

An Overview of the Literature on Sustaining Caring Relationships.

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An Overview of the Literature on Sustaining Caring Relationships.

Executive Summary

Introduction

- This document is an overview of the research on caring relationships. It is not a systematic or comprehensive review of the literature.
- The review encompasses literature on supporting carers of all ages and covers the areas of Aged Care, Mental Health and Disability.

History of services for carers

- A gradual move away from institutionalised care for people with disabilities has occurred in Australia over the twentieth century.
- The growth of community care has meant that informal carers have an important role in the provision of support to people with disabilities and the frail aged.
- It is only since the mid 1980's that carers have been specifically mentioned as part of the target population in service provision.

Brief history of caregiving research

- Caregiving research began with a focus on descriptive studies of the impact on carers, moved to descriptions and evaluations of interventions, and more recently has focussed on mediating factors and the positive aspects of caring.
- The majority of caregiving research has the limitation that participants are recruited from people using services or involved in some type of carer organisation.
- Two Australian population-based studies present valuable information on a representative group of carers: The Victorian Carers Program research; and the Australian Bureau of Statistics surveys of people with disabilities and carers of people with disabilities.

The impact of caregiving

- The literature most commonly focuses on the negative impact of caregiving.
- Negative aspects of caregiving include psychological, social, and physical losses.
- Population-based studies indicate that carers frequently report that their well-being is affected by their caregiving role, that they experience less positive affect and greater overload than non-carers.

- The positive aspects of caring reported by carers include giving pleasure to the care recipient, maintaining the dignity and maximising the potential of the care recipient, enhanced relationships, meeting perceived responsibilities, mutual love and support, and personal development.

Predictors of impact

- Some generalisations may be made about the predictors or correlates of the impact of caring, although there are many inconsistencies in the literature.
- There is limited evidence that women experience greater negative impact of caring than men.
- There is some evidence that older caregivers experience less negative impact of caring compared with younger carers.
- The relationship between carer and care recipient influences various aspects of the impact of caring.
- The nature of the care recipient's disability affects the impact of caring.
- Many caregivers themselves have disabilities.

Moderators of the impact of caregiving

- The literature indicates that a number of factors can moderate the impact of caring.
- Socioeconomic factors have been shown to affect the impact of caring. A lack of financial resources exacerbates the impact, while access to financial resources may buffer the impact of caring.
- There is some evidence that the amount and quality of social support available to carers moderates the impact of caring.
- Carers use a broad range of coping strategies in their caring role. Different coping strategies may be used by different families facing similar situations. Some strategies have been shown to be more successful than others.
- Higher levels of self-esteem and a sense of mastery have been associated with a reduced negative impact of caring.

Interventions

- A table lists the factors affecting the impact of caring on the carer, and examples of interventions which relate to each factor.
- Appendix A presents a summary of a selection of research which examines the value of individual interventions.

Respite

- In qualitative studies carers who have used respite care are generally positive about the experience, although its benefits may be transitory.
- A number of barriers to the use of respite exist, including guilt about leaving the care recipient, thinking it is an admission that one cannot cope, lack of confidence in the respite carers, carer resistance, and cost.
- The overall findings of the quantitative evaluations of the effectiveness of respite care in reducing the negative impact of caring are equivocal.
- One review of 29 studies of respite provided for various types of care recipient concluded that there was little evidence of a consistent or enduring beneficial effect of respite on carers' well-being.
- Methodological problems in the quantitative research make it difficult to draw conclusions about the factors which contribute to the effectiveness of respite care.
- Carers themselves are consistently positive about respite care, regardless of the findings of quantitative analyses.
- Research on the effect of respite care on care recipients has produced mixed findings.
- The effect of respite care on the institutionalisation of care recipients is uncertain, with research producing mixed findings.
- Some authors suggest that respite care services must be more sensitive to the caregiver's needs, consideration needs to be given to the length of the respite break, and respite care may not always be the most appropriate type of support.

Educational programs

- Educational programs described and evaluated in the literature include education about the disease process, communication skills, social skills training, behaviour management, and skills relating to assisting care recipients with ADLs.
- It is difficult to assess the effectiveness of educational programs alone as they are often combined with another approach, such as a support group.
- There is some evidence that education programs improve coping, reduce anxiety, and increase knowledge in carers.

Support groups and counselling

- There is evidence that participation in support groups for carers is associated with improvements in a number of outcome measures.
- Unintentional evidence of the value of support groups has been reported in the literature when control groups meeting to complete forms have functioned like a support group.

- There is evidence of the benefits of group counselling sessions, although it has been suggested in one review that group psychosocial interventions are less effective than individual sessions.

Technological innovations

- A number of technological innovations including multi-media interventions are described in the literature.
- There is limited research evaluating such interventions.

Multi-faceted programs

- Various programs which provide multi-faceted support are described in the Australian literature, for example the Making a Difference and Continuity of Care programs for families of children with significant disabilities.
- These programs have been positively received by carers who have appreciated both the practical assistance and the personal support provided.

Flexible financial assistance

- Programs offering carers flexible financial assistance are described in the literature.
- One aspect of such programs appreciated by carers is their ability to choose the services they require.

Carer support kit

- A Carer Support Kit has been developed in Australia and distributed by the Carers Associations in each state.
- An evaluation of the kit was limited by the small number of carers who requested and used the kit.
- There was some indication of the importance of disseminating the type of information provided in the kit to carers early in their caregiving career.

Home-based assessment

- Aged care assessment teams were utilised in a project as part of the Victorian Carers Program which aimed to identify unmet need for services among family carers and their frail or disabled relatives, and to facilitate links to services.
- In most cases the need for new services was identified. Caregivers' perceptions of the service were positive.

Do interventions replace informal support?

- There is no evidence that formal support services reduce the use of informal supports by care recipients.

Methodological issues

- The research in this area is often flawed by the use of small sample sizes, the lack of any control group, and the comparison of non-identical groups.
- Many studies suffer from a high attrition rate of participants.
- Recruitment of participants is problematic, with many researchers recruiting participants from members of organisations or service users. This method produces participants who are predisposed to benefiting from the interventions.
- Another problem in some research is that interventions are tested on a range of different types of caregivers. As the impact of caring varies for different types of caregivers, this could confound the effect of the intervention.
- Interventions are often accessed by carers who are a long way into their caregiving career. The problem of providing services to carers who are new to their caregiving role is acknowledged in the literature.
- Studies which have included a control group have at times reported changes in the control group due to minimal contact with researchers. Other studies have experienced difficulty in being certain that there are substantial differences in the support received by the intervention group and the control group.
- A large range of different measurement instruments have been utilised in research in this area. It is possible that some may be inappropriate for use with carers.

The preferences of care recipients

- There is little research on the preferences of care recipients themselves.
- A broad range of goals and aspirations across many facets of life have been reported by people with a disability in Victoria.

Cultural differences

- The health and well-being of Anglo and NESB carers were similar in the Victorian Carers Program research, however less service use was noted in the NESB carers.
- There are many contradictory findings in the literature relating to cultural differences and the caregiving experience.

Caregivers' needs

- Research on caregivers' needs is limited by being based largely on surveys of carers who are using some services.
- The Victorian Carers Program research indicated between 6% and 17% of carers had an unmet need for six community care services, while the majority of carers interviewed reported that they had not used and did not need respite.

- The need for respite varied according to various factors such as age and relationship to the care recipient.
- A summary of the key findings of 22 Australian reports on carers needs is provided.
- Needs identified in these and other reports include the need for greater availability and flexibility of services, especially respite services.

Differences between users and non-users

- There is some indication that non-users of services such as respite may be considered in need of them.
- The use of services was not necessarily related to the level of care required by the care recipient.
- A review of service use by carers of learning disabled adults concluded that service use was associated with carers reporting higher levels of distress, carers who were older, and carers of a dependant who was younger.

Theoretical approaches

- A brief description of some theoretical approaches relevant to the area of caregiving research is provided.
- The transactional model of stress emphasises an individual's appraisal of a situation as stressful, and their appraisal of the coping resources they have to deal with the situation or event.
- The stress process model comprises four domains: the background and context of stress; the stressors (primary and secondary); the mediators of stress; and the outcomes or manifestations of stress.
- The resiliency model of family stress, adjustment and adaptation focuses on understanding those family strengths and capabilities which buffer the family from the negative impact of certain events.

Service delivery models

- Four approaches to the relationship between carers and formal services were briefly described: carers as resources; carers as co-workers; carers as co-clients; and the superseded carer.
- The family support approach focuses on how services are provided and gives a central role to family-centred helping and the empowering of families.

Assessment of carers' needs

- The importance of the careful assessment of individual carers' needs emerged from this overview of the literature.

- Examples of some instruments used to assess carers' needs are provided in Appendix B.

Research proposals developed

Two research proposals have been developed and submitted to appropriate bodies for funding. The Executive Summaries of these projects are presented.

- *Caring for carers: An enrichment orientation*
The outcome of this project will be an analytic tool that will allow the physical, social and psychological needs of individual carers to be more readily identified. This analytical tool will reinforce positive aspects of caring, while being respectful of diverse concerns. The tool will be tested and evaluated.
- *Enhancing the coping skills of carers*
This is a health promotion project that aims to identify and describe useful coping skills for people caring for a child with a disability, and to apply this information to improve the well-being of carers who would benefit from the development of positive coping strategies. A "Skills for Carers Kit" will be developed, in both print form and as a web site, based on the findings from interviews with carers.

An Overview of the Literature on Sustaining Caring Relationships.

The aim of this literature review is to provide an overview of the research on sustaining caring relationships. It does not attempt to provide a systematic or comprehensive review of the available literature as this would not be possible in the given timeframe. Much of the literature included is framed in terms of supporting carers rather than sustaining the caring relationship, the assumption being that providing support to carers will benefit the caring relationship as well as the carers. Generally the focus of this review is on services provided specifically for carers, although it is acknowledged that carers frequently benefit from services provided to meet the needs of care recipients (Twigg & Atkin, 1994). The review encompasses research on supporting carers of persons of all ages and covers the areas of Aged Care, Mental Health and Disability.

