

1995

# Healthy and unhealthy caring: towards a constructivist analysis of carers of the aged

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## Recommended Citation

Gillies, Christine Kay, Healthy and unhealthy caring: towards a constructivist analysis of carers of the aged, Doctor of Philosophy thesis, Department of Psychology, University of Wollongong, 1995. <http://ro.uow.edu.au/theses/1662>

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# **HEALTHY AND UNHEALTHY CARING :**

Towards a constructivist analysis of carers of the aged

A thesis submitted in partial fulfilment of the requirements  
for the award of the degree of

DOCTOR OF PHILOSOPHY (CLINICAL PSYCHOLOGY)

from

THE UNIVERSITY OF WOLLONGONG

by

CHRISTINE KAY GILLIES, BA (HONS.)

DEPARTMENT OF PSYCHOLOGY

JULY 1995

University of Wollongong

Candidate's Certificate

I certify that the thesis entitled "Healthy and Unhealthy Caring: Towards a constructivist analysis carers of the aged," and submitted for the degree of Doctor of Philosophy (Clinical Psychology), is the result of my own research, except where otherwise acknowledged, and that this thesis (or any part of the same) has not been submitted to any other university or Institution.

Signed: .....

Date: .....13/7/95.....

## **ABSTRACT**

Using a constructivist framework, ideas about healthy and unhealthy caring, from a number of populations, were drawn together and applied to carers of the aged. It was acknowledged that the ongoing decline displayed by the elder constantly threatens the carer's core needs and values (see: Braithwaite, 1992) thus necessitating reconstruing by the carer (Kelly, 1955). In this study the relationship between the carer's self-determined style of approaching or avoiding reconstruing (Berzonsky, 1990, 1992b) and tendency to relate through the caring role, a concept taken from codependency theory, (Whitefield, 1991), were studied in terms of their ability to determine the level of burden experienced by the carer, tendency to use and be satisfied with community services and the presence of codependency issues.

Differences in self-determined construing style were identified and service use could be predicted in terms of this. However, construing style type did not predict satisfaction with services or codependency issues. It was also found that carers who form serial caregiving relationships, reported more frequently that they descended from a disrupted family of origin and, when caring, engaged in a broader range of negative caring behaviours, while experiencing the same level of burden and using more community services, than did people caring for the first time. This was taken as support for a codependency model of the carer. However, it was felt that, with improved measurement, the constructivist model would have greater future research utility.

## **ACKNOWLEDGEMENTS**

I wish to firstly acknowledge the efforts of my supervisor, Dr. Beverly Walker. Once again she provided excellent, direct supervision, in which it was clear she had thought about the problems I was facing and possible solutions. I also wish to thank her for her efforts beyond the call of duty in considering my draft whilst on holiday, when busy, and even whilst flying to exotic locations. This was greatly appreciated.

I wish to also acknowledge Enid Sherwin for her assistance with the typing of both this thesis and the majority of my work since I began my university career in 1979. Having to never meet another university deadline will be as big a blessing to her as it will be to me.

I also wish to thank and acknowledge the help of staff from a number of community services in Wollongong and Dr BG Thompson who helped me recruit survey participants. The support of family, especially my mother and husband, Barbara and Simone and my good friends, especially Petria, Lesley and Peter, who encouraged me to continue working when I did not think I could finish this thesis and for their practical help, which was greatly appreciated.

Lastly I wish to thank my children, Thomas and Meghan, who, though 'motherless' for the past six months, have not complained.

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# **CHAPTER 1**

## **INTRODUCTION**

## **CHAPTER I**

### **A BRIEF INTRODUCTION TO AGED CARE POLICY IN AUSTRALIA AND ISSUES WITH HOME-BASED CARERS OF THE AGED**

In the past twenty years most western countries have been influenced by conservative policy which seeks to restructure welfare services and reduce welfare spending (Bozic, Herrman & Schofield, 1993; Taft, 1987; Wilenski, 1987). This approach was adopted in the Australian Aged Services sector when the House of Representatives Standing Committee Enquiry on Expenditure, chaired by McLeay (McLeay, 1982) recommended moving funding away from nursing home care towards community-based care for the aged. This was implemented, first by introducing mandatory admission criteria for nursing homes and hostels which excluded new, previously eligible applicants from this form of care and accommodation. Then, secondly, by passing the Home and Community Care Act in 1985 (see: HAAC, 1989) which allocated funding for services to be provided in the aged person's home.

As a consequence, more home-based nursing and domestic care services became available and greater responsibility for care was apportioned to family carers. Research findings suggest that the family carer is frequently the elder's spouse; however, if the spouse is not available, then this care is generally provided by a middle-aged daughter (Shanas, 1979a, 1979b). Thus carers of the aged may be either aged themselves, possibly

with their own health problems, or 'carers in the middle' - that is those women attempting to meet the requirements of multiple roles, such as mother to teenage children, wife, daughter, employee and carer (Brody, 1981).

The benefits of community-based care have been acknowledged at a policy level as a method of coping with health care and accommodation costs associated with having an increasingly large, aged population (Kinnear & Graycar, 1982; Sax, 1984). The magnitude, however, of care provided by family members is somewhat hidden from the community, resulting in all carers being labelled as the 'invisible providers' (Fengler & Goodrich, 1979).

Promotion of home-based community services for the aged was initially conducted along more emotive lines. It was simply said that aged people would or should prefer to be cared for at home and to be looked after by their family. In a society where the family is valued, and notions such as the 'good Samaritan' are alive within the dominant religious tradition, it was easy to promote the ideal that aged people should remain at home with their family. The likelihood that most people feel fearful at the prospect of ending their life alone in a nursing home may have influenced the willingness of the community at large to accept this argument. In addition, dissatisfaction with nursing homes is well documented (see: Social Welfare Action Group, 1982) leaving social welfare policy clearly endorsing the view that the family is the ideal provider of care for the aged (NSW Parliament, 1982; O'Neill, 1983).

Today, there has been more evaluation of the usefulness of social support and community-based services (see: Dunkel-Schetter & Bennett, 1990). It is generally agreed that, when used, community-based services

help to reduce the impact of caring on the carer (Cantor, 1983; Delaney, 1989; George & Gwyther, 1986; Montgomery, Gonyea & Hooyman, 1985; Pearlin, Mullan, Semple & Skaff, 1990). However, the mechanism by which this occurs is less clear because studies tend to confine themselves to descriptive features of support (e.g. availability of support, hours of service, etc.).

It is equally clear, however, that the carer experiences a substantial degree of difficulty providing care, even if formal and/or informal help is provided. Experiences of severe economic, social and emotional costs borne by the carer are well documented (Braithwaite, 1992; Jutras & Veilleux, 1991a; Quayhagen & Quayhagen, 1988; Rossiter, Kinnear & Graycar, 1984). When surveyed, high proportions of carers are clinically depressed and neglecting their own social, recreational and interpersonal needs (Gillies, McClatchie and Troiani, 1987).

It is also clear that, when a carer takes on the role of family caregiver, they overwhelmingly provide the care which is most needed (Brody, 1981). In other words, caregiving is not generally equally shared by all members of the family. Why one family member alone generally takes on this task is not clear; however, any model which seeks to provide a theoretical understanding of caregiving to the aged needs to be able to account for this.

When confronted with findings regarding the difficulties associated with caring, the assumption made is that the government needs to provide additional community services to strengthen the floundering carer's well-being and capacity to care. The question as to whether the carer is currently fit to care, or was ever fit to care in the first place, has mostly been absent. It

has been predicted that, in the future, more and more people will be called upon to provide care for their parents and grandparents, and that this may escalate to the point where women spend more years caring for parents and grandparents than for dependent children (Edgar, 1992). The possibility that some individuals are less able, for a range of social and psychological reasons, to provide this form of assistance for their dependent relatives needs to be addressed.

Overseas, feminist writers have noted that most carers are women and the burden they experience is an unacceptable gender issue (Finch, 1987; Ungerson, 1987). In Australia, Braithwaite (1992) has recommended the reconceptualisation of carers' burden methodology into a format which allows carers' issues to be evaluated from a social justice perspective. This would allow the identification of the proportions of carers who are living in conditions which, on the basis of a welfare/social justice analysis, are unacceptable by western standards.

In addition, the assumption that community service provision alone can ameliorate unacceptable caring situations is not borne out empirically. Burdened carers, who most need assistance, are less satisfied with perceived available support than carers who are coping (Vitaliano, Russo, Young, Becker & Maiuro, 1991a) and Australian Census data indicates that many needy caregivers do not make use of available services. For example, of the 322,600 carers who participated in the Handicapped Persons' Survey of Australian Households (ABS, 1988), 62% received no help from anyone with the tasks of caregiving (ABS, 1988). Those in spouse-carer relationships received the least help. It was noted by the statistician that:

*Eighty-six percent of carers indicated they needed no help (or no more help if they were already receiving some) with caring tasks, although one third (33 percent) of carers were never absent from the handicapped person for a period of four hours or more.*

(ABS, 1988, p.2)

Individuals confined in their home for this period of time with a very dependent or even demented family member are unlikely to be experiencing any sense of well-being, yet they apparently do not feel predisposed to ask for or accept formal help. In addition, personal relationships (e.g. friendships, family, etc.) do not always result in support being provided (Barusch & Spaid, 1989). After documenting the plight of very needy carers in this situation, survey after survey has called for greater assistance for carers. For example, the author has, in fact, assisted in producing such a survey which recommended improved service provision and co-ordination but which, in retrospect, failed to focus on factors from within the carer which might have constrained their ability to utilise help and hence impact on the level of burden they experienced (Gillies *et al.*, 1987).

The need to stop focusing on service deficiencies alone as the cause of some carers having little support with their caregiving became apparent to the author when very depressed and over-burdened carers were observed reporting at support group meetings that they had never heard of the community services available to them. Detailed information about such services had, in fact, been personally provided to them by the author. Initially, this was put down to their depression and tiredness, and that perhaps the service details had not been explained sufficiently. However,



over a number of years, this phenomenon was observed again and again, and many logical variations were heard on why a particular method of assistance, which objectively appeared appropriate, would not be utilised.

A similar phenomenon may have occurred amongst participants in a survey commissioned by the National Consultation and Assistance Program for Women (see: Watson & Mears, 1986). Survey participants were recruited through services, thus all carers were using at least one service and in contact with service staff who would presumably educate them regarding other forms of available assistance.

Accordingly, the researchers expected a positive bias in their data regarding services which the carers received and of which they had a knowledge. However, this was not found. Carers still reported receiving little help and having no knowledge of help available to them. Again, poor service provision was blamed; however this, in the author's opinion, is unlikely to be the complete explanation for why the survey participants seemed oblivious to the help they were receiving and other assistance they could utilise.

While the author does not wish to encourage 'blaming the victim' for inadequate service provision, which is clearly a problem in itself (see Gillies, *et al.*, 1987), there does appear to be a need to focus on some carers' ability to 'hear' information about help and their ability to 'accept that being helped is desirable'. Such skills may be a prerequisite for the carer's ability to negotiate healthy styles of caring and may be differentially distributed amongst carers.

In addition, there is a need to consider the findings in other fields of study regarding caring and helpseeking and to assess their application to the carers of the aged. For example, in the chemical dependency field, it has long been recognised that, when the carer of an alcohol or chemically dependent family member provides care to the exclusion of their own needs, and fails to accept help, they themselves have a psychological problem requiring as much treatment as the chemical dependant (Cermak, 1986b; Whitfield, 1991). These individuals are categorised as codependent and the self-help movement which aims to help individuals heal themselves from compulsively over-committed caring is the fastest-growing self-help organisation in the world (cited Cermak, 1986b).

Similarly, non-carer based research into failed helpseeking indicates that many individuals with all types of problems do not seek help when it is required. Initially research into helpseeking focused on factors associated with failure to use needed professional services, including medical, psychiatric and legal consultation (Kadushin, 1969). Studies looking at demographic and attitudinal correlates of helpseeking were common but more recently, factors constraining the use of a wider range of community services and everyday helpseeking, as opposed to crisis helpseeking, have been considered (Wills, 1982).

It is clear from this research that failure to seek or accept help is not a carer specific problem. DePaulo (1982), in his review of socio-psychological processes in informal helpseeking, has commented on this:

*The basic fact about helping is that people with problems - even potentially debilitating problems - often do not seek the help that*

*they need (e.g. Bergin, 1971; Dohrenwend et al., 1980). These problems might include medical conditions that are continually worsening, severe financial difficulties, or a variety of personal coping problems, often precipitated by stressful life events.*

*Although the seriousness of these problems might be expected to act as a facilitator of helpseeking, it is also clear that there are costs associated with seeking help that act as deterrents.*

*(DePaulo, 1982, p.222)*

It is also clear that helpseeking is not a unitary activity. Helpseeking involves a number of stages, such as recognising a need for help, making the decision to seek help, the process of finding suitable sources of help, and negotiating for the service to be provided (Albert & Scrivner, 1977; Gross & McMullen, 1981). Carers' helpseeking could fail during any stage of this process.

Rossiter (1984) has suggested that carers will not use services which are in some way threatening to their self-concept. While this has not been broadly evaluated with carers, it is consistent with findings regarding failed helpseeking in other populations (DePaulo, 1982; Willis, 1982). However, an explanatory model of the mechanism, by which challenges to self-concept might constrain service use in carers, has not been proposed.

If carers are to be helped, it is necessary to identify those parameters which predict equitable and usable home-based services. It is also necessary to identify those carer-based parameters which make service use costly for the carer. It is the author's implicit underlying assumption that some people accepting responsibility for the care of their aged relatives may

not have evolved the prerequisite personal requirements necessary to negotiate healthy caregiving.

Such carers may, therefore, be either unsuited to this task or unable to provide healthy care without some form of clinical intervention which focuses on them rather than on caring *per se*. This is compatible with the social justice perspective which suggests that we should not simply ask “*how to relieve stress but rather how to organise society to make the care of the dependent population more just and humane*” (Abel, 1990, p.147).

Thus it is intended in the current work to develop a preliminary research-guiding model which delineates healthy and unhealthy caring, with special emphasis on the carers' capacity to be educated regarding forms of assistance available to them and their ability to tolerate threat to self concept. Some aspects of the model will be tested empirically as part of the current project.

To summarise, information presented in the current chapter has seven (7) important implications for a model of healthy and unhealthy caring.

Firstly, the carer role generally appears to be carried out by one family member alone; it is not shared. Secondly, carers do not always use available help which can reduce their workload. When those who are most over burdened do use services, they often report that the service provided is not helpful. Thirdly, clinical observation by the author suggests that some carers have difficulty ‘hearing’ or taking in information about services.

Fourthly, the factors leading to non-use of services are unlikely to be

carer specific because individuals in non-caring situations also fail to use apparently needed help. Fifthly, there are costs associated with using help. One cost may be that the carers' sense of self is threatened by the idea of a service taking over 'their role', thus threatening their self-esteem. While such an idea has face validity, the mechanism by which this occurs requires further theoretical and empirical development.

In the sixth case, as non-carer-specific issues are implicated in failure to seek apparently needed help in other populations, other factors which delineate healthy from non-healthy caring in other special populations may also be implicated in defining the parameters of healthy versus non-healthy caregiving to the aged. Finally, some carers may not be suited to the tasks of caring.

The issues raised above will be considered further in the following chapters. Information will be presented in the following format.

In Chapter Two, the traditional carers' burden literature will be reviewed to highlight the need for better measurement, conceptualisation and theory-driven research. The role of threat to self-relevant values in conceptualising carers' self- concept will be considered.

In Chapter Three, an account of the role of threat to self concept in reducing service use in non-carer populations will be presented.

In Chapter Four, a model of unhealthy caring developed in the drug and alcohol field in which unhealthy caring is thought to be related to a damaged self - a concept related to threatened self-concept will be

presented.

In Chapter Five an account of self-concept, using a broad constructivist approach, will be presented. In this theory, self-concept (or 'identity theory', as it has been termed) is seen as playing a role in organising all thought, including that related to caring and service use. 'Self' is seen as having an organising function. This account of self provides a model for understanding how threat to self concept can impact on both the carer's emotional state and ability to organise services. The hypotheses to guide the current research are also given in this chapter.

# **CHAPTER 2**

## **CARER BURDEN**

## CHAPTER 2

### CARERS' BURDEN

#### 2.1 Burden

The majority of research into the problems of carers has been carried out in what is known as the 'Carers' Burden Paradigm'. In this chapter, an account of the manner in which carers' burden has been conceptualised and measured in this research and the problems associated with the model, will be presented. However, personally the author feels that there is a sense in which this research presents a very sanitised and remote account of the sheer suffering to be observed amongst carers. Therefore, before reviewing the literature, the author's first contact with a homebound carer will be recalled.

##### 2.1.1 A Personal Recollection of a Carer's Burden

*Mr. B., a 65-year-old retired master seaman and harbour-master, was referred to the author for home-based psychological assessment seven years ago. The horror felt regarding his situation and poverty of life-style still remains with the author. He was in the fifth year of caring for his wife who suffered with Alzheimer's disease. When the author arrived at the house, the door was answered by a very tired looking man with flat affect. He invited the author into the lounge area, where the carpet had been lifted,*



*leaving exposed boards. He apologised, saying his wife was given to wandering and was incontinent of faeces. He had cleaned the carpet as many times as possible, but could no longer eliminate the smell - so he had had to remove the carpet. As he had left work prematurely to care for his wife he could not afford alternative floor coverings. He attempted to finish feeding his wife. She was very thin but spat the food he had prepared out of her mouth. The food was well prepared and he looked distraught that, once again, his efforts to nourish her had been to no avail.*

*When a history was collected, it was found that he lived most of his life in this room. His wife had a bed in the corner and he frequently slept in his chair. He estimated that he never slept for longer than four hours at a time due to her wandering. He was worried about her getting out of the house from other rooms when he was asleep, so they lived in the one room from which she could not escape. Only a few months before she had 'escaped' and was found by the Police walking naked in the rain, several miles from home. She had no memory for recent events and no longer recognised him. Her conversation mostly consisted of asking him when her nice husband was going to come and see her. She might ask him this one hundred times a day. He had long since given up explaining that he was her husband. His daughters called twice weekly so he could have a rest for two hours on each occasion. They also delivered the shopping. He did all of the cooking and*

*cleaning. He showered his wife, dressed her, toileted her, cleaned up after her and sat with her. Though the person he had married was long since gone, he intended to care for her until she died. However, he talked about putting her in a wheelchair and stepping in front of a bus - thus putting an end to the misery of both of their lives .*

*Ongoing contact was established with Mr. B. He was observed to be maintaining this lifestyle until his wife died more than four years later. While he accepted counselling - which he saw as "that nice girl who visits me" - he would never accept help from Community Services. He continually swung between wanting to care for her alone and wanting to commit suicide. For two years before she died she was bed-bound, non-verbal and incontinent - a shadow in the corner of the room, from which he was only absent for a maximum period of 208 hours in an entire year. When she died he was grief-stricken and without any social support outside of the family. During his period of caregiving he had lost contact with friends, given up his work and had turned into an old man. He continued to contact me for support for a further two years after her death; in this time his psychological state did not improve.*

### **2.1.2 Conceptualising Carers' Burden**

The impact on the caregiver when caring for an ill relative at home has been a topic of research since the 1950s (see: Thompson & Doll, 1982).

Later, the concept of 'family burden' was introduced by Grad and Sainsbury (1963). Most early research was conducted in the mental health (including the psychiatric) field; however, interest soon turned to assessing burden in carers of the aged. Carer distress was found to be correlated with a range of negative feelings in the carer and behaviours displayed by the elder. As a result, burden has come to be operationalised in terms of a diverse range of variables. For example :

- \* Emotional costs due to feelings of embarrassment and overload (Thompson & Doll, 1982);
- \* Changes in caregivers' day-to-day lives due to disruption of daily routine etc. (Grad & Sainsbury, 1963);
- \* Financial difficulties, role strain and physical health deterioration. (Robinson, 1983; Zarit, Reever & Bach-Peterson, 1980);
- \* Troublesome behaviour on the part of the elder (e.g. restlessness, acting in harmful ways to either themselves or others, not sleeping, behaving oddly) (Stanford, 1972);
- \* Carer's inability to recuperate (e.g. lack of time to oneself, sleep disturbance) (Stanford, 1972); and,
- \* Disturbance of mental health in the carer ( e.g. dysphoria, depression and anxiety) ( Lezak, 1978).

Cross-study comparisons of the correlates of burden are difficult due to the variable methods used to operationalise burden in past research. However, from the burden research it is clear that the demands of caring are often so excessive and the impact on the carer so severe, that the caring lot has been labelled as a '36-hour day' (Mace & Rabin, 1981).

Lawton, Kleban, Moss, Ravine and Glicksman (1989) have noted that a general agreement exists amongst researchers, that carer burden includes: carer's fatigue; depression; poor health; worry; anxiety and frustration, and that measures of each need to be included to operationalise the distress experienced by a carer when providing care. Thus, most self-scored measures of burden include a measure of both the tasks of caring and the effects experienced by the carer (see: Burden Scale (Zarit *et al.*, 1980); Caregiver Strain Questionnaire (Robinson, 1983); Cost of Caring Index (Kosberg & Carl, 1986); Multidimensional Caregiver Burden Inventory (Novak & Guest, 1989).

The need to make a clear distinction between subjective and objective burden has been emphasised (Poulshock & Deimling, 1984; Thompson & Doll, 1982). As early as the 1960s, there was a suggestion that the level of burden experienced by the carer was not directly correlated with the magnitude of burden suggested by objective indicators such as elders' level of functional decline, their psychological deterioration nor the carers' associated financial loss.

For example, Hoenig and Hamilton (1966) interviewed families who cared for at least one elder. They found two-thirds of families interviewed experienced some form of objective burden, such as disruption to life with family members and financial loss. However, when asked what they thought about the patient's 'presence' and to what extent they thought they had carried any burden as a result of caring for this person (e.g. subjective burden), far fewer reported feeling burdened. Following their analysis of this phenomenon, Poulshock and Deimling have concluded that:

*although the more concrete or instrumental effects on families' experience are important, it is the subjective experience of the caregiver that colours and filters their report of its effects. As a result they must be included in any analysis of caregiving impact"*

(Poulshock & Deimling, 1984, p.239).

However, while it is quite clear that objective burden or the impact of caring and subjective burden or distress from caring are not correlated, both forms of burden continued to be combined conceptually and on measures. Despite calls to distinguish concepts and measures more carefully, researchers have been loath to separate impact from distress (Braithwaite, 1992). Braithwaite (1992) further notes that the introduction of the stress paradigm to carers' research also emphasised the need to develop a more conceptually rigorous model with well-defined terms. Although this tended to be acknowledged by researchers they still continued to use the existing measures. As a consequence, there is now a clear confound in the empirical literature which makes interpretation difficult (Braithwaite, 1992).

The failure to empirically separate impact from distress has resulted in research findings reflecting the composition of impact and distress items used in the particular measure (Braithwaite, 1992), rather than the carers' actual state of distress. There is a clear confound in the results of studies which, for example, look at the relationship between the tasks of caring and burden, but operationalise burden in terms of the tasks of caring. Thus, it is essential to operationalise burden in a manner which is free from contamination between the independent and dependent variables or to abandon the burden model totally.

There are also other problems associated with the use of the traditional Burden Paradigm. Burden measures which use tasks of caring to operationalise distress, preclude the use of a control group in the research design. One cannot compare the level of distress experienced by carers and non-carers on tests which operationalise distress in terms of task of caring, since the non-carers would not be performing the tasks targeted on the measure.

Recently there have been calls to: (i) work seriously towards the elimination of confounds in carers' research; (ii) adopt a conceptualisation and methodology for measuring burden which has functional utility for those allocating welfare funding; (iii) conceptualise burden at a relational level without blame to either the carer or the elder; and (iv) abandon traditional burden measures but adopt measures which are conceptually related to past research so that previous results can be re-interpreted, rather than being rendered redundant (Braithwaite, 1992).

These recommendations are clearly made with the aim of restructuring the current research methodology to produce findings which can attract welfare spending for carers. Braithwaite emphasises that one must be able to demonstrate that the burden experienced by carers is at least as valid as that experienced by other applicants for welfare spending (e.g. the homeless, AIDS sufferers, etc.) if it is to attract funding.

It is important to acknowledge that, in this study, the aim of collecting carer burden data is more clinically oriented. However this does not

necessarily place the current approach at odds with Braithwaite's aims.

Clinical interventions for carers also can only be provided if funding is attracted. Thus, the same utilitarian requirements for data apply in the clinical field. Braithwaite (1992) has highlighted several alternative approaches to conceptualising carers' burden and these are discussed below.

(1) Adjustment measures: Some authors have attempted to dispense with traditional burden methodology by using measures of adjustment. These are useful since adjustment of carers can be compared to the adjustment of individuals in the general population. An example is the Indices of Well-being (see: George & Gwyther, 1986; Gilhooly, 1984). Measures of general burden which are not linked to caring might also be used in this manner. An example is the Global Measure of Perceived Stress Scale (Cohen, Kamarck & Mermelstein, 1983).

(2) Psychiatric symptoms: Distress has also been operationalised in terms of psychiatric symptoms (Anthony-Bergstone, Zarit & Gatz, 1988; Gillies *et al.*, 1987; Schultz, Visintainer & Williamson, 1990). This method is not favoured by all since it does not generate the type of results required for attracting welfare spending (Braithwaite, 1992). However, it is clearly conceptually relevant to a researcher, such as the author, interested in clinical interventions. It is essential that a theoretical model aimed at identifying clinical strategies for carers be able to demonstrate that well-being can be improved by a recommended intervention. While this argument may not attract funding for social services, it may well attract funding for clinically-based programmes. However, this is not to say that assessment of well-being and psychiatric symptoms in carers is not without its problems (see: Becker & Morrissey, 1988). Braithwaite (1992) also suggests that

measures of psychiatric symptoms are less desirable because they are susceptible to the effects of unknown personality effects. However, this may indicate that personality effects should be identified and their impact quantified, rather than eliminating well-being and psychiatric symptoms as a dependent measure.

(3) Stress paradigm: The stress paradigm has generated a huge research literature and has been applied to many problems. Researchers traditionally associated with this approach, such as Dohrenwend and Dohrenwend (1981) and Lazarus (1986), recommend that three concepts be independently and rigorously defined. They are: (i) environmental stressors (those things which the carer does for the elder); (ii) carers' interpretation (how the carers view what they do); and (iii) the carers' adaptation. While conceptually clear, this independence is difficult to achieve empirically. However, the concept of the carers' adaptation capacity as a separate measure is clearly relevant to therapists working with carers.

(4) Frustration of basic needs: This model proposed by Braithwaite (1992) is based on Maslow's theory of needs (see Maslow, 1954, 1962). Braithwaite suggests that carers have basic physiological, safety, love and self-esteem needs which must be met to ensure health and quality of life. However, these are seen as being threatened in the caring context. Further to this, it is suggested that, in a modern western society, it is a person's basic human right to have these needs met and appropriate for government to provide welfare intervention when basic need achievement is frustrated by a task such as caring for an aged relative.

Braithwaite (1990, 1992) provides an analysis of how the burden



associated with caregiving is differentially experienced by those caring for aged people and those caring for children. She notes that many of the disruptions used to operationalise carers' burden in the past (e.g. routine disruption, mood change, financial disruption, etc.) are also experienced by parents caring for children. However, in the child-care setting, these demands are not generally perceived as inducing the same level of burden.

Braithwaite (1990, 1992) sees the differences in experience as being perceptually based and linked to the caregivers' inability to prevent the elders' physical, psychological and social deterioration. Children grow and prosper from the care they receive, whereas aged people continue to deteriorate and die, regardless of the quality of care provided. Carers are seen as living with the 'threat' of: witnessing the elders' loss of independence; unpredictable disease; loss of former relationship; lack of choice; as well as an inability to distribute the caring workload across a range of services.

This is seen by Braithwaite as threatening to the carers' physiological needs for rest and recreation, but also their prized feelings of and values about safety, love and esteem. Braithwaite concludes that burden is most severe when it does not " *follow the desired path, where it does not make things better and when it accompanies losses rather than gains* " (Braithwaite, 1990, p.8). This involves inherent challenges to the carers' prized values and expectations about what they personally can achieve through their caregiving. It is when one conceptualises threat to basic needs as influencing the carer at the level of values and expectations that the current author begins to see what is 'self-relevant to the carer' as also being threatened.

