptive Coping Study

Thank you for agreeing to take part in this study of the ways in which family carers cope with the issues involved in providing care to a mentally ill family member. Your input is appreciated and valued.

In this folder you will find a Plain Language Statement setting out what is involved in participating in this study. Also enclosed is a Consent Form and questionnaires about your concerns and how you coped at different stages of your relative’s illness. If you are willing to continue, would you please sign the consent form and complete the questionnaires. The questionnaires are intended to be self-explanatory; however, if you have any difficulties with them or queries about them, please feel free to discuss them at interview.

I will be contacting you, by phone, to make an interview appointment and I look forward to meeting you then. Once again, thank you for participating.

Kind regards,

Beverly Eramo
Participation in Study

If you are willing to be interviewed, you should:

(1) Read the plain language statement and the Hospital's Ethics Committee Statement

(2) Sign the Consent Form

(3) Complete the Questionnaires

(4) Write your contact phone number below

(5) Return the questionnaires, the consent form and this sheet, showing your contact phone number, in the stamped addressed envelope provided.

Name:...........................................

Phone No:.......................................
APPENDIX K

Coder Reliability
Would you please read the following coping responses and rate them according to the attached Ways of Coping Scales

<table>
<thead>
<tr>
<th>Coping Response</th>
<th>Coding</th>
<th>Rater 1</th>
<th>Rater 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>We made a special effort to be together. We tried to organise things to do together.</td>
<td></td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I’d nag him and try to get him going</td>
<td></td>
<td>CON</td>
<td>CON</td>
</tr>
<tr>
<td>We just hid away from everyone.</td>
<td></td>
<td>E/A</td>
<td>E/A</td>
</tr>
<tr>
<td>I can put it, put it right out of my mind while I’m there.</td>
<td></td>
<td>DIST</td>
<td>DIST</td>
</tr>
<tr>
<td>I try to tell myself he’s not well, not doing this deliberately.</td>
<td></td>
<td>SC</td>
<td>SC</td>
</tr>
<tr>
<td>We’d ask people to visit but he always had an excuse why he couldn’t make the effort.</td>
<td></td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>The other thing is, I’ve put some limits on what he can and can’t do.</td>
<td></td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I hit him and once I threw a phone book at him.</td>
<td></td>
<td>CON</td>
<td>CON</td>
</tr>
<tr>
<td>We got on to [doctor] again and this time he organised for him to go in to hospital.</td>
<td></td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I bite my tongue now and leave it to [wife].</td>
<td></td>
<td>SC</td>
<td>SC</td>
</tr>
<tr>
<td>I told him, either you go to the doctor or I’m getting him to come around here.</td>
<td></td>
<td>CON</td>
<td>CON</td>
</tr>
<tr>
<td>I had this overpowering desire to put food in my mouth. I think it’s called chocotherapy.</td>
<td></td>
<td>E/A</td>
<td>E/A</td>
</tr>
<tr>
<td>I hid the car keys because I didn’t know what he might do.</td>
<td></td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I tried not to think about it.</td>
<td></td>
<td>DIST</td>
<td>DIST</td>
</tr>
<tr>
<td>I check on him and I put it [medication] out for him.</td>
<td></td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>From time to time I’ve talked with a friend and that’s helped.</td>
<td></td>
<td>SSS</td>
<td>SSS</td>
</tr>
</tbody>
</table>
I've had to become a stronger person and more independent because of all that's happened.

I've learnt to laugh at it.

My nerves are shot and I've had to, I got, the doctor gave me sleeping pills and something for depression.

I prayed. I believe in a higher force in our lives.

I look for the sunshine behind the clouds.

I've had good friends and family that I can talk to about how I'm feeling.

I have called the Police and had them take him back in to hospital.

I'd just try to talk to her, to reason with her.

I won't take no for an answer.

We got him to hospital, they pumped his stomach out.

[Husband] had to knock him out once to control him.

I try not to be negative, not to focus on it.

I try to block out the dark side.

We've tried banning it but he just goes outside to smoke.

I took over the money side and we've managed somehow.

I didn't know what I was supposed to do. I left the planning to [wife].

I look for something positive every day.