Throughout this literature review, the persons who are doing the caring will be described either as carers or caregivers. A carer is defined as a relative, friend or neighbour who provides practical day to day support for a person unable to complete all of the tasks of daily living. The person who is receiving care will be described as the care recipient, and defined as a person who lives with some form of long term condition that creates difficulties with the tasks of daily living.

There is a larger volume of studies in the published literature focussing on elderly care recipients than on other age groups. Throughout this review more recent literature, and Australian research, is included wherever possible. Other relevant reviews are summarised where possible. There is an extensive review of the literature on supporting families with children with disabilities currently being undertaken by DHS with a team from LaTrobe University. It covers approaches to family functioning in general and presents details on theoretical models appropriate to this area. The present overview does not present material which is covered by the forthcoming review.

Where appropriate, the words of carers themselves are included in the present review via quotations from qualitative studies of carers.

Summary of Findings

History of services for carers

To understand the history of services for carers it is necessary to have an overview of the changing approaches to persons with disabilities in our society. In the earliest days of white settlement in Australia, disability was viewed as an indication of divine disfavour, and mental defects were seen as the same as moral defects (Lindsay, 1996). People with disabilities were confined in hospitals, gaols or asylums. Custodial institutionalisation was the norm for persons with disabilities who were unable to work until the end of the nineteenth century (Lindsay, 1996).

Government and community attitudes towards disabilities changed after the end of the first world war. The Repatriation Commission was established to reintegrate ex-

servicemen with disabilities into the community, for example by providing vocational training. It contributed to a change in community attitudes to disability from “fear, blame and neglect to growing acceptance of the need for community support” (Lindsay, 1996, p. 9). During the 1920’s and 1930’s various institutions for people with specific types of disabilities were established, initiated by family members of people with disabilities and also receiving financial support from the government. In Australia income support had been available for some time. With Federation the Commonwealth government had assumed responsibility for income support, and in 1908 the Invalid and Aged Pension was introduced.

After the second world war the work of the Repatriation Commission was expanded with the establishment of the Commonwealth Rehabilitation Service (CRS) in 1948. Importantly, the CRS provided vocational training for all people of workforce age with disabilities, not just returned servicemen. The voluntary organisations were active in setting up sheltered workshops, and sometimes hostels, usually disability-specific. While these were initially established with private funds, the Commonwealth government did provide financial support in response to public pressure (Lindsay, 1996). There was a move away from institutions, but in the middle of the twentieth century many people with moderate or severe disabilities were in institutions which were funded and administered by State governments. In the aged care area, for the first half of the twentieth century, caring for the elderly still took place mostly within the extended family.

In 1954 the Commonwealth provided subsidies for non-profit organisations building facilities for older people through the Aged and Disabled Persons Act. This led to smaller, community based facilities rather than the earlier nursing facilities which were built as hospitals rather than as homes (Hastrich, 2001). A boost in home based nursing services occurred in 1956 when the Home Nursing Subsidies Act provided increased Commonwealth subsidies to local organisations receiving State funding for home nursing activities. Consumer activism was evident in this period with the establishment by parents of the Spastic Society of Victoria in 1948 and the Karingal service in 1953 (Hastrich, 2001).

From the early 1950’s the Commonwealth government was increasingly involved in the funding and administration of aged care and disability services. Numerous legislative measures relevant to these areas were enacted between 1954 and 1974 (Lindsay, 1996). In the early 1970’s the Commonwealth government significantly increased the levels of subsidy to non-government organisations already funded by the States for community based supports for people with disabilities. The emerging demand for ‘normalisation’ in disability services was reflected by increased funding for day activities, training and therapy. In 1974 the Commonwealth Government also dramatically increased subsidies to providers of nursing homes.

The late 1970’s was an important period in the history of the care of persons with disabilities. The Victorian Commission on Mental Retardation’s review of the effectiveness of the St Nicolas Hospital, an institution for children and young people with intellectual disabilities, concluded that the hospital style of permanent care isolated the residents and reinforced stereotypical views of difference (Hastrich, 2001). Rosemary Crossley’s actions in claiming that a profoundly disabled resident was capable of both independent thought and communication further opened up the

debate. The ultimate result was the establishment of Community Residential Units (CRUs) which accommodate no more than five residents in a domestic type setting, in a location close to family members (Hastrich, 2001). Large, hospital-style institutions were no longer seen by the community as appropriate accommodation for people with disabilities.

An important milestone for carers was the introduction of the Home and Community program in 1985, with carers being specifically mentioned as part of the target population (Murnane, 1995). Respite provision, both in home and day care, was included. These measures were seen as the most appropriate way of supporting carers' needs. The recognition of carers was formalised in 1992 when the Commonwealth Government established a network of state carers associations. "Prior to this period the people we now call 'carers' were called parents, daughters, sons, neighbours, aunties, brothers and sisters" (Hastrich, 2001).

The growth of community care means that informal carers now have an important role in the provision of support and in keeping people with disabilities and the frail aged living in the community. Australian data indicate that 60% of people with a disability received informal assistance only (Shaver & Fine, 1996). It has been suggested that it is rare for formal services to maintain a person at home without additional input from informal sources (Shaver & Fine, 1996).

The area of services for carers is a relatively new field. It is only since the 1990's that the specific needs of carers have really been translated into policy in Australia (Murnane, 1995). The joint role of the Commonwealth and State governments in funding services for the aged and persons with disabilities, and their carers, has been a feature of this area for decades. This partly explains the fragmented nature of service provision in Australia. Demographic trends in Australia have had and will continue to have a significant impact on both the need for and the availability of carers, and on the need for support services for carers. The ageing of our population, the increased numbers of women in the paid workforce, changes in family composition and the fact that people with and without disabilities are living longer are all important factors in this area (Davis, 1995; Howe & Schofield, 1996).

Brief history of caregiving research

Initially research focussed on providing an account of the demands and burdens of caregiving, and how these affected the well-being of carers. Qualitative studies and small quantitative projects were undertaken which were largely of a descriptive nature. Interventions aimed at reducing caregiver burden were described and evaluated, with varying degrees of rigour. Then a more complex approach to understanding the experience of carers began looking at the dimensions of caregiving stress, the importance of how the carer appraises the situation, the type of coping strategies carers use, and the role of factors such as social support as buffers. This was in response to the observation of the variability in the impact of caregiving on family members (Pearlin & Zarit, 1993). More recently researchers have looked at the positives of caring as well as the negatives (Marsh & Lefley, 1996; Nolan, Grant & Keady, 1996).

Simultaneously, service providers have been evaluating the services they provide to carers, and looking at unmet needs. This has largely been based on surveys of service

users. The problem with this approach is that it excludes carers who do not use the services. It also focusses attention on what is available rather than seeking alternative approaches to supporting carers.

Some key points emerge from the literature on supporting carers. Most importantly, the heterogeneity of carers, the caregiving situation, and how carers respond to the situation must be considered. Carers differ in their gender, their age, their relationship to the care recipient, their other roles and responsibilities, their financial situation, their cultural background, and their coping styles. In addition there are generational differences in expectations about caring, differences in the nature, severity, and changeability of the care recipient's disabilities, and differences in the age of the care recipient and of the caregiving career experienced by the carer. All of these factors may affect the responses of carers, and thus should be taken into account in considering the value of efforts to support carers.

The majority of research published on caregiving has a serious limitation in the selection of participants. Most often participants are recruited from organisations providing services to carers. Thus individuals who have not come into contact with such organisations, who may be caring for a disabled person but not identify themselves as a "carer", are largely excluded from the research. This limitation must be kept in mind when reading the majority of literature on caregiving.

Population-based studies

There are some population-based studies of carers available which overcome this limitation. The Australian Bureau of Statistics (ABS) completed surveys of people with disabilities and carers of persons with disabilities or older persons in 1993 and 1998 (ABS, 1998). The ABS defined carers as people providing informal assistance to older people and / or people with a disability which is ongoing and lasting for at least six months (ABS, 1998). In 1998 almost 37,000 persons in households were surveyed using computer-assisted personal interviews (ABS, 1998).

Some useful data was obtained as part of the Victorian Carers Program, with research funded by VicHealth. This project included a wide range of carers (Schofield, Bloch, Herrman, Murphy, Nankervis & Singh, 1998). Telephone interviews were conducted with 976 carers who were identified via a random survey of 26,000 households throughout Victoria. Carers were identified by the question "Do you or does anyone in your household take the main responsibility in caring for someone who is aged or has a long-term illness, disability or other problem?". This project also interviewed a comparison group of 219 'non-carers' and re-interviewed carers twice more over three years (between 1993 and 1996), so some longitudinal data is available. These population-based studies will be referred to wherever possible in this literature review, as reliable sources of recent information on all carers, not just those already utilising available services.

The impact of caregiving

Any overview of the literature on supporting caring relationships needs to have some examination of the impact of caregiving on carers. Information on the experience of caregiving, and the correlates or predictors of the impact of caregiving provides a context within which to examine what type of interventions are appropriate in various situations.

What is the impact?

The negative impact of caring

The literature most commonly focuses on the negative impacts of caregiving. These have been found to encompass psychological, social, and physical losses such as loss of personal freedom and privacy, the deterioration of social relationships, deterioration in physical and psychological health, reduction or loss of employment and fewer leisure opportunities (Rogers, 1999, pp. 2-3).

In qualitative studies, carers themselves have described the physical exhaustion and feelings of despair they experience as carers (Ashworth & Baker, 2000), and the lack of personal time and space (Kleffel, 1998).

“You don’t relax for any part of the night or day – if there is a noise in the night you think, ‘Has she fallen?’ You’ve got that tension all the time.” (Schofield et al., 1998, p. 15).