Though not included in Braithwaite's model, the author would add that witnessing the elders' deterioration leading to death may also vicariously challenge the carers' view of their own mortality. Grief appears to be an inherent component of caring for the aged (Rudd, 1993) but this may also include preparatory grief for their own death. There can be little as challenging to one's sense of personal self than consideration of one's own mortality.

Carers who value their ability to comfort others, and believe they can reduce the elders' suffering and prolong life, will have these views severely threatened by the reality of caring for an aged person. Those who use these characteristics to define their sense of personal self - that is, who they are in terms of these caring characteristics - will also have their sense of 'self' challenged in this situation. Threat, of the nature conceptualised by Braithwaite, can be operationalised using the Threat to Basic Needs Domain Index (TBNDI) (Braithwaite, 1990). This measure can be thought of as providing an index which reflects all that is threatening in the caring context.

## **2.2 Conclusion**

It is clear that caring can be a very negative experience for carers. The carers' burden paradigm has helped to identify a range of distresses associated with caring. However, this research is largely atheoretical and cannot generate predictions about why some needy carers do not accept help when they clearly are not coping. In order to carry out psychologically-oriented research with carers, it is essential, from an empirical perspective,

that the carer burden be conceptualised using a method which prevents dependent and independent variable confounds and can adequately account for the carers' subjective experience. In addition, the conceptual parameters of the carers' distress should have relevance to psychological treatment parameters and be linked to valid and reliable, easily-administered tests.

It is clear from the analysis provided above that traditional measures of carers' burden do not provide this. However, the measurement of carer distress, in terms of frustration to basic human needs, well-being or frequency of psychiatric symptoms compared to the general population and within groups of carers, are more in keeping with what is required from a clinical perspective. Thus, each of these measures has some relevance to the current aim of distinguishing healthy from unhealthy caring.

The frustration of basic needs paradigm has, however, clear advantages as a method of evaluating carers' burden and has greater conceptual sophistication. It provides a theoretical approach for studying carers' burden, attempting to go beyond a descriptive account of carers' workload. It also aims to provide a mechanism to explain the carers' active experience of what they do and what they experience in the caring context.

Early traditional research with carers adopted a position that carers could be viewed as passive recipients of the elder-inflicted burden. This was not borne out empirically. In contrast to this, the threat to basic needs approach sees the carer as actively evaluating the changes which take place in the elder as decline occurs, to arrive at an experience of burden. This is an interactionist perspective and burden is seen as occurring at a

relational level. Implicit in Braithwaite's conception of carer burden is the view that the carer is a construer of their own reality. The carer actively participates in creating the meaningfulness of their situation.

This position is also adopted by the current author but it is further asserted that, when the carer is seen as a construer of the elders' decline, they must also be seen as a construer of themselves within the caring context. Thus the caregiving situation is seen by this author as not only physically demanding, but also demanding for the carer in a psychological and experiential sense. Though carers have little time for reflection, they must re-evaluate and test out the meaning they ascribe to possibly their most valued ideals about how an aged person should be cared for and their view of 'self as carer', as the elder deteriorates. Thus, threat of decline may also be associated with threat to self when so many self-relevant values are necessarily questioned as part of caring.

Thus, past researchers may not have come to terms with the complex levels of reconstruing the carer must undertake whilst performing the tasks of caring. For example, a question such as: "How do you feel about bathing the elder?" is unlikely to capture the burden a carer feels when they disrobe their relative for a bath, note a new sign of a declining body, which they once knew as healthy and strong, and think to themselves: "How long can they live like this?" and: "Is this going to happen to me?"

While the carer may feel happy to lift the elder in and out of the bath, and their responses on a task of caring burden questionnaires may reflect this, the burden associated with the thoughts which arise whilst performing the task might have a burden-inducing significance of their own.

It is only by conceptualising the carer as a construer that we begin to have a framework from which to understand this subjective experience of the caring context and 'self-as-carer' on the carers' core values and understanding of themselves.

## **CHAPTER 3**

### **THREAT TO SELF AND FAILED**

### **HELP SEEKING**

## **CHAPTER 3**

### **THREAT TO SELF AND FAILED HELPSEEKING**

Rossiter (1984) has suggested that use of services may be belittling in some way for care-givers and a threat to their self-esteem. Thus, once again the carers' sense of self appears important. Rossiter's suggestion is consistent with the view that seeking or receiving help has costs as well as benefits (DePaulo, 1982). Much of the general helpseeking research suggest that people in a range of settings will not seek or use professional services which, in some way, threaten a positive aspect of their conception of 'self'.

A request for help involves a recognition of personal inability to cope alone. In a society which values individualism, self-efficacy and personal competence, such an admission is likely to threaten the individual's self-esteem. However, the way in which self-esteem interacts with helpseeking is at times paradoxical (Wills, 1982). For example, Wills found that, firstly, individuals with low self-esteem are less threatened by being helped than individuals with high self-esteem. Secondly, people with low self-esteem respond more positively to the provision of help, but, thirdly, the provision of non-threatening help results in dependency (Wills, 1982). In addition, unsolicited offers of help are more threatening to the recipient's self-esteem when the offerer has similar attitudes to the recipient (Fisher & Turner, 1970) and a similar level of skill (Fisher, Harrison & Nadler, 1978).

Thus, a potential cost of receiving help is a reduction in achievement motivation for the person being helped. People who are high in achievement

motivation are unlikely to consult services which facilitate their performance (Tessler & Schwartz, 1972). DePaulo (1982) has hypothesised that people with a high need for achievement motivation will attempt to remain self-reliant while they know they can succeed on their own, but that they may elicit help if failure appears imminent. If this is the case, then it can be expected that people who use caring to increase self-esteem via achievement motivation will not seek help before they have actually reached the burnout stage. Carers may be susceptible to this.

The way in which needy individuals evaluate when they will accept help is not fully understood but task size, perceived attitude of the likely assistance provider and their affiliation with the helper has some relevance (DePaulo, 1982). Individuals have been found to feel better about seeking help when the helper acknowledged the importance of the identified problem. Carers are reluctant to ask for help with a task which they feel the helper will perceive as small and/or not serious and with tasks which are very large. Interestingly, the individuals in need of help are mostly accurate in their prediction about the likely response they will receive to a request for assistance (DePaulo, 1982). In the same study, it was also found that workers from whom help was received were described as 'friends' rather than professional helpers (DePaulo, 1982).

In addition, people have been found to dislike receiving help from others when they cannot return the favour (Greenberg & Shapiro, 1971). This is also true of aged people (Kendig, 1972). An inability to reciprocate can create a feeling of indebtedness and dependence. Greenberg, Doth, Johnson and Austin (1980) developed the indebtedness formulation, in which they defined indebtedness as *'a state which individuals try to avoid, as*



*they dislike being unable to return help*" (Greenberg *et al.*, p.25). Providing the opportunity to reciprocate facilitates helpseeking, even when reciprocity is made to a person other than the helper (Castro, 1974). This suggests that caregivers may not make use of help from informal sources if they feel they will become indebted to the assistance provider and unable to neutralize this by doing something in return. This is consistent with the commonly held 'Protestant Work Ethic' maxim - that one should not 'take something for nothing'.

In addition, the use of services may result in the carer experiencing feelings of inadequacy. People who value anonymity, and see individual rather than collective problem-solving as the best approach, can be made to feel inadequate by the provision of help (Homans, 1961). Blau (1955) and Homans (1961) have suggested that individuals may fail to use help because it requires an open admission of personal inadequacy. This may be conceptually linked to the inclusion of an inadequacy scale in Braithwaite's Burden Index (TBNDI: Braithwaite, 1990). This has been supported in laboratory studies (Broll, Gross & Piliavan, 1974). It has also been found that helpseeking is more likely to occur when anonymity is maintained (Broll *et al.*, 1974; Tessler & Schwartz, 1972).

Based on the findings in the helpseeking research and his own research, DePaulo (1982) has hypothesised a curvilinear model of helpseeking in which, to avoid feelings of indebtedness, helpseekers are seen as reluctant to request help with either very large or very small tasks. What is unfortunate about this approach of avoiding possible negative feedback, is that the individuals in need of help never actually attempt to negotiate assistance - a process which could result in them becoming

aware of possible solutions to their problem that they had not previously considered. They also fail to learn to tolerate the anxiety associated with trying a new approach.

These findings have implications for care-givers who may face many small daily tasks which only become difficult when combined. Their reluctance to use help in this situation is unfortunate, since a sequential combination of stressors can lead to illness and inability to cope (Dohrenwend & Dohrenwend, 1981). The helpseeking research also suggests that the personal attributes of the service provider may influence a carer's willingness to accept help.

Another interpretation of these results is that the needy individual shows an over-concern for others at the expense of himself or herself. A study by Castro (1974) has indicated that people who need help frequently will not request this help if they feel that they are imposing on the helper.

To conclude, research into reluctant helpseekers suggests that carers, like many individuals, avoid helpseeking, preferring to face adversity alone rather than sacrificing self-esteem, by using services which may increase their feelings of indebtedness and inadequacy. With such a strong need to protect their ego functions, including a positive view of self, those who succumb to the use of services without resolving the issues surrounding threat to self concept, may lose their prized feelings of self-competence and self-efficacy, and slip into dependency. Perhaps the very act of using services without adequate preparation - services intended to prolong the care-giver's ability to provide care - deprives carers of their final reserves of

ego strength and renders them unable to carry on. This suggests a need for a more phenomenologically-based study of the carers' experience of receiving services.

To summarise, information presented in the current chapter has two (2) important implications for a model of healthy and unhealthy caring:

Firstly, threat to self-concept appears to be related to failure to use services in a range of clinical and non-clinical populations.

Secondly, threat to self may manifest as feelings of indebtedness, the need to reciprocate, the need to maintain achievement motivation, and the need to maintain self-esteem. In this sense, services may be threatening to carers in terms of the inadequacy dimension of burden proposed by Braithwaite (1990).

## **CHAPTER 4**

### **DAMAGED SELF:**

#### **A Codependency Model of Unhealthy Caring**

## CHAPTER 4

### DAMAGED SELF

#### A Codependency Model of Unhealthy Caring

When looking at carer-centred variables which may influence the carer's willingness to accept help and negotiate a healthy style of caring, it is useful to consider the concept of co-dependence. Codependency can also be conceptually related to the view that carers may experience threat to view of self whilst caring, an idea which will be expanded upon in this chapter.

Codependants are people who are said to inappropriately *"derive their sense of wholeness by receiving approval from others and by solving the problems of, relieving the pain of and protecting others"*. (Al-Anon, 1979, 1980). They *"sacrifice their own values to be close to others; they trust the opinions of others more than their own, and they believe that the quality of their lives depends upon the lives of other people."* (Whitfield, 1991, p.26).

Codependence is also described as an ongoing process of committed caring and self-denial for family members, based on the assumption that family acceptance and love will result. Though validated for caring by the family, other personal needs are never met (Wright and Wright, 1991). As individuals defined in this way are said to derive their sense of identity, or 'sense of self', from feeling loved when they help and care for others and solve their problems, it can be assumed that they feel a loss of identity and love when they are not providing care. Thus, individuals viewed as codependent have something very valuable to lose when they give up an aspect or all of their caring relationship.

It is possible that these characteristics may also be present in carers of the aged. What is most important for the purpose of this study is to recognise that therapists working with codependency see the condition as a relational style or psychological disorder of the self, which prevents an individual from recognising their own needs, rather than a burden to be indexed in terms of their caring workload. Codependents' high reactivity to factors outside of themselves is seen as a consequence of their 'other', rather than 'self', focus. The presence of any codependency issues in a carer of the aged could make receiving help difficult, since it would threaten their sense of who they are (their identity) and their feeling of family closeness.

It is necessary to be clear it is not being suggested that carers of the aged are codependent. As will be seen in the ensuing discussion, the lack of rigidity associated with the concept alone would make such an assertion unwise. In addition, the author does not wish to apply a 'Disease Model' conceptualisation to all distressed carers, pathologising them, as has happened to the family members of alcoholics (Miller, 1994, p.342). Rather, the concept of codependency highlights relational changes that can occur when living with a dysfunctional, unpredictable person. This concept may then give some clues as to unhealthy styles of caring developing as a consequence of living with and caring for a person with physical and cognitive disabilities. The concept of codependency may also give some clues as to the antecedents of over-committed caring style from one member of a family, and the lack of support from others. The author sees this model as hypothesis-generating only, and would warn against unsubstantiated application of the disease aspect of the theory to the carer population.

## **4.1 Assumptions Underlying Codependency Theory**

### **4.1.1 Disordered Self and Childhood Relational Patterns**

As noted above, the characteristics associated with codependence are considered to indicate the presence of a disorder of the self. This is said, by codependency theorists, to develop in response to participation in a close relationship with a drug and/or alcohol dependent person or a person with a significant personality dysfunction. Supporters of the groups for Adult Children of Alcoholics (ACOA) suggest that if one is exposed to this type of 'dysfunctional family' when young, the effects can continue to influence relational style and tendency for caring for others long after the child has left the family of origin. Relational patterns influenced by the exposure to an alcoholic in childhood, are thought to predispose these children to re-establishing unhealthy patterns of behaviour which include over-committed caring in adult life (see: Beattie, 1987; Bradshaw, 1988).

Based on therapist reports of clients in treatment, it has been concluded that the children of families with a chronically dysfunctional member were unable to act in terms of their real self as a child, due to a lack of environmental validation. This suggests that the child could not experiment with alternative ways of being, and with all coping strategies apparent to them, due to the unpredictable responses of the alcohol-affected family member. Thus, the unpredictable nature of the alcoholic's behaviour is seen as limiting the child's experimentation. Instead the child adopts stereotypic behaviours and roles, known to be viewed positively by the dysfunctional family member, capable of outbursts and other negative

behaviour when drinking etc. Over time, these controlled behaviours, roles, etc., are seen as internalised by the child, leading them to develop a 'false self'.

The false self is also sometimes referred to as the 'adaptive self', indicating that the change in self occurs as an adaption to dysfunctional behaviour (Whitfield, 1987). When individuals relate through their false, adaptive or codependent self, their behaviour is said to be more regimented and routinised, as they have lost contact with their capacity for enthusiasm, bliss, joy, compassion and empathy (Whitfield, 1991, p.61). Equally important, in terms of carers of the aged, is that such individuals would be seen as learning to be passive and powerless when faced with dysfunctional behaviour. Thus the full range of experience and coping options are not available to them.

While codependency theorists do not appear to have analysed their model of self, what they are describing appears to be what Waterman (1984) would call a "discovery model of self". Self is seen as an 'intrinsic essence' and something they must search to regain contact with if they are to have psychological health. Treatment for codependents thus aims to restore the individual to contact their true self.

#### **4.1.2 Roles and Messages**

It is presumed that children who grow up in a family with a member who is afflicted by a compulsive condition, such as alcoholism - will adopt one of a number of predictable roles to cope with the family dysfunction. In



the short term this is useful because the child knows how the unpredictable adult reacts to the role-determined behaviours. Thus an unpredictable environment becomes more ordered for the child.

Common roles have been described by Wegscheider (1981) as the Lost Child, the Scapegoat, the Enabler and the Hero. According to Wegscheider, the role played is often determined by their position in relation to the dysfunctional person or their birth order (e.g. wife, first-born child, subsequent child). The Enabler role, for example, is normally played by the spouse who has to take care of things in her partner's absence, and invests energy in trying to help the dependant give up drinking.

The Hero role is said to be played by the first-born child, who also learns to invest energy in trying to care for the alcoholic, but also plays a special role in attempting to restore the family's pride, which has been sorely tested by having an alcoholic member. Such individuals often do well academically and work in helping professions. They are also said to form a relationship with people who are chemically dependent or dysfunctional in some other way, and complete a cycle by becoming enablers themselves.

The Lost Child is described by Wegscheider (1981) as normally the second-born child in the dysfunctional family. He or she initially attempts to cope by adopting the same strategy as the Hero but is unable to compete, and so 'drops out' of the family dynamic. They are described as playing alone as a child, day dreaming, pursuing hobbies, reading or playing sport. They become loners, expect little from others and take pride in possessions.

The Scapegoat role is said to be played by the next child. Again, this

child withdraws from the family and their peers become his/her primary reference group. The behaviour of this child becomes characterised by a lack of responsibility, poor school performance, unco-operativeness and open rebelliousness. Despite having a large peer group, they also frequently lack the honesty and genuine concern for others needed to form intimate, co-operative and loving relationships. It is this child who is thought to complete the cycle by growing up to become chemically dependent and marrying someone with the prerequisite to become an Enabler.

It is through these roles that alcoholism is thought to be transmitted across the generations, with the Hero becoming Enabler, and the Scapegoat becoming alcoholic. The one thing that all members of this family are said to have in common is an inability to communicate honestly and to form intimate relationships (Wegscheider, 1981).

Those individuals most likely to form intense caring relationships are those in the Hero-Enabler role. This caring orientation may also render them as suitable candidates for caring for the aged members of their family, though this has not been addressed by codependency theory. The observations of Wegscheider (1981) outlined above are consistent with the cybernetic epistemology which states that interaction between members of a system is assumed to lead it along an evolutionary path (Bateson, 1972). In addition, the identification of roles within family systems is not unique to the codependence theorist. They have also been noted by other systems theorists.

Recently there has been interest in early family antecedents of contemporary relating between the family members of aged people

(Whitbeck, Hoyt & Huck, 1994; Whitbeck, Simons & Conger, 1991), but this has been more concerned with how close affectional bonds in childhood re-emerge at the time of aged parents requiring care. However, consistent with the suggestions of codependency theorists, it has been concluded that interactional patterns and role expectations established in early childhood remain remarkably persistent throughout the lifespan (Jackson, 1965). In addition, Whitbeck *et al.* (1991) commenting specifically on the area of relational bonds in later life, have concluded:

*Although lineage systems members may conspire to avoid main areas of conflict to maintain harmony (Cirirelli, 1981; Hagestad, 1984; Troll, 1972) negative interactional style established early in life may emerge in times of serious need or family trouble to influence the family's ability to negotiate solutions (Simos, 1970, 1973).*

(Whitbeck *et al.*, 1991, p.331)

This would appear to support the view that caring style for the aged may be influenced by roles and expectations established in childhood.

Returning to codependency theory, Wright and Wright (1991) have noted that a similar set of roles to those described by Wegscheider (1981) have been described by Black (1982) who also apparently suggests that people in these systems internalise three basic rules: don't trust, don't talk, don't feel. In fact, considerable work has been carried out by therapists attempting to catalogue, though not empirically demonstrate, the range of damaging family messages and rules which are communicated to children in

a family setting which is attempting to cope with a less functional member. It is through the adaption of these rules and messages that rigid role types are said to be reinforced. Whitfield (1990) has reviewed the finding of this work and produced a tabulated summary. This is reproduced below.

**Table 1     Summary of Negative Rules and Negative Messages Commonly Heard in Alcoholic or Other Troubled Families**  
**(Reproduced from Whitfield , 1990)**

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**Negative Rules (generally implied)**

Don't express your feelings; Don't get angry ; Don't get upset; Don't cry; Do as I say, not as I do; Hurry up and grow up; Be good, "nice", perfect ; Avoid conflict (or avoid dealing with conflict); Don't think or talk - just follow directions; You're stupid (or bad, etc.); You caused it; I'm sacrificing myself for you; No back talk; Don't contradict me ; Always look good; I'm always right, you're always wrong; Always be in control; Focus on the alcoholic's drinking; I promise (though breaks it); You make me sick; We wanted a boy/girl

**Negative Message (verbalised)**

Shame on you; You're not good enough; I wish I'd never had you; Your needs are not all right with me; Be dependent; Be a man; Act like a nice girl (or a lady); You don't feel that way; Don't be like that; Don't betray the family; Do well in school; Don't ask questions; You owe it to us; Of course we love you!; Be seen and not heard; Don't discuss the family with outsiders ( keep the family secret); How can you do this to me?; We won't love you if you....; You're driving me crazy!; You'll never accomplish; It didn't really hurt; You're so selfish; You'll be the death of me yet; That's not true; Focus on the drinker's or troubled person's behaviour; Drinking (or other troubled behaviour) is not the cause of our problems; Always maintain the status quo; Everyone in the family must be an enabler.

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This approach of documenting family patterns observed in therapy is also reminiscent of the early observational work of family therapists which

did eventually lead to a rich field of research (Olson, 1970) If present in carers of the aged, 'closed' communication styles such as those catalogued above would make the negotiation of a flexible style of care difficult.

## 4.2 Brief History

The concept of codependency has its origins firmly in the chemical dependency field. A brief account of work from area can help us appreciate those areas of codependency theory which can be applied to carers of the aged and those which cannot. In the 1940s, it was noted that the alcoholic's spouse frequently displayed a characteristic set of behaviours which enabled the alcoholism displayed by the partner to be masked, whilst they were in the active drinking and early sobriety stage (Wegscheider, 1981). Treatment for the 'alcoholic wife' was found to be essential if the male alcoholic was to remain sober. Later it was recognised that this pattern of behaviour was present in most family members who had regular contact with an alcoholic.

Family members were not felt to be co-alcoholics in the sense that they engaged in drinking (Mendelhall, 1989) but, rather, that they 'supported' the alcoholic and 'enabled' him or her to continue drinking. A similar observation could be made about carers who enable elders to avoid using respite services, etc. when they themselves require a rest. The support group for the families of alcoholics, Al-Anon, "*all began with the wives of early A.A. members who realised their own need for change*" (Al-Anon and the Twelve Step Tradition, 1981, xi).

The Al-Anon family-based approach to treat alcoholism came at the

same time as Family Systems Therapy was being developed (Gieryski & Williams, 1986). However, there is one significant difference between these treatment strategies. Family therapists see family members as changing to accommodate the presence of a chemically dependent person. Kaufman (1985) noted that the use of alcohol is purposeful, adaptive, homeostatic and meaningful within a family unit and can be treated using family systems therapeutic strategies (Anderson & Henderson, 1983; Kaufman, 1985).

In comparison, the codependency/chemical dependency therapists consider it a 'family disease' (Olson, 1970; Wegscheider, 1981). The disease model of alcoholism which dominated the chemical dependency field at the time was applied to other family members. Alcoholics are diseased - so are the family members who live with them. Thus, individuals with this extreme caring tendency, which might also be present in some carers of the aged, were thought to have a diagnosable disorder. This gives cause for concern since it clearly pathologises the family members (Miller, 1994), leads to the medicalisation of women's lives (Riessman, 1983) and, in some cases, can extend to blaming the spouse for the dependent's pathology. For example, the comment was made in the literature: *"Who would not drink with a crazy wife like that?"* (Beattie, 1987, p.3) and: *"Those crazy co-dependants are sicker than the alcoholics"* (Beattie, 1987, p.3). The author would not encourage a similar assessment of carers of the aged.

Recently, at the First International Conference on Codependency, participants jointly agreed to define codependence as an: *"addiction in and of itself characterised by an uncontrollable urge to search for people or external objects for fulfilment of the self"* (cited: Prest & Storm, 1988). This definition clearly labels the condition as a disorder of self or identity and

highlights the compulsivity associated with the need to care. In other words, rational thought does not guide and limit caring; rather, there is an insatiable drive. In addition, it is now accepted that codependence can develop as a consequence of living with any individuals displaying a wide range of disorders causing dysfunction, and can thus develop independently of alcoholism (Beattie, 1987; Cermak, 1986b, 1988). This definition may define unhealthy caring in some carers of the aged.

Documentation of the presence of codependence in relationships where alcoholism is absent has begun. For example, no significant difference was found in the codependent relationships of married couples with a compulsive eater and a compulsive drinker (Prest & Storm, 1988). In addition, issues of codependency also have been identified as existing among helping professionals and their clients (Fausel, 1988; Schaef, 1986; Whitfield, 1984) and some gay and lesbian relationships (Smalley, 1990).

*In carer research* two sorts of caregivers, formal and informal, have commonly been distinguished. In other words, there are professional caregivers - which include doctors, nurses, psychologists, social workers, drug and alcohol counsellors, and any employee in the social service fields - and there are informal or family caregivers. To the author's knowledge, this will be the first study looking at codependent styles of behaviour and identity in caregivers for the aged, although there are some studies looking at it in formal caregivers. It has been found that the health professions are the ideal vehicle through which codependent individuals can express their need to nurture and that many health professionals are, in fact, codependants (Reverby, 1987; Sherman, Cardeo, Gaskill & Tynan, 1989; Smalley, 1990; Wilson-Schaef, 1987).

It will be recalled that codependency had its origins in work with alcoholic families. Being a daughter or a son of an alcoholic alone is still considered by codependence workers as a strong indicator of the likely presence of codependency issues. Wegscheider-Cruise (1985) has looked at the frequency with which nurses come from families with an alcoholic parent and found that, in the United States, 83% of nurses are the first-born child of an alcoholic parent. This is the child most likely to develop the Hero role and develop behaviours in childhood, such as caring for younger brothers and sisters (i.e. the parenting child) which can establish early codependent relational patterns.

In addition, Laign (1989) reports on attendance statistics from the Sierra Tucson Treatment Centre - which is a centre for treating codependents in Arizona. Between 1982 and 1986, 22% of all persons seeking treatment for codependency issues worked in the human services fields. It is probably no coincidence that it is these professions which suffer the highest rates of burnout since, as Clark and Stoffel (1991) have noted, burnout has been defined as the disease of over-commitment, which is also an apt description of codependence and possibly of caring for the aged when severe cognitive disturbance is present.

It is, therefore, not unreasonable to suggest that informal carers of the aged might also have a problem associated with codependence which could influence their helpseeking and/or help accepting ability. However, as noted previously, the field of codependency is not without its critics (see: Gierymski & Williams, 1986; Miller, 1994). From an academic perspective, there are very clear shortcomings associated with this model. These shortcomings will be outlined below.



### 4.3 Shortcomings

#### 4.3.1 The Definition Problem and Multiple Perspectives

From an academic perspective, the codependency literature is plagued by a definition problem. Each of the six major authors in the area (Viz. Wegscheider-Cruise, Smalley, Subby, Whitfield, Larsen and Wilson-Schaef) have, in the past, defined codependence differently. In fact, codependence has been defined as everything from a 'primary disease', present in every member of an alcoholic family, to an active systemic disease affecting 96% of the population (Wegscheider-Cruise, 1985). As noted above, the disease model of codependency which was co-opted from the disease model of alcoholism by drug and alcohol workers, guided much of the early work in this field. There has, however, been little support for the concept of codependency as a unitary disease state or diagnostic syndrome (see: Miller, 1994).

While, from a research perspective, differential definition is cause for concern, the different definitions given in the literature may also reflect differences in theoretical orientation. In other words, workers who are focusing on different aspects or layers of the condition may use different definitions. A similar analogy in traditional psychology would be comparing the analysis and definitions used by behaviourist and humanistic psychologists to study a similar topic.

Approaches to definition which appear in the literature (and variables of interest) are: (1) Interpersonal level definition, which emphasises the cataloguing of spoken rules which govern communication in the family of

origin (e.g. prohibition against honest communication, keeping secrets: see: Black, 1982); (2) Ego psychology level definition which emphasises the cataloguing of Unspoken or implied rules leading to identity disturbance; (3) Behavioural level definition which emphasises a primary illness model with a recognisable, diagnosable and treatable range of symptoms (see: Whitfield, 1984); (4) Combined behavioural and intrapsychic level definition which emphasises the presence of symptoms, delusions, compulsion, frozen feelings, low self-esteem and stress-related medical complications (see: Cermak, 1986b); and, (5) Feminist level definition which emphasises that the codependent displays the same symptoms as the unliberated woman (e.g. passive, low self-esteem, not caring for oneself (see: Wilson-Schaef, 1986).

Working on these various approaches to codependency has led to an evolution in thinking and there is general agreement that an upbringing in any dysfunctional family can result in codependent reactions (Cermak, 1986; Friel & Friel, 1988; Subby & Friel, 1984; Whitfield, 1987; Woititz, 1983). In addition, there have been theoretical and empirical challenges to the concept of codependency as a unitary discrete condition (el-Guebaly, West, Maticka-Tyndale & Pool, 1991).

#### **4.3.2 The Problem of Rigor**

Shortcomings of the model which are relevant to the current project will be considered. Codependency theory has been developed by drug and alcohol counsellors, trained in therapy but not in research. Their orientation is non-academic, preferring instead an anecdotal approach. Concepts tend to be passed on through workshops and the popular press

(e.g. self-help literature) not via the scientific literature (Martin, 1988). There has also been little interest in carrying out randomised research by drug and alcohol workers.