I told him, not here you don't. You're not bringing that rubbish into this house.
<table>
<thead>
<tr>
<th>I went once and talked with this psychologist about what</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I could do.</td>
<td>SSS</td>
<td>SSS</td>
</tr>
<tr>
<td><img src="image" alt="" />Anyway, we’ve got a community treatment order for him now</td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I helped him find a little flat. He had to have somewhere to go.</td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I had to get treatment myself. I thought I was going to crack up too.</td>
<td>SSS</td>
<td>SSS</td>
</tr>
<tr>
<td>I wanted to play it down.</td>
<td>DIS</td>
<td>DIS</td>
</tr>
<tr>
<td>I put myself in God’s hands.</td>
<td>POS</td>
<td>POS</td>
</tr>
<tr>
<td>I tried locking him in, locking him in his room.</td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I haven’t bottled up my feelings.</td>
<td>CON</td>
<td>CON</td>
</tr>
<tr>
<td>I brought him back here to live with me.</td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I made it clear to him that I wasn’t going to tolerate that sort of behaviour.</td>
<td>CON</td>
<td>CON</td>
</tr>
<tr>
<td>Mostly, I just try to keep thinking positive.</td>
<td>DIS</td>
<td>DIS</td>
</tr>
<tr>
<td>I used to walk a lot. I’d go for long walks on my own.</td>
<td>E/A</td>
<td>E/A</td>
</tr>
<tr>
<td>We got him to a doctor. That took some doing.</td>
<td>PPS</td>
<td>PPS</td>
</tr>
<tr>
<td>I’ve tried to get support from family and from the group.</td>
<td>SSS</td>
<td>SSS</td>
</tr>
<tr>
<td>We went to counselling to see if we could sort out the relationship.</td>
<td>SSS</td>
<td>SSS</td>
</tr>
</tbody>
</table>

...if you don’t like what he’s doing, try to distract him or tell him. That’s what I do. | PPS | PPS |
I certify that I have read and coded in accordance with the Ways of Coping Scales a selection of carers' coping statements.

(Signed) Signature Redacted by Library

(Dated) ......!

Steven William Morris
B.H. Sc. (T.C.M.) V.U.T.
749a Nicholson Street
North Carlton, Victoria
APPENDIX L

Credibility of Content Statement
ARAFEMI Victoria  
615 Camberwell Road  
Camberwell 3124

August 31, 2001

Dear Support Worker

I am a mature age student in the Psychology Department at Deakin University. I am currently completing a Doctorate in Clinical Psychology. My supervisor is Prof. Malcolm McMillan. My research topic is entitled “Adaptive Coping Strategies of Carers of the Mentally Ill”. This study was approved by the Deakin Ethics Committee.

Sixty carers volunteered to participate in the study and completed questionnaires about the strategies they have used to cope with their relative’s illness. Additional to completing questionnaires, forty three of the original sample agreed to be interviewed. I have been advised that I should establish the validity of the transcripts of interviews by having them appraised by two workers in the field of family support services and I am writing seeking your assistance.

Four transcripts (approximately ten percent of the sample) have been selected for that purpose. They have been selected bearing in mind the importance of maintaining confidentiality. To ensure that participants cannot be identified from the transcripts names of carers and care recipients have been deleted. Dates and the names of treating medical doctors and hospitals have also been deleted. Some minor details have been altered to further ensure confidentiality. None of the carers whose interview transcripts have been submitted for appraisal are members of ARAFEMI. Only one copy of each transcript is submitted and these should be returned in a sealed envelope following appraisal.

If you are prepared to assist and, in your professional experience, you consider the transcripts likely to be valid representations of carer interviews, I would be grateful if you would sign the attached form. I would be pleased to answer any further questions you may have and to make available to ARAFEMI a copy of my research findings when completed.

Yours Sincerely,
20 August 2001

Ms Beverly Eramo
Box Hill Counselling
46 Hamilton Street
MONT ALBERT 3127

Dear Ms Eramo,

Enclosed are the four transcripts and the forms completed by Elise Whatley and me.

Ms Whatley is an occupational therapist who has worked in both in-patient and community based services and has been worked as a dedicated family support worker with ARAFEMI for more than two years.

I am a registered psychologist and have worked in family support for seventeen years.

Yours sincerely,

[Signature Redacted by Library]

Judith Player
Executive Director
TO WHOM IT MAY CONCERN

I have read and appraised the transcripts of four interviews conducted with carers of the mentally ill. The interviews form part of a research study entitled Family Carers of the Mentally Ill and Adaptive Coping.

In my professional opinion the interview transcripts that I have read appear to reflect the kinds of issues and concerns that I have encountered in working with family carers of the mentally ill. They appear to be genuine accounts of the experiences of family carers.

Name: JUDITH PLAYER
Position: Executive Director

(Signed) Signature Redacted by Library
Date: 20 August 2001
TO WHOM IT MAY CONCERN

I have read and appraised the transcripts of four interviews conducted with carers of the mentally ill. The interviews form part of a research study entitled Family Carers of the Mentally Ill and Adaptive Coping.