“There is no ‘by myself’ time. I don’t even have it in the bathroom because Ann [a disabled child] kicks up against the door. So I’ve learned to leave it open.” (Kleffel, 1998, p. 465)

For many, caregiving is a lonely experience. The loss of previous friends and opportunities to socialise is a common theme in the literature. For many carers isolation is an important aspect of their experience of caregiving.

“I mean dying for somebody just to listen, or even dying for someone just to pick the phone up and say, ‘How are you?’” (Ward & Cavanagh, 1997, p. 282).

“We used to have friends, but when my wife got sick they stopped coming.” (Kleffel, 1998, p. 468).

Some aspects of the impact of caregiving differ depending on the nature of the care recipient’s disability. For example, caring for a person with mental illness may involve a degree of uncertainty, a lack of control and manipulation.

“I felt like...life was totally out of [my] control. And especially [because] ... there were so many times when he [the son] would turn things around to make it look like I was the insane person [respondent laughs]. I mean, I’m just trying to help him, and then he would twist it and say, ‘I think you need a doctor’.” (Karp & Tanarugsachock, 2000, p. 11).

For carers whose care recipient has dementia, there is the loss of the person who once was, and witnessing the gradual decline of that person. Carers of children with disabilities may need to deal with the knowledge that their child will not develop as other children do, and the milestones celebrated by other parents may be times of grief for them. As carers of adults with disabilities age themselves, they face the additional concern of who will care for their child when they are no longer able to (Bigby & Ozanne, 1999).

The quantitative literature demonstrates the widespread nature of the negative impact of caring reported in the qualitative studies. The Victorian Carers Program population-based study demonstrated differences in well-being between carers, as a group, and non-carers (Schofield et al., 1998). They found less life satisfaction, less positive affect, more negative affect and greater overload among carers compared with non-carers, regardless of age or marital status. In the ABS data, around 30% of carers reported that their well-being had been affected, and that they were often worried or depressed (ABS, 1998). A review of 41 studies published between 1990 and 1995 on the psychiatric and physical morbidity effects of caring for a person with dementia has been published (Schultz, O'Brien, Bookwala, & Fleissner, 1995). It reports that increased levels of psychiatric morbidity are generally found in caregivers of persons with dementia, with elevated levels of depression being a consistent finding. The findings in relation to physical health were somewhat mixed, with caregivers perceiving their health to be worse than non-caregivers, but more objective measures indicated that clinically significant health outcomes among caregivers may depend on other risk factors such as social support, gender, and existing health problems (Schultz et al., 1995).

Apart from the psychological and physical impact of caregiving, there are financial costs and effects on participation in the paid workforce for carers. The ABS data reported that 22% of employed primary carers stated that their weekly hours in paid work had been reduced since taking on the caring role, and 24% required time off work due to their caring duties (ABS, 1998). The Victorian research found that almost half of non-employed carers under 65 reported that their caregiving had made them leave their job or remain out of paid work, and that those in the paid workforce had made substantial work adjustments including declining promotion and reducing hours (Schofield et al., 1998). The most disadvantaged carers were high-intensity women carers, and carers of workforce age generally wanted to work (Schofield et al., 1998).

The positive aspects of caring

While much of the literature has focused on the negatives of caring, some researchers have investigated the positives such as the satisfactions experienced by caregivers in performing their caring role. This area may be important in understanding the difference between families who cope well with caring compared with those who do not. It has been suggested that satisfactions may be important in three ways: (1) as a coping resource or therapeutic intervention; (2) as a quality control measure; and (3) as a 'risk' indicator (Nolan et al., 1996). Important positive aspects of the caregiving role include giving pleasure to the care recipient, maintaining the dignity and maximising the potential of the care recipient, enhanced relationships, meeting perceived responsibilities, mutual love and support, and personal development of the carer (Nolan et al., 1996; Lundh, 1999a). In the Victorian Carers Program research, 84% of carers indicated that they get a great deal of satisfaction from caring (Schofield et al., 1998). Other researchers have described the positive aspects of caring as evidence of resilience and have categorised them as family resilience, personal resilience and consumer (care recipient) resilience (Marsh & Lefley, 1996). Evidence of personal resilience was provided by 99% of 131 close family members of persons with mental illness (Marsh & Lefley, 1996).

The following quotes illustrate the positive side of caring:

“If you do a good job and your partner is content, that’s satisfying” (Cahill, 2000, p. 53).

“To see an appreciative smile on the face of my severely mentally and physically handicapped son” (Nolan et al., 1996, p. 89).

Carers also describe some benefits of caring such as a sense of closeness to the care recipient, and enhanced self-esteem (Ashworth & Baker, 2000). In the ABS data, 33% of carers indicated that their relationship with the care recipient was closer as a result of their caregiving role (ABS, 1998).

Predictors of impact

Most notably, the impact of caregiving differs depending on a number of factors including the gender of the caregiver, their relationship with the care recipient, the type of disability the care recipient has, and how the carer appraises the situation. Because the nature and severity of the impact of caregiving varies, the effectiveness of interventions aimed at reducing caregiver impact will be influenced by these factors.

There are many inconsistencies in the literature on factors which are predictive of the impact of caregiving on the carer. This may be due to the confounding role played by factors such as caregiver appraisal and coping styles.

Gender

The Victorian Carers Program study reported that gender was associated with aspects of the impact of caring (Schofield et al., 1998), with women experiencing greater negative affect and more overload than men, and also reporting more anger than men. Women also reported more aggressive and cognitive behaviour problems in their care recipient than men. Evidence on the relationship between the gender of the caregiver and depression was inconclusive in a review of dementia caregiver studies (Schultz et al., 1995). In a review of research on burden in caregivers of persons with mental illness, gender was not identified as a predictor (Baronet, 1999). Avison, Turner, Noh and Speechley (1993) found some evidence that mothers were more affected by the burden of caring than fathers. A researcher who interviewed a sample of 26 male caregivers to wives with dementia disputed the notion that there are large differences between male and female carers (Cahill, 2000). The data suggested that like women, men performed personal care tasks and used few formal services. It was suggested however that men are more task-oriented in their approach to the caring role (Cahill, 2000).

Some differences in the satisfactions in caring perceived by men and women have been reported, although not necessarily in areas where these might be expected (Nolan et al., 1996). Men and women for example, obtained similar levels of satisfaction from nurturing aspects of the caregiver role. Nolan et al. (1998) found that to some extent men and women used different coping strategies, and found different strategies helpful.

Caregiver’s age

Increasing age was associated with less positive affect, less negative affect and less overload generally in the Victorian Carers Program research (Schofield et al., 1998).

The relationship between the age of the caregiver and depression was inconclusive in the review of dementia caregiver studies (Schultz et al., 1995). Younger caregivers of persons with mental illness were generally found to experience more burden than older carers (Baronet, 1999). It has been reported that older carers of adults with intellectual disability experience less stress and more satisfaction than their younger counterparts (Bigby & Ozanne, 1999).

Relationship between carer and care recipient

The relationship of the carer to the care recipient has been reported as another influential factor. In the Victorian Carers Program research, spouse carers experienced lower positive affect and less overload than parents and adult offspring. Parents reported more satisfaction with the caring role than spouses, and spouses reported more satisfaction than adult offspring. Parents and spouses reported more closeness in their family than adult offspring. Parents reported more aggressive behaviour in the relatives they were caring for, and both parents and adult offspring reported more cognitive behaviour problems. Spouse and adult offspring reported more depressive behaviours in their relatives than parents reported (Schofield et al., 1998). Being the patient's spouse was associated with increased depression in the review of research on dementia caregivers (Schultz et al., 1995). Differences were noted by Nolan et al. (1996) in the perceived satisfactions of carers who were spouses compared with children of the care recipient.

Living with the care recipient was associated with increased feelings of weariness and lacking energy, a greater effect on well-being, and less satisfaction than not living with the care recipient in the ABS data (1998). Baronet (1999) found that residing with a relative with a mental illness increased the experience of burden.

How close the relationship is between carer and care recipient appears to be important also. Parents and spouses tended to be more positively involved in caregiving than adult offspring and to report more closeness in the family (Schofield et al., 1998). Intimacy and love in the relationship between carer and care recipient have been associated with lower levels of minor psychiatric symptoms and burden (Braithwaite, 2000), and the quality of the relationship between a carer and a parent care recipient may have an influence on the ability to be satisfied with family functioning (Carruth, Tate, Moffett, & Hill, 1997). It has also been suggested that depressive symptoms, anger and resentment may be experienced by caregivers in very close or enmeshed families if they have taken on the caregiving role to conform to family rules (Carruth et al., 1997).

Care recipient's disability

The nature of the care recipient's disability is another influential factor. In a comparison study of caregivers of dementia and non-dementia patients, dementia carers reported higher levels of burden and more problems in the care recipient than non-dementia caregivers (Burdz, Eaton & Bond, 1988). In another comparison of dementia and non-dementia carers, those caring for a dementia patient spent significantly more hours per week providing care and assisted with more ADLs and IADLs (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

A comparison of mothers of adults with mental health problems with mothers of adults with intellectual disability found that the latter group experienced less objective

burden, greater gratification and a better relationship with the care recipient than mothers of an adult with mental health problems (Greenberg, Seltzer & Greenley, 1993).

Greater distress in carers of severely intellectually disabled children was associated with increased disability in the child (Hoare, Harris, Jackson & Kerley, 1998). The presence of difficult behaviours in the care recipient has been associated with increased negative impact. For example, the presence of symptomatic behaviours presented the strongest and most consistent relationship with caregiver burden in the review of studies on caregivers of persons with mental illness (Baronet, 1999). Similarly, the presence of behavioural problems in the care recipient was associated with increased depression in the review of research on dementia caregivers (Schultz et al., 1995).

Disabilities in caregivers themselves

When considering the impact of caregiving on carers, it should be noted that many caregivers, particularly older ones, have some type of disability themselves. It is reported in the ABS data that carers are twice as likely as those who are not carers to have a disability (32% compared with 17%) (ABS, 1998). Chiverton and Caine (1989) noted that 29 of 40 spouses of AD patients had one or more physical disorders.