A more rigorous approach could resolve the methodological and conceptual problems inherent in codependency theory . However, there has been little interest in applying academic psychological analysis to codependency theory. Academic studies of codependency are few in number. The author was able to identify only twenty (20) academic references using the NSW State Drug and Alcohol Library data base, which includes Medline. It has also been reported that even fewer studies can be accessed via the data base Psychological Abstracts. Only eight empirical studies on codependency were published in a journals search by Psychological Abstracts between January 1983 and September 1988 (Mellody, Miller & Miller, 1989). The current author's review suggests this situation has not improved dramatically since 1988. There are, of course, hundreds of articles and popular self-help books describing but not validating the condition. There is also a counter-argument, put by drug and alcohol workers, in response to those studies which have been produced. They claim the studies are too simplistic in their approach to properly investigate the complex patterns they are describing (see: Miller, 1994). There is probably some truth in this assertion.

#### **4.4 Alternative Approaches to Codependency**

In recent times there have been three approaches to reconceptualising codependency which may be relevant to carers of the aged and are worthy of consideration.

#### **4.4.1 Codependence as a Personality Disorder**

Cermak (1986b) presented a serious attempt to have codependence included in the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM, IV) and developed a DSM-style criterion. This was considered in the last up-grade of the DSM but rejected until further supporting research is provided. Given the state of Codependency research, this is not surprising. The criteria suggested for diagnosis of Codependency as a personality level disorder were:

1. Continual investment of self-esteem in the ability to influence / control feelings and behaviour in self and others in the face of adverse consequences;
2. Assumption of responsibility for meeting others' needs to the exclusion of acknowledging own needs;
3. Anxiety and boundary distortions in situations of intimacy and separation;
4. Enmeshment in relationships with personality disordered, drug-dependent, impulsive individuals;
5. Exhibits (in any combination of three or more) constriction of emotions with or without dramatic outbursts, depression, hypervigilance, compulsions, anxiety, excessive reliance on denial, substance abuse, recurrent physical or sexual abuse, stress-related medical illness and/or a primary relationship with an active substance user for at least two years without seeking outside support.

There is little doubt in the author's mind that some carers of the aged exhibit symptoms 1 and 2 and at least some of symptom 5. As noted previously, helpseeking is sometimes limited in carers of the aged. The flavour of criterion 4 is also met by carers of individuals with dementing disorders. The traits of codependence have been considered as continuous rather than discrete variables by Cermak, with some individuals displaying elements of the condition but others being totally impaired (also see: Miller, 1994). Thus, caring for others is clearly not seen as an indicator of deviance in all cases. In fact, it is mostly seen as very desirable.

Using this model, many individuals could display codependent behaviours without warranting a disease level diagnosis. This type of behaviour is only considered deviant when it dominates relationships to a degree which necessitates the carers totally ignoring their own needs. Cermak (1986b) has noted that the trait of narcissism equally occurs in most people. However, the diagnosis narcissistic personality disorder is only made when narcissism dominates the personality and occurs within a particular configuration of behaviours. He believes that some people are affected by codependence to the degree of a personality disorder, though others display only some of the characteristics. The indicator of impaired caring would be that the total configuration of symptoms from the diagnosis were present.

In developing systematic diagnostic criteria, Cermak (1986b) was forced to consider why it is that codependent individuals could not be classified under existing personality disorder such as mixed personality disorder (301.89) or dependent personality disorder (301.6). In doing so, it was recognised that neither disorder allows the codependant's central need

to control others to be evaluated.

It was felt that, at the core of codependency is an issue of control and will-power. Chemical dependency workers had long recognised that alcoholics have a similar problem. Instead of solving the problems that led to drinking in the first place, most active alcoholics are said to *continue* believing they can control their drinking by an act of will. Similarly, codependants are thought to believe they can solve the problems of those *they care for and themselves* by control and willpower, rather than by negotiation and problem-solving. In a sense they have a propensity towards omnipotence, failing to recognise their own human limitations.<sup>1</sup> Such characteristics, if present in carers of the aged, would limit the carers' capacity to engage in sharing of the tasks of caring.

It has been noted that the personality disorder view of codependence is "*virtually identical to Karen Horney's work on the neurotically compliant personality*" (Horney, 1942, 1945)" (Wright & Wright, in press, p.8). Horney's concept of the "*morbidly dependent*" personality is similar to what the codependent theorists are describing. Thus, conception of this problem would have greater currency in the psychological field.

#### **4.4.2 Sub-group Hypothesis**

In a sense, Cermak's conception of codependent personality disorder does not require one to support the unitary conception of codependency. He recognises that codependent type behaviours may be present in those

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<sup>1</sup> The willingness to recognise human limitations and personal powerlessness in some situations is the first step in the 12- step programmes which form the foundation of AA and Codependency programmes.

who are not personality disordered. This is supported by studies which have failed to find a support for a unitary model. For example, el-Guebaly *et al.*, (1991) carried out a discriminate and confirmatory factor analysis on the symptoms displayed by members of Adult Children of Alcoholics treatment programmes. There was considerable variety in the types of symptoms they displayed. He could find no support for the concept of a unitary or single condition called codependence.

This is consistent with the findings of studies in which the psychological state of the wives of alcoholics were investigated using personality measures (e.g. MMPI. see: Kogan, Jackson and Fordyce, 1963; Corder, Hendricks and Corder, 1964; Hammond, 1985; Steinglass, 1981). After reviewing these studies it was concluded by Gieryski and Williams (1986) that “(1) Wives (and possibly other members) in the families containing an alcoholic are, as a group, likely to suffer more emotional problems than the spouse of nonalcoholics; and (2) The precise degree and form of their emotional problems vary considerably”. This, of course, suggests a variable rather than unitary adaption to living with an alcoholic.

In response to such findings there have been attempts to reconceptualise codependence as: firstly, a continuum of behaviours (Miller, 1994); secondly, as subgroups of behaviours (Hawks, Bar & Wang, 1994; Kellerman, 1978); and thirdly, as impaired relational patterns (Wright & Wright, 1990, 1991).

The subgroup approach was proposed as early as the 1950s but abandoned. For example, as Miller (1994) notes, Whalen (1953) carried out

systematic observation of nine women involved in relationships with alcoholic partners. He noted four trends which he described in terms of the four metaphors: the sufferer; the waivering wife; the controller; and the punisher. These were abandoned as a concept of four different types of dysfunctional relating but, according to Harper and Capdevilla (1990) and Miller (1994), were reconceptualised to form the dysfunctional roles theory of Wegscheider (1981).

Kellerman (1978) also described three types of codependence which resemble Whalen's formulation. They were: the Enabler, who rescues the dependant; the Victim, who adopts responsibility and holds the suffering; and the Provocateur, who controls, coerces and adjusts but never gives in or lets go. Kellerman suggests dividing codependence into these three types. This led Hawks, Bar and Wang (1994) to empirically examine three types of codependence: firstly, Persecutory Style Codependence, characterised by nagging, threatening and blaming; secondly, Suffering Style Codependence, characterised by feelings of guilt, shame and inadequacies; and, thirdly, Rescuing Style Codependence, characterised by saving individuals from the consequences of their own behaviour, covering up the difficulties, denying and lying. They found only the suffering style to be present in their sample, thus providing support for the now growing idea that a group may display some but not all possible codependent behaviours.

Kellerman's (1978) suggestion that there are three styles of codependence (i.e. Persecutory, Suffering and Rescuing) may be a useful way to evaluate unhealthy behaviours in carers. A Persecutory style of caring would not be desirable for the carer nor the elder for whom they care. However, it is well documented that elder abuse occurs at the hands of



carers (Gillies *et al.*, 1987;), suggesting that a Persecutory approach may be present in some carers. In addition, studies on the carer's emotional state suggest that a Suffering style may be adopted by many carers.

The concept of the carer as an Enabler has not been considered. However, it is a basic tenet of rehabilitation that the elder's optimal functional status be maintained for as long as possible. Thus, independence is always encouraged in an elder. This is not always easy and carers must vigilantly resist the temptation to do things for the elder because it is quicker, or because it will save the elder from discomfort. In a caring situation, enabling may manifest as carers doing tasks for the elder that the elder is capable of doing for themselves -thus encouraging dependency. Hence, these constructs have relevance to delineating unhealthy caring. They are also easily measured using Hawk *et al.*'s (1994) approach. There is, unfortunately, no reliability data given for the measure.

#### **4.4.3 Relational Patterns**

Wright and Wright (1985, 1990, 1991) propose that codependency be conceptualised at a relational level rather than as a disease or personality syndrome (Cermak, 1986b). The approach of Wright and Wright is interesting, as they are both therapists working with codependants and academics, and see both sides of the codependency argument. They note that the relational difficulty inherent in codependency was emphasised in early codependency work (Wright & Wright, in press, p.1), and that this should be restated:

*We have attempted to reinstate the original meaning of*

*codependency by conceptualizing the characteristics of codependent relating independently of any assumptions about pre-existing dispositions. We reasoned that if codependent relating were definitively associated with a personality syndrome, this association would eventually be borne out in research. But to establish such an association, it would be crucial to have independent measures of codependent relating and the presumably relevant personality syndrome.*

(Wright & Wright, in press, p.8)

Thus, these workers have attempted to develop measures of operationalise codependent relating by modifying the Acquaintance Description Form (ADF: Wright, 1985) to operationalise thirteen commonly reported characteristics of codependency. They have conducted research into codependent relating with a sample comprising 175 men and 170 women, and the scales purport to distinguish those involved in codependent relationships from those who were not. Their factor analytical investigations also support the view that codependency is not a unitary concept. Eight scales were found to load on one factor, which appeared to describe defensive and overprotective care-taking (see below) and five scales were found to load on a different factor, a possible description of enmeshment in the relationship (cited, in press, p.9). Thus, individuals could be overprotective and/or enmeshed.

The authors propose that 'codependency' is present when an individual loads on both factors. This might also operationalise dysfunctional caring. The Wrights have also proposed a distinction between exogenous and endogenous codependency. Exogenous (reactive) codependence is

described as the type of relating that develops when *“nice, ‘normal’ people whose socialization has emphasized loyalty and commitment to maintaining relationships and a deep personal concern for the well-being of one’s partner and family members”* (Wright & Wright, in press, p.9) provide support and care. According to Wright and Wright, the concept of exogenous codependency is in keeping with the idea of enactment of a situational identity (Alexander & Wiley, 1981; Jackson, 1988). Endogenous codependence (chronic codependency), of course, indicates a more entrenched form of relating, which is more likely to be related to what codependency theorists have been describing as present in the families with a dysfunctional member. The authors do not discredit family influences in codependency - they just do not see it as a useful explanation in all cases:

*In all probability, the most common appropriate mix of situational and personal influences that promote codependency comes about when two people from dysfunctional families of origin ‘find’ each other and form a ‘codependent-dependent’ relationship based on shared mental models, complementary attitudes and self perceptions. A different kind of mix may occur when a person socialized to express co-operativeness, compassion and concern in close relationships becomes involved with a troubled and troubling partner who is skilled at altercating.*

(Wright & Wright, in press, p.10)

This may also be true for carers of the aged. Early socialisation may have an influence on their style of caring and relating in the caring context. Wright and Wright (in press) also note that the conceptualisation of

codependency at a relational level is consistent with the treatment approach for codependency which emphasises changing the relational pattern between codependent and dependent. They note that this approach is inherent in many of the slogans used in treatment: e.g. "If nothing changes, nothing changes"; "Insanity is doing the same thing and expecting a different result"; "Recovery is a process ... not an event".

Wright and Wright (1990) have conducted a number of factor analytical studies to eliminate any items which reduce internal consistency from their scale. At present they measure codependent relating in terms of the following eight dimensions which are summarised in Table 2.

**Table 2 Names and Definitions of the Provisional Codependency Scales** Reproduced from Wright and Wright (1990, p.339)

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**Control:** The degree to which the subject attempts to maintain influence over the target and to feel uneasy if (s)he regards himself or herself as having too little influence in the relationship and/or the target person as having too much.

**Worth Dependency:** The degree to which the subject regards his or her own sense of self-worth as contingent upon both the presence of positive or complimentary responses and the absence of negative or uncomplimentary responses from the target person.

**Exaggerated Sense of Responsibility:** The degree to which the subject regards himself or herself as a predominant influence in determining the target person's behavior, decisions, and overall level of happiness and well-being.

**Exaggerated Sense of Permanence:** The degree to which the subject regards the dissolution of their relationship with the target person as a possibility with such dire consequences that (s)he maintains, or would maintain, the relationship in spite of serious problems or personal unhappiness.

**Active Dependency:** The degree to which the subject regards his or her own pattern of interests and activities as contingent upon that of the target person.

**Table 2 continues Names and Definitions of the Provisional Codependency Scales.**

**Rescue Orientation:** The degree to which the subject regards her or his relationship with the target person as a predominant influence in drawing the target person away from self-defeating, personally destructive, and socially ineffective patterns of behavior, attitudes, and values.

**Change Orientation:** The degree to which the subject regards himself or herself as a continuing influence in encouraging and sustaining changes in behavior, attitudes, and values that the target person needs to make to become an adequately effective and well adjusted person.

**General Favorability-Relationship:** The degree to which the subject responds to her or his relationship with the target person in a globally positive way, that is, by regarding the relationship to be essentially trouble-free or, if troubled, due to factors that are circumstantial or impersonal.

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This approach to codependent relating is by far the most sophisticated and rigorous available. However, to be used in the aged care context, the scale would require modification. This could not be done without repeating the studies to validate the scale with the aged-carers population. Given that the scale is complex, this would require a major study in itself. However, should the presence of codependent behaviour in carers of the aged be demonstrated with other measures, *modifying this scale for further research* would most likely be the second step.

#### **4.5 Codependency as a Model of Unhealthy Caring**

There can be little doubt that, in recent times, the concept of codependency as a unitary disease state has been used in an over-inclusive manner. One must agree that these are: *"connotations far exceeding*

*justification*" (Gierymski & Williams, 1986, p.7). The range of associated codependent behaviours and emotional states are likely to be present in only a few extreme cases. The unquestioned belief held by exponents of the chemical dependency approach, that clinical observation and the face validity apparent in the comments of clients, is sufficient data upon which to build a theory and treatment approach, had led from what were valid observations requiring further empirical valuation into overstated concepts attracting very harsh criticism and contempt (e.g. Miller, 1981; Weinberg, 1987). It must also be said that the huge profits associated with self-help book sales, workshops and private codependency clinics, firstly in the United States of America but also now in Australia, may have helped fuel these strong concerns.

However, the question is asked: Can codependency provide any sound ideas about unhealthy caring in the aged care context? It is felt that, if the more recent grandiose claims are ignored, favouring the early observational data and more recent research findings, there are a number of concepts which may help to guide the search for a model of healthy and unhealthy caring for the aged.

Clinically, it has been observed by the author that the concept of codependency is useful and that, as drug and alcohol workers claim, clients from a range of settings immediately recognise themselves in role descriptions, which often facilitates change. It would thus be inappropriate to totally discredit concepts because they were developed in a field without a research orientation. The Wrights, who, as noted previously, have both drug and alcohol and academic training have also commented on this :

*The clinical experience of the second author (with addiction counseling) and the research experience of the first author (with personal relationships) convinced us that the problem of codependency is both highly significant and, in principle, eminently researchable. (Wright and Wright , 1991, p.436)*

Thus, in line with Braithwaite's (1991) suggestion that carers' burden should be conceptualised at a relational level, the aim here is to relinquish those chemical dependency notions about codependency as a disease and tendency to shift blame, but take heed of the observations made in this field about the relational disturbance which occurs when one person provides care for another 'dependent' who is displaying less functional behaviour.

To summarise, information presented in this chapter may suggest, with regard to unhealthy caring for the aged, that firstly, relational disturbance is an inherent component of caring for a dependent person. The impact of troublesome and embarrassing behaviour by the elder (Thompson & Doll, 1982) is recognised as associated with carers' burden. However, these types of behaviours have been conceptualised in terms of medical symptoms or increases in workload for the carer. While it would *not* be appropriate to classify most elders' decline as dysfunction in the codependency sense, there are clearly some elder behaviours that can be thought of in this manner. The troublesome behaviour of an alcoholic is unlikely to be as severe as that of a person with even moderate levels of dementia.

However, in codependency theory, dysfunctional behaviour in the dependent is also defined in terms of the consequences it has for the carer.

Those behaviours in a dependent which limit the carer's ability to have their own needs met and challenges their capacity for psychological and spiritual growth are being referred to when the term 'dysfunctional behaviour' is used (Whitfield, 1991). This is reminiscent of Braithwaite's view that burden should be conceptualised in terms of threat to basic needs (Braithwaite, 1990,1992). However, beyond this, the codependency theorists are suggesting that *dysfunctional behaviours* are those which elicit a defensive self construction and relating style which inhibit open and honest interpersonal relating.

This concept can be easily applied to carers of the aged. Interpersonal relating will always be affected when the elder has an organically based communication problem or dementing disorder. However, perhaps less obvious are relational changes that might occur as loving carers save their charges from embarrassment and the feeling that they are a burden. For example, when a physically dependent person says something like, "I wish you did not have to put me on the toilet or make my lunch", and the carer responds, "It's no bother", whilst really thinking about how on earth they can have some time off, the relating is at the level of the false self. Honest and open communication is not occurring.

Whilst the carers' approach in this situation is understandable, when it dominates the carers' social interaction over a prolonged period, it would be seen by codependency theorists as having emotional and spiritual consequences for the carer and leading to abandonment of their optimal self functioning. In this sense, such relating is seen as threatening to the carers very core - their 'self'.

Secondly, such unhealthy patterns may develop more rapidly in



individuals who have descended from families, in which a similar dynamic existed in childhood. In addition, individuals from such families may also be more prone to adopt the caring role in the first place. According to codependency theory, the presence of repeated caring for others may suggest the presence of an over-involved caring style learnt as a coping strategy in childhood. Serial caring may not be confined to care of alcoholics etc. It may also exist in carers of the aged.

The author has reported data in a previous Survey of Carers (see: Gillies *et al.*, 1987) which suggests that serial caring is pronounced. Of the 146 carers who participated in this survey, 49% had provided care for at least one other person - normally a parent, parent-in-law, spouse or close relative; 16% of the total sample had cared for two or more people in the past. In addition, 24% of the total sample were also currently assisting another person in addition to their main dependent. There was an overlap between serial caring in the past and current multiple caring (Gillies *et al.*, 1987, pp.57-58). This suggests that some carers do adopt 'caring' as a lifestyle and engage in serial caring. Other studies in which this was addressed could not be identified. In addition, studies in which tendency to provide care for the aged was investigated in terms of family of origin type do address this exact issue (Whitbeck, Hoyt & Huck, 1994; Whitbeck, Simons & Conger, 1991).

Thirdly, codependency theory would suggest that, if a carer has readopted a caring role learnt in childhood as a defensive coping strategy, other family members may also revert to the roles they established in childhood, thus re-establishing the former family dynamic. Troublesome behaviour and dependency in an elder in care might also be viewed as

'purposeful, adaptive, homeostatic and meaningful within the family unit', to coin Kaufmann's (1985) phrase. Just as the carer plays a role in caring, other family members may re-adopt the roles which originally took them out of the family dynamic (e.g. the Loner and the Scapegoat). The presence of such roles would predict failure by other family members to provide support to the elder and the carer. This is consistent with the finding that one family member alone normally provides the care that is needed.

Finally, according to the endogenous/exogenous hypothesis proposed by Wright and Wright (1990), the most pronounced enmeshed and unhealthy caring would be found where carers have a history of relational disturbance in childhood and a tendency towards serial caring in adult life. However, it also appears unlikely that a unitary set of criteria will define unhealthy caring. The healthiness of a caring relationship may occur along a continuum, however with several categories of dysfunctional caring being present.

Variables identified in the codependency field as indicators of unhealthy caring, which are worthy of investigation, in the population of carers of the aged are: enmeshment, defensiveness, over-protective caring, persecutory style of care, rescuing style of care, suffering style of care and family of origin antecedents of overly-committed care, serial caring phenomena and the threat to optimal self-functioning.

## **CHAPTER 5**

# **SELF AS AN ORGANISING PRINCIPLE AND OTHER ASSUMPTIONS ABOUT HEALTHY CARING**

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In the preceding chapters, several bodies of clinical and social research findings were reviewed to highlight possible parameters of healthy and unhealthy caring style. When considering carers' burden, antecedents of over-committed caring and failed helpseeking, one theme emerges as central for understanding the subjective experiences of carers. This was the carers' 'self-concept' or 'theory of self', and its capacity to withstand threat and the need for change.

It has been apparent in the carers' burden research since the 1980s that it is the carers' subjective processing which colours their experience of burden (Poulshock and Deimling, 1984). An understanding of the mechanisms by which carers approach or avoid threat to self and self-relevant values would advance current knowledge of the subjective processes underpinning carers' burden and possibly extend the model of threat to needs (Braithwaite, 1990, 1992).

In this chapter it is intended that a preliminary 'self-focused' model of carers will be developed which allows healthy and less healthy caring to be studied in carers of the aged. The parameters of this model arise from the past research presented above, but are also filtered in terms of the present author's observations regarding the difficulties carers experience in the clinical setting. As all variables influencing the development of a research

model should be available for scrutiny, those personal observations and views which filter the author's approach are clearly stated. First, the author suspects that the provision of services which assist with the tasks of caring, such as bathing, additional housework, etc., even when utilised, will not always relieve subjective burden in the carer and ensure the best possible care is provided for the elder. Secondly, the author also suspects that specific psychological therapies need to be developed for carers and that psychologists have a role to play in identifying what they might be. Thirdly, the author also suspects that many carers do not appear to be educable about services. However, literature presented in the previous chapters suggests that the carers' view of self and ability to withstand threat to self are the most relevant determinants of the model suggested.

### **5.1 Assumptions About Carers and the Caring Context**

In an attempt to develop a model of healthy and unhealthy caring for the aged, the author wishes to propose four preliminary assumptions regarding the nature of carers and the caring context. These assumptions are not posed as known fact but, rather, as a starting point to guide preliminary empirical investigation of 'carer-centred' variables in the carers' experience of burden.

Thus the author's assumptions are:

(1) Carers are active construers of the caring context: The carer is seen as an active interpreter of the caring situation, the demands of caring and of themselves as carers. They are seen as personally creating the

meaningfulness of their situation and personally determining what is stressful and what is helpful.

(2) Carers' self-theory plays a central role in directing subjective experience of the caring context: The carers' theory of 'self' is seen as filtering the carers' interpretation of the demands of caring and assistance given. In this sense, self is seen as having an organising function.

(3) Carers are exposed to constant experimental stress: The caring context is seen as containing inherent experimental and associated stress for the carer. Due to the constant change in the elders' physical and possibly their mental state, the carers must constantly reconstrue their most prized values and expectations. This involves constantly having to experiment with new constructions of their experience. The continuous nature of experimental process, in the caring context, is seen as psychologically and emotionally demanding for the carer and a source of burden in itself.

(4) Carers will have variable levels of self-development which regulate the manner in which they respond to the inherently stressful caring context: Not all carers are seen as bringing the same level of self-development to the caregiving situation. As a consequence, carers will vary in terms of the functional utility of their self theory, the complexity of their sense of self and in their willingness to re-evaluate self following threat to self-relevant values associated with caring for a declining elder.

Given the clear evidence in the carers' burden research that it is the carers' subjective experience which determines their level of burden, and findings presented in this paper which allude to the possibility that carers'

self-type may be a useful explanatory tool, it is important to further develop the assumptions made about the nature of carers and the caring context in a framework which is compatible with the subjective traditions of psychological theory. To achieve this, a broad constructivist framework will be adopted to expand the four assumptions presented to guide the author's research model of healthy and unhealthy caring.

There are, of course, numerous schools of constructivism (e.g. Radical, Critical, etc.), each with their own underlying assumptions regarding objective reality and epistemology. In general, however, a broad constructivist approach differs from traditional psychological theory in that the positivist ideal of directly knowable objective reality is rejected. While constructivists vary in the degree to which they endorse objective reality, all agree that the world can never be known directly and seek to understand the process by which individuals, in this case carers, construct the meaningfulness of their experience.

George Kelly provided arguably the most comprehensive and detailed constructivist model of psychological process but this work followed in the tradition of theorists such as Piaget. Kelly's theory and recommended empirical methods were presented in his major two-volume work, *The Psychology of Personal Constructs* (Kelly, 1955); however, he also published many papers and presented lectures on constructivism, many of which were published posthumously.

Constructivist concepts of personalised theories of self and core processes (Kelly, 1955) can help us to understand the carer as they experience the threat-to-self concept when the use of services is suggested

(Rossiter, 1984), as they experience the threat to basic needs associated with the elders' decline (Braithwaite, 1992) and possibly threat to 'false self' functioning as part of overly-committed caring in some cases (Whitfield, 1984, 1987). However, this is proposed with the clear recognition that Kelly himself did not use the concept of core process as a direct analogy for self-concept.

Thus, this approach is of the ilk of theorists who, whilst not strict Kellians, have been influenced by Kelly's view of core processes when seeking to understand the organising role of self and have produced models which are generally considered useful within a constructivist analysis. (e.g. Berzonsky 1990). As this work is equally important in the current analysis, a broad constructivist approach, as defined above, will be retained and the more philosophic questions regarding the precise constructivist model under which the findings should be classified can be considered at a later date.

## **5.2 Advantages of a Broad Constructivist Framework**

A broad constructivist approach is a useful framework in which to consider the problems of carers' subjective experience of 'self' in the caring context, since it provides an approach to the study of subjective experience which is grounded in well-established theory and an increasingly vibrant and innovative research tradition. There are many existing constructivist concepts and research methods which could be applied to the problem of understanding carers' experience of their burden and of threat per se. Many do not require the abandoning of group research or require a decline into uninterpretable subjectivity, which is something those in the carers'



burden field may fear.

An additional benefit of using a constructivist framework for investigating carer issues is that a therapy can immediately be recommended for any problems which might be found to be present (see: Bannister and Fransella, 1986; Winter, 1992). Given the author's clinical orientation, this is a major advantage.

A further benefit of a constructivist framework is that it allows methods of operationalising a number of concepts relevant to carers which might otherwise appear too subjectively based to be investigated.

### **5.3 Towards a Broad Constructivist Framework for Studying the Experience of Carers**

#### **5.3.1 Assumption 1: Carers are Active Construers of the Caring Context**

As noted above, carers are seen as active interpreters of the caring situation, of the demands of caring, and of themselves in the caring context. They are seen as personally creating the meaningfulness of their situation, personally determining what is stressful and what is helpful, and how they should react to the stresses which confront them when caring. Whilst the author does not underestimate the difficulties associated with performing the tasks of caring, the view that the carer is the passive recipient of the elder-inflicted burden is rejected. Braithwaite (1992) also sees the carer as actively evaluating the changes that take place as the elder declines. However, in

her approach there is no attempt to define the parameters of the carers' constructional process<sup>2</sup>. However, some ideas expressed by the constructivist Kelly (1955) are useful for this purpose.

For example, the 'Construction Corollary' defines construing as "*placing an interpretation*" (Kelly, 1955, p35) and the construing mechanism as the process by which "*a person anticipates events by construing their replications*" (Kelly, 1955, p.35). Just as the author is seeking to develop a theory of carers, Kelly would see the carer as building personal theories or interpretations about topics such as: what good caring is; the carer role; the appropriateness of assistance, etc., based on the recurrent themes they have apprehended. A Kellian approach appreciates the reflexive nature of the carers' construing. It also places heavy accent on the process of anticipation to direct construing.

With thinking reminiscent of Plato's Theory of Forms, Kelly would postulate that carers create their own unique internal representations about daily experience, which never perfectly represent the objective world and are always revisable, using a system of internal building blocks:

*Man looks at his world through transparent patterns or templates which he [or she] creates and then attempts to fit over the realities of which the world is composed. The fit is not always very*

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<sup>2</sup> Braithwaite's Threat to Basic Needs approach to carers' burden is more concerned with the final effects of construing than with the construing process itself. With the aim of producing an easily administered group test which operationalises burden at the relational level, it was hoped that the processes of construing the decline of the elder could be recognised, but only its impact measured. This is quite acceptable in the research domain. However, in the clinical setting, the process of construing becomes more of an issue. There is, however, an active attempt by Braithwaite to discourage consideration of mediating variables (see: Braithwaite, 1992) in this paradigm. The author of this work does not see construing as a mediating variable but clarification from Braithwaite regarding her position on this point would be useful.