In my professional opinion the interview transcripts that I have read appear to reflect the kinds of issues and concerns that I have encountered in working with family carers of the mentally ill. They appear to be genuine accounts of the experiences of family carers.

Name: Elise Whatley
Position: Family Support Worker
ARAFEMI

(Signed) [Signature Redacted by Library]
Date: 15/8/01
APPENDIX M

Correlations between Ways of Coping at Stage 2 and Caregiver/Care Recipient

Demographics
Correlations between Ways of Coping at Stage 2 and Caregiver/Care Recipient Demographics.

<table>
<thead>
<tr>
<th>Ways of Coping</th>
<th>Demographic</th>
<th>Pearson’s $r$</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Distancing</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>Employment</td>
<td>-.26</td>
<td>.04*</td>
</tr>
<tr>
<td>Seek Social Support</td>
<td>Caree’s Age</td>
<td>-.30</td>
<td>.02*</td>
</tr>
<tr>
<td>Years since signs</td>
<td>Yrs since diagnosis</td>
<td>-.36</td>
<td>.01**</td>
</tr>
<tr>
<td>Accept Responsibility</td>
<td>Age of Caregiver</td>
<td>.28</td>
<td>.03*</td>
</tr>
<tr>
<td></td>
<td>Length of Care (Yrs)</td>
<td>.36</td>
<td>.01**</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>Extent of Care</td>
<td>-.29</td>
<td>.03*</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>Extent of Care</td>
<td>.30</td>
<td>.03*</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: *$p < .05$, **$p < .01$*

A weak negative correlation between Self-Controlling and employment status is shown. Since employment was measured on a three-point scale with lower numbers indicating more full-time work, the results suggest that caregivers who are engaged in full time work use self-controlling slightly more frequently.

There was also a weak negative correlation between Seeking Social Support and three demographic variables: care recipient’s age, years since first signs of mental illness and years since diagnosed. The results suggest that caregivers with a younger mentally ill relative were more likely to seek social support, as were caregivers reporting recency of diagnosis and of signs of illness.

The age of the caregiver and the length of time they had been providing care had a weak positive correlation with Accepting Responsibility, suggesting that older caregivers accept more responsibility for the care recipient, and the longer they have been providing care the more likely they are to accept responsibility.

Escape-Avoidance had a weak negative correlation with extent of care suggesting that full-time caregivers use slightly more Escape-Avoidance coping. Extent of care also has a weak positive correlation with Planful Problem Solving, suggesting that part-time caregivers are more likely to use Planful Problem Solving than full-time caregivers.
APPENDIX N

Correlations between Ways of Coping at Stage 3 and Caregiver/Care Recipient

Demographics
Correlations between Ways of Coping at Stage 3 and Caregiver/Care Recipient Demographics.

<table>
<thead>
<tr>
<th>Ways of Coping</th>
<th>Demographic</th>
<th>Pearson’s r</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Distancing</td>
<td>Education Level</td>
<td>.26</td>
<td>.05*</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>Current Condition</td>
<td>.27</td>
<td>.04*</td>
</tr>
<tr>
<td>Seek Social Support</td>
<td>Caree Age</td>
<td>-.26</td>
<td>.05*</td>
</tr>
<tr>
<td></td>
<td>Years since signs</td>
<td>-.26</td>
<td>.04*</td>
</tr>
<tr>
<td></td>
<td>Yrs since diagnosed</td>
<td>-.31</td>
<td>.02</td>
</tr>
<tr>
<td>Accept Responsibility</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>Caregiver’s Age</td>
<td>.32</td>
<td>.01*</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>Education Level</td>
<td>.33</td>
<td>.01**</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: *p < .05, **p < .01

Distancing is shown to have a weak negative correlation with education level, suggesting that caregivers with lower levels of education are currently more likely to use Distancing as a way of coping than those with higher levels of education.

Self-controlling is shown to have a weak negative correlation with care recipient’s current condition, indicating that the more stable the care recipient’s condition, the more likely that the caregiver now engages in Self-Controlling coping.

The same three variables that correlated with Seeking Social Support when caregivers first became aware of their relative’s mental illness did not change. Again, they all had a weak negative correlation, suggesting that caregivers with a younger mentally ill relative, recent diagnosis and recent signs of illness are currently more likely to seek social support.

Caregiver’s age had a weak negative correlation with Escape-Avoidance coping, suggesting that the younger the caregiver is the more likely that they now use this way of coping. Planful Problem Solving had a weak positive correlation with education level, suggesting that caregivers who are better educated are currently more likely to use this way of coping.