Moderators of the impact of caregiving

When examining the impact of caring on caregivers, it is necessary not only to consider the challenges carers face, but also a number of factors which affect, or moderate, the impact of these challenges. Moderating factors include the financial situation of carers, the amount of social support carers have, the coping strategies they employ, and their own sense of mastery or self-esteem. Many of these factors can be described as coping responses, and categorised as coping resources or coping strategies (Nolan et al., 1996). Coping resources are the kinds of resources people are able to call upon in managing situations, and include one's financial position and the social support available to one. Coping strategies are *how* people cope (Nolan et al., 1996).

The important role played by such mediating factors is affirmed in the literature. Pearlin, Mullan, Semple and Skaff (1990) suggest that while the mediating factors of coping and social support cannot explain all of the difference between the stress experienced by different caregivers in similar situations, they can have a major explanatory role. A recent study which involved 58 parents of an autistic child concluded that stressors were not a direct predictor of negative outcomes, but their influence was moderated by social support and coping style (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). A number of coping resource variables explained 36% of the variance in a measure of parent and family problems in a sample of 140 mothers of intellectually disabled children (Friedrich, Wiltner, & Cohen, 1985).

Socioeconomic factors

The literature indicates that financial instability, as well as itself being caused to some extent by the caregiving role, may exacerbate the negative impact of caring on carers. Financial resources have been discussed as one type of coping resource. In their discussion of the mediators of stress and coping, Folkman, Schaefer and Lazarus (1979) suggest that utilitarian resources such as money greatly increase the coping

options available to any person. One study reported that being middle class with few financial worries appeared to buffer the effect of stressful behaviour for mothers of children with severe learning difficulties (Quine & Pahl, 1991). Schofield et al. (1998) concluded that financial difficulties were associated with poorer well-being in the carers surveyed. The variables which were associated with increased depression in the review of research on dementia caregivers included low income or financial adequacy (Schultz et al., 1995). Low financial adequacy was also associated with negative physical health outcomes in that review.

In a study of 72 parents with children with developmental disabilities, aged 18 and under, the adequacy of money resources and time resources had significant negative correlations with depression / demoralisation (Herman & Marcenko, 1997). Greene and Monahan (1989) noted that participants in their intervention whose care recipients were clients of the county case management system showed significantly less amelioration of anger, and less improvement in anxiety after a support and education program. They suggested that the case management system was a proxy for the income level of care recipients and perhaps indicated problems created by poverty in providing care, which were not affected by the intervention.

Social support

Social support can be provided both formally and informally. Informal social support has been described as “both individuals (kin, friends, neighbors, minister etc.) and social groups (church, social clubs, etc.) who are accessible to provide support as part of daily living, usually in response to both normative and nonnormative life events” (Dunst, Trivette, & Deal, 1988, p. 28). Formal social support is seen as “both professionals (physicians, infant specialists, social workers, therapists, etc.) and agencies (hospitals, early intervention programs, health departments, etc.) that are, on an *a priori* basis, formally organized to provide aid and assistance to persons seeking needed resources” (Dunst et al., 1988, p. 28).

There is evidence in the literature that the amount and quality of social support available to carers is an important factor in moderating the impact of caregiving. Data from the Victorian Carers Program research indicate that carers who reported having larger informal support networks reported greater life satisfaction, greater perceived support from family and friends, and less resentment and anger than carers reporting smaller informal support networks (Schofield et al., 1998). Satisfaction with 18 sources of social support, both formal and informal, was significantly related to emotional and physical well-being, with higher satisfaction indicating fewer physical and emotional problems in 137 parents of children with disabilities (Dunst, Trivette, & Cross, 1986). Social support was found to moderate the impact of stressors in a study of 58 parents of children with autism Dunn et al., 2001). Personal well-being has been found to be related to both intra- and extra-family support (Deal, McWilliam, Cooper, & Trivette, 1989). Higher family functioning was associated with more family social support in families providing care for a family member with schizophrenia (Saunders, 1999), and low social support was associated with poorer health of carers of persons with dementia (Schultz et al., 1995).

However, other researchers report some inconsistencies in the mediating role of social support. The review of carers of persons with mental illness reported mixed findings regarding the relationship between social support and subjective or overall burden,

although perceived sufficiency of professional support and receiving practical advice were associated with decreased objective burden (Baronet, 1999). Avison et al. (1993) found little evidence that differences in distress experienced by carers could be attributed to deficits in perceived social support, and reported that the buffering role of social support is different in different groups of carers.

There is evidence that it is the quality of social support rather than the quantity available which is most important (Deal et al., 1989). This finding may in part explain some of the inconsistencies in the literature.

Coping strategies

A useful definition of coping has been provided by Turnbull and Turnbull (1993): “The term *coping* refers to the things people do (acting or thinking) to increase a sense of well-being in their lives and to avoid being harmed by stressful demands” (p. 11). Coping takes on a particularly important role in the transactional model of stress in which people appraise the situation, decide if they need to respond, and select an appropriate response such as a coping strategy, to deal with the situation. Coping strategies include behavioural and cognitive approaches to coping (Nolan et al., 1996).

The literature shows that carers use a broad range of coping strategies (Lundh, 1999b; Nolan et al., 1996), and there is no clear indication that any type is the most effective. Different families facing similar stressors may cope very differently (Lefley, 1997). It has been suggested that caregivers’ capabilities in coping with the stresses change over time (Lefley, 1997), and that different coping strategies are used at different stages of caregiving (Nolan et al., 1996). Thus, problem solving strategies are most likely to be useful when situations can be changed (Lundh, 1999b). One author noted that while problem-solving coping strategies have traditionally been seen as the most useful, there is now a growing awareness of the importance of cognitive / emotional approaches and stress reduction techniques (Lundh, 1999b). A cognitive coping strategy, realising that the care recipient is not to blame for his / her behaviour has been found to be the most used and most helpful strategy in both a Swedish (Lundh, 1999b) and a UK (Nolan et al., 1996) study.

One study of 166 mothers of children with severe learning disabilities used the mothers’ assessment of their coping skills as a measure of problem solving skills (Quine & Pahl, 1991). It was found that mothers who felt able to influence their own lives and achieve positive outcomes had lower stress scores (Quine & Pahl, 1991). Depression was significantly and positively correlated with distancing and escape-avoidance coping strategies, while confrontive coping was associated with reduced depression in a recent study of mothers of autistic children (Dunn et al., 2001). Carers with greater distress and lower self-esteem used emotion-focused coping strategies more often, while those with higher self-esteem used more task-focused coping methods in a survey of carers of 143 children with severe disability (Hoare et al., 1998).

There is evidence of carers being aware of the value of coping skills. In a study of the problems identified by family caregivers in counselling, improving coping skills was one of the areas identified that caregivers wanted to deal with in the sessions (Smith, Smith & Toseland, 1991). Time management, dealing with stress, and other coping

mechanisms were areas the carers wanted to cover (Smith et al., 1991). Enhanced coping effectiveness has been reported as an area of personal resilience by close family members of persons with mental illness (Marsh & Lefley, 1996).

Differences have been reported in the type of coping strategies used by different cultural groups. For example, coping strategies which involved emotional release were seen as more helpful by a sample of 123 Swedish family carers compared with a sample of UK carers (Lundh, 1999b).

Sense of mastery or self-efficacy

One of the coping resources described by Folkman et al. (1979) are general or specific beliefs, which include a sense of mastery or self efficacy, and also religious beliefs. Baronet (1999) noted in the review of research on carers of persons with mental illness, that a decreased subjective burden was experienced by caregivers with a greater sense of mastery and sense of self-efficacy. Similarly, low levels of self-esteem and mastery were associated generally with increased depression in the review of caregivers of persons with dementia (Schultz et al., 1995). The buffering role of mastery was found to differ between different groups of caregivers (Avison et al., 1993).

An association between coping styles and self-esteem has been found in parents who were carers of children with severe disability (Hoare et al., 1998). Carers who reported greater distress and lower self-esteem were found to use emotion-focused coping strategies more often, while those with higher self-esteem used more task-focused coping methods (Hoare et al., 1998). Some carers report that drawing on strong personal or religious beliefs helps them to cope with the caregiving situation (Lundh, 1999b; Nolan et al., 1996).

Szabo and Strang (1999) ascribe an important role to the amount of control carers experience in their caregiving situation. They describe two main dimensions of control in caregiving: maintaining control and lacking control. The five properties of maintaining control described are: use of confident language; identifying positive internal resources; recognising a need for help and asking for it; anticipating the future; and taking corrective action when impending loss of control was felt (Szabo & Strang, 1999). The properties of lacking control were: identifying negative internal resources; being unable to recognise the need for help, or to ask for help; and not anticipating the future. Szabo and Strang (1999) found evidence that carers moved from one dimension to the other – losing control and regaining control. It was suggested that this information could be used by service providers by recognising that carers who lack control need support and do not anticipate the future, by being alert to when these carers need interventions, and by assisting them to access resources. The authors also noted a need to evaluate carers longitudinally, as those who function well at one time may not continue to do so.

Interventions

The majority of interventions which aim to support carers have been developed in an ad hoc way, responding to what was perceived as the caregiver's burden, with little conceptual framework. Table 1 lists the factors described above as having an impact on carers, indicates if it is possible to alter them, and possible approaches to altering

their impact on carers. It is hoped that Table 1 will provide a useful link between the issues discussed above and the following details of particular interventions.

A number of different approaches to supporting caregivers are described in the literature. Various forms of respite feature prominently. Other approaches include educational programs, support groups, counselling, and technological innovations. The following section provides an overview of the literature rather than a comprehensive analysis of all available research. A summary of a selection of research which examines the value of individual interventions is included in Appendix A. Section (a) presents research which has particularly considered the effect of respite care on care recipients. Section (b) presents studies of respite care and section (c) interventions using other approaches, or a combination of respite care with other approaches. A small number of studies which are of poorer quality are included in section (d) of Appendix A which is attached to this review.