*good. Yet without such patterns the world appears to be such an undifferentiated homogeneity that man is unable to make any sense out of it. Even a poor fit is more helpful to him than nothing at all.*

(Kelly, 1955, p.8-9) (Brackets added)

These personalised templates, known as constructs, would be seen by Kelly as the vehicle through which the carer construes the caring context. The constructs allow the carer to organise all personal experience and expectations. The carers' current construction of reality, including the degree of burden they experience when caring, is apprehended at the point of applying their personalised constructs to the daily experiences of caring.

Constructs were described by Kelly as having specific properties which help to determine the nature of construing (see: Kelly, 1955, Ch.3). For example, the carers' constructs would be seen as bipolar in nature (Kelly, 1955, p.208) with each pole providing a competing hypothesis about the meaningfulness of the situation to which they are applied. Thus the carers would be seen as applying dichotomous constructs, such as good - bad; helpful - not helpful; liked by mum - not liked by mum, to all facets of the caring context and their role in it.

However, in Kelly's system for organising meaning with dichotomous constructs, things are never just alike. In the process of construing, the carer will make an assessment of "*a way in which some things are construed as being alike and yet different from others*" (Kelly, 1955, p.102). For example, a carer may construe one form of assistance they are offered to be like another form of assistance, but at the same time as different from the help they have used in the past. Thus, Kelly suggests we remain mindful that the

*“ways in which two things are like each other should be the same as the way in which they are different from the third”* (Kelly, 1955, p.78).

In addition, each of the carers' current constructs would be assumed to have evolved whilst construing past experience. Thus in this sense, parameters of current construing have an historical context. Some constructs may have entered the system recently but others may have originated in the distant past, even in childhood. Other constructivists would also suggest that constructs may be shared within the family system (see Procter, 1981) and may continue to have an ongoing powerful influence over family members. This is consistent with ideas reported from codependency theory.

The carers' constructs or theories about the world would also be assumed to be governed by rules applied to all scientific theories. For example, just as a scientific theory about the process of nuclear fusion has no apparent relevance to understanding the process of seed germination, the carers' personal constructs would also be seen as having a *“limited range of convenience”* within which they can be usefully applied (Kelly, 1955, p.41). This raises the possibility that the constructs a carer has developed in other settings, or even in past periods of caring, may become irrelevant to the current caring situation once an elder's level of decline exceeds a critical level. Previous inexperience with this level of decline may leave the carer without constructs capable of making viable anticipations about their situation. Such carers would be unable to impose order upon their experience.

Kelly would see the experience of such chaos as occurring as a multi-channel and not simply a verbal channel process because constructs may

contain preverbal, verbal, physiological and psychological nuances (Kelly, 1955, p.36). Thus, in this framework the affective experience of a carer and their somatic symptoms are as essential to the construing process as the verbalisations they make about the difficulties of caring. Such symptoms also have special diagnostic implications within this framework.

In addition, Kelly would say that, to accommodate change inherent in their situation, carers' personal constructs may have to undergo change and evolution. However, it is during the transition from theme to theme that carers will experience most problems (see: Kelly, 1955, p.359). For Kelly, carers' difficulty in coping with certain situations would be seen to occur, not only because of the objective situation, but also because of the carers' inability to make appropriate transitions in their personal construct system to fit with the experience to which they must apply meaningfulness.

### **5.3.2 Assumption 2: Carers' Self-theory Plays a Central Role in Directing the Carers' Subjective Experience of the Caring Context.**

The carers' self-theory is seen by the author as playing a major role in organising the experience of the carer and their willingness to be helped. Carers' self-theory is seen as a powerful processor which directs, filters and organises experience.

Epstein (1973), in a review of the literature regarding self, has noted that there are polarised views in the field of psychology regarding the explanatory usefulness of the concept of self, but those in the subjective traditions see it as a critical concept. Epstein notes:

*Self theorists identified as phenomenologists consider the self concept to be the most central concept in all psychology, as it provides the only perspective from which an individual's behaviour can be understood.*

(Epstein, 1973, p.404)

Epstein also pointed out, in the same article, that theorists such as James, Cooley, Mead, Leckey, Sullivan, Hilgard, Snugg, Combs and Rodgers have all adopted the position that self-concept is a necessary explanatory concept. Thus, considering carers' subjective experience of burden from a 'self' standpoint, would also be positively received by these theorists and their followers. However, using 'self' in its popular sense, which has mostly occurred in the carers' burden field, only provides a hollow and conceptually weak explanatory tool, whereas a broad constructivism can help to provide a more rigorous approach.

Constructivists would not see the carer as having a tangible self-concept, or an essence to be rediscovered, as do Codependency theorists and researchers such as Waterman (1984,1982). They would see the carer as personally construing a theory about themselves and their operation in the world, in the same way that they impose order on other experience.

The constructivist Kelly would see the carers' constructs which define self-theory as located in the core of their construct system, in immediate proximity to other constructs which define values. All of the carers' core constructs would be seen as highly interrelated and very resistant to change (Kelly,1955). This allows the carers' personal experience of self and their

most prized theories about how they should operate in the world to remain stable over time. However, this same interrelatedness of core constructs may also make the process of changing self-relevant values difficult. This approach is consistent with William James' (1890-1920) dualistic model of the self, which included Self-as-Knower and Self-as-Object. The carers' self is seen as the topic of their own construing as they experience themselves as Self-as-Object.

However, more interesting is the parallel between the core construct concept (Kelly, 1955) and James' idea of Self-as-Knower. In a Kellian framework, a core construct is defined as that which "*governs the client's maintenance processes*" (Kelly, 1955, p.7). Simply stated, this suggests that carers' core constructs, which include self-theory, not only define a sense of personal identity but also play a role in organising and maintaining the system used for evaluating all self-relevant experience (see: Kelly, 1955).

Other constructivist theorists have expanded this view and would see the carers' self-theory and other core constructs as a central 'processor' (Mahoney, 1988; Berzonsky, 1990) for evaluating all information which is relevant to how the carers see themselves and all other self-related experience. Mahoney (1988) has provided a review of constructivist metatheory and identified three concepts which explicitly define the functioning of the 'core processor'.

The first is 'Proactive Cognition'. Mahoney stresses that the normal construing process is anticipation-driven, and thus proactive. This is well illustrated by Kelly's metaphor of 'man-the-scientist'. For Kelly, carers would be seen as approaching the task of construing the caring situation like a

scientist. They would engage in the processes of observation, hypothesis generating and then testing out the assumptions inherent in the prediction. This would lead to the original anticipation either being confirmed or rejected. Hence this process is clearly anticipation-driven. The later steps of this process cannot occur without the initial anticipation to guide them.

In adopting proactive construing, the carers would be seen to utilise their "*natural interpretive talents*" (Kelly, 1989a, p.36) and adopt "*prediction as a way of life*" (Kelly, 1989b, p.5). In the fundamental postulate, which Kelly describes as "*the basic assumption on which all else hinges*" (Kelly, 1955, p.4), it is suggested that "*a person's processes are psychologically characterised by the ways in which he anticipates events*" (Kelly, 1955, p.4). This suggests that what carers anticipate will direct the meaningfulness of the caring context. For example, what they anticipate about the costs and benefits of being helped and making changes in their caring role, will direct the type of information they seek etc. In addition, Mahoney (1988) has noted that recent neuropsychological models of brain function concur with this approach, by focusing on the driving role of expectation and intention to guide cognitive analysis.

The second concept identified by Mahoney (1988) as defining a constructivist model of core process, is 'Morphogenic Nuclear Structure.' Mahoney notes that constructs group together to form a meaning-generating system which is hierarchically organised (see Kelly, 1955). Constructs which are integral to the individual's construing of self-relevant information, which the author is assuming will include caring-relevant information, will have implications for other core role constructs and have a superordinate position within the system. As noted above, these constructs are the most



difficult to change; however, they also evoke the greatest emotion when change is necessary.

The core system is not simply vertically organised. The core has a *"morphogenic nuclear structure"* whereby the *"central, core or nuclear processes dictate and constrain that expressed at the peripheral or surface levels"* (Mahoney, 1988, p.6). Thus, the self-relevant core processes which have been defined as being *"involved in a person's experience of reality (order), self-identity, value (valence) and power (control)"* (Mahoney, 1991, p.18) exert a moderating process over the construction of all daily experience. It will be noted that power and control are also core processes. These were also recognised as critical issues in unhealthy caring by codependency theorists (Cermak, 1986b). In a constructivist framework, a change in one core construction such as self-theory, power and control issues, will imply a need to change the others.

The third of Mahoney's concepts to define a constructivist model of core process is 'Self-organised Development'. Mahoney suggests that *"individual human systems organise themselves so as to protect and perpetuate their integrity and develop via structural differentiations selected out of their trial-and-error variations"* (Mahoney, 1988, p.9). By this, it is meant that self-relevant construing generated by the core processor, must protect the integrity of the entire construing system.

Due to the modulating influence of superordinate self-related constructs over the entire system, failure to protect the viability of the centre puts the whole system at risk. Thus, the central point for the construction of all experience is self-theory. Not only does the individual's sense of self-

consistency rely on it, but so does the integrity of the very system through which she or he makes sense of the world.

In summary, when we talk of threat to the carers' self, we are no longer referring to 'self' in its popular sense. Instead, a constructivist analysis of core process helps us to appreciate the organising and modulating power of the self-theory as the carer undertakes the scientific enterprise of construing the meaningfulness of the caring context.

Our understanding of how the carer might act as a personal scientist has also been aided by a recent elaboration of post-positivist philosophy of science and epistemology (Berzonsky, 1992). Berzonsky has noted that epistemologists have come to understand that every scientific theory has a hard core of values, ideals and assumptions about reality and how one gains knowledge which directs the activities of the scientists who subscribe to them (Lakatos, 1970). Thus carers, acting as personal scientists, will also make anticipations about possible caring outcomes determined by their underlying theory about the caring situation. The anticipations generated by their theory will, in turn, also constrain what the carer even conceives of as possible.

Thus, self-relevant values can also play a constraining role, preventing certain types of anticipations from being made. In a Kellian concept of core process, or in terms of Mahoney's core processor, constructs which define values are highly correlated with constructs which define self. They both reside inseparably at the centre of the system. Thus threat to carers' values is experienced in much the same way as direct threat to personal sense of self.

Walker (1992, p.260) has noted that Kelly dismissed the positivist approach to the study of psychology because it denied the possibility that values influence the process of creating meaning. Thus it is central to the constructivist view, that self and self-relevant values equally define the action of the process through which the carers will make sense of all that confronts them in the caring context.

### **5.3.3 Assumption 3: Carers are Exposed to Constant Experimental Stress**

The caring context is seen as threatening to the carers' theory of self and self-relevant values and thus experimentally demanding for the carer. It is assumed by the author that the caring context can deteriorate to a point where the carer is exposed to serial threat. When the carer is seen as an active construer, living in a situation requiring constant re-construction a critical point may be reached where the rate of decline in the elder is so rapid that even the most efficient 're-construer' would find this process taxing. At such times the carer cannot rest in a knowable, predictable environment. Rather they are caught in a spiral of unpredictability and its associated sense of meaninglessness. When the caring context is seen as inherently threatening, a constructivist view of 'threat' and the 'experimentation' it necessitates, can help our understanding of the carers' subjective burden.

When one talks of threat to self-concept or self-relevant ideas, Kelly's definition of threat as "*the awareness of an imminent and comprehensive change in one's core structures*" (Kelly, 1955, p.91) is relevant. For Kelly, threat is experienced as potentially overwhelming. Given the pivotal position

of the core, threat to the core is associated with a paralysing sense of terror (Leitner, 1985), highlighting the danger associated with retaining the current position.

In this situation, maintenance of perceived identity becomes as important as life itself (Guidano, 1987; Kelly, 1955). In a constructivist framework, protection of core understandings and theories, including theory of self, is essential for the individual's mental health, as they would lose their sense of reality without it. Kelly even goes so far as to say that loss of the core construction is life-threatening. Carers experiencing such threat should be thought of as not simply having difficulty making a choice about services and style of care; they are also experiencing a challenge to their capacity to order their experience in a meaningful way. A need to protect their self-relevant organising constructs becomes paramount. Epstein makes this point, when he says:

*The need for people to defend desperately certain concepts or values, no matter how unrealistic they are can be comprehended readily once it is recognised that a self- theory is necessary in order to function, and that any theory is better than none .*  
(Epstein, 1973, p.415).

When threatened in this way carers have only two options: they must either submit to the subjectively and experimentally taxing process of reconstruing; or they form hostile attachments to a construction of their experience which has already been invalidated. In either case, one would expect to find carers displaying high levels of emotional distress, which of course has been repeatedly found in carers' burden studies (Gilleard,

1984a; Gillies, *et al.*, 1987; Grad & Sainsbury, 1968).

Constructivists would see the best functioning carers as adopting the reconstruing option. The greatest step forward occurs by "*venturing to place a sweeping new construction upon events*" (Kelly, 1966, p.1). To move forward, individuals must be able to overcome conservatism and dogmatism to consider new possibilities (Kelly, 1955; Walker, 1992). Thus, Kelly suggests:

*"Unless he [or she] has been willing, at some point in the sequence, to open his mind to possibilities contrary to what was regarded as perfectly odious, he would have been unable to come up with anything new"*

(Kelly, 1969, p.150) (Brackets added)

The concept of the experience cycle helps us understand the taxing nature of this process. As noted previously the carer must develop new anticipations about the elder as decline occurs, and then engage in experimentation to test out the implications of their new hypothesis. All carers doing 'good science' must "*immediately start putting it [their new view] to the test*" (Kelly, 1955, p.14). Similarly, healthy carers must develop and test out the predictions which arise when all that they know is under threat. This will involve engaging in social interaction and experimentation in which their hypothesis is either validated or invalidated, leading to confirmation or revision of their construct system. It is through this process that change occurs (Botella & Gallifa, 1993; 1992) and carers will be able to modify their world view to cope with the demands of their situation.

To arrive at a satisfactory solution, a carer may have to participate in many cycles of experience (Kelly, 1955). This will not simply be a mental process. They will need to try new approaches, talk to family and friends and act in ways that were totally inconceivable to them in the past. Failure to complete such cycles of experience will result in stagnation and a construct system which is increasingly unable to generate functional anticipations. To retain the most functional construct system the carer will need to experiment again and again ... and again!!

Walker (1990) has noted the process of testing our anticipations can only occur while people are in relationship with each other. Without social contact, the constructional hypothesis cannot be validated or invalidated. Thus social isolation may interrupt this process for carers. In addition, Leitner and Pfenninger (1994) have suggested that, in order to complete the experience cycle, one must possess a number of what the author would call 'personal virtues'.

They suggest that one must have a capacity for Discrimination, Flexibility, Creativity, Responsibility, Openness, Commitment, Courage and Reverence. Leitner and Pfenninger (1994) give an account of the problems associated with too much or too little of each of these virtues when attempting to complete the experience cycle. These are also the characteristics said to be unavailable to those with a codependent-chronic need to care and would suggest that they lack the personal attributes to remain healthy as the elders' functioning deteriorates.

Those characteristics and personal qualities which allow ease of change, by facilitating active participation in the experience cycle, help to

define optimal and less healthy functioning in all individuals (Kelly, 1980; Leitner & Pfenninger, 1994; Walker, 1992) and are equally relevant to understanding healthy functioning in carers. The presence of these qualities can be seen as enhancing capacity for coping with transition (see: Viney, 1980) and allowing the carer to maintain a theory about 'self' and the caring context which is useful and allows the carer to tolerate the threat associated with caring. However, the process of construing is not only experimentally taxing for such a person, it would also have emotional consequences.

*The relationship of emotion to the self-system, identified as a cognitive structure, is elucidated when it is recognized that the self-theory is a working theory whose most general function is to make life livable, meaning emotionally satisfying. Thus, the self theory, as described, does not exist apart from emotions, and to a large extent the opposite is true .*

(Epstein, 1973, p.415).

In a constructivist framework even those carers adopting the optimal coping strategy of reconstruing that which is threat-provoking, could be expected to appear emotionally taxed. This is because emotional experience is an integral and inseparable component of construing. Thus in response to the threat associated with the elders' decline, described by Braithwaite (1992), even the carer functioning optimally may be expected to also experience: Fear, "*the awareness of imminent incidental change in one's core structure*" (Kelly, 1955, p.7); Anxiety - "*the awareness that the events with which one is confronted lie mostly outside of the current construct system*" (Kelly, 1955, p.7); Guilt - "*the awareness of dislodgement of self from one's core role structure*" (Kelly, 1955, p.7);

*Aggressiveness* - “the active elaboration of one’s perceptual field” (Kelly, 1955, p.7); and *Hostility* - “the continued effort to extort validational evidence in favour of a type of social prediction which has already been recognised as a failure” (Kelly, 1955, p.7). Thus when carers verbalise that they feel terror about what the future will bring, this may be literally true.

Many carers will be unable to withstand the terrors of reconstruing and will seek to avoid experiences which are threatening, as is evident in the number of carers who would rather struggle with an unreasonable workload than suffer the threat associated with organising assistance. However, when this occurs, it needs to be recognised that the carers’ behaviour is purposeful rather than ill-prepared. This does not necessarily suggest a need for service education. Instead, it may suggest that, for the carer, the need to protect their self-theory is greater than their need for assistance. Such a carer may require help with the task of self-reconstruction, not training in the tasks of caring or education about services. Using a broad constructivist approach can help in the appreciation of this.

#### **5.3.4 Assumption 4: Carers Will Have Variable Levels of Self-development Which Influence the Manner in Which They are Willing to Reconstruct Self-relevant Experience in the Caring Context**

It is assumed by the author that carers must have reached a critical level of self-development to have the capacity to withstand the threat inherent in caring for an elder, helpseeking and attempting flexible and novel approaches to caring. The carers’ current level of self-development is seen as also reflecting the degree to which they have adopted an openness



to experience and negotiated to 'satisfy self' in the past. The view, that carers have variable levels of self-development which will differentially direct their processing and construing tendency in the face of threat, can be elaborated upon by drawing on the work of Berzonsky (1981, 1985, 1986a, 1986b, 1986c, 1986d, 1987a, 1987b, 1987c, 1987d, 1987e, 1988a, 1988b, 1988c, 1990, 1992a, 1992b, 1993, 1994).

Berzonsky proposes a model of the social and processing components of self. In other words, the model attempts to index an individual's approach to or avoidance of reconstruing and willingness to engage in what Kelly would call 'the experience cycle'. This approach is compatible with a constructivist model of development, also based on the experience cycle (see, Botella & Gallifa, 1993).

This social-cognitive model of identity, which focuses on the social and processing aspect of identity, can help to expand our understanding of the organising role of the carers' theory of self (see: Berzonsky, 1988, 1989a, 1990, 1992). Berzonsky's work draws on empirical studies of identity using the Marcia Identity Status Paradigm, an approach to identity research which has generated over 300 studies (Kroger, 1993).

The Marcia Identity Status Paradigm (Marcia, 1966) and Berzonsky's more recently developed model of Identity Style (Berzonsky, 1986, 1987a, 1990, 1992a, 1994) attempts to operationalise two concepts from an Eriksonian model of identity development, which can be applied to the carer.<sup>3</sup> These are: (1) Self-exploration: Has the carer undertaken personal analysis, experimented with various roles, questioned their values, beliefs,

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<sup>3</sup> This is Erik not Milton Erikson.

etc., during a time of crisis? and, (2) Commitments: Has the carer been able to form a commitment to objectives in their life? Responses to questions which operationalise these dimensions would allow the carers' Identity Status or style to be measured.

Erikson, in developing the identity model on which this approach is based, adopted a psychoanalytic orientation towards understanding identity; however, there are a number of features of his work which make it acceptable in the broad constructivist framework being adopted here (Viney, 1987). Firstly, Erikson sees self-identity as emerging from experience (Erikson, 1959, 1969). This, of course, is a basic tenet of constructivist theory. Secondly, the 'self' is presented as actively appraising, electing and organising self-perception. Erikson was aware of the "*constructive, psychosocial nature of identity*" (Berzonsky, 1990, p.127).

Berzonsky further notes that Erikson distinguishes between that aspect of the self which integrates self and role images, which was called 'self identity', and that aspect of self which tests reality by appraising, electing and adapting, which he calls 'ego identity'. Thirdly, Erikson saw that individuals must experiment with roles and actively question and evaluate their basic values and beliefs if they are to evolve optimal identity development. This, again, is compatible with the notion of reconstruing and the experience cycle given in Kelly's theory (Kelly, 1955).

Thus, Eriksonian Identity theory and broadly defined Constructivist theory both see the identity development process as occurring in the psychosocial context, generally at times when crisis dictates changes in construing of self and/or the method of having needs met.

In terms of the Eriksonian dimensions detailed above, Marcia would classify the carers in terms of four possible identity types which are conceptualised as the developmental stages of self-evolution. These would include :

- (1) Achievers: those carers who are given to self-exploration to resolve self-relevant crises and thus have arrived at a clear perception of their own values;
- (2) Moratoriums: those carers who are also given to self-exploration to resolve self-relevant crises but have not committed to values on the basis of this;
- (3) Foreclosures: those carers who have developed the ability for effective self-examination but continue to adopt the values prescribed by others, generally their parents, without evaluation; and
- (4) Diffuse status: those carers who are without identity-relevant values or the willingness for self-evaluation.

The four status categories represent a hierarchically-organised identity pathway. Mostly, people progress through the status categories in a predictable fashion from diffusion to foreclosure status, then to moratorium status, and finally, to achievement status (Marcia & Miller, 1980). As they do so, their construct system becomes more highly differentiated and they change in their manner of approaching novel situations and processing information (Berzonsky & Neimeyer, 1988; Berzonsky, Rice & Neimeyer, 1990).

Individuals classified in this way have been found to have variable capacities for a broad range of processing and social approaches to problem-solving. A comprehensive review of these findings is given in Berzonsky (1990) and further information is summarized in Kroger (1993).

For example, it has been found that subjects with variable Identity Status classifications also have variable and predictable methods of integrating multiple and conflicting sources of information, are differentially resistant to change, intolerant of ambiguous information, and have variable levels of flexibility in their belief systems (Berzonsky & Neimeyer, 1988; Marcia, 1966, 1967; Marcia & Friedman, 1970; Schenkel & Marcia, 1972).

They are also differentially intolerant of less traditional sources of information (Berzonsky, Schlenker & McKillop, 1987), and vary in terms of having traits, such as authoritarianism, in their personality make-up (Berzonsky & Neimeyer, 1988; Marcia, 1966, 1967; Marcia & Friedman, 1970; Schenkel & Marcia, 1972).

Such findings have been taken to indicate that individuals classified by the four status groups have different processing styles and experimental approaches to reconstruing self-relevant information (Berzonsky, 1990). In terms of linking the healthiness of caring approach to level of identity development, the moratoriums' period of self evaluation can be equated with the beginning of a carer attempting to function as what Kelly (1955) would see as a 'good scientist' (Walker, 1992).

Carers who have reached this stage could be seen as attempting to break free from the dogmatism which characterised earlier stages of

development (Walker, 1992). Not surprisingly, ongoing moratorium search is associated with increased cognitive complexity (Berzonsky, 1988b; Berzonsky & Neimeyer, 1988; Rice, Neimeyer & Berzonsky, 1987) which, according to Viney's Constructivist Model of Development (Viney, 1992), is the hallmark that development has occurred. Interestingly, it is possibly this developmental stage which those with a chronic caring need, described as codependant, avoid as they cling to their prescribed 'false self'.

Achievement status can be reached by a carer who is able to resolve the issues they identified in the moratorium crisis period. At this stage, a carer would be able to evolve styles of problem-solving and possibly styles of care, which are based on self-determined goals and values, and on what is possible in the situation at hand. This would be functioning at the level of what the codependent theorists are calling the 'real self'.

The Eriksonian model of 'identity development' clearly views identity changes as continuing to occur across the life-span. However, it is only in recent times that identity changes in the post-adolescent period have been empirically investigated (see: Archer, 1982; Kroger & Haslett, 1987; Waterman, Besold, Crook & Manzini, 1979; Waterman, Geary & Waterman, 1974; Whitbourne, 1979).

As can be seen from the information presented above, carers classified via the Marcia (1966) status characteristics might be expected to differ in their cognitive-social approach to personal decision-making and problem-solving (Berzonsky, 1986c, 1988a, 1988b; Grotevant, 1987). For example, individuals classified as moratoriums or achievers are information-oriented and oriented towards evaluation and elaboration of options.

Those with the remaining classifications do not have the same orientation towards information. It is this view that underpins Berzonsky's social-process model of Identity Style (Berzonsky, 1990).

Berzonsky (1990) is clear that carers who do not have an information-oriented Identity Style, and thus use a defensive or avoidant approach rather than a re-construing approach to dealing with threat to self-relevant values, may be more subject to biased data searches to protect their position. In other words, they are more likely to be, what the author would call, 'information screeners', whereby they protect their core at the cost of fully objective analysis of experiences :

*Individuals are apt to engage in biased information searches in order to defend and conserve beliefs, attitudes and self protection to which they are firmly committed. Thus normalized judgments and social cognitions are characterized by a variety of shortcomings, errors and distortions. (see, e.g. Greenwald, 1980; Kahneman, Slovic & Tversky, 1982; Nisbett & Ross, 1980; Ross, 1981).*

(Berzonsky, 1990, p.126)

This is consistent with the observation of the author, that some carers appear to have a 'selective deafness', when it comes to being educated about services available to them.

Berzonsky (1992) reports that it eventually became difficult to study processing orientation associated with Identity type using the Marcia measure. He noted that the Marcia Identity Status Inventory (1966)

operationalised several aspects of identity development at once, and that the global nature of this measure made it impossible to conduct independent analysis of the discrete concepts which combine to give each status type. In addition, the identity status classifications tended to "*confound commitment with processing orientation*" (Berzonsky, 1992, p.773). Thus it was considered necessary to develop a unidimensional measure in which cognitive style was measured separately from commitments.

The Identity Style Measure (Berzonsky, 1989) was subsequently developed but was based on the traditional Marcia (1966) measure items. Berzonsky describes himself as developing the measure by "*decoupling the commitment and self-exploration components used to operationally define Identity Status*" (cited: Berzonsky, 1992, p.773). Identity Style has been defined as "*the different ways in which individuals approach or manage to avoid the task of identity exploration*" (Berzonsky, 1992, p.774).

The social cognitive reconstruing styles operationalised are: Information-Oriented (Scientific approach), Normative-Oriented (Dogmatic approach) and Diffuse/Avoidant (*ad hoc* approach). This measure operationalises Identity Style not Identity Status; however they are clearly conceptually related.

Kelly's metaphor of man-the-scientist helps us to understand, using a post-modernist view of sciences (Lakatos, 1970) that all individuals engaged in the process of creating meaning, including scientists, adopt variable themes with hard-core assumptions that determine the manner in which they theorise and experiment (Berzonsky, 1988b). Thus, according to this model, the carers' core ideals of identity will determine how they respond to the

threat to basic needs and self-relevant material in the caring context.

They may become exponents of the 'scientific approach', a 'dogmatic approach', or a diffuse 'avoidant approach'. Clearly Kelly and other constructivists would, from a theoretical perspective, see the scientific approach as that most likely to be associated with optimal functioning.

Berzonsky has built an impressive body of research which defines the processing styles of each Identity Style group. Those with an Information orientation have been found to be more open to experience (Costa & McCrae, 1976) which is associated with willingness to attend and process different facets of experience, having liberal arts values, a rich fantasy life, and a propensity to actively seek information from many sources.

Those with Normative orientation are thought to be more susceptible to being threatened when self-relevant ideas are challenged, as they are closed to ideas and actions, but more cognisant of the attitudes and beliefs of their reference group (Berzonsky (1990, p.193). Those with a Diffuse orientation, however, are generally unaware of their own fantasy life and have decreased sensitivity to inner life in general (Berzonsky, 1990). Berzonsky (1994) has presented a table to summarise further characteristics associated with each of the identity styles. For convenience, this has been reproduced here.