Respite

Respite care has been defined as “those services that provide alternative care arrangements with the primary purpose of giving the carer and / or the care recipient a short term break from usual care arrangements” (Aged and Community Care Division, 1996). Respite care may be for a period of a few hours, a day or weekend, or for several weeks. It may occur in the care recipient’s home or in other venues. Respite care in various forms is provided in Victoria for carers of persons with a range of disabilities, and by a number of different service organisations.

Qualitative literature

In the qualitative literature, carers who have used respite care are generally positive about the experience. For example, a caregiver of a person with dementia recommended regular respite:

“If I was to set down a schedule of what people should do, it would be every 6 months, you need to recharge those batteries often. Because you know what happens to the battery. If you let it run too low, you have to buy a new one” (Strang & Haughey, 1999, p. 453).

After a period of respite, a caregiver of a person with dementia commented:

“I’ll tell you one thing...I was more easy going, I had a better sense of humour...even when he got angry with me, it didn’t bother me the same way... I felt that I had [been] rejuvenated.” (Strang & Haughey, 1999, p. 455).

Table 1: Factors affecting the impact on carers

<i>Factors affecting impact on carer</i>	<i>Possible to change or assist?</i>	<i>Examples of what can be done</i>
Carer's gender	No	
Carer's age	No	
Relationship between carer and care recipient	Some aspects, such as tension in the relationship	Counselling to deal with family conflict.
Care recipient's disability: Type of disability	No	
Extent of disability / amount of assistance required by care recipient	Can assist	Practical assistance such as home care, day programs, range of respite services.
Difficult behaviours	Yes	Training in managing and coping with these behaviours.
Disabilities in caregivers	No	
Moderators: Socioeconomic factors	To some extent	Provide assistance so that carer can remain in employment. Workforce reforms. Provide increased income support. Provide cash subsidies.
Social support	Yes	Support groups. Programs to encourage involvement of other family members. Training in how to obtain support. Programs linking carers to community.
Coping strategies	Yes	Training in the use of different strategies.
Sense of mastery or self-efficacy	Yes	Self-esteem classes. Training in the use of different coping strategies, managing difficult behaviours etc.

Some studies of respite care interventions report the transitory nature of the benefits to carers, and this is expressed by one carer:

“Yes, I could see the difference. It was nice to have her home, but everything fell right back to where it was before. I couldn’t draw that much upon the respite to keep you going anew. For a brief period of time, I guess, you could. But, while it was happening the Friday after that, it all came back again.”
(Smyer & Chang, 1999, p. 45).

Barriers to using respite care

Interviews with carers have highlighted barriers to the use of respite by caregivers (Aged and Community Care Division, 1996; Ashworth & Baker, 2000; Carers Association of Australia, 1994; Carers Association Victoria, 2000; Coe & Neufeld, 1999; Strang & Haughey, 1999; Ward & Cavanagh, 1997). These include guilt about leaving the care recipient, thinking that using respite is an admission that you cannot cope with the situation, not being confident that the alternative carers would be suitable, appropriate respite services not being available, care recipient resistance, and the cost of respite. The lack of flexibility in the provision of respite care has been cited as an important barrier for carers who need both planned and emergency access to respite care (Carers Association of Australia, 1994; Twigg, Atkin & Perring, 1990). Another issue for some carers is the problem of re-settling the care recipient back into their usual routine after a period of respite care (Carers Association of Australia, 1994; Twigg et al., 1990):

“Residential respite is difficult to access, disturbing the client, often takes months to settle afterwards and is costly.” (Carers Association of Australia, 1994).

One carer of a twenty year old son with multiple disabilities stated:

“I was reluctant to use respite services. I thought he was too young to be away from home. He was our responsibility. If we couldn’t manage him, then others wouldn’t be able to either. We loved him yet he tested our limits constantly. I believed strangers would not have the commitment nor the capacity to be as resilient as we were.” (Rook, 2000).

An Australian pilot project which assisted people to use residential respite found that the financial barriers to using residential care were not as significant as expected (Aged and Community Care Division, 1996). The project was effective in increasing the use of residential respite care, particularly in nursing homes. Reasons for this success were factors such as giving clients the choice of a nursing home, involving the carer and recipient in the choice, and having staff able to counsel and assist the carer and recipient through the transition into respite, for example by providing practical information (Aged and Community Care Division, 1996).

Quantitative research

The overall findings from the quantitative evaluations of the effectiveness of respite care in reducing the negative impact of caregiving for carers are equivocal. Various reviews of such research have commented that the majority of the research is methodologically poor (Gottlieb & Johnson, 2000; McNally, Ben-Shlomo, &

Newman, 1999). Details on methodological problems are discussed later in this review. The fact that much of the literature is flawed must be kept in mind when considering the findings discussed here.

It is useful to examine the conclusions of reviews of empirical literature on the value of respite care. One recent review included 29 studies of respite care provided for carers whose care recipients ranged in age and type of disability (McNally et al., 1999). The authors' overall conclusion was that "there was little evidence that respite intervention has either a consistent or enduring beneficial effect on carers' well-being" (McNally et al., 1999, p. 1). A closer investigation of their findings reveals that 10 of 17 studies reported some improvements in measures of psychological well-being of carers; 8 of 13 studies reported improvements in carer stress or carer burden; and 1 of 3 studies reported improvements in the physical health of carers, but only among carers whose care recipient had a stable condition (McNally et al., 1999). An earlier review applied a meta-analytic technique to 15 evaluations of interventions which aimed to relieve caregiver distress in carers of elderly persons (Knight, Lutzky & Macofsky-Urban, 1993). The results of the meta-analysis on studies examining respite care demonstrate the problems in research in this area: of 8 studies which included respite care, only 3 reflect comparisons between groups that received differing amounts of respite care (Knight et al., 1993). An effect size of .63 was calculated for these three studies (Burdz et al., 1988; Mohide, Pringle, Streiner, Gilbert, Muir & Tew, 1990; Montgomery & Borgatta, 1989), suggesting that respite care was moderately effective in reducing caregiver distress in carers of elderly persons (Knight et al., 1993). The studies which were used to calculate this effect size had some methodological problems, including small sample sizes. Two other reviews which focussed on caregivers of patients with Alzheimer's disease or dementia concluded that the available experimental investigations indicated only modest benefits from respite care for caregivers (Bourgeois, Schultz & Burgio, 1996; Gottlieb & Johnson, 2000).

Problems of studies not providing full details of the demographic characteristics of their samples, different types of carers and different types of respite care being included in the one study, and the use of different outcome measures make it difficult to draw conclusions about the type of factors which contribute to the effectiveness of respite care.

Some researchers have reported an improvement in caregivers during the respite period, but a return to previous levels of stress or burden after respite is over (Adler, Ott, Jelinski, Mortimer, & Christensen, 1993). It has been noted that perhaps the benefits carers receive from respite may be like those associated with any vacation (Adler et al., 1993). One possible contribution to the lack of impact of facility based respite care reported by Homer and Gilleard (1994) was that many carers visited their dependent regularly during respite. The authors suggested that carers did not want their relative to feel abandoned, and also that the carers visited so often because they felt guilty (Homer & Gilleard, 1994).

A common finding in the evaluation research of respite services is that regardless of the results of the quantitative data, carers are consistently positive about respite care (Scharlach & Frenzel, 1986; Theis, Moss & Pearson, 1994). When asked open-ended questions about services they would like, more respite services have been the most

frequent response (Lawton, Brody & Saperstein, 1989). Australian research also indicates that carers want more respite care (Rhys Hearn, Hewitt, Lindsay-Smith, Barratt, Hendrie & McCarthy, 1996). Reviews of respite services in Australia indicate that carers are generally satisfied with respite care, but want more of it, and more respite available for emergencies, for evenings and weekends (Aged and Community Care Division, 1996).

There are clearly discrepancies between the comments by carers who have used respite care services and the findings from quantitative research examining the effectiveness of respite in reducing the negative impact of caring on carers. There are a number of methodological issues, discussed below, which may partly explain these discrepancies. Some authors have questioned the need for empirical evidence in order to justify the provision of respite care services for carers: "In short, the question is whether our values allow us to justify respite care simply because, as this study and all other studies have demonstrated, the caregivers needed it, wanted it, and reported that it had given them some welcome temporary relief." (Lawton, Brody & Saperstein, 1991, p. 141.).

Effect on care recipients

Respite care involves a change for the care recipient, and some research has investigated the impact of respite care on them. Findings have been somewhat mixed. One study of care recipients with dementia suggested that after a 2 week facility-based respite stay, patients with more severe dementia showed some improvement on a behaviour adjustment scale and on the Bedford Alzheimer Nursing Scale, but the patients with less severe dementia showed some deterioration (Seltzer, Rheume, Volicer et al., 1988). Another study with dementia patients reported an increase in dependence in the Alzheimer's Disease group of veterans staying in hospital for 2 weeks for respite care, but the researchers suggested this was no more than expected due to disease progression (Adler et al., 1993). In a study by Burdz et al. (1988), caregivers of both dementia and nondementia patients reported fewer problems in their care recipient after a mean period of 15 days facility-based respite care. Homer and Gilleard (1994) reported that elderly patients of highly stressed carers showed some improvement in functioning while they were in facility-based respite care. No differences were found in mortality rates among elderly persons admitted to hospital for 2 to 3 weeks to provide respite for their carers, compared to those waiting to be admitted (Howarth, Clarke, Bayliss et al., 1990).

Respite care and institutionalization

It has been reported that respite care both increases the likelihood of the care recipient being institutionalised (Gottlieb & Johnson, 2000) and decreases the likelihood (Lawton et al., 1989). A combination of respite care and other services was found to delay placement among adult child carers but encouraged placement by spouse carers (Montgomery & Borgatta, 1989).

Appropriateness of respite care services

It is important that support for carers does not act to negate the positive aspects of the caring role. Nolan et al. (1996) have labelled some carer services as inhibitory or obstructive. These are services which fail to take account of the caregiver's needs, and can "inhibit carers' efforts to engage in preservative, reconstructive and reciprocal care" (Nolan et al., 1996, p. 50). It is argued that respite care can fall into this

category at times, and while it is used by carers, this will be with reluctance and accompanied by feelings of guilt (Nolan et al., 1996). An example is provided of staff of a day care respite service not heeding a carer's advice regarding the personal care of his wife with dementia. The carer was distressed and disappointed and less than happy to use the service (Nolan et al., 1996). If respite care is to enhance the caring relationship, there needs to be sensitivity to the caregiver's needs.

One carer has expressed the need not to have a break away from his disabled son, as respite care would usually provide, but rather to be released from some household duties so that he can do "father / son" things with his son like swimming, riding on a motor bike or attending sporting events (Rook, 2000).

The length of a respite break, especially day care, can be problematic. One carer described how she would feel anxious about getting home towards the end of a game of golf, as she needed to get home to be there when her care recipient returned (Strang & Haughey, 1999). Another study reported that on days when their care recipient went to day care, the carers actually spent more time on caregiving activities (Berry, Zarit & Rabatin, 1991).

Educational programs

Interventions which provide education programs for carers have been described and evaluated in the literature. Programs have included educating carers about the disease process, communication skills, social skills training, behaviour management, and skills relating to assisting care recipients with ADLs. To a certain extent the effectiveness of educational programs is difficult to assess as education is frequently combined with a different approach, such as a support group. Research in this area is also plagued by the methodological problems described below.

There is some evidence of the value of education programs in improving coping (Chiverton & Caine, 1989), reducing anxiety (Greene & Monahan, 1989), and increasing knowledge (Kaasalainen, Craig & Wells, 2000) in carers of elderly care recipients. Greene and Monahan (1987) noted that participation in their support and education program lowered the likelihood of placement in an institution. However, other researchers have reported no significant findings in dementia carers (Brodaty, Roberts & Peters, 1994). The latter researchers suggested that the failure of the training program they utilised may be due to the different needs of individuals, the lack of hands-on skills training, and the problem of a 'floor-effect' caused by non-distressed caregivers decreasing the chances of demonstrating that the intervention was effective (Brodaty et al., 1994). One intervention with carers of children with developmental disabilities found significant improvements in problem-solving abilities and the achievement of individualised goals, but only small improvements on the measures of stress (Gammon & Rose, 1991).

A review of family interventions for relatives of psychiatric patients argued that such interventions, which incorporated information and support, had moderate effects on relatives' burden (Cuijpers, 1999). The author suggested that interventions need to have at least 10 sessions to have any important effect on relatives' burden (Cuijpers, 1999).

The need for training parents of children with developmental disabilities in the management of aggressive and violent behaviour has been noted, and descriptions of training programs are provided in the literature (Cohen-Almeida, 1989).

Support groups and counselling

Evaluations of the effectiveness of support groups and counselling are also at times confounded by the inclusion of more than one approach in each intervention. There is some evidence of their value however. One Australian study found that attending regular group meetings was associated with reduced state anxiety and gains in positive affect (Schultz, Smyrnios, Grbrich & Schultz, 1993). Participation in peer-led or professional-led groups was associated with improvements in psychological functioning, increases in informal networks and positive personal changes in handling the caregiver role (Toseland, Rossiter & Labrecque, 1989). Carers participating in a peer telephone network group gained significantly in perceived social support and in satisfaction with social support (Goodman & Pynoos, 1990).

The potential impact of support groups has been unintentionally demonstrated at times. Some researchers have found an inadvertent effect when control groups meeting for the purpose of completing measurement instruments actually functioned like a support group. Robinson and Yates (1994) reported a decrease in subjective and objective burden in their control group, and that “perception sharing and problem solving were noted to occur” at the two control group meetings (p. 318). Similarly, Chiverton and Caine (1989) noted that the improvements in Emotional Competence they reported may have grown out of the overall group process, as there was group discussion after the educational component in each of three sessions. They noted that the groups provided a supportive environment conducive to self-expression and greater personal awareness.

Participants in five caregiver support groups which comprised education, emotional health, and directed activities, commented that the socialisation that occurred in the groups was the most beneficial aspect of the program (Kleffel, 1998):

“I think that the most wonderful thing is the camaraderie. We’re all in the same boat and we can air our feelings” (Kleffel, 1998, p. 469).

The benefits of a group counselling program for spouses of persons with dementia included participants resuming hobbies, social activities, relationships with relatives and friends, and participants reported being able to cope with situations they couldn’t cope with before the program (Brannstrom, Tibblin & Lowenborg, 2000). Attending group sessions can provide a sense of solidity and social connectedness, and reductions in anxiety and depression (Greene & Monahan, 1989). However, a meta-analytic review of interventions for caregivers of elderly persons concluded that psychosocial interventions provided in groups were less effective than those provided to individuals (Knight et al., 1993).

The need to provide respite care to enable caregivers to attend support groups has been noted, as one author noted that about 20 of the 40 participants in five support groups could not have attended without respite care (Kleffel, 1998).

Technological innovations

A number of technological innovations including multi-media interventions are described in the literature. An example is the ACTION project – “Assisting Carers using Telematics Interventions to meet Older peoples’ Needs” (Hanson & Clarke, 2000). The ACTION system utilises the carer’s own television and remote control, a multimedia PC and CD ROM, and a video-telephone and small camera. Carers are able to access a range of multimedia programs in their home, such as education and information programs on a range of issues of relevance to carers. In addition, they are able to access support from District Nurses, GPs and other family carers participating in the project using the video conferencing equipment (Hanson & Clarke, 2000).

Other multi-media approaches include REACH for TLC system – Resources for Enhancing Alzheimer’s Caregiver Health – Telephone Linked Care (Mahoney, Tarlow & Sandaire, 1998) which comprises several modules, all utilising the caregiver’s telephone. Modules include an automated monitoring of the caregiver’s stress levels and health status with counselling or referral for negative changes, a voice mail component allowing caregivers to send and receive confidential mail and access an Ask-the-Expert feature, and an in-home caregivers support group that uses a voice mail bulletin board. One module is a care recipient distraction module which aims to reduce the care recipient’s disruptive behaviours using an electronic conversation and instructions to perform a relaxation exercise (Mahoney et al., 1998).

A review which included two comparisons of technology-based interventions with conventional care or support for carers of dementia patients reported no evidence of a significant difference in impact on carers’ mental health (Thompson, & Spilsbury, 2001).

The use of such multi-media interventions may be problematic for some carers. For example, one woman would not have a video-telephone in her home because she felt it was an invasion of privacy and also because she had concerns about her body image (Hanson & Clarke, 2000). Such technology may be most familiar and acceptable to carers who are better off financially (Hanson & Clarke, 2000).

“They said you could go into other people’s home. And you don’t know who’s in these other people’s homes, do you, that’s looking into your home?” (Hanson & Clarke, 2000, p. 131).

“Well I’m finding out that there are a lot of things out there that I might be able to come into contact with. I found that very interesting, that video about nursing homes.” (Hanson & Clarke, 2000, p. 134).

Multi-faceted programs

A number of programs which provide multi-faceted support are described in the Australian literature. The evaluation of such programs is typically in the form of surveys of service users. It is difficult to ascertain which elements of a program are most helpful to carers, as the total program is evaluated.

The Making a Difference and Continuity of Care programs for families with children with significant disabilities are an example of such programs (McVicar & Reynolds Pty Ltd, 1996). These programs were developed to: focus on supporting the whole family; work collaboratively with families to identify how they can best be assisted

and develop individually tailored responses to meeting their needs; provide case management support; and use discretionary funding in a diversity of ways to meet the needs of families (McVicar & Reynolds Pty Ltd, 1996).

The various ways in which the Making a Difference program assisted families are apparent from these responses from carers:

“Making a Difference provided safety fencing, emergency respite during my illness and support. They acted as an advocate with an incident at the CRU and gave me support and they provided financial support when I had a burst water main.” (McVicar & Reynolds Pty Ltd, 1996 p. 138).

“The moral support from the Co-ordinator has been wonderful. The financial help for bills gas, electricity, phone and nappy supply and the taxi to the Independent Living Centre and to visit the hospital while my grandson was an outpatient (have been very helpful). Next week the Co-ordinator is taking me to Paraquads to see about the Continence Aids and Assistance Scheme for nappies. It’s nice to know that if you’re really down you can ring the Co-ordinator and she will be there.” (McVicar & Reynolds Pty Ltd, 1996, p. 135).

It is clear that carers involved in the program appreciated both the practical assistance and the personal support provided.

Flexible financial assistance

Programs in the US where families with a family member with a disability are given cash subsidies or “flexible financial assistance” which can be used as they choose are described in the literature (e.g. Freedman & Boyer, 2000). One aspect of this type of support greatly appreciated by the carers was their ability to choose the services they require:

“Having (flexible funds) gives us a voice and an authority that we know what we’re talking about, we know what’s best for our child ... I feel like I’ve been validated and listened to. And what I express that I need for my family is important, and, you know, somebody will allow me to do that.” (Freedman & Boyer, 2000).

Carer Support Kit

A Carer Support Kit has been developed in Australia by the then Commonwealth Department of Health, Housing and Community Services, and distributed by Carers Associations in each state. The kit includes:

- fact sheets relating to home safety, respite care, self-care and financial help
- information about specific disabilities
- a directory of services
- an emergency care plan
- a ‘medi-list’ for recording medications
- a relaxation tape
- a tape of discussions with carers (Schofield et al., 1998).

An evaluation of the usefulness of the kit was conducted as part of the Victorian Carers Program research. This evaluation was limited by the small number of carers who took the opportunity of requesting and actually using the kit: only 23% of the eligible 103 carers (Murphy, Schofield & Herrman, 1995). However, of those carers who did request and use the kit, almost all found it relevant to their needs and informative (Murphy et al., 1995). Of some concern is the finding that half of the carers who had received, but not used, the kit indicated that they had been dealing with a crisis during the time when they had the kit. The authors argue that this indicates a need for the dissemination of information early in the caregiving phase (Murphy et al., 1995).