**Table 3: Identity Processing Orientations**

(Reproduced from Berzonsky, 1994, p.2)

Processing Style	Characteristics	Identity Status
Information	Systematic	Self-Explorers
	Processors	Moratoriums
	Self-Reflective	Achievers
	Problem-Focused Copers	
	Introspective	
	Need for Cognition	
	Vigilant Decisional Style	
Normative	Need for Closure	Foreclosures
	Need for Structure	
	Rigid Self-Constructs	
	Inflexible Value Systems	
Diffuse/Avoidant	Procrastination	Diffusions
	External Control	
	Non-Reflective	
	Avoidant Coping	

Berzonsky has been able to develop a theoretical model which allows one to consider the method by which a carer might reconstrue when all that is self-relevant is threatened in the caring context. Such an approach is consistent with developing an understanding of the parameters which define the subjective experience of the carer (Poulshock and Deimling, 1984) and may be related to the experience of Threat to Basic Needs (Braithwaite, 1990). The construct of Identity Style does not suggest differences in ability

when it comes to seeking information about possible ways of solving problems (see: Berzonsky, 1990, p.173), but it does suggest that individuals at different stages of engaging in self-evaluation, will use different information processing and social strategies to protect their current view of self. Some approaches to this task are likely to be more adaptive in the caring context than others.

#### **5.4 Conclusion**

To conclude, when developing a model of healthy and unhealthy caring, the concept of carers' 'self' appears important, yet traditionally 'self' has been conceptualised in a manner which is conceptually and empirically hollow. However, by using a broad constructivist analysis of four assumptions about the carers developed in the review of relevant literature, it can be seen that it is possible to transform the concept of 'carers' self' into a theoretically sophisticated model with considerable research-generating capacity.

When the shackles of 'carer-as-victim' are thrown off and we begin to look at carer-centred contributions to the healthiness of a caring relationship, we appreciate that carers are active construers of the caring context. Their construing of what is difficult for them will be directed by their powerful core processor (Mahoney, 1988), which will always move to protect their view of self in the face of threat. If they are unable to face the terrors of reconstruing (Leitner, 1985) or, indeed, lack the necessary personal attributes, as might be the case in those with a chronic caring need established in childhood, they will adopt a defensive strategy to maintain the integrity of their theory of self.

We also see that, even when the carer takes the healthy option and reconstrues that which is threatening, there will be enormous emotional costs, whilst they withstand the anxiety of attempting new approaches. Thus, it is unlikely that healthy caring can be equated with a lack of signs of emotional distress. Perhaps all carers are depressed etc., but the manner in which they approach the threat that surrounds them whilst caring will determine how well they recover when caring is complete.

Finally, we see that it is not necessary to be lost in a sea of subjectivity in order to study the carers' self-relevant and subjectively experienced contribution to the healthiness of the caring situation. In constructivism, concepts such as 'core process', 'Identity Style', 'threat' and 'experimentation' are all theoretically linked to a 'solid' research base which can be applied to understanding the subjective nature of carers' burden and possibly extending Braithwaite's model of Threat to Basic Needs.

## **5.5 Current Research**

Caring for an aged person in decline is an inherently threatening experience (Braithwaite, 1990, 1992). In the broad constructivist model proposed here, this threat to basic needs for love, safety and security which occur in the caring context, are seen as self-relevant. It is therefore assumed that the threat associated with the elders' decline will be experienced at the level of the powerful core processor, which is the second and less commonly discussed aspect of 'self' (Mahoney, 1988, Berzonsky, 1990).

The manner in which the carer confronts the threat to core values and identity in this context will have important implications for the healthiness of

the caring relationship. Consistent with observations in the chemical dependency field, it is also suggested that carers with a chronic caring need, indexed by serial caring, will approach reconstruing of self-relevant material in a more rigid or avoidant manner, than carers who are less prone to repeated caring.

Serial carers are assumed to have a codependent or 'false-self' which, in this framework, might be thought of as an Identity Style characterised by avoiding reconstruing (e.g. avoidant or *ad hoc* strategies), whereas those episodic carers who approach this task from a true self might be thought of as Information oriented.

If this were the case, one would expect to find an interaction between caring status and reconstruing style, and different use of services and other indices of healthy caring on the basis of this. This approach allows one to investigate the assumption that chronic caring tendency occurs due to the carer operating from a restricted self and is associated with less healthy caring. However, it also suggests a way of operationalising false and real self, associated with chronic caring tendency, for rigorous research.

Implicit in the approach adopted in this research are the assertions that: firstly, carers' burden can only be understood from the perspective of the carer and this will need to involve some consideration of their inner "self", and; secondly, that, in addition to investigating the content of construing, the subjective experience of the carer can also be operationalised in terms of the manner by which they process information regarding the elders decline and their ability to continue caring, which is threatening to their personal theory of "self" and "self-relevant values. Thus a

process as opposed to a content evaluation of the carers subjective experience is suggested.

### **5.5.1 General Research Aims**

It is the aim of the current study to investigate the relationship between carers' self-determined methods of approaching or avoiding the experimentally taxing task of reconstruing and the degree to which caring tendency has featured in the carers life, to determine if they jointly or independently predict their level of burden, the adoption of healthy and unhealthy caring behaviours, and the degree to which Identity Status, as currently measured, can operationalise the codependency ideas of false and real self.

To investigate these issues in carers of the aged, four hypotheses are proposed to guide the research.

### **5.5.2 Hypotheses to Guide the Research**

#### **Hypothesis 1**

##### **Aim**

The aim is to determine the relationship between the carers' method of reconstruing self-relevant information and their tendency to make use of healthy and unhealthy caring practices.

##### **Prediction**

It is anticipated that carers with an Information orientation to

reconstructing self-relevant information, when compared to those who have a Normative or Diffuse orientation, will have less burden, greater service use, greater satisfaction with help, less codependent relating styles, and less tendency to come from a family of origin which included a dysfunctional member.

### **Hypothesis 2**

#### **Aim**

The aim is to investigate the relationship between serial caring tendency and use of healthy and unhealthy caring practices.

#### **Prediction**

It is anticipated that serial caring tendency will be associated with greater burden, less use of services, less satisfaction with services, and a greater tendency to come from a family of origin which included a dysfunctional family member.

### **Hypothesis 3 and 4**

#### **Aim**

The aim is to determine the relationship between the carers' method of reconstructing self-relevant information and caring tendency, to jointly predict the use of healthy and unhealthy caring practices, thus suggesting some commonality between the processing function of the self structure

underlying both.

### **Prediction 3**

It is anticipated that carers with an open approach to reconstruction, operationalised by Information-oriented Identity Style, who lack a history of chronic caring for individuals other than their children, will have the lowest burden, use services more frequently, be more satisfied with the services they receive, and be less likely to descend from families containing a chronically dysfunctional member.

### **Prediction 4**

Secondly, it is specifically anticipated that carers with a less open approach to reconstruction, operationalised by Normative and Diffuse-oriented Identity Style, with a history of chronic caring for individuals other than their children, will have the highest level of burden, use services least frequently, be the least satisfied with the services they receive, and descend more frequently from families containing a chronically dysfunctional member.

## **CHAPTER 6**

### **METHOD**



## CHAPTER 6

### METHOD

#### 6.1 Participants

The sample consisted of 96 adult carers who were providing primary and significant levels of care for a spouse, parent or friend at home, who was 55 or more years of age and afflicted with diseases causing reduced functional status. The carers had a mean age of 62.03 years ( $SD = 10.99$ ); however, the sample had an age range of 46 years and included carers who were middle aged, young aged and old aged themselves. A comprehensive description of the sample, the person they cared for, and the level of care they provided is given in Appendix 1 of this report.

Participants were selected to take part in the study on the basis of three criteria: firstly, they had to have been providing a substantial level of care for another person; secondly, they had to reside with the person for whom they cared; and, thirdly, the person they cared for had to be 55 or more years of age. Carers of people from the age group 55 and onwards were included in the sample, as the findings of the survey of *Handicapped Persons* (ABS, 1981) indicated that, in Australia, the frequency of persons with handicaps due to disability or illness has already increased considerably as a proportion of population, by age 55 years.

Participants were not assigned to experimental groups prior to testing. All participants were provided with the same interview and test materials and

then assigned to groups on the basis of the Identity Style type they achieved (e.g. Information, Normative or Diffuse self-relevant reconstruing style) on the ISI3 ( Berzonsky, 1986c, 1987a, 1992a) and their carer status (e.g. serial or episodic carer). Participants took part in the study voluntarily and no payment was provided for participation.

## **6.2 Materials**

The materials used in this study were confined to a structured interview form and research instruments. However, it was also necessary for interviewers to make use of telephones, vehicles to drive to the participants' homes and maps to locate residences.

### **6.2.1 Structured Interview Form**

A structured interview and data collection form was developed by the current author to obtain descriptive information from the carer. A copy of this appears in Appendix 2.1. The style and content of some questions was influenced by those used in the survey form of Gillies *et al.* (1987). The form was structured to allow rapport to be established whilst gathering descriptive information, prior to administering the major scales. The structured interview form consisted of five questions regarding the carers' demographic details, four questions to define the caring relationship, six questions regarding the elder and their care needs, two questions regarding service use and one question on satisfaction with services.

The question asked of the carer were: the carer's age, country of birth, gender, highest educational level achieved, past employment status, main source of income, combined family income, relationship to the person cared for, the age of the elder, gender of the elder, main diagnosis of the elder, level of care the elder required with self-care, continence, memory and staying organised, length of caregiving to the current elder, and the main reason for accepting responsibility for caring. This information was collected to allow the sample to be broadly defined but also to gain details of socio-economic variables known to influence the use of services (see: Cutrona and Russell, 1991).

The interview questions were recorded on the structured interview form in conversation style (e.g. "Can you tell me how old you are?") to provide interview structure and continuity. The form also provided spaces to directly record and code responses and to record information in detail if the coding was unclear. Some questions recorded on the structured interview form were developed to obtain information to be used as independent and dependent measures. These are:

- (1) Carer Status: To determine if the carers were serial or episodic carers, they were asked, "Is this the first person you have cared for? " If they had cared for another person they were asked to provide details regarding the extent to which they had provided care in the past. If this was their first experience of providing care, of the type which could be categorised as significant support and/or home nursing, they were classified as episodic carers. If they had provided this substantial level of care for one or more people in the past at a significant support and/or "nursing care" level, in addition to the

current person being cared for, they were classified as serial carers.

(2) Family Type: To determine exposure to a family member in childhood which may have necessitated early role adaptations, the carer was asked, "Now I would like to ask you a question about when you were a child. Did you have a parent, caregiver or person living in the house with you who displayed ongoing, obviously difficult behaviour, such as a drinking problem, gambling, a psychiatric condition, unpredictability or verbal or physical abusiveness, or who was always sick?" This question has face validity and is in keeping with the questioning described by Wegscheider-Cruse (1985) in her codependency research with health professionals.

(3) Volume of Support Utilised in the Past Month: In the past, the main method of collecting service utilisation data has been by survey question (see: Walinsky, Mostly and Coe, 1986 and Glandon et. al., (1992). This approach was adopted here. Volume of support from three sources was targeted. Carers were specifically asked, "Have you made use of help in the past month from Home care, Home Nursing and Respite Care Services (day or long term). These are the locally used names of services offering nursing, domestic and holiday relief. When the response was "Yes", the carer was asked, "How many hours was this service used for in the past month?" The hours of service use over the past month for each service were combined to produce a summative index of service use. This summative approach is recommended as a method of indexing breadth and volume of service use (Strain, 1991).

This approach was consistent with the suggestion in the literature, that occasions of service data and volume of service data should be collected separately (Wilinsky and Arnold, 1988). With occasions of service data alone, it is not statistically possible to combine the data regarding the myriad of discrete services provided for carers, without access to very sophisticated measures utilising multidimensional scaling techniques. Unfortunately, no such measure has been developed and to do so would be beyond the scope of the current project.

Volume of support however, can be conceptualised as the time for which the service was provided. There is no assumption being made that the tasks being provided by different services are equivalent (eg: dusting, vacuuming, washing, ironing, bathing, holiday care etc). Instead, the assumption is that one hour of service provision by a nursing service, frees up the carer for one hour, just as one hour of domestic service frees the carers time for the same period. Thus, the volume of support across community services operationalized in terms of hours of service is seen as impacting at the level of carers experiencing overload (Thompson & Doll, 1982).

It is not possible to provide validation statistics for this method of data collection. Though it is recommended in the literature that when collecting service use data, over and under estimates of service use should be detected by verification against medical and/or service use records. This is to control for “telescoping” or moving events into an earlier time period, (Neter and Waksberg, 1964; Sudman and Bradburn, 1974) or over estimating the frequency of visits which tends

to happen when service use is high and the user very ill (Kosa Albert and Haggerty, 1967).

However, service providers refused to assist with this verification process. Home nursing and Respite Services policy would not allow records to be cited or discussed with staff. They saw this as a confidentiality issue. Home-care services refused because they did not have the manpower to check their monthly records. In addition the author was the twelfth researcher requesting verification information from them in six months. Thus, Kasper, (1979), appears correct when it was suggested that failure to assist with verification generally occurs because of the the volume of requests received by services.

However, there are four (4) reasons to expect the data collected will produce valid results. Firstly, data was only collected for service use in the last month. This time period was chosen to minimise distortions in the information obtained due to poor memory. It has been noted in the literature that self-reporting of service use may be inaccurate because of poor recall over a long time period. However, the recommendations in the literature, for appropriate data collection periods to overcome this period have not been consistent. Periods of two weeks, a month, six months and a year have been recommended to produce valid results. (See: Mechanic, 1978 and Strain, 1991 for a general discussion, and Gerald, Glandon, Count & Tancredi, 1992, for special requirements for the aged.) However, the shorter the period for retrospective data collection, the better. The period of one month used here meets this criteria.

Secondly, concerns about poor of reliability of service use data have been raised in studies about use of intermittently used hospital and medical practitioner services. There is less of a concern in this study because community services to carers are provided on a more regular basis. Carers may continue to receive the same service, on the same day (s), over a prolonged period.

Thirdly, under reporting of service use is more likely to occurs when subjects have prepaid health service plans or are unaware of the cost on a weekly basis,(Marquis, Marquis and Newhouse, 1976). While community services are subsidised, they are not free. The the carer would be keenly aware of the number of hours of service provision they are paying for each week, increasing the likelihood of more accurate memory.

Finally, as noted above, poor recall of service use data is associated with high service use and the survey participant having ill health. In this study, it was the elder not the carer who had the ill health and for the most part service use was low.

Thus due to the long term nature of the assistance arrangements between carers and community services, the relatively short period of time which carers were asked to retrospectively recall service use information, the requirement for the carer to pay for the services via an hourly fee and the generally small number of hours which services were used for, one would expect a reliable assessment of volume of service use in this study.

(4) General Satisfaction With Help Received: To determine satisfaction with assistance received, the carer was simply asked, "Generally, how satisfied are you with the help you receive?" After allowing the carer to give some details, the interviewer then asked them to clarify their response by saying, "Are you generally satisfied, a little dissatisfied or dissatisfied?" This measure was adapted from the approach suggested by the Centre for Epidemiological Studies (Radoff, 1977).

A copy of the structured interview form is contained in Appendix 2.1.

#### **6.2.2 The Threat to Basic Needs Domain Index (TBNDI) (Braithwaite, 1990)**

This scale was used to operationalise carers' burden. The scale is a paper and pencil questionnaire, requiring the carer to rate 17 statements such as "having to consistently be on-call to assist the person you are caring for" as being a problem for them or as not being a problem for them. The scale can be rated in two ways: on a four-point Likert scale (e.g. Never, No, Somewhat or Very Difficult to Cope With) or in Yes/No format (e.g. Yes - this has been a problem, or No - this has not been a problem). The second method was used in this study, as pre-existing reliability data only appears to exist for this approach. Using the Yes/No format, Braithwaite has reported that the scale yields a range of scores from 17 to 34 (mean = 28.38, SD = 4.11) with an alpha reliability coefficient for internal consistency of .84 (Braithwaite, 1990, p.10).



When developing the TBNDI, there were originally two components to the measure. They were a separate scale of feelings of deprivation (e.g. being unable to get the housework done, constantly being on call, having to change plans at the last moment) which included eight questions and produced an independent mean of 13.20 (SD = 2.28), with an alpha coefficient for internal reliability of .78. The separate scale of feelings of inadequacy included nine items (e.g. not being on top of things, losing patience, etc.) which produced an independent mean of 15.20 (SD = 2.54) and an alpha reliability coefficient of .80. However, these scales were found to be highly correlated with each other, leading Braithwaite to combine the items to produce the single threat index of 17 items, which was used in this study.

This combined approach appears valid in that both the disruption and inadequacy scores of the Burden Index were found to correlate with a number of indicators of psychological distress. For example, Braithwaite (1990) reports that higher scores on the disruption and inadequacy sections of the scale are both associated with a greater likelihood of minor psychiatric symptoms, as measured by the Delusion-Symptoms State Inventory (DSSI) (Bedford, Foulds & Sheffield, 1976) and the Scale of Four Neurotic Symptoms (4NS) (Henderson, Byrne & Duncan-Jones, 1981) and with negative affect on the Affective Balance Scale (ABS) (Bradburn, 1969). Thus the TBNDI appears to be internally consistent and valid.

### **6.2.3 The Revised Identity Style Inventory (ISI3)**

**(Berzonsky, 1992a)**

This is a pencil and paper test consisting of 40 questions, which provides separate measures of one's committedness to self-relevant values and three styles of reconstruing, or avoiding reconstruing self-relevant values. These are: (a) Information Orientation (e.g. actively searching for, elaborating and evaluating information that have a bearing on self-relevant values); (b) Normative Orientation (e.g. focusing on internalised conventions, standards and expectations; and (c) Diffuse Orientation (e.g. avoiding or procrastinating until the affective cue in a given situation dictated the required behavioural reactions) (Berzonsky, 1986c, 1992a, 1992b).

According to Berzonsky (1990) the original measure was developed to allow identity commitments to be measured separately from status types, and to operationalise the social-processing component of the Marcia Status approach to identity. In turn, the measure has operationalised Eriksonian constructs about the nature of identity. It is reported that the test was developed by "*decoupling the commitment and self-exploration components*" (Berzonsky, 1992b, p.773) of the the Marcia Status Interview. Earlier versions of the scale (Berzonsky, 1986c) had only moderate internal reliability and a new version was published by Berzonsky (1992a).

The Identity Status scale used in this study is the revised version, with improved psychometric properties. Berzonsky, (1993) reports the following reliability information. He notes the scale includes a 10-item, Information-oriented identity scale which yields an alpha reliability coefficient of .73, a 9-item Normative-style scale which yields an alpha reliability coefficient of .68,

and a 10-item Diffuse/Avoider scale which yields an alpha reliability coefficient of .78. Thus, the internal reliability of the scale is adequate. Berzonsky also reports that each of the scales has test - retest reliability of between .71 and .75 over a two month interval (see: Berzonsky, 1993, p293).

The scale, however, was developed for use with adolescents and probes attitudes and values in the educational, political and religious domains. There were three questions from the educational domain, regarding difficulties with school tasks, which were clearly inappropriate with the current sample. Thus the word 'school' was substituted with 'caring'. Thus the statement, "I am not really sure what I am doing at school; I guess things will work themselves out", was modified to read, "I am not really sure what I am doing as a carer; I guess things will work themselves out". Thus, the domain but not intent of the question was changed.

During the interview, participants were asked to rate to what extent 40 statements such as, "When I have to make a decision, I like to spend a lot of time thinking about my options". The possible responses were: "Not at all like me" to "Very much like me" on a 5-point Likert scale. The exact instructions given to the client appear on the copy of the scale, which is in Appendix 2. The scale renders each participant an Information, Normative and Diffuse raw score. This is then converted into a Z score to correct for unequal item numbers on each of the three scales. The style type with the highest Z score was then taken to be the participant's preferred Identity Style.

Thus, each participant obtained two measures from the scale - their preferred Identity Style and their commitments score, both of which were in Z

score format. Details regarding the commitment scale have not been given here as it was not used in the current analysis. This method of arriving at an Identity Style classification is described in Berzonsky and Sullivan (1992).

#### **6.2.4 Codependent Relating (Modified From Hawks, Bahr Wang, 1993)**

This measure was developed for use with the parents of children with drug problems and seeks to operationalise three styles of codependent relating (e.g. Suffering, Persecutory and Rescuing). The original scale operationalised three relating styles in terms of six questions. However, one question, which indexed suffering in terms of missing sleep and tiredness due to worrying was omitted. It was considered unsuitable in a population of sleep-deprived and overworked carers who miss sleep because of elders wandering, etc.. The remaining questions had to be slightly modified to make them appropriate to the aged carers population. Where the original items referred to "your teen", the item was modified to "the person you care for".

To index suffering style of relating, the carers were asked, "Do you sometimes feel upset and embarrassed about the behaviour of the person you care for?" and "Do you cover up the way caring affects you?" To index rescuing style, the carer was asked, "Do you, or have you in the past, taken over chores and other responsibilities the elder can still do?" and "Do you try to conceal the misbehaviour of the person you care for, from family members, neighbours or friends, by lying or denying or covering up?" To index persecutory style, the carer was asked, "Do you, without meaning to, nag, ridicule, make demands upon or threats to the person you care for?" All questions were scored as either Never = 1 or Sometimes = 2.

No reliability data has been reported for this scale. This may be because a maximum of two items is used to index each style of codependent behaviour, making it impossible to generate an alpha reliability coefficient. However, the measure was found by Hawks *et al.*, (1993) to distinguish suffering from persecutory and rescuing codependent style.<sup>4</sup>

### **6.3 Procedure**

#### **6.3.1 Recruitment**

To recruit subjects, a letter inviting carers to participate in the survey, with a consent form included, was prepared and distributed in the community to inform potential participants about the project and to provide them with details about how to register for participation. A copy of the recruitment letter can be found in Appendix 3. In carers' research, subjects are normally recruited through health services such as community nursing, Homecare or day care centres. This approach was also adopted here; however, in an attempt to recruit some subjects from outside of the health system, to give a more randomly selected sample, letters were also distributed through ladies' bowling clubs. In this case, the letters were taken to the bowling organisation and older members were asked to give them to a carer with whom they were acquainted, or to the carer of a friend who was now being cared for. This group was chosen as they were easily accessible and mostly of an

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<sup>4</sup> The only alternative measure which could have been used was that produced by Wright (1985) (also see Wright and Wright, 1990). However, this would require major modification for use with this population, which was beyond the scope of this project. No other scale of codependency phenomena with known reliability exists. All other scales include items which continue to suggest a relationship between codependency and alcoholism, which was unsuitable.

appropriate age to know people in care and those providing care.

In all, 500 Recruitment letters were distributed by staff of a number of community services and by bowling club members. Staff from services who assisted included a Community Options Teams; a Geriatric Assessment Team; Co-ordinators of support groups (ADARDS, etc.); a Carers' Support Worker located with the local Health Service; 15 Community Nurses from three Community Health Centres; Co-ordinators of two branches of Homecare; a Co-ordinator and the staff of a Respite Care Service, doctors and allied health professionals from two private rehabilitation services and a hospital discharge planner.

In order to recruit in this manner it was necessary to provide six educational talks, regarding the research aims, target sample group recruitment criteria and University ethics requirements to groups of staff from the various health centres. Staff working alone were given this information individually. This allowed the sampling criteria to be maintained and ensured that those distributing the letters were fully informed about the project and could answer questions raised by potential participants. However, at no time was information which could bias the result given to health service staff who would be talking to potential participants. In addition, staff were requested to distribute the letters to all individuals they provide services for, rather than selecting their apparent "worst" cases. This was done with the aim of sampling in a more random manner.

In order to recruit in this manner and in addition to the normal University Ethics Committee requirements, it was also necessary to obtain the permission of the local Area Health Service to recruit through their staff.

This involved submitting a copy of the research design to an appointed officer of the Illawarra Area Health Service, and registering the project on a register of research projects being supported by the Health Service. It was also required that the author negotiate with service co-ordinators or nurses in charge of the centres, to write a covering letter from the health service, indicating that the clients' participation in this project was to be on a voluntary basis and that no information, from their confidential medical records, was released to assist in the recruitment process (see Appendix 4).

### **6.3.2 The Interview Process**

As all participants were interviewed in their home, it was necessary to organise an interview roster. All health workers were requested to telephone with details of participants who had agreed to be interviewed and signed the consent form. The person's name, address, telephone number and three possible times for an interview were recorded in a book. Details of the person's address were marked on one of three maps of the Greater Wollongong and surrounding rural areas. When sufficient people in one area were available, interview times were allocated and the participant was contacted by telephone to confirm the time. In addition, all participants were contacted again on the morning of the interview and reminded that they would be seen that day. In arriving at possible interview times, the participants were asked to choose a time when the elder generally rested or was attending a respite service, etc. This was mostly, but not always possible.

When the interviewer arrived for the interview, proof of identification was produced and participants were thanked for agreeing to participate.

They were re-informed that, should they decide to terminate the interview at any time, no pressure would be placed on them to continue and that, should they decide that some questions were too confidential, they should simply say so. Some carers did refuse to answer some questions. Participants were also reminded that all information would be treated confidentially and that no details of their medical history had ever been released by the health service to the researcher.

Participants were informed that they would be participating in a structured interview and this meant that the interviewer would need to follow the format of questions in the interview form, rather than have an open discussion. They were also informed that the results of the study could be biased by other conversation between questions, but that the interviewer was happy to spend some time talking to them after the interview. Participants were also requested to have their reading glasses available at the beginning of the interview.

The interview proper took half-an-hour and a further 15 minutes was spent debriefing the participants. This was necessary as isolated carers frequently just wanted to talk. However, by using the strategy given above, the interview times were limited and the data collection process was consistent from interview to interview. All of the descriptive data was collected by interview, however the participants filled in the rating scales from the Research Instruments themselves.

The instructions on these scales were read to the participants and they were 'talked through' the first three questions of each scale. This was found to be essential in the case of older participants. If the participant



appeared to be having difficulty with the questions, further assistance was given. However, there was no prompting of answers. Half of the interviews were conducted by the researcher, and the other half by a research officer who was trained by the researcher.

### **6.3.3 Data Coding and Analysis**

Most responses to the interview section of the data collection were coded immediately; however, if a code did not exist which covered the participant's answer, it was recorded on the sheet and additional codes were developed after the interview was completed. On a few occasions it was necessary to recontact the participant by telephone to ensure the codes reflected their intent. All other measures were completed at the time of interview. All data was entered into a computer and analysed using the statistics package -SASS.

### **6.3.4 Allocation Into Experimental Groups**

Participants were not assigned to experimental groups prior to testing. All participants were provided with the same interview and test materials and then assigned to groups on the basis of the Identity Style type they achieved (e.g. Information, Normative or Diffuse self-relevant *reconstructing* style) on the ISI3 (Berzonsky, 1986c, 1987a, 1992a) and on the basis of their carer status (e.g. serial or episodic care).

### **6.3.5 The Research Design**

This allocation of subjects into experimental groups resulted in the construction of a 2 x 3 Block Design to allow four hypotheses to be tested.

There were two independent and five dependent measures with a sample size of 96 participants. Although randomly selected, exactly half of the sample were classified as episodic and half as serial carers. There were 31 Information-oriented cases, 23 Normative cases, and 40 Diffuse cases. Cell sizes for the main analysis were 15, 12, 20, 16, 11 and 20 participants. The design is illustrated visually below.

**Table 4: The Research design**

**Identity Style Orientation**

	Information	Normative	Diffuse
<b>Episodic Carers</b>	Dependent measures		
	Burden Service use Satisfaction Cd relating Family Type	Burden Service Use Satisfaction Cd relating Family Type	Burden Service Use Satisfaction Cd relating Family Type
	N = 15	N = 12	N = 20
<b>Serial Carer</b>	Burden Service use Satisfaction Cd relating Family Type	Burden Service Use Satisfaction Cd relating Family Type	Burden Service Use Satisfaction Cd relating Family Type
	N = 16	N = 11	N = 20

\* Cd relating = Codependency Style

This design allows the relationship between burden, service use, satisfaction with services, Codependent relating style and a family of origin type to be assessed in terms of current Identity Style and chronicity of caring independently and when combined.

## **CHAPTER 7**

### **RESULTS**

## CHAPTER 7

### RESULTS

#### 7. Major Analysis

To test the hypothesis that carers' self-types (i.e. Information, Normative and Diffuse oriented Identity Styles) will combine with their caring status (i.e. Episodic and Serial caring) to predict the level of burden experienced, hours of community service used, satisfaction with services, tendency towards codependent behaviours, and the family of origin type, five separate analyses of variance (ANOVA) were performed, using a multiple general linear model procedure. A statistical significance level of  $p < .05$  was chosen to test all hypotheses.