Home-based assessment

Another project which formed part of the Victorian Carers Program research focused on home-based assessment for carers. This project utilised aged care assessment teams (ACATs) to identify unmet need for services among family carers and their frail or disabled relatives, and to facilitate links to services (Nankervis, Schofield, Herrman, & Bloch, 1997). The usual home-based assessment strategy performed by ACATs was extended to cover the carer / care recipient dyad. In 93% of dyads a service deemed beneficial to the carer or recipient was mutually identified, indicating an unmet need. In 78% of these the ACAT planned to subsequently organise a referral to community services, a secondary assessment, or to provide detailed information about services. Of the 174 recommendations requiring ACAT action, the most common were for respite care, aids and paramedical services. Caregiver's perceptions of the service were positive when they were interviewed at the two months follow-up, with 75% rating it as helpful or very helpful. Reasons given by carers as to why the service was rated as helpful were: benefits from new services (21%); morale boost (19%); information obtained (18%); and knowing someone in the system (16%) (Nankervis et al., 1997).

Do interventions replace informal support?

The important role of informal support to carers has been recognised (Aged and Community Care Division, 1996), and formal support services are not intended to replace informal support. There is limited data available on this issue. Lawton et al. (1991) reported that the availability of respite care services during the twelve months of their intervention did not substitute for family care. They emphasise that: "The added respite and other services to which the experimental group of caregivers were referred did not encourage the caregivers to reduce or withdraw their own services." (Lawton et al., 1991, p. 137). In fact, the authors reported that caregivers in both groups increased the amount of help they provided during the year of the intervention. Some of the education programs include training in how to mobilise informal support networks (e.g. Robinson & Yates, 1994). Shaver and Fine (1996) cite overseas research that indicates that adequate publicly financed formal support actually enhanced and complemented the viability of informal care provided by family members.

Given the considerable numbers of carers who do not use formal services, and the substantial proportion of primary carers who have assistance from secondary carers or other informal support (Schofield et al., 1998), it does not appear that the availability of formal services replaces informal services. An analysis of the third wave of the

Victorian Carers Project data indicated that there was no statistically significant relationship between the use of formal respite services and the frequency of informal support available (Aged and Community Care Division, 1996). This again indicates that knowledge and use of formal supports does not lessen the use of informal support. However, it has been argued that respite care fails to facilitate the maintenance of socially supportive relationships, and that such relationships are important in reducing the strain of caring after the respite care period has ended (McNally et al., 1999).

Methodological issues

Size and design of studies

Studies need to be controlled, of a sufficient size to detect differences between groups, and have random assignment to groups, or at or at least have comparable groups to start with. (Flint, 1995; McNally et al., 1999). A sample size of 64 participants in each group has been calculated as necessary to detect a moderate effect on a continuous outcome variable (Brodaty & Gresham, 1990, Cited in McNally et al., 1999). Much of the published research utilises smaller samples.

Randomisation is important given the large number of patient and caregiver variables that may influence the outcome. These variables include the age, sex, type of disability, level of ADL function, level of cognitive function, presence and type of behavioural disturbance, and co-existing physical problems in the care recipient (Flint, 1995). Similarly variables relating to the caregiver which need to be considered include age, sex, relationship to the care recipient, family structure and support, psychological and physical status, availability and use of social resources, and types of caregiving tasks performed (Flint, 1995).

Attrition rates

Many writers in this area conclude that what is really needed are longitudinal studies. The problem is that attempts at longitudinal research with carers suffer from high attrition rates – especially in research with elderly people. People die, are institutionalised, or they withdraw from the program. Even a carefully designed research project such as that reported by Zarit, Stephens, Townsend and Greene (1998) is limited by the considerable attrition rate experienced, with only 193 of 324 participants who completed the measures at 3 months completing the 12 months measures (and even more started). Another study reported an attrition rate of 30% (Mohide et al., 1990).

Recruitment

A major problem with much research is that participants are most often recruited from members of organisations or service users. There is therefore a bias towards individuals who are predisposed to benefit from the interventions because they have sought help (Bourgeois et al., 1996).

Problems in recruiting appropriate participants is one reason for the small sample sizes in some cases. Bland and Harrison (2000) describe the difficulties they experienced in recruiting caregivers of persons with bipolar disorder. They were unable to have a control group using a wait list method as they felt it was important to

commence the program rather than wait until sufficient numbers had been recruited. Other researchers have been unable to randomly assign participants to groups due to concerns raised by referring agencies (Greene & Monahan, 1989).

Combining different types of caregivers

Some researchers have examined the impact of interventions on a range of different types of caregivers. As noted above, the impact of caring differs to some extent depending on various carer and care recipient characteristics, which could confound the effect of the intervention. Some researchers have acknowledged the important role of caregiver characteristics and have limited participants in interventions accordingly. Toseland et al., (1989) for example investigated the impact of support groups in a sample of daughters and daughters-in-law of frail elderly care recipients.

Some differences in the care patterns between adult child and spouse carers for impaired elderly have been reported. Montgomery and Borgatta (1989) suggest that spouses care for younger, less healthy elderly people and continue providing extensive time demanding care, and that children do fewer hands-on care tasks. They suggested that children are likely to place their parent in a nursing home when they need extensive personal care and thus end their caregiving role at about the time spouses start to identify themselves as caregivers (Montgomery & Borgatta, 1989).

Timing of interventions

Where carers are in their caregiving trajectory is another important consideration in the implementation of interventions. Several researchers have commented on the difficulties in accessing caregivers early in their caregiving role (Montgomery & Borgatta, 1989). Too often caregivers respond to services late, at a crisis point when they can benefit less (Lawton et al., 1989; Montgomery & Borgatta, 1989).

It is particularly important with some types of interventions that they are accessed by carers at an early stage in their caregiving career. It has been suggested that the appropriate time for a support program for family members of a person with bipolar disorder is close to the time of greatest family distress, most likely when the patient is admitted to a hospital or presents at a community service for treatment (Bland & Harrison, 2000). Researchers concluded that their multimedia intervention for carers was possibly most appropriate for newer caregivers (Hanson & Clarke, 2000). Others have suggested that periodic booster sessions or other counselling opportunities could be provided after a support group program has finished (Toseland et al., 1989).

Nolan et al. (1996) discuss in some detail the stages of caring in the case of dementia, and argue that a major problem in the caregiving literature is the failure to fully explore the temporal and longitudinal aspects of caring. They suggest that services for carers should be 'stage specific', and tailored to meet their needs at varying times in the caring trajectory (Nolan et al., 1996). They assert that if services are to be effective, greater attention must be paid to the stage of the caregiving process. Most of the literature examined in this review fails to consider the stage of caregiving, which may impact on the effectiveness of the interventions examined.

Changes in control groups

Another problem noted in some studies is that the control group – the people who are not supposed to be receiving any intervention, or anything that will benefit them more than usual care, actually improve slightly during the course of the research (Chang, 1999; Robinson & Yates, 1994). This diminishes the effect of the intervention being investigated. It appears that even small amounts of contact with the research team, or with other carers in a similar situation, have led to improvements in carer well-being. Chang (1999) reported a decrease in anxiety in both the intervention and control group. The latter group received a weekly telephone call from a nurse which lasted for an average of 11 minutes, during which the nurses informally assessed caregiver general well-being. Individuals in the intervention group also received a weekly telephone call that was of a longer duration than calls to individuals in the control group, and which provided problem-solving guidelines for behavioural disorders. Participants in the control group were positive in their responses to the telephone calls (Chang, 1999). As noted above, another study reported that participants in the control group condition obtained some benefits from two group meetings (Robinson & Yates, 1994).

Other studies have difficulty in being sure that there are sufficient differences in what the intervention group and control groups receive. Some researchers report that the intervention group do not use the services offered (Lawton et al., 1989; Montgomery & Borgatta, 1989). In other cases the carers in the control group may in fact be having respite provided by their informal support network.

Inconsistency in intervention

Some studies have evaluated the impact of different types of intervention simultaneously. For example, Conlin, Caranasos and Davidson (1992) examined carers who utilised either facility-based or in-home respite care. Similarly, Lawton et al. (1989) offered a range of respite services to participants.

Measurement instruments

It is possible that the failure of some evaluations to demonstrate a significant effect of the intervention may be due to problems in the type of outcome measures used.

Hoare et al. (1998) reported that the level of distress in carers, measured by the General Health Questionnaire (GHQ), was not much higher than that found in a large community survey, and suggest that either the GHQ is not an appropriate instrument or that carers adapt to their situation. Fluctuations in depression over time within individuals have been measured and researchers need to be aware of intraindividual variation when measuring the impact of caregiving (Smyer, 1993).

A large number of different instruments have been used in the caregiving literature. The following list is not comprehensive:

Affect Balance Scale (Bradburn)

Beck Depression Inventory

Behavior and Mood Disturbance Scale, Relatives' Distress Scale (Greene et al., 1982)

Caregiver Appraisal Measure (Lawton et al., 1989)

Caregiver Burden Inventory (Novak & Guest, 1989)

Caregiver Hassles Scale (Kinney & Stephens, 1989)

Caregiver Quality of Life Instrument (CQLI)
 Carers Assessment of Difficulties Index (CADI) (Nolan & Grant, 1990)
 Carers Assessment of Managing Index (CAMI) Nolan et al., 1995)
 Carers Assessment of Satisfactions Index (CASI) (Nolan et al., 1996)
 Centre for Epidemiologic Studies - Depression (CES-D)
 Family Adaptation and Cohesion Evaluation Scales II (FACES II)
 Family APGAR
 General Health Questionnaire – 28 (GHQ-28)
 Geriatric Depression Scale (GDS)
 Health Specific Family Coping Index for Non-Institutional Care (HSFCI)
 McMaster Family Assessment Device (FAD)
 Norwich Depressed Mood Scale
 Personal Resource Questionnaire (PRQ-85)
 Profile of Mood States (POMS)
 Questionnaire on Resources and Stress (QRS-F)
 Robson Self-Esteem Questionnaire
 Screen for Caregiver Burden (Vitaliano et al., 1989, 1991)
 Short Psychiatric Evaluation Schedule
 Social adjustment (SAS-SR)
 State Trait Anxiety Scale (STAI)
 The Burden Interview (Zarit et al., 1980)
 Zung (depression).