#### 7.1 Results of Multiple Analysis of Variance

##### 7.1.1 Carers' Burden

The results of ANOVA 1 to assess the degree to which the carers' style of reconstruing self-relevant information and caring status combined to predict Carers' Burden, as measured by the Threat to Basic Needs Domain Index (TBNDI), is reported in Table 4. It can be seen that there was no significant difference observed in the mean total burden score of carers with differing Identity Style ( $F(2, 91) = .2$ ) carers' status ( $F(1, 91) = .50$ ) or the interaction between them ( $F(2, 91) = .68$ ). Thus carers' burden was not predicted on the basis of method of reconstruing self relevant material, history of caregiving, or the interaction between them

**Table 4 Means, Standard Deviations and Wilk's Lambda F From ANOVA 1 to Investigate the Effect of Identity Style and Caring Status on Carers' Burden (as Measured by the TBNDI).**

Carers' Status	Identity Style								
	Information			Normative			Diffuse		
	N	M	SD	N	M	SD	N	M	SD
Episodic	15	25.4	5.29	11	23.1	5.38	20	23.5	4.96
Serial	15	24.4	5.15	11	24.7	4.61	20	24.3	5.47

\*\*  $\underline{P} < .05$ .    \*  $\underline{P} < .01$ .

Whilst there was no significant main or interaction effect for the total burden scale, it should be noted that carers with an information orientation had a slightly higher mean than those with a non-information orientation, but standard deviations were larger than the difference between means. It is possible that variability within groups may be a problem in terms of achieving significant between-groups effects.

### **7.1.2 Use of Assistance**

To assess the degree to which the carers' style of reconstruing self-relevant information and caring status combined to predict use of community services, ANOVA 2 was performed using the number of hours of assistance received from all services in the past month as the dependent measure. The results of this are reported in Table 5.

**TABLE 5 Means, Standard Deviations and Wilk's Lambda F From ANOVA 2 to Investigate the Ability of Identity Style and Caring Status to Predict the Total Hours of Assistance Utilised From all Community Services in the Past Month.**

Carers' Status		Identity Style								
		Information			Normative			Diffuse		
		N	M	SD	N	M	SD	N	M	SD
<hr/>										
		**								
Episodic		15	15.1	12.8	12	46.1	106.1	20	37.5	62.5
Serial	**	16	53.8	76.0	11	164.0	279.0	20	34.3	33.7

with a Normative Identity Style make use of a greater number of services. However, the large standard deviations indicate there is variability in service use within the group.

### 7.1.3 Satisfaction with Services

To assess the degree to which the carers' style of reconstruing self-relevant information and caring status combined to predict general satisfaction with assistance received, ANOVA 3 was conducted. It can be seen in Table 6 that there was no significant difference in the mean rating of services satisfaction on the basis of the carers' Identity Style ( $F(2, 91) = 1.17$ ), caring status ( $F(1, 90) = .04$ ) or the interaction between them ( $F(2, 91) = .72$ ).

**TABLE 6 Means, Standard Deviations and Wilk's Lambda F From ANOVA 3 to Investigate the Effect of Identity Style and Caring Status on Satisfaction With Services Received.**

Carers' Status	Identity Style								
	Information			Normative			Diffuse		
	N	M	SD	N	M	SD	N	M	SD
Episodic	14	1.6	1.16	11	2.3	1.42	20	1.7	1.21
Serial	16	1.9	1.91	11	1.91	1.22	20	1.55	0.89

\*\*  $P < .05$ .      \*  $P < .01$ .

Thus carers' style of reconstruing self-relevant information and prior

history of caregiving did not, individually or when combined, predict the level of satisfaction they reported regarding the services they used.

#### 7.1.4 Codependency Issues

To investigate the degree to which the carers' style of reconstruing self-relevant information and caring status combines to predict, first, by the number of codependent behaviours (i.e. 1-5) the carer endorsed as present in their relating to the elder and, secondly, the frequency with which carers reported that they descended from a family of origin in which a family member displayed chronic 'dysfunctional behaviour' (e.g. alcoholism, gambling, abusiveness, chronic illness), two further ANOVAs were conducted.

**TABLE 7 Means, Standard Deviations and Wilk's Lambda F From ANOVA 4 to Investigate the Effect of Identity Style and Caring Status on the Number of Codependent Relating Styles Adopted by the Carer.**

Carers' Status		Identity Style								
		Information			Normative			Diffuse		
		N	M	SD	N	M	SD	N	M	SD
Episodic		14	1.57	1.09	11	1.45	1.44	19	1.42	1.20
Serial	**	16	2.06	1.48	11	2.27	1.19	20	2.10	1.59

\*\*  $P < .05$ .   \*  $P < .01$ .

It can be seen in Table 7 that serial carers persistently reported



making use of a broader range of codependent styles of relating than did episodic carers. This difference in means produced a significant main effect for carer status ( $F(1,90) = 5.03$ ,  $p < 0.05$ ). However, there was no effect due to Identity Status ( $F(2, 90) = 0.04$ ) or the interaction between them ( $F(2, 90) = 0.09$ ). This suggests that carers who had a history of providing a significant level of care to at least one other person in the past, were more likely to have relationships with the current elder characterised by a greater range of codependent relating styles (e.g. embarrassment, persecution, rescuing and secretiveness) than individuals who have no prior history of caregiving.

#### 7.1.5 Family of Origin With a Dysfunctional Member

The result for the evaluation of family of origin are given in Table 8.

**TABLE 8 Means, Standard Deviations and Wilk's Lambda F From ANOVA 5 to Investigate the Effect of Identity Style and Caring Status in Predicting Family of Origin Type**

Carers' Status		Identity Style								
		Information			Normative			Diffuse		
		N	M	SD	N	M	SD	N	M	SD
Episodic		15	1.5	0.52	12	1.45	0.52	20	1.45	.51
Serial	**	16	1.67	0.49	11	1.83	0.39	20	1.85	0.37

\*\*  $p < .05$ .      \*  $p < .01$ .

It can be seen in Table 8 that serial carers reported that they descended from a family of origin in which a family member displayed chronic dysfunctional behaviour with greater frequency than did episodic carers. This main effect for Carer Status was significant ( $F(1, 93) = 10.14$ ;  $p < 0.01$ ). There was, however, no difference in family of origin due to Identity Style ( $F(2, 93) = 0.20$ ) or interaction between Carers' Status and Identity Style ( $F(2, 93) = 0.61$ ).

To clarify this relationship further, the frequency tables for episodic and serial carers reporting that they descended from this type of family were inspected. It was found that of the 37 carers who came from this background, 26 (70.26%) were now serial carers. In terms of the proportion of each group, 54.17 % of serial carers compared to 22.92% of episodic carers descended from a background in which they were exposed to a family member with the target dysfunctional behaviour.

This concludes the description of the main analysis. Findings of the secondary analysis which includes information relevant to interpreting the findings of the primary analysis will now be reported.

## **7.2 Reliability of Scales Used in the Main Analysis**

### **7.2.1 Reliability of Scales**

To determine reliability of the Revised Identity Style Inventory (ISI3) (Berzonsky, 1986c, 1987a, 1992a) and The Threat to Basic Needs Domain

Index (TBNDI) (Braithwaite, 1990) with the combined young, middle and older aged sample in this study, the internal consistency of both scales was assessed. Prior to examining the alpha coefficients, measures of central tendency for the Revised Identity Style Inventory (ISI3) (Berzonsky, 1986c, 1987a, 1992a) were examined. On the Information scale, the range = 1 - 50.  $X = 35$ ,  $Sd = 6.50$ ; on the Normative scale, the range = 1 - 45,  $X = 30.0$ ;  $SD = 7.64$  and; on the Diffuse Scale, the range = 1 - 50,  $X = 37.3$ ;  $SD = 8.75$ . The standard deviations on each of the scales are large enough to suggest some variability exists within the scales. However, the standard deviation size does not approach the range size on any of the sub-scales, as would be the case in severe problem with variability.

In Table 9 it can be seen that the three Identity Style scales of the Identity Style Inventory (Berzonsky, 1986c, 1987a, 1992a) produced variable levels of internal consistency within the current sample.

The Information subscale produced a Cronbach alpha coefficient of .7712. which suggests it is reliable with this sample.

The Normative subscale produced a Cronbach alpha coefficient of .6578 which suggests only moderate reliability with this sample. However, in this type of research this is arguably adequate.

The Diffuse subscale, however, produced a Cronbach alpha coefficient of only .5864. This certainly suggests questionable reliability with the current sample. However, inspection of the correlation matrix indicated that, when the alpha level was considered without item 10, an item modified to indicate problem with caring rather than school, the reliability increased to

.6789. There was no apparent effect due to other modified items.

The Threat to Basic Needs Domain Index (Braithwaite, 1990), on the other hand, was found to have high internal reliability. A Cronbach alpha coefficient of .896 was obtained with the current sample.

**Table 9     Reliability of the Scales Used in the Main Analysis**

**(Sample: N=96, M =62.03, SD=10.99)**

<b>Measure</b>	<b>Data Type</b>	<b>Cronbach Alpha Coefficient</b>
<u>Identity Style Inventory</u>		
(Berzonsky, 1992a)		
Information	Standardised	0.7712
Normative	Standardised	0.6578
Diffuse	Standardised	0.5864
<u>TBNDI *</u>		
(Braithwaite, 1990)	Standardised	0.8957

\* TBNDI = Threat to Basic Needs Domain Index of carers' burden.

As the structure of the Codependent Relating Scale (Hawks *et al.*, 1993) prevents the use of a Cronbach alpha reliability coefficient from being calculated, and no information regarding reliability is available, the correlations between the two items purporting to index 'Suffering' and 'Rescuing' were inspected.

They were found to be extremely low for Suffering (embarrassment x covering up effect on self,  $r = .1885$ ) and Rescuing (taking over x elders' misbehaviour,  $r = .1885$ ). Thus, even without an alpha measure, it appears extremely unlikely that the three individual styles of codependent relating are being assessed by this scale. Thus, it is only appropriate to discuss the findings in terms of five separate behaviours reported by carers, and not as three relating styles. ANOVA 4 was compiled in this manner (e.g. frequency of carers with 1 - 5 behaviours).

### **7.3 Frequency Distributions of the Major Dependent and Independent Measures**

As the Identity Style Inventory has not been used broadly with a population with a mean age as old as that in the sample in the current study, and since this information is not obvious in the main analysis, it was considered appropriate to report the frequency distribution achieved by carers on each of the Identity Style scales.

It can be seen in Table 10 that, regardless of their advanced years and more time to develop an information orientation towards reconstruing self-relevant material, 63% of this older group of carers achieved a score which suggests they have a non-information-orientated approach to reconstruing self relevant material. The largest component of the non-information-oriented group was those with a Diffuse orientation. It is unfortunate that the identity status subgroup with the highest sample size is the one with the poorest reliability.

Individuals with each of three self-relevant reconstruing styles were approximately equally divided into Episodic and Serial caring status. It should be noted that, despite the very similar cell size for these groups, carers were not recruited in terms of their identity style nor caring status. They were randomly selected and put into groups on the basis of scores on the relevant tests.

**Table 10 Frequency Distribution for Carers with an Information, Normative, and Diffuse Identity Style (Berzonsky, 1992a) and Episodic and Serial Caring Orientation for the Sample of Carers with a Mean Age of 62.03 years of age and SD = 10.99 years.**

Carers' Status	Identity style (Berzonsky, 1992b)							
	Information		Normative		Diffuse		Total	
	N	%	N	%	N	%	N	%
Episodic	15	15.6	12.	12.5	20.	20.8	47	50
Serial	16	16.7	11	11.6	20	20.8	47	50
TOTAL	31	32.9	23	24.5	40	42.6	94	100

\* 2 missing cases

#### **7.4 Frequency Distribution for the Threat to Basic Needs**

##### **Domain Index**

It can be seen in Table 11 that the level of burden experienced by carers was well distributed throughout the sample of carers. In fact, a better

distribution of burden existed in this study than in Braithwaite's original study, where a skew in the distribution occurred (see: Braithwaite, 1990). However, as a group, the carers in this sample were less burdened than those from Braithwaite's reference group. For example, 36.6% of this sample reported experiencing only four or less of the target problems and could be considered as having only mild burden.

**Table 11    Proportion of Carers Experiencing Mild, Moderate, Severe and Extreme Burden as a Consequence of Care.**

Degree of burden	Number of 17 TBNDI items endorsed	n	%
Mild burden	0 - 4	34	36.6
Moderate	5 - 8	16	17.2
Major	9 - 12	34	25.4
Extreme	13 - 17	19	20.4

However, despite this sample being less burdened in a group sense, significant levels of burden existed in individual carers. 62% of carers were experiencing major or extreme levels of burden in that they identified with between 9 and 17 of the Threats probed by this measure. It can be seen in Table 12 that the most commonly endorsed threats were: having to be on constant call to assist the elder (57.9%); not being able to do their job as well as they liked (54.3%); feelings of resentment about what had happened to the elder (53.1%); and feeling that they could not get on top of the things they had to do (52.1%). Most items were endorsed by less than half of the sample as problematic, whereas, in past research, up to 90% found some

situations problematic (Braithwaite, 1990, p.55). Thus, in the current sample, there was great variability in what the carer found stressful rather than a lack feeling of burden. Whilst variability is likely to affect the results of this study, it is clear that a skewed distribution on this scale has not occurred and can be ruled out as a possible contributing factor to the failure to achieve a significant effect on ANOVA 1.

**TABLE 12 Percentage of Carers Endorsing the Total, Disruption and Inadequacy Scale of the Threat to Basic Needs Domain Index (TBNDI).**

<u>Items</u>	<u>Proportion experiencing problems (N = 96)</u>	
	<u>N</u>	<u>%</u>
<u>Disruption</u>		
1. Not being able to do your job as well as you'd like.	55	54.3
2. Having to constantly be on call to assist the person you are caring for.	55	57.9
3. Having to change plans at the last minute.	43	45.3
4. Being unable to get your household chores done.	40	41.7
5. Being unable to get enough sleep.	40	41.7
6. Being unable to rest when ill yourself.		
7. Having health problems as a result of caregiving.	40	41.7
<u>Inadequacy</u>		
8. Not having a regular daily routine.	35	36.5
9. Feeling divided loyalties between the person you are caring for and other members of your family.	43	44.8
10. Feeling that you cannot get on top of all the things you have to do.	50	52.1
11. Feeling guilty about what you have or have not done for the person you are caring for.	37	38.5
12. Losing patience with the person you are caring for.	46	47.9
13. Feeling that you are not doing anything as well as you should.	37	38.5
14. Feelings of resentment that this has happened to you.	35	36.5
15. Feeling that you don't understand the nature of the		



other person's illness.	18	18.8
16. Feelings of resentment at what has happened to the person you are caring for.	51	53.1
17. Feeling that you have lost control of your life.	40	42.1

In developing the TBNDI, Braithwaite (1990) combined two scales to produce the one domain index. The two scale tapping disruption to the carer's life and tapping feelings of inadequacy, were combined. Consistent with Braithwaite's report, the two scales were found to be highly correlated with each other ( $r = .893$ ).

#### **7.4 Frequency of Engaging in Codependent Behaviour**

Information regarding the frequency with which each style codependent behaviour was adopted is not given in the report of the main analysis. As the findings are worthy of discussion, they are reported here.

**Table 13 Proportion of Carers Indicating That They at Times Engage in Codependent Style Behaviours When Relating to the Elder for Whom They Care (n= 96)**

Style of Codependent Relating	N	%
Suffering Style (Embarrassed)	33	34
(Effect on self)	48	50
Persecutory (Nagging, demanding)	33	34
Rescuing (Taking over prematurely)	44	46
(Hiding elders' dysfunction)	15	16

It can be seen in Table 13 that, with the exception of remaining secretive

about the elders' level of dysfunction, at least one third of the sample reported engaging in each of the codependent styles of behaviour sampled. Half of all carers reported that they engaged in a suffering style of codependency by being secretive regarding the negative consequences of caring on them. In addition, 46% of carers could be seen as rescuing and, in doing so, unnecessarily encouraging dependency in the person they care for. Thirty four percent of carers reported that they relate to the elder in a persecutory codependent style.

Information regarding the frequency of service use and service satisfaction will not be reported separately as this information is evident in the tables from the main analysis.

## **7.5 Summary of results**

Thus to summarise the results of the main analysis, it was found that the carers' methods of reconstruing self-relevant material never interacted with their status as a serial or episodic carer to predict the dependent measures. However, in isolation, effects were achieved. Serial carers, when compared to episodic carers, had made significantly greater use of hours of assistance in the past month, and reported that they engaged in a significantly broader range of codependent styles of relating to the elder. They also reported significantly more frequently that they had originated from families containing a member who suffered with a chronic condition such as alcoholism, gambling or chronic illness. However, serial carers were no more or less burdened than episodic carers.

In terms of Identity Status, those carers with a normative style of

reconstructing self, used significantly more services than did individuals with an Information or Diffuse orientation. This concludes the report of the results.

# **CHAPTER 8**

## **DISCUSSION**

## CHAPTER 8

### DISCUSSION

The principle aims of this study were to identify new approaches to understanding the parameters of healthy and unhealthy caring with carers for the aged. An exploratory study was conducted to determine the relevance of concepts developed with other populations, which emphasise the active nature of the carers' construing and the organising functions of the carers' self-concept. This synthesis was attempted under the rubric of three constructivist assumptions regarding the active, construing and organising function of the carers' core processor (Berzonsky, 1990; Mahoney, 1988) and the stress inherent in the caring context.

However, as with much theoretical work, concepts developed are often initially more sophisticated than the measures used to operationalise them. In this study the measure of reconstruing self-relevant information, the Identity Style Inventory (Berzonsky, 1992a), developed for use with an adolescent population coping with the demands of study and coming to terms with religious and political ideology, has been used to determine if there is any sign of difference in reconstruing style remaining in a sample of carers with a mean age of 62.03 years.

Clearly, age and domain-specific effects are likely to be influential here (see: Geary & Waterman, 1979; Whitbourne, 1979). Whilst carers of the aged are a much older population than the test reference group, with life stage issues vastly different to those sampled by this measure, there was a degree of support, at this stage, for the usefulness of such an approach, in

that reconstruing style, as measured by this inventory, predicted some caring strategies.

One of the five outcome measures - total hours of services used, could be predicted on the basis of Identity Status groupings. In addition, the finding alone, that a randomly-identified group of middle, young and old aged carers, were assessed on this scale as having differences in the way they approach the task of reconstruing self-relevant information, was also interesting in itself and suggests that this course of investigation is worthy of refinement.

As suggested by the clinical observation made by the author, that many carers appear oblivious to information regarding ways of modifying their personally-relevant caring style, 66% of carers were assessed on the Revised Identity Style Inventory (Berzonsky, 1992a), as having a non-Information-oriented approach to reconstruing self-relevant material (eg: Normative and Diffuse).

This is at variance with the finding that information orientation should increase with age (Berzonsky & Kinney, 1994; Waterman, 1982). One might ask why, as a group, these carers in the later stages of their life span have this apparent, less developed level of approach to the task of reconstruing. In addition, this study has helped to clarify the direction in which refinements in measurement technique should proceed for reliability and validity in measurement to be improved.

However, before these issues are discussed in greater detail, an interpretation of the findings for each hypothesis will be presented.

## 8.1 Evaluation of Hypotheses

It will be recalled that the aim of Hypothesis 1 was to determine the relationship between the carers' method of reconstruing self-relevant information and their tendency to make use of healthy and unhealthy caring practices. The anticipation that the carers' style of construing self-relevant information would predict use of and satisfaction with services and the presence of codependency issues was partially supported. Use of services was predicted on the basis of Identity Style but the effect was due to increased service use by the Normative group, not the Information-oriented group as was expected. This finding illustrates that the social orientation of the Identity Style model is as important when explaining findings as is the processing style component of the model.

Specifically, those carers with an Information orientation will have better resources for identifying and seeking out information about services but their orientation is more individualistic than that of Normative carers. For example, under stress an Information-oriented person will adopt a problem-focused strategy to solve it (Berzonsky, 1992b). However, a Normative-oriented person will seek support from authorities or from another reference group such as their family. Thus the Information-oriented carer using less, not more services than those carers with a Normative orientation is consistent with Identity Status orientation.

Carers who adopted an Information orientation were, however, no more resistant to burden nor evaluated services differently from carers with a non-Information-oriented approach. Nor did they relate less in terms of codependent behaviour, or descended from a family of origin with a

dysfunctional family with less frequency.

In addition, when considering the increased service use by the Normative group, an inspection was made of the detailed socio-economic status information collected as part of this study, and the residential addresses of the participants. Interestingly, a high proportion of this group were pensioners which, in itself, is not suggestive of anything because of the age group of the participants and because over half of the sample were aged pensioners.

However, 60% of the Normative group had a residential address which indicated that they lived in government-funded housing in Housing Commission estates. Whilst not wishing to stereotype the participants, this may suggest that, for participants living in government-subsidised housing and accepting a government pension, using government-subsidised services is Normative and supported by peers, and thus not viewed as threatening. This is consistent with the view that Normative individuals are greatly influenced by their peer group.

In addition, the number of hours of service used by this group was substantially higher than any other category. This might also provide support for the findings reported in the helpseeking literature that, when non-threatening support is provided, it encourages dependency (Wills, 1982). In addition, it could equally be suggested that, when service use is accepted as appropriate by this group, and thus non-threatening, they will apply their dogmatic approach and expect more regular service provision.

The aim of Hypothesis 2 was to investigate the relationship between



serial caring tendency and use of healthy and unhealthy caring practices. The anticipation that serial caring tendency will be associated with greater burden, less use of services, less satisfaction with services, and a greater tendency to come from a family of origin which included a dysfunctional family member, gained partial support. However, serial carers, as predicted, reported that they made use of a broader range of codependent styles of relating and descended more frequently from a family which contained a dysfunctional family member.

The serial carers were, however, no more or less burdened than the episodic carers. Contrary to the prediction, serial carers used more services than the episodic carers. Thus serial caring appears to be a qualitatively different caring experience from episodic caring. In terms of the healthiness of the caring relationship, this finding raises matters of concern. It suggests that serial carers with the same level of burden as episodic carers are significantly more likely to engage in a broader range of unhealthy caring practices, which might include being embarrassed and denying the effect on self, nagging and demanding, taking over prematurely and being secretive. This significant difference remained even though they used more services than the episodic group.

In addition, descending from a family with a dysfunctional member was significantly more common among serial carers. Conceptually, this finding is consistent with the codependency view that growing up in a family with a dysfunctional member can predispose one to forming serial caring relationships in which the needs of self are not heeded.

This result also raises the possibility that, under lower levels of

burden than their episodic counterparts, and whilst using more services, negative behaviours possibly learnt in the family of origin setting can re-emerge, possibly leaving the elder vulnerable to emotionally abusive behaviour and behaviour which robs the elder of their independence.

It is a basic tenet of geriatric rehabilitation that the elders' functional status be maintained for as long as possible. Thus the preferred approach is to encourage the elder to do things for themselves, even when it is difficult for them. For example, once a frail aged person gives up walking, for even a short time, they become immobile and it is considered better not to let this happen in the first place. However, for those carers with an overly-developed caring tendency, there may be difficulties complying with this geriatric rehabilitation approach. Commenting on the item "Taking over tasks that the elder is still capable of doing for themselves" over 46% of carers indicated that they had done this in the past.

The findings generated by Hypothesis 2 suggests that there is a need to understand more about the episodic-serial carer dimensions, particularly as they may relate to emotional persecution of the elder, encouragement of dependency, and failure on the carers' behalf to look after self. It should be noted that the inferred codependency syndrome of increased caring tendency, a greater range of codependent behaviours and family of origin issues has co-existed in this subgroup of carers of the aged. However, these findings should be viewed conservatively in light of the fact that the codependency scale cannot be demonstrated to be reliable and is unlikely to index three styles of codependent relating. On the other hand, the results support the view of Wright and Wright (1990) that the concepts from codependency are worthy of further investigation.

In addition, correlational findings presented in Appendix 2 highlighted a relationship between cognitive problems, the carer's burden and codependent type behaviours. This raises the possibility that very dysfunctional behaviour on the part of the elder, as is seen in dementia sufferers, may increase the likelihood of the re-emergence of codependent behaviour in predisposed carers. This also suggests that, the codependant traits hypothesised as present in carers of the aged, may be disproportionately found in carers of the demented aged. It further suggests that, in future, research into codependency in aged carers, some focus should be on the population - carers of the demented aged.

It was the aim of Hypotheses 3 and 4 to determine if carers' methods of reconstruing self-relevant information and caring tendency would combine to jointly predict the use of healthy and unhealthy caring practices, thus suggesting some commonality between the processing function of the self-structure underlying both measures. There was no support found for either of these hypotheses in the current study because serial caring, as defined in this study, did not interact with Identity Style to predict use of and satisfaction with services or codependency issues. This suggests that the measures for Identity Style and Carer Status, in their current form, provide an account of quite separate aspects of the carers' underlying mechanisms of self-relevant construction, as they relate to use of and satisfaction with services and codependency issues.

At a conceptual level, there was no support for the view that a rigid, overly-defended self-type called 'false self', said to be present in those prone to serial caring, can be equated with an Identity Style which defends their self-relevant ideas by using *ad hoc* or avoidant methods of reconstruing self.

In addition, the view that threat to basic needs is experienced at the level of the core processor cannot be demonstrated at this time because of the failure of these above measures to predict burden. In all but the case of predicting service use, the  $F$  values for the interactions were so low that other interpretation seems unlikely, with the variables in question measured as they are.

Thus, to summarise, this study has indicated that services are used more frequently by serial carers and by those carers with an orientation to seeking assistance from authorities when under pressure, ie. Normative carers. This is consistent with what the Identity Style model predicts. It gives support to the view that the method by which a carer reconstrues self-relevant information will influence their experience of caring, relevant behaviour.

Similarly, there was support for the codependency model in that serial carers display a broader range of codependency type behaviours, and descend from a family of origin in which a dysfunctional member was present. However, such individuals would normally be expected to struggle alone rather than seek help. This was not found. Thus, overall the results of this study provide support for constructivist and codependency concepts.

## **8.2 Theoretical Consequences in Terms of the Model**

One question which arises from the current findings is "Should the constructivist model be abandoned for a codependency model?" This would not be recommended. In terms of the broad constructivist model providing a preliminary framework for operationalising the carers' subjective experience,

as a process of avoiding or approaching self-relevant construing, there were a number of findings which suggest this line of research is worth pursuing. First, service use was able to be predicted in terms of style type, in a manner consistent with the underlying theory, and the interaction between carer type and style type was approaching significance. Similarly, the finding that equally-burdened carers react differently in the caring situation, highlights the importance of the construing process, despite familial antecedents. Similarly, the report by carers on the codependency measure, indicating that 50% of carers hide the negative effect of caring on themselves, further suggests that carers are closed to self evaluation.

The Identity Style approach appears to be a promising research tool but is in need of modification. The Identity Style Inventory may provide a mechanism for operationalising the processing rather than the content component of carers' self, which organises responses to threatening or self-relevant information in the caring context. However, the moderately high raw score standard deviations found on each of the scales for Identity Style and the correlation between the Diffuse and Normative scale (see: Appendix 4) suggest there is a need to improve the Identity measure, with an older carers' sample.

One of the major advantages of the constructivist approach over the codependency model, is that methods for initiating the improvement of the rigour of this approach exist. Whereas the codependency model gives very few research options which are acceptable in the more advanced stages of developing a model. The results of this study are encouraging enough to suggest further elaboration of the constructivist approach is warranted.

Further to this, the descriptive data produced about carers indicates that many carers provide assistance for their elders for an extended period. With 23% of carers providing care for over eight years, the constructivist model would also begin to generate hypotheses about avoidance of role relating through the adaption of a social role (Leitner and Pfenninger, 1994).

#### **.8.2.1 Improving Measurement of Identity Status in the Carer Population**

In terms of the Identity Status Inventory (ISI3), there are a number of measurement issues to consider. First, as noted above, this measure was developed for adolescents construing information in the educational, religious and political domains. Secondly, the degree to which measurement in the domains sampled transfers to the caring context must now be questioned. There have been suggestions that Identity Status should be measured in a domain-specific manner. Certainly, the observation that the items be modified to ask the carer to think about the caring context was the most poorly correlated with any other item on the Normative scale, suggesting that a more carer-specific domain index may need to be developed.

Using the Identity Style Inventory basic question format, the items could all be made specific to the caring context. Questions regarding education from the original scale could be modified to directly measure orientation to acquiring information about sources of help from service providers and informal sources. Questions regarding political beliefs could be modified to reflect underlying political beliefs about the way aged people should be cared for. Items in the religious domain might remain the same,

but their relevance to an Australian as opposed to an American sample would need to be considered.

If such a scale could be demonstrated to distinguish between carers on the basis of how open or closed they are to reconstruing self-relevant information, it would have valuable clinical, as well as empirical use, for those screening clients for educational programmes, etc. Developing such a scale would, however, be a relatively major project, requiring significant work to ensure reliability and validity. There is precedence for this approach.

Changes across different domains have been investigated using the original Marcia Status Interview (Marcia, 1966). This could be extended to Identity Style. The Identity Status measure has been modified to test the following domains: Friendship; Interpersonal Concerns; Sexual Expression and Sex-role Beliefs (see: Grotevant & Adams, 1984; Grotevant & Cooper, 1981; Melgosa, 1985; Schenkel & Marcia, 1972).

### **8.2.2 Measurement of Carers' Status**

Caring, in this study, was defined in terms of having cared for at least one other person and a major and prolonged period of care being required. When caring for an aged person was involved, doing this twice was thought of as indicating a significant caring tendency. Perhaps a more rigid definition, in which people had cared for at least three people, would have been more in keeping with the chronic caring tendency described by codependency theorists, as it would eliminate those people who only assisted both parents. Had this been the case, only approximately one-third of the sample in this study would have been classified as serial carers.

Conceptually, there is a different caring tendency in a person who cares for both parents and a person who has cared for six aged people, as was the case with one study participant. However, this tighter definition would exclude people who have provided care over many years for two people. This may even suggest that, in carers' research, the distinction between serial and prolonged caring should be drawn.

### **8.3 The Problem of Variability**

#### **8.3.1 The Current Research Sample**

It can be noted by inspecting the means and standard deviations in the sample that there was significant variability in the sample in this study. Yet, when correlations were inspected, there were few significant trends or relationships. The level of variability in the sample, due to socio-economic indicators, etc, is immediately evident from the detailed description of the sample given in Appendix 1.

The sample size in this study was 96 with five independent measures. This is an adequate study size from a design perspective, particularly with a clinical population. However, it is possible that, with a greater sample size, further trends may have emerged. Thus the author would consider it a shortcoming of the research that the sample size was too small for research with identity types.



### **8.3.2. Variability and the Pure Types Paradigm**

Problems with variability in the results, of studies with Identity types, have been observed by other researchers. This has led to the development of the Pure Types paradigm (Grotevant & Adams, 1984). It is suggested that variability could be improved in future research by the adoption of this approach. Details of one method by which this could be addressed in Australia are also given in the following discussion.

The Pure Types method (Grotevant & Adams, 1984) basically involves using a larger sample and a second method of scoring the identity measures to exclude participants who have not fully completed their transition from one type to the next. This is done by selecting a cut-off point of one standard deviation above the mean and excluding all participants who did not reach that criterion on their preferred Identity Status type. Participants who reached this criterion, but who also had a score higher than the cut-off point for the preferred style on another scale, were also excluded. Analysis was then conducted with only those participants who had a pure identity type, that is, those who achieved a score within one standard deviation from the mean on their preferred Identity Style. However, only one third of subjects could be expected to achieve a Pure Type. The practical realities of conducting research with Pure types is difficult due to the sample size required. The approach which has been used in the past is to develop a registry of pure type cases that could be accessed at any time.

This system could easily be developed in Australia by using the Australian Institute of Family Studies' computer-assisted telephone interviewing system and a team of trained interviewers (see: Schofield &

Herrman, 1993) to randomly identify households with a carer and conduct a telephone interview, including administering the Identity form. This method of identifying a sample has been used successfully with carers in the past and would allow a Pure types register to be developed.

#### **8.4 Codependency**

There can be no doubt that the measurement of codependency will need to be improved. Scales should be constructed in a manner which allows reliability and validity to be assessed.

The best method of measuring codependency is undoubtedly the Wright (1995) measure described in Chapter 4. However, it will require significant modification for use with an aged sample to ensure that tasks used to operationalise overcaring in this model are not daily care tasks when looking after a frail, aged person. However, the results of this study also suggest it is worth pursuing the concept of three styles of codependence in carers of the aged.

#### **8.5 Carers' Burden**

Despite the fact that the level of burden was well distributed in the sample, and the Threat to Basic Needs Domain Index was demonstrated to be reliable with the current sample, burden was not predicted in terms of any of the measures. Again, the analysis of the burden data suggests that there was little commonality between what was found to be burdensome from carer to carer, and further supports the suggestion that the current sample needed to be larger to allow trends to arise.

The degree to which the randomised sampling technique contributed to this is perhaps unclear. However, there is unfortunately little support, at this stage, for the predicted relationship between manner of construing and burden when conceptualised as a threat to security, love and other basic needs.

## **8.6 Volume of Service Use**

A number of conclusions regarding the future measurement of service use data were evident in the further analysis of the 'volume of support' data reported in Appendix 3. By analysing volume of support received across services, the hours for which the carer was relieved of caring duties was adequately indexed in this study.

However, additional analysis of this variable left no doubt that this combined measure does not allow the the prediction of specific service use. There is a clear dichotomy between "help in general" and "help from specific services". They appear to be discrete variables and their use is predicted by different criteria.

It appears that in future, the best analysis would be obtained from considering both service use and volume data. Four (4) issues which may be associated with using volume data alone, were detected. These are: Firstly, that help provided by a single service can be over represented in the volume data; Secondly, there may be an inability to focus on the help obtained from less used services; Thirdly, there may be a need to control for referral procedures effecting use patterns in the analysis of service volume

data and; finally, the different time allocations inherently required for different services may also need to be controlled for.

Though five logical reasons were outlined which suggest that volume of service use data collected in this study should be valid, no reliability studies or verification procedures were implemented. Thus, the inability to provide statistical measures of reliability and validity for the service use measures should be considered a shortcoming of this research.

## **8.7 Conclusion**

This study represents an initial attempt to operationalise carers' 'self using the Identity Style/Status paradigm'. This allows that component of self which organises and processes information to be measured. Whilst this approach was developed for use with adolescents, it is increasingly being considered for use with other populations. The results achieved here are encouraging enough to suggest modifications to improve reliability and validity with carers, are warranted.

Though variability in the sample was a problem in the study, and age and domain effects can be assumed to reduce the effects achieved, the results suggested that one can predict service use on the basis of method of construing self relevant information and caring type. As measurement becomes domain-specific and more suited to the age category under investigation, it is hoped that reliability will improve. In addition, by using the Pure Type paradigm, it is hoped that variability will be controlled for, allowing more complex interaction to arise.

This study has demonstrated the utility of adopting a broad theory-driven approach to the study of carers' subjective experience and indicators of healthy and unhealthy caring from other population, allowing, the distinction between episodic and serial carers to be identified.

To conclude, it was the findings of the current study that -

1. Service use by carers can be predicted on the basis of the manner by which they reconstrue self relevant information and by their status as a serial carer.
2. Sixty three percent of carers achieved an Identity Style score which suggests they have a non-Information oriented approach to reconstruing self relevant information - they are what might be called *information screeners*.
3. Serial carers are more likely to use services but still engage in a greater number of negative codependent Behaviour, which can include taking over responsibility for the elder, hiding the effects of caring on self, nagging and demanding and hiding the elders decline from the family, when no more burdened than episodic carers.
4. 70.26% of carers from this sample of 96 carers who descend from a family of origin with a chronic dysfunctional person are now serial carers.
5. Twenty three percent of the 96 carers interviewed had provided care for eight years or longer. suggesting that some carers probably adopt

caring as a lifestyle,

### **8.8 Recommendations for Further Research**

(1) As the codependency model of serial caring was also supported in this research, it may also be useful to investigate the possibility that roles established in childhood also underlie the frequently-reported finding that other family members usually do not share the burden of care.

(2) The results of this study suggest a need to consider the issue of quality of care for homebound elders. In the clinical setting, professional carers must submit to performance appraisal and participate in quality assurance programmes. However, there have been no standards set to evaluate the quality of home-based care or to protect the carer when it is inappropriate for them to provide care. Thus, it may also be time to ask if it is ethical to leave aged people in the care of carers who lack the personal attributes necessary for the task.

(3) There is a need to have a clearer understanding of what healthy and unhealthy caring is, in order to make appropriate assessments of the carers' capacity to provide care without adopting the types of negative behaviours suggested in this study. The current research provides preliminary indicators that, with improved measurement and attention to managing sample variability, the approach suggested here might guide such research and allow further elaboration of a constructivist model of healthy and unhealthy caring.

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**APPENDICES**

## **APPENDIX 1**

### **DESCRIPTIVE ACCOUNT OF THE SAMPLE, THE ELDER AND THE NATURE OF CARE PROVIDED**

## DESCRIPTIVE ACCOUNT OF THE SAMPLE, THE ELDER AND THE NATURE OF CARE PROVIDED.

### A1.1 Demographic Description of the Sample

The sample for the current study consisted of 96 carers, all of whom were currently accepting responsibility for the care of at least one person over 55 years of age or older. The carers included 73 (76%) females and 23 (24%) male. They had a mean age of 62.03 years ( $SD = 10.99$  years). Table A1 shows that carers' age range was from 37 to 83 years of age and that 27% of the sample of carers, not the people for whom they care, were over 70 years of age and can be classified as 'aged' or 'old aged' themselves. Thus the sample includes carers from three age spans, namely, the middle aged, the young aged and the old aged.

**Table A1** Demographic Description of the Carer Sample

<u>Carers' Age</u>			<u>Carers' Country of Birth</u>		
<u>Years</u>	<u>N</u>	<u>%</u>	<u>Country</u>	<u>N</u>	<u>%</u>
30 - 39	01	1.0	Australia	64	66.7
40 - 49	15	15.6	United Kingdom	17	17.7
50 - 59	24	25.0	Italy	4	4.2
60 - 69	29	30.2	Switzerland	2	2.1
70 - 76	21	21.9	Germany	2	2.1
80 - 89	<u>06</u>	<u>6.3</u>	India	2	2.1
	<u>96</u>	<u>100.0</u>	Holland	2	2.1
			The Ukraine	1	1.0
			The Philippines	1	1.0
			Spain	<u>1</u>	<u>1.0</u>
				<u>96</u>	<u>100.0</u>



Most of the carers were Australian born, but migrant carers were also included; 66.7% of carers were born in Australia and the remaining non-Australian born or migrant component in the sample (i.e. 33.3%) were mainly born in the United Kingdom, followed by a European country. There were only three exceptions to this: one carer was born in the Philippines and the other two in India. Of the migrant sample, 14 carers (43.8 % of migrants and 14.6% of the total sample) were born in countries where English was not their first language.

All carers in this study were able to articulate in English and had at least basic reading skills in English. When attempting to predict use of services in terms of Identity Style and carer status (see ANOVA 2) the migrant component of the study is unlikely to be denied access to services due to literacy or language problems. Thus, it was considered that ethnicity did not have to be controlled for in that main analysis.

#### **A1.2. Carers' Socio-economic Status**

Table A2 indicates that, whilst the main source of income for 66.6% of carers was the age pension (e.g. single rate = \$8,630 per annum p.a.; married rate = \$14,279 p.a.), the sample mean household income was much higher at \$22,000 p.a. This is explained by some carers having comparatively higher wages, and by pensioners sharing accommodation. The median income, however, was \$14,606 p.a.. As the range of total household incomes was \$7,000 p.a. to \$ 96,000 p.a., it would appear that some carers have a greater financial capacity, from within their household, than others, to purchase privately provided assistance and have medical benefits which allow access to privately provided respite care and other

forms of assistance. Thus, the correlation between total household income and service use was inspected. As this was not high ( $r = -.023$ ) it was not considered necessary to use total household income as a covariant in ANOVA 2 of the main analysis.

**Table A2 Carers' Socio-economic Status in Terms of Income and Source of Income.**

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<u>Carers' household income</u>			<u>Carers' main source of income</u>		
<u>\$ per annum</u>	<u>N</u>	<u>%</u>	<u>Source</u>	<u>N</u>	<u>%</u>
< \$10,000	10	11.0			
\$10,000 - \$19,999	54	59.0	Pension	63	66.3
\$20,000 - \$29,999	11	12.0	Wage of Spouse	14	14.7
\$30,000 - \$39,999	5	5.0	Wage	10	10.6
\$40,000 - \$49,999	2	2.0	Superannuation	6	6.3
More than \$50,000	<u>10</u>	<u>11.0</u>	Investments	<u>2</u>	<u>2.1</u>
* 4 missing cases	<u>92</u>	<u>100.0</u>	* 1 missing case	<u>95</u>	<u>100.0</u>

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It can be seen in Table A3 that carers who participated in this study also varied in terms of their exposure to education; 12.5% of carers had only a primary school level of education. Most carers (i.e. 56.3%) had an early secondary school level of education, with a further 17.7% having a senior level high school education and 13.5% having a technical or tertiary level of education. However, no carer was totally uneducated. Again the correlation between education and service use was inspected and found to

be too small ( $r = .398$ ) to warrant use of education as a covariant in ANOVA 2.

**Table A3 Carers' Educational Level**

<u>Carers' Level of Education</u>		
<u>Level</u>	<u>N</u>	<u>%</u>
Primary	12	12.5
Early Secondary	54	56.3
Advanced Secondary	17	17.7
Trade/Technical	6	6.2
Tertiary	7	7.3
	<u>96</u>	<u>100.0</u>

In addition, all carers, regardless of gender, reported that they had been engaged in paid work in the past. This is surprising for a sample which includes women carers over 70 years of age.

### **A1.3 Elders' Demographic and Functional Status**

The elders for whom the carers provided care had a mean age of 74.7 years ( $SD = 10.99$ ) but ranged in age from 55 to 96 years of age. It can be seen in Table A4 that 41.7% of carers were providing care for an elder over 80 years of age. In addition, there were more males than females being cared for. The closeness of age between carer and elder being cared for is explained by 46 carers (47.9%) who were caring for a spouse. However, 36 (37.5%) were caring for a parent, 3 (3.2%) for a parent-in-law, 4 (4.1%) for a friend, and 5 (8.3%) for a neighbor.

**Table A4    Elders' Age and Gender**


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<u>Elders' Age</u>			<u>Elders' Gender</u>		
<u>Years</u>	<u>n</u>	<u>%</u>	<u>Gender</u>	<u>n</u>	<u>%</u>
55 -59	12	12.5	Male	57	59.0
60 -79	15	15.6	Female	<u>39</u>	<u>41.0</u>
79 - 79	29	30.2		96	100.0
80 - 89	34	35.4			
90 - 99	<u>6</u>	<u>6.3</u>			
	<u>96</u>	<u>100.0</u>			

---

The period of time for which care was provided was surprising. More than half the carers sampled had provided care for longer than four years, while 22 (23%) carers had provided care for longer than eight years. Table A5 shows that cognitive dysfunction, caused by conditions such as Alzheimer's disease, multi infarct dementia and cerebro-vascular accident were the main conditions leading to the elder needing care. However, a further 11.5% of elders were suffering with musculo-skeletal conditions such as debilitating arthritis and 19.8% had organ disease, most of which was caused by cancer. Only 2.1% of the sample were simply old and frail. Thus, the carer population under investigation in this study are caregivers to an older population significantly afflicted by disease.

**Table A5 Elders' Category of Main Diagnosis and Period for Which Care has Been Provided**

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<u>Category of Main Diagnosis</u>			<u>Period for Which Care</u>		
<u>Area</u>	<u>n</u>	<u>%</u>	<u>Years</u>	<u>n</u>	<u>%</u>
Cognitive	60	62.5	> 2	19	19.8
Musculo-skeletal	11	11.5	3 - 4	23	.0
Organ Disease	19	19.5	5 - 6	25	26.0
Sensory	3	3.1	7 - 8	7	7.3
Frail	2	2.1	9-10	10	10.4
Emotional	1	1.0	> 10	12	12.5
	<u>12</u>	<u>12.5</u>		<u>12</u>	<u>12.5</u>
	<u>96</u>	<u>100.0</u>		<u>96</u>	<u>100.0</u>

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The disease suffered by the elder and frailties associated with the elders' age translated into significant workload for the carer. In Table 8 that 55% of carers were providing major levels of support to the elder with self-care (e.g. bathing, dressing, etc.). Over half the carers had to provide some level of care with toileting, with 26% of carers appearing to be caring for a person who was incontinent of urine and faeces. Forty six percent of carers also stated that they provided major assistance due to the elders' problems with memory and staying organised. This suggests that of the 60 carers caring for a person with cognitive loss, 78% were responsible for a person with relatively advanced dementia or a significant stroke.

**Table A6   Level of Care Required by the Elder**

	Functional Area					
	Self-Care		Continence		Remembering and Organising	
Level of care required	n	%	n	%	n	%
None	18	18.8	41	42.7	25	26.05
Mild to Moderate	25	26.0	30	31.3	25	26.05
Major	53	55.2	25	26.0	46	47.90
	96	100	96	100	96	100

In summary, this descriptive account of the sample indicates that the carers who participated in this study ranged from being middle aged, young aged to old aged themselves. Most were born in Australia, Great Britain or Europe, but all could speak and read basic English. All had been employed at some stage of their life. However, the carers varied in terms of their access to prior higher secondary and advanced education and current financial resources.

The carers provided principle care for aged people with an average age of 74.7 years but the oldest elder was 96 years of age and 41.7% of carers were caring for an elder over 80 years of age. Carers were not simply providing a 'bit of assistance to a relative'; rather, they were 'nursing' elders at home who were suffering with specific medical diseases causing debility and the need for significant levels of assistance with daily self-care (bathing,

dressing). Many carers had to cope with cognitive loss and incontinence problems. This should be borne in mind when interpreting the results of the main analysis. In addition, the caring situation could not be considered temporary care, with more than half the carers providing care for longer than four years. It appears that, in most cases, caring had been adopted as a lifestyle rather than as a stop-gap measure.

## **APPENDIX 2**

**STYLE INVENTORY (ISI3; BERZONSKY,  
1992b) AND THE CARERS'  
AGE AND GENDER.**



**ANALYSIS OF RAW SCORES FROM THE REVISED IDENTITY  
STYLE INVENTORY (ISI3; BERZONSKY, 1992b)  
AND THE CARERS AGE AND GENDER.**

As this research is the first time the Revised Identity Style Inventory (ISI3, Berzonsky, 1992b) has been used with an older population, it was felt that the carers' raw scores on this scale, should be inspected to determine if discernible age effects exist. This information is presented in Table A7. which appears on the following page. The raw score means and standard deviations are given for the total sample across six age categories. When inspecting this data it should be noted that the sample size is very small in some groupings, calling into question the ability to interpret the data as valid age norms.

**TABLE A7 The Raw Score Means and Standard Deviations on the Four Scales of the Revised Identity Style Inventory (ISI3, Berzonsky,1992b) Achieved by 95 Carers of the Aged from Six (6) Age Categories.**

AGE	GENDER	INFORMATION			NORMATIVE			DIFFUSE		
		X	SD	N	X	SD	N	X	SD	N
30-30	Female	28.	-	01	28.	-	01	33.	-	01
40-49	Female	31.9	6.51	13	28.6	5.	13	26.4	6.7	13
	Male	42.5	2.21	02	30.5	3.54	02	28.	4.2	02
50-59	Female	31.5	7.9	20	31.9	5.8	21	32.2	6.9	20
	Male	27.7	14.6	03	26.3	9.2	03	25.7	11.	03
60-69	Female	33.3	8.8	22	33.5	8.8	21	30.2	8.1	21
	Male	33.	6.7	07	31.6	3.5	07	27.4	7.1	07
70-79	Female	36.9	8.2	10	34.7	5.5	10	31.2	7.3	10
	Male	33.	10.	09	30.4	6.	09	30.4	8.	09
80-89	Female	29.8	6.3	05	29.	5.5	05	30.6	11.8	05
	Male	31.	-	01	29.	-	01	32.	-	01

Upon visual inspection it appears that there are differences in scores due to gender at most age categories but less dramatic effects due to age. It also appears that the scores for Information and Normative reach a peak in the 70 -79 age bracket and then fall off in the 80-89 age bracket. However, further statistical analysis would be needed to determine if these differences are significant.

## **APPENDIX 3**

### **THE USE OF COMMUNITY SERVICES**

## THE USE OF COMMUNITY SERVICES

When evaluating differences in the use of community services by carers of different Identity Style (Berzonsky, 1992b) and Carer's Status, a global measure of service use was used. The global service use measure was arrived at by totalling hours of face-to-face service provision across three domains of possible assistance (eg, home nursing, domestic assistance from Homecare and respite care)<sup>5</sup>.

As noted in the body of the report, the combined services use figure was thought to provide an index of the hours of relief from face to face caring, received by the carer, in the allotted time period (see: Section 6.2.1.). This was felt to operationalize the 'volume' (Strain, 1991) of help received. In the main analysis it was found that carers with a Normative Identity Style used a greater volume of combined assistance however, other significant results were not found.

Though it was never an aim of this study to investigate or predict the use of specific services, it was felt that it may be useful for future research to clarify the degree to which 'service use' data and 'volume of services' is measuring discrete and separate information.

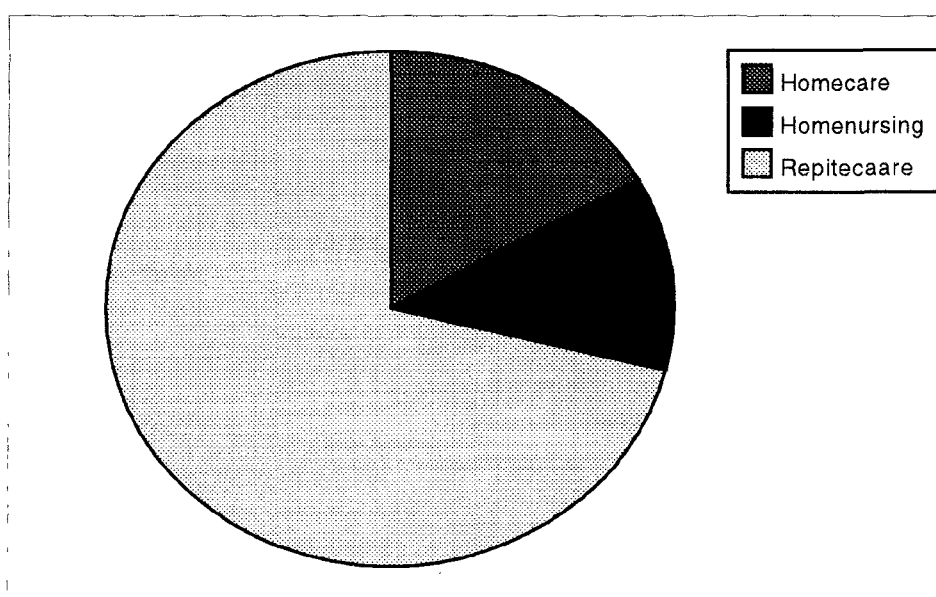
Thus to better describe the variable 'total hours of service use' and to evaluate how representative this variable was of the individual domains from which it was drawn, further description and evaluation is provided below.

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<sup>5</sup> Originally, data was also collected about the use of food services from Meals on Wheels, however, this was not included in the analysis as this service could not be conceptualised in terms of hours of service provision and was thus excluded from the analysis. However, only two people from this study were using this service.

### **A3.1 Total Hours of Service Use - Composition**

The total hours of service use was a composite figure arrived at by combining 412 hours of Homecare (Domestic assistance), 290 hours of Home Nursing (eg, bathing etc) and 1726 hours of Respite care (eg, holiday relief, etc). In Figure 1, it can be seen that the use of respite care services is disproportionately high when compared to the other sources of support.



**Figure A3.1 A Pie Diagram Illustrating the Proportion of Total Service Hours provided by Home care, Home Nursing and Respite Services.**

However, in the area of respite care use, there were a small group of carers using a very large number of service hours. For example, there were five carers using a massive 1173 of the total 1726 hours of Respite Hours.

With such a clear skew in the proportion of hours that each service

contributes to the total service use data, it was felt to be unlikely that the total service use figure would be equally representative of each of the service domains from which it was drawn. This was investigated further.

### **A3.2 Total Hours of Service Use - Correlation with Individual Service Use.**

To determine if the global service-use figure was representative of each of the three domains from which support was drawn, the relationship between the total hours of support and the individual support domains (eg, Homecare, home nursing and respite care) from which they were drawn, was assessed using correlational analysis. The results of this are presented below.

**TABLE A8 PEARSONS-r COEFFICIENTS TO ASSESS THE CORRELATION BETWEEN TOTAL HOURS OF SERVICE USE AND HOURS OF HOME CARE, HOME NURSING AND RESPITE CARE INDEPENDENTLY.**

<b>Hours of service use</b>	<b>r</b>	<b>p</b>
<hr/>		
Total services X Hours of Homecare	.006	.954
Total services X Hours of home nursing	.503	.0001 *
Total services X Hours of respite care	.671	.0001 *
<hr/>		

\* = significant correlation

It can be seen that the pattern of services provided directly to the elder (eg, home nursing and respite care) correlate with the composite measure of service use. However, it appears that the service - Homecare which provides the carer with domestic support is less well described by the composite service use measure. This was the service which was least used by the carers. The over representation of respite care in the total service use figure may have simply weakened the Homecare use data. However, it can also be seen in Table A9 that under regression analysis conditions, the use of the service - Homecare is predicted by a different set of descriptive variables than that which predicted the use of the composite measure - Total Service Use.

**TABLE A9 A COMPARISON OF THE SIGNIFICANT DESCRIPTIVE PREDICTORS FOR CARERS' TOTAL HOURS OF SERVICE USE AND CARERS' HOURS OF HOME CARE USE: A SUMMARY OF TWO SIMPLE REGRESSIONS (N=97)**

Descriptive Variable	Predictors of Homecare Hours	Predictors of total Hours of service
Carers' Education	Sr2=.010 : p=.005	
Household Income	Sr2=.011 : p=.047	
Reason for caregiving		Sr2=.119 : p=.012
Elders' Age	Sr2=.101 : p=.001	
Elders' Selfcare needs	Sr2=.090 : p=.001	
Normative Identity Style	Sr2=.136 : p=.01	

\* Sr2 = Partial Corr.

\* Regression for Respite and Home nursing were invalid.

There appear to be two possible explanations for this result: firstly, the results may reflect a real relationship between the pattern of allocation and use of home nursing and respite care services which does not extend to Homecare services. The community nurse who assesses and authorises access home nursing services may also be the person who assesses need and refers for use of respite care services. Thus, some correspondence in the use might be expected in their pattern of use. However, Homecare services are assessed and allocated independently by their service based assessors.

Secondly, the results could be the results of measurement artifacts created by the disproportionate representation of respite care services.

Thus, while the measurement of volume of service use across services is felt to have provided a valid measure of volume of support in this study (see: Section 6.2.1), it is clear that use of specific service and volume data are measuring independent constructs.

In future research into service use it is recommended that the assessment process for gaining services and different time allocation inherently required for different services should be more closely controlled for. It is clear that the combined data used to operationalise service use in this study has resulted in adequate measurement and testing of the main hypothesis with home nursing services and respite care services but probably not for Homecare services.



## **APPENDIX 4**

### **CORRELATIONS BETWEEN THE MAIN VARIABLES**

## **CORRELATIONS BETWEEN THE MAIN VARIABLES**

In an attempt to further *understand* the manner in which the theoretically important variables from this study were interrelated, a correlation matrix was constructed from the variables found in the measures for: Identity Status; Co-dependency; Services Use; Elders' Functional Status and the descriptive variables.

The complete *correlation matrix* was too large to reproduce here. However, a summary of all correlations which reached statistical significance are presented below. The significant correlations are organised in terms of each of the main measures used in the study. Both a table of outcomes and a brief discussion regarding the significant correlations are given.

Should an account of the non-significant findings be required they are available from the author upon request.

### **A3.1 Correlations for the Identity Style Inventory** **(ISI3:Berzonsky,1990)**

Information Identity Style was positively correlated with the carers' past education which is consistent with Identity Status research (see: Berzonsky,1990) and with the use of Homecare services. However, Information Identity Style was also negatively correlated with the carers' past

employment, cognitive problems being present in the elder and the use of respite service hours.

Diffuse Identity Style was also correlated with elders' main diagnosis and Normative Identity Style was correlated with the use of Homecare hours.

**TABLE A10 Significant Correlations between the scales of the Identity Style Inventory and Dependent, Independent and descriptive measures.**

---

Information x Carers Past Employment	rs=-.361	p=.0004
Information x Carers' Education	rs= .274	p=.0079
Information x cognitive Problems	rs=-.180	p=.0838
Information x Respite	rs=-.207	p=.0477
Normative x Information	r = -.547	p=.0001
Normative x Homecare Hours	r = -.469	p=.0001
Diffuse x Normative	r = .276	p=.0001
Diffuse x Elders Main Diagnosis	r = .276	p=.0081
Information X Homecare	r = .207	p=.0466

---

**r** = Pearson's r ( r = .205: a = 0.05, n=96)

**rpb** = Point biserial Corr (rpd = .205: a = 0.05, n = 96)

**rs** = Spearman's Rank Order Corr (rs= 0.201: a = 0.05, n=96)

However, the final two correlations for Identity Style have implications for the research design and future measurement of Identity Style with the

aged population. Information and Normative Identity Style were negatively correlated ( $r = -.547$ ), and Normative and Diffuse Identity Style were positively correlated ( $r = .276$ ). The first correlation suggests that when a carers' score is high on Information their score is low on Normative and when it is high on Normative it is low on Information. Had the correlation been positive, it would have called into question the independence of the scale.

However, this negative correlation only suggests that if the carer was dominant on one scale they had few of the attributes of the other. This is consistent with Identity Styles theory, which sees those with a Normative Identity Style as having failed to develop the orientation towards processing information and information oriented problem solving, of a carer with a Information Oriented Style. This theory would also see the carer with the Information Identity Style as having given up the approach of only using normatively based processing and problem solving approaches (see: Berzonsky; 1990).

However, the correlation between the Normative and Diffuse scale indicates that some overlap remains in the way carers with a Diffuse and Normative Identity Style approach problem tasks. Though the correlation between Diffuse and Normative is only moderate, it raises the possibility that the scales are not totally independent. This may have led to the masking of significant effects in this study. This also suggests that, in future research the Identity Style Inventory requires further refinement for use with an older sample. However, the moderate size of this correlation suggests this is not a major problem.

#### **A4.2 Correlations for the Service Use Data**

The correlational analysis suggests that use of Homecare services was positively correlated with an elder having continence problems, but negatively correlated with having a Normative and an Information Identity Style and the elder's Age. Home nursing use, on the other hand was positively related to the number of co-dependent traits the carer had and the total hours of service use.

Respite care use was again negatively correlated with an Information Identity Style. Total hours of Homecare use was correlated with the use of home nursing and the use of respite care. Thus, all measures of service use, when treated independently, and not combined, were correlated in some way to a measure of Identity Style. The correlations ranged from  $-.207$  to  $-.409$  and all were negative. This raises the possibility that rejection of particular service types is associated with each of the Identity Styles. This again highlights the different trends obtained when evaluating service use data as opposed to the service volume data used in the main analysis. Though the correlations are only small to moderate in size, they suggests that in future reseach both types of data be considered in the main anaysis.

**TABLE A11 Significant Correlations Between the Service Use Data and Other Dependent and Independent Measures.**

---

Homecare Hours X Normative	rpb=-.469	p=.0001
Homecare Hours X Continence	rs= .205	p=.0045
Home Nursing Hours X No. co Codep.	rs= .219	p=.0034
Homecare X Elders Age	r = -.333	p=.0001
Homecare X Information	r = -.207	p=.0466
Total Hours X Home Nursing Hours	r = .456	p=.0001
Total Hours X Respite	r = .238	p=.0197
Respite care x Information	r = -.207	p=.0477

---

**r** = Pearson's r ( r = .205: a = 0.05, n=96)

**rpb** = Point biserial Corr (rpd = .205: a = 0.05, n = 96)

**rs** = Spearman's Rank Order Corr (rs= 0.201: a = 0.05, n=96)

#### **A4.3 Correlations for Carers Burden**

It can be seen in Table A12 that carers burden was positively correlated to the presence of a dysfunctional family member in the carer's past, the number of co-dependent traits the carer displayed and the presence of cognitive problems in the elder. This relationship suggests that codependency problems in carers of dementia sufferers is a topic worthy of further analysis.

**TABLE A12 Significant Correlations Between Carers' Burden Measured on the Threat to Basic Needs Domain Index (Braithwaite, 1990) and Other Dependent and Independent Measures.**

---

Disfunc. Family X Carers Burden	rpb =-	.226	p=.0284
No of Codep. Traits X Carers Burden	r	= .457	p=.0001
Cognitive X Carer's Burden	rs	= .430	p=.0001

---

**r** = Pearson's r ( r = .205: a = 0.05, n=96)

**rpb** = Point biserial Corr (rpd = .205: a = 0.05, n = 96)

**rs** = Spearman's Rank Order Corr (rs= 0.201: a = 0.05, n=96)

#### **A4.4 Correlations for Functional Status**

It can be seen in Table A13 that the elders' self care needs were associated with the carers age and level of continence. The elders continence status was associated with the carers age, their self care needs, Homecare needs and their cognitive status. It is not unexpected that the presence of continence problems would be associated with increased service use, given the increased workload associated with this condition.

**TABLE A13 Significant Correlations Between Functional Status and Other Dependent and Independent Measures.**

---

Self care X Carers' Age	rpb= .208	p=.0422
Continence X Carers' Age	rpb= .239	p=.0186
Cognitive X Carers Gender	rs= -.232	p=.0233
Self care x Continence	rs= .359	p=.0003
Cognitive X Carer's Burden	rs= .431	p=.0001
Cognitive X Main Diagnosis	rs= -.457	p=.0001
Information X Cognitive	rs= -.180	p=.0838
Embarrassed X Cognitive	rs= .285	p=.0049
No of Codep. Traits X Cognitive	rs= .309	P=.0027
Cognitive X Continence	r = .301	p=.0029
Cognitive x Cover-up effects of Caring	rs= .333	p=.0009
Continence x Home care	rs= .205	p=.0449

---

**r** = Pearson's  $r$  ( $r = .205$ :  $\alpha = 0.05$ ,  $n=96$ )

**rpb** = Point biserial Corr ( $rpb = .205$ :  $\alpha = 0.05$ ,  $n = 96$ )

**rs** = Spearman's Rank Order Corr ( $rs = 0.201$ :  $\alpha = 0.05$ ,  $n=96$ )

When the correlates of the elders' cognitive status are examined, co-dependency and burden issues are apparent. Cognitive status is correlated with carers embarrassment, their tendency to cover up the effects of caring on themselves, the number of co-dependent traits they have, the level of burden experienced and the carers gender. It is negatively correlated to the elder's main diagnosis. The high proportion of co-dependency variables correlated with cognitive status raises the possibility that co-dependency



issues may be a particular problem for carers of demented clients. No causal effect is inferred. However, as noted previously, this is a subject worthy of further research.

#### **A4.5 Correlations for Co-dependency**

It can be seen in Table A12 that the overall number of co-dependency traits was correlated with burden, main source of income, cognitive problems in the elder, home nursing service use and sub-scales of the measure (Persecutory, Cover-up (elder) and carer takes over) and coming from a family with a dysfunctional family member. The sub-scale measures for codependency were again inter-correlated, suggesting that presence of one co-dependent trait might be related to having other codependent tendencies.

**TABLE A14 Significant Correlations Between the Co -  
Dependency Variables and Other Dependent, Independent and  
Descriptive Measures.**

---

Dysfunc. Family X Relationship to Elder	rpb = -.208	p=.0420
Dysfunc. Family X Carers Status	rpb = .321	p=.0014
Disfunc. Family X Carers Burden	rpb = -.226	p=.0284
Embarrassed X Elder Main Diagnosis	rpb = -.219	p=.0327
Embarrassed X Cognitive Problems	rs= .285	p=.0049
Persecutory X Main Source of Income	rpb= .229	p=.0256
Persecutory X Dysfun. Family Member	rpb= -.226	p=.0271
No of Codep. Traits X Carers' Burden	r= .457	p=.0001
Persecutory X Dysfunct. Family Member	rpb = -.226	p=.0271
Cover-up Self X Main Reason for Caring	rpb = .239	p=.0455
Cover-up Self X Additional Caring	rpb = -.258	p=.0150
Cover-up Self X Period of care giving	rs= -.168	p=.1025
Cover-up (Elder) X No. of Codep.	rs = .441	p=.0001
Cover-up (Elder) X Persecutory	rs= .264	p=.0093
No. of Codep.. X Dysfun. Family Member	rpb = -.225	p=.0300
No. of Codep.. X Main Source of income	rpb = .241	p=.0209
No. of Codep. X Carer Takes Over	rs= .563	p=.0001
No. of Codep. X Cognitive	rs= .309	p=.0027
Home care Hours X Continence	rs= .205	p=.0045
Home Nursing Hours X No. Codep.	rs= .219	p=.0034
Persecutory X Embarrassed	r = .346	p=.0005
Homecare X Information	r = -.207	p=.0466

---

**r** = Pearson's r ( r = .205: a = 0.05, n=96)

**rpb** = Point biserial Corr (rpb = .205: a = 0.05, n = 96)

**rs** = Spearman's Rank Order Corr (rs= 0.201: a = 0.05, n=96)

However, being embarrassed about the elder was also correlated

with the elder's main diagnosis, cognitive problems and the tendency to act in a persecutory fashion. Persecutory was also correlated to the main source of income and dysfunctional family member in the carer's past. Covering up the effects on self was also correlated to the main reason for caring (a relationship which may suggest effects due to a third variable - sense of duty), the elder's cognitive status and carer's gender. This variable was also negatively correlated with the tendency to engage in additional caring and the period of care giving.

Covering up the misbehaviour of the elder was correlated with home nursing hours, number of co-dependency traits, being embarrassed, Persecutory and covering up the effects on self. This suggests that when carers covering up the negative effects of caring on themselves and the elder's difficult behaviour, that other negative behaviour such as Persecutory behaviour will also be present. This may be relevant to the elder abuse literature.

#### **A4.6 Remaining Significant Correlations**

There were five other significant correlations found in the correlation matrix produced from the variables used in this study. They are contained in Table 16.

**Table 15: Other inter-correlations**


---

Carers' Age X Relationship to Elder	rpb = -.427	p=.0001
Additional Caring X C. Past Employment	rpb = .236	p=.0207
Elders Age X Main Reason for Caring	rpb = -.311	p=.0020
Carers Status x Carers Gender	rpb = .268	p=.0082
Carers Status X Additional Caring	rpb = .261	p=.0101

---

**r** = Pearson's  $r$  ( $r = .205$ :  $\alpha = 0.05$ ,  $n=96$ )

**rpb** = Point biserial Corr ( $rpb = .205$ :  $\alpha = 0.05$ ,  $n = 96$ )

**rs** = Spearman's Rank Order Corr ( $rs = 0.201$ :  $\alpha = 0.05$ ,  $n=96$ )

This concludes the analysis of the intercorrelations.

## **APPENDIX 5**

### **INSTRUMENTS**

Record method of recruitment: \_\_\_\_\_

**Part 1. Demographic and relevant details about the carer:**

1. Can you tell me how old you are?

2. Where were you born?

1. Australia
2. Switzerland
3. Great Britain
4. Italy
5. The Ukraine
6. Germany
7. Philippines
8. India

3. At what stage did you finish your education?

1. Primary
2. Early High School
3. Advanced High School
4. Trade / TAFE
5. Tertiary

4. What sort of work do you do, or have you done in the past?

1. Professional
  2. Skilled
  3. Labouring or other unskilled
- # Note previous employment in helping field

5. What is your main source of income now?

1. Pension or benefit
2. Superannuation
3. Still work
4. Wage of spouse
5. Investments

6. Please estimate the

combined family income: \$\_\_\_\_,\_\_\_\_ pa.

6. What is your relationship to the person you care for ?

1. Spouse
2. Parent
3. Parent -in-law
4. Friend
5. Daughter-in-law

7. How long have you provided care for this person?

( Record in months)

8. Have you ever provided care like this for any other person in the past ?

1 = this the first caring episode

2 = person has cared for at least one  
other person in the past

\* Record in detail examples of past caring

---



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9. Now I would like to ask you a question about when you were a child. Did you have a parent, caretaker or person living in your house with you, when you were young who displayed ongoing, obviously difficult behaviour, such as a problem with drinking, gambling, a psychiatric condition, unpredictability, or verbal or physical abusiveness, or who was always sick.)

1. Yes.
2. No

**Part 2. Details about elder**

1. Is the person you care for male or female?

1. Female
2. Male

2. How old is the person you care for ?

3. What is the main medical condition affecting the person you care for?

1. Cognitive (e.g. Alzheimers Disease, Multi-infarct dementia, alcoholic dementia, CVA, Parkinsons Disease)
2. Musculo-Skeletal (eg. Osteoporosis, arthritis, broken bones)
3. Organ Disease (eg. heart disease, CA)
4. Sensory ( eg. Blindness, glaucoma)
5. Frail
6. Emotional (e.g. depression)



4. Please rate the level of assistance the person  
you care for requires with:

a. Self care (e.g. bathing, dressing)

1. none
2. mild to moderate
3. major

b. Incontinence

1. none
2. mild to moderate
3. major

c. Remembering and staying organised

1. none
2. mild to moderate
3. major

**Part 3. Pattern of Support Utilized by the Carer**

- (1) Have you made use of help in the past month from  
Homecare, Home Nursing, Meals-on-Wheels, respite  
care (day or longterm), or family and friends?
- (2) How many hours was the service used for?

<b>Serviceused</b>	<b>Hours</b>
1=yes	for the
2 =no	month

Homecare

Home nursing

Respite care

Total

5. Generally how satisfied were you with the help  
you received?

1. Satisfied
2. A little or more dissatisfied

**APPENDIX 5.2****THREAT TO BASIC NEEDS DOMAIN INDEX (TBNDI)**

Instructions: Caring for a friend or relative can give rise to feelings that are difficult to cope with. Please circle the number which best describes how difficult it has been to cope with the following feelings:

1. Not being able to do your job as well as you'd like.
2. Having to constantly be on call to assist the person you are caring for.
3. Having to change plans at the last minute.
4. Being unable to get your household chores done.
5. Being unable to get enough sleep.
6. Being unable to rest when ill yourself.
7. Having health problems as a result of caregiving.
8. Not having a regular daily routine.
9. Feeling divided loyalties between the person you are caring for and other members of your family.
10. Feeling that you cannot get on top of all the things you have to do.
11. Feeling guilty about what you have or have not done for the person you are caring for.
12. Losing patience with the person you are caring for.
13. Feeling that you are not doing anything as well as you should.
14. Feelings of resentment that this has happened to you.
15. Feeling that you don't understand the nature of the other person's illness.
16. Feelings of resentment at what has happened to the person you are caring for.
17. Feeling that you have lost control of your life.

1	2	3	4 <sup>6</sup>
Never difficult to cope with	Not difficult to cope with	Somewhat difficult to cope with	Very difficult to cope with

<sup>6</sup> A Likert scale appeared under every question in the form given to carers.

**APPENDIX 5.3**  
**Revised Identity Style Inventory (ISI3)**  
**(Berzonsky, 1992b)**

**PERSONAL SIMILARITIES**

**Instructions:**

You will find a number of statements about beliefs, attitudes, and/or ways of dealing with issues. Read each carefully, then use it to describe yourself. On the answer sheet, circle the number which indicates the extent to which you think the statement represents you. There are no right or wrong answers. For instance, if the statement is very much like you, mark a 5; if it is not like you at all, mark a 1. Use the 1 to 5 point scale to indicate the degree to which you think each statement is uncharacteristic (1) or characteristic (5) of yourself.

(Not at all like me 1\_\_\_\_\_2\_\_\_\_\_3\_\_\_\_\_4\_\_\_\_\_5 very much like me) <sup>7</sup>

1. Regarding religious beliefs, I know basically what I believe and don't believe.
2. I've spent a great deal of time thinking seriously about what I should do with my life.
3. I'm not really sure what I'm doing as a carer; I guess things will work themselves out.
4. I've more-or-less always operated according to the values with which I was brought up.
5. I've spent a good deal of time reading and talking to others about religious ideas.

---

<sup>7</sup> A likert scale was provided under every item on the scale given to the carers

6. When I discuss an issue with someone, I try to assume their point of view and see the problem from their perspective.
7. I know what I want to do with my future.
8. It doesn't pay to worry about values in advance; I decide things as they happen.
9. I'm not really sure what I believe about religion.
10. I've always had purpose in my life; I was brought up to know what to strive for.
11. I'm not sure which values I really hold.
12. I have some consistent political views; I have a definite stand on where the government and country should be headed.
13. Many times, by not concerning myself with personal problems, they work themselves out.
14. I'm not sure what I want to do in the future.
15. I'm really into caring ; it's the thing that is right for me.
16. I've spent a lot of time reading and trying to make some sense out of political issues.
17. I'm not really thinking about my future now; it's still a long way off.
18. I've spent a lot of time and talked to a lot of people trying to develop a set of values that make sense to me.
19. Regarding religion, I've always known what I believe and don't believe; I never really had any serious doubts.
20. I'm not sure what I should do or how I should change how I am caring.
21. I've known since high school that I was going to be the one to care and how I was going to do it.
22. I have a definite set of values that I use in order to make

personal decisions.

23. I think it's better to have a firm set of beliefs than to be open minded.
24. When I have to make a decision, I try to wait as long as possible in order to see what will happen.
25. When I have a personal problem, I try to analyze the situation in order to understand it.
26. I find it's best to seek out advice from professionals (e.g. clergy, doctors, lawyers) when I have problems.
27. It's best for me not to take life too seriously; I just try to enjoy it.
28. I think it's better to have fixed values, than to consider alternative value systems.
29. I try not to think about or deal with problems as long as I can.
30. I find that personal problems often turn out to be interesting challenges.
31. I try to avoid personal situations that will require me to think a lot and deal with them on my own.
32. Once I know the correct way to handle a problem, I prefer to stick with it.
33. When I have to make a decision, I like to spend a lot of time thinking about my options.
34. I prefer to deal with situations where I can rely on social norms and standards.
35. I like to have the responsibility for handling problems in my life that require me to think on my own.
36. Sometimes I refuse to believe a problem will happen, and things manage to work themselves out.
37. When making important decisions, I like to have as much

information as possible.

- 38. When I know a situation is going to cause me stress, I try to avoid it.
- 39. To live a complete life, I think people need to get emotional.
- 40. I find it's best for me to rely on the advice of close friends or relatives when I have a problem.

**APPENDIX 5.4****Codependent Relating****( Modified from Hawks, Bahr and Wang, 1993)**

Caring for a person at home is demanding and sometimes it makes us act in ways we are not always happy about. Please read the following questions and circle the correct answer.

1. Do you sometimes feel embarrassed about the behaviour of the person you care for?
  - 1 Never
  - 2 Sometimes or more often (Suffering)
  
2. Do you, without meaning to, nag, ridicule, make demands of or threats to the person you care for?
  - 1 Never
  - 2 Sometimes or more often (Persecutory)
  
3. Do you try to conceal the misbehaviour of the person you care for, from other family members, neighbours or friends by lying or denying or covering up?
  - 1 Never
  - 2 Sometimes or more often (Rescuing)
  
4. Do you cover up the way caring affects you?
  - 1 Never
  - 2 Sometimes or more often (Suffering)
  
5. Do you, or have you in the past, taken over chores and other responsibilities that the person you care for can still do?
  - 1 Never
  - 2 Sometimes or more often (Rescuing)



## **APPENDIX 6**

### **RECRUITING FORMS**

**APPENDIX 6****Consent Forms**

RESEARCH TITLE: HEALTHY AND UNHEALTHY CARING: Towards a constructivist synthesis of potential indicators of caring status in carers of the aged

RESEARCHER'S NAME: Christine Gillies

This research is being conducted as part of the course requirements for the degree of Doctor of Philosophy (Clinical Psychology) and is being supervised by Dr. Beverly Walker from the Department of Psychology at the University of Wollongong.

The aim of this study is to gain an understanding of how carers evaluate potential sources of help and to identify factors which prevent carers from obtaining the help they need. I am, therefore, attempting to contact carers who care for a husband, wife, parent or other person at home, who is 55 years of age or older, to participate in the study. If you agree to assist with this study, you will be asked to participate in a brief interview and to fill in two short questionnaires which only require you to circle a number to choose a correct response. There is no writing involved. In all, this should take no longer than half an hour.

In recognition of the fact that many carers cannot leave the person they care for, the interview can be conducted at your home, at a time which is convenient for you. However, should you prefer, the interview can be conducted in my office which is situated in central Wollongong.

You should be aware that, if you initially agree to participate in this research, you remain free to discontinue at any stage. Under no circumstances will you be

encouraged to continue if you change your mind. In addition, all information given will remain totally confidential. At no time will your name even be recorded with the information collected. Only group results will be reported. At no time will individual cases be referred to when writing up the results in thesis form, or for publication in journals. Following the data analysis, you will also be provided with an account of the research findings.

Your assistance in participating in this study would be greatly appreciated. If you have any enquiries regarding the conduct of research, please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (042) 213079. For further details regarding the content and aims of this research, please contact Chris Gillies on (042) 263371 or Dr. Beverly Walker on (042) 213623.

Thank you for reading this letter .

If you wish to take part in this research, please sign below.

## CONSENT

I, ..... of .....

..... Tel. No.: .....

consent to participate in the research project to study the help given to carers. I understand that all data collected will be used to prepare a research thesis and papers for publication in scientific journals.

This form may be sent to : Chris Gillies, 5 / 61 Market street. Wollongong, N.S.W., 2500 or Telephone 263371 to register that you are willing to participate in this survey and the form can be collected at the time of interview.

**CONSENT FORM : Copy to be retained by the carer**

RESEARCH TITLE: HEALTHY AND UNHEALTHY CARING: Towards a constructivist synthesis of potential indicators of caring status in carers of the aged.

RESEARCHER'S NAME: Christine Gillies

This research is being conducted as part of the course requirements for the degree of Doctor of Philosophy (Clinical Psychology) and is being supervised by Dr. Beverly Walker from the Department of Psychology at the University of Wollongong.

The aim of this study is to gain an understanding of how carers evaluate potential sources of help and to identify factors which prevent carers from obtaining the help they need. I am, therefore, attempting to contact carers who care for a husband, wife, parent or other person at home, who is 55 years of age or older, to participate in the study. If you agree to assist with this study, you will be asked to participate in a brief interview and to fill in two short questionnaires which only require you to circle a number to choose a correct response. There is no writing involved. In all, this should take no longer than half an hour.

In recognition of the fact that many carers cannot leave the person they care for, the interview can be conducted at your home, at a time which is convenient for you. However, should you prefer, the interview can be conducted in my office which is situated in central Wollongong.

You should be aware that, if you initially agree to participate in this research, you remain free to discontinue at any stage. Under no circumstances will you be encouraged to continue if you change your mind. In addition, all information given

will remain totally confidential. At no time will your name even be recorded with the information collected. Only group results will be reported. At no time will individual cases be referred to when writing up the results in thesis form, or for publication in journals. Following the data analysis, you will also be provided with an account of the research findings.

Your assistance in participating in this study would be greatly appreciated. If you have any enquiries regarding the conduct of research, please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (042) 213079. For further details regarding the content and aims of this research, please contact Chris Gillies on (042) 263371 or Dr. Beverly Walker on (042) 213623.

Thank you for reading this letter .

If you wish to take part in this research, please sign below.

## CONSENT

I, ..... of .....

..... Tel. No.: .....

consent to participate in the research project to study the help given to carers. I understand that Chris Gillies will also contact and briefly interview my health worker regarding services which might be suitable for me and that all data collected will be used to prepare a research thesis and papers for publication in scientific journals.

This form may be sent to : Chris Gillies, 5 / 61 Market street. Wollongong, N.S.W., 2500 or Telephone 263371 to register that you are willing to participate in this survey and the form can be collected at the time of interview

## **APPENDIX 7**

### **LETTERS GIVING PERMISSION TO COMMENCE RESEARCH**

**APENDIX 7 : LETTERS GIVING PERMISSION TO**  
**COMMENCE RESEARCH**

**7.1 Human Research Ethics Committee, University of Wollongong**



UNIVERSITY OF WOLLONGONG  
 Office of the Vice-Principal (Administration)

Academic & Student Services Branch

APPROVED

In reply please quote: DC:KM HE95/113  
 Further Information: Karen McRae (Ext 4457)

7 June 1995

Ms Christine Gillies  
 57 Woodlawn Avenue  
 Mangerton NSW 2500

Dear Ms Gillies,

I am pleased to advise that the following Human Research Ethics application has been approved.

Ethics Number:	HE 95/113
Project Title:	Helpseeking behaviour by carers of the dependent aged
Name of Researcher:	Christine Gillies
Approval Date:	2 June 1995
Duration of Clearance:	1 June 1996

This certificate relates to the research protocol submitted in your application of 30 May 1995. It will be necessary to inform the Committee of any changes to the research protocol and seek clearance in such an event.

Please note that experiments of long duration must be reviewed annually by the Committee and it will be necessary for you to apply for renewal of this application if experimentation is to continue beyond one year.

Chairperson  
Human Research Ethics Committee  
 cc. Head, Department of Psychology  
 Beverly Walker, Supervisor

7.2 Illawarra Area Health Service (for recruiting)

# Illawarra Area Health Service

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Address all correspondence:  
Chief Executive Officer  
Private Mail Bag 3  
Port Kembla N.S.W. 2505

Telephone: (042) 755 111

Ext. .... 114

YOUR REF tr.mw

OUR REF

07 June 1995

Ms C Gillies  
5/61 Market Street  
WOLLONGONG NSW 2500

Dear Ms Gillies

I have received your request to access carers through the Illawarra Area Health Service (IAHS) for your doctoral thesis entitled "Healthy and Unhealthy Caring".

I am happy to approve IAHS involvement in this project subject to:

- 1 agreement of Area Health Service staff participation in identifying potential research subjects.
- 2 no costs being incurred by the Area Health Service in the postage/delivery of the invitation letters.
- 3 some changes to the proposed letter from the Area Health Service which I have attached.

I wish you luck with the project and would be interested to receive a summary of the results when these are available.

Yours faithfully

A handwritten signature in cursive script, appearing to read 'Tineke Robinson'.

**TINEKE ROBINSON**  
**Director of Health Services Development**

enc



#### **7.4 Covering Letter Required by the Illawarra Area Health Service**

To Whom it may Concern.

You are invited to participate in a research project about the problems faced by carers. The project is being conducted by Chris Gillies and information about the project is attached.

Chris Gillies is a Psychologist who has work extensively with carers. She is also a Post Graduate student at the University of Wollongong.

As part of her course, Chris is undertaking a research project about the problems of carers. To help her contact carers, the Illawarra Area Health Service has agreed to distribute information about this project to you. The approach she will use has also been scrutinised by the joint Ethics Committee of the University of Wollongong and the Illawarra Area Health Service.

All information given during an interview will be treated confidentially.

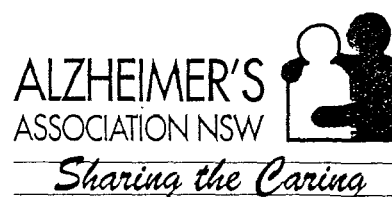
The Area Health Service supports this project and invites you to contact Chris Gillies to participate.

Signed: .....

Position: .....

Date: .....

### 7.3 Alheimers Association



23 June 1995  
Our Ref 0028

Ms Christine Gilles  
Clinical and Consulting Psychologist  
Suite 5  
The Mews Chambers  
61 Market Street  
WOLLONGONG NSW 2500

Dear Ms Gilles

I am writing further to verbal advice by Dr Robert Yeoh, Convener of the Association's Research Policy Committee concerning your request for the involvement of the Association/members in your research project.

The Committee is pleased to support your proposal. There were minor comments on the questionnaire from two of the members but we understand that it would prejudice your research to seek changes at Stage 2.

I apologise for any inconvenience the Association's procedures may have incurred.

As a consequence we are proceeding to develop an article on how this Committee can best co-operate with researchers whilst at the same time protecting the interests of carers. Once finalised we will then publish details in the Association's journal *Intouch*.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'Joan Simms'.

Joan Simms  
Executive Director