The preferences of care recipients

Within the literature on supporting carers there is limited research available on the preferences of care recipients generally. To some extent there is tension between the needs of carers and the interests of care recipients (Twigg & Atkin, 1994). One barrier to the use of respite services by carers is care recipient resistance (e.g., Carers Association of Australia, 1994).

“My husband hates it when he feels as if he is being ‘minded’.”
 (Carers Association of Australia, 1994, p. 28).

An in depth examination of the aspirations of people with a disability in Victoria found that participants expressed a broad range of goals and aspirations across many facets of life (DisAbility Services Victoria, 2000). It is difficult to determine to what extent these goals and aspirations are taken into account in the provision of support to carers.

Some care recipients are more able than others to participate in decisions made about their care. Some people with disabilities demand the right to be their own care managers and to select and employ their own attendant carers (Cox & Spalding, 1996), thus ensuring that their preferences are met.

Cultural differences

Generally the reported health and well-being of Anglo and carers from a non-English speaking background (NESB) were similar in the Victorian Carers Program research (Schofield et al., 1998). However it was noted that use of services was less common

in NESB carers. It has been suggested that the dissemination of information to NESB carers is an issue, and also that NESB carers' concerns that the care recipient would be unhappy about the use of respite services may prevent this group from using respite care services (Gibson, Butkus, Jenkins, Mathur & Liu, 1996). The special needs of Aboriginal carers also need to be considered.

"My mother doesn't want to have to rely on white people to do things for her because of her past experiences – being brought up in the dormitory on the mission. Also they talk too much always questioning you about something."
(Carers Association of Australia, 1994, pp. 26-27).

One American paper reviewed 12 studies comparing Black or Hispanic carers with White carers, or Black with Hispanic carers of persons with dementia (Connell & Gibson, 1997). The authors reported that in general, White caregivers reported higher levels of caregiver stress, burden, and depression and less strongly held beliefs about filial support than non-White caregivers. This difference was not found in a few studies (Connell & Gibson, 1997).

A review of American research on carers of persons with mental retardation and persons with mental illness commented that while the cultural context is important for understanding dimensions of the caregiving experience, there are many contradictory findings in the literature (Lefley, 1997).

A number of factors which may distinguish cultural groups in terms of providing care have been described in the literature. These include: how the disability is perceived; who is considered part of the family; who provides care; how the family makes decisions; what family members expect of each other; whether and how closely the family adheres to traditional values; and how willing the family is to accept outside help (Lustig, 1999).

Caregivers' needs

The problem with the majority of literature on caregivers' needs is that it largely surveys caregivers who are using some services. There is therefore a tendency for them to focus on the services they use. Research in this area is frequently in the form of evaluations of specific services.

The data from the Victorian Carers Program provide an overview of the services used and needed by carers in Victoria (Schofield et al., 1998). They reported 6% to 17% unmet need for six community care services: general home help, personal home help, community nursing service, meal services, home maintenance, and transport services. Just over half of 862 carers were not receiving any of these services, and for most services, most carers reported not needing the services. General home help and transport were the most commonly used services (Schofield et al., 1998).

Specific questions in the Victorian research addressed the use of a range of respite services. Only 12% of carers interviewed had used respite care in the last 12 months. Over a quarter of carers reported that they would like more respite. The majority of carers reported that they had not used respite and did not need it (70%), and 18% reported an unmet need, that is, needing respite but not using it in the past (Schofield

et al., 1998). In the ABS data, 87% of carers reported that they had never used respite care, the majority of these (65%) indicating that they did not need it, and 14% that they did not know enough about it or the service is not available (ABS, 1998). Schofield and colleagues divided carers into those whose care recipient was aged over or under 65 years. Among the carers of younger persons, 15% reported having used respite, and the main factors in their use were aggressive behaviour problems in their care recipient, and longer hours of care provided. Among carers of older recipients, 10% reported using respite, with those caring for relatives with high ADL dependencies, and female carers, using respite most (Schofield et al., 1998). Among the younger group ($n = 333$), 25% needed respite care. The factors associated with this need was the relationship between carer and care-recipient, with parent and 'other' carers more likely to need it than spouse and offspring carers, and amount of informal help, with people receiving less help needing respite more. For the older group, 27% reported a need for respite care, and high ADL dependencies and more frequent aggressive behaviour problems were associated with a need for respite (Schofield et al., 1998).

The following points are a summary of the key findings from 22 Australian (predominantly Victorian) reports on carer needs and respite services (1988 – 1992) provided in a report on Commonwealth Respite for Carers (McVicar & Reynolds Pty Ltd, 1993). The carer needs are listed in four categories based on the age group of the care recipients, or the type of service provided.

- Respite care needs of people caring for children and adolescents with disabilities in the 0-18 age group
 - Need for more flexible services
 - Need for emergency, weekend, overnight (at home) services
 - Need for more information about respite services
 - Need for stimulation etc. for care recipient
 - Problems with inconsistencies across municipalities
 - Importance of staff providing care being good quality and well trained
 - Some groups disadvantaged in access to services: rural location, NESB, high needs or difficult behaviours in recipient
 - Specific Home Care used very much
 - Lack of co-ordination between services.
- Respite care needs of people caring for people with disabilities in the 18-60 age group
 - Need for more services for adults
 - Need for age-appropriate community based services for adults
 - Need for more emergency, after-hours, extended, respite
 - Need for stimulating activities / programs for recipient
 - Having to book respite in advance a problem
 - Lack of information on services available
 - Acquired brain injury (ABI) – particular need for social activities, community friend
 - ABI – not want to attend activities, venues seen as inappropriate, prefer to be involved in mainstream activities

- Difficult to obtain services for people who are “difficult to manage”.
- Respite care services – Specific Home Care
 - Need for more standardised service provision
 - Need for emergency service / after-hours contact
 - Need for transport
 - Need for better information for users and workers
 - Need for more training for workers
 - Need for culturally appropriate service / staff
 - Assistance with siblings and leisure activities important
 - Access to consistent carer (worker) important.
- Respite care needs of people caring for older people in the community (65+ and those with dementia)
 - Problems in identifying some carers who could need assistance
 - Problem of duplication of assessment
 - Special needs of NESB people
 - Need for facilities suitable for people with dementia, or with behavioural problems
 - Some carers distrust substitute carers
 - Need for co-ordination between services
 - Need for greater flexibility, choice, and immediate response.

Many of these issues were also identified in a national consultation with carers undertaken by the Carers Association of Australia (1994). The latter report highlighted the need for greater availability and more flexible services, especially respite services, and for more information for carers. It also identified financial difficulties experienced by carers, their problems in staying in paid employment, and the need for increased financial recognition of the caring role (Carers Association of Australia, 1994). Another concern for older carers is the problem of what happens to their care recipient, particularly adult offspring, when the carer is no longer able to care for them (Bigby & Ozanne, 1999; Carers Association of Australia, 1994).

Differences between users and non-users

Information on the differences between users and non-users of carer support services is of interest in promoting an understanding of what it is about some carers that enables them to cope without formal support. It also highlights problems in service provision which inhibit carers accessing appropriate services.

There is limited research available on carers who do not use respite care services. The Victorian Carers Program research provides some information on non-users. Of some concern is the finding that unmet need for services in general was highest among carers who were more overloaded and dealing with more frequent behaviour problems and more severe disability and dependency (Schofield et al., 1998). Lawton et al. (1991) reported that many non-users of the range of respite services offered in their intervention could be considered to be in need of such assistance. For example there was no difference between users and non-users by mental health indicators, physical

health, or availability of other formal or informal respite help before the intervention began (Lawton et al., 1991).

A review of factors associated with the use of services amongst carers of learning disabled adults concluded that three variables were reliably related to service use: services were more likely to be received by carers reporting high levels of distress; by carers who were older; and by families with a dependant who was younger (Cowley & Orbell, 1999). Not surprisingly, different types of respite care are used more by certain types of caregivers. In-home respite rather than day care or nursing home respite was used by caregivers of elders who showed more frequent social and behavioural symptoms in a program which provided a range of respite services to carers (Lawton et al., 1991).

One comparison of users and non-users of hostel respite for adolescents with developmental retardation reported that hostel usage related to attributes of the family rather than the dependency needs of the adolescent (Dossetor, Nicol & Stretch, 1993). The authors concluded, from their research with 92 families, that families who do not use hostel respite seem to be better functioning environments than families that do use this service (Dossetor et al., 1993). Another study concluded that an important factor in differentiating carers who planned to use or not use respite in the future was intimacy and love in the relationship with the care recipient (Braithwaite, 1998). High scores on intimacy and love were negatively associated with planned future respite use.

Theoretical approaches

A number of theoretical models are relevant to the area of supporting caregivers. A brief description of some is included. A more comprehensive description is included in the forthcoming review.

The transactional model of stress

The transactional model of stress sees stress as resulting from a transaction between an individual and the environment. Appraisals of a potentially stressful situation play an important role in this approach. When a demand or event occurs, the individual makes a primary appraisal, evaluating the significance of the event for their well-being. If the event poses a threat, a secondary appraisal occurs in which the individual evaluates what coping resources they have to deal with the event. Reappraisal occurs after a response has been selected and implemented (Folkman et al., 1979). Stress occurs when the coping resources available are not sufficient to deal with an appraised threat (Nolan et al., 1996).

Folkman et al. (1979) outline five categories of coping resource:

- utilitarian resources (e.g. socio-economic status, money, available services)
- health, energy or morale (e.g. depression, pre-existing physical and psychiatric illness)
- social networks (e.g. close interpersonal relationships)
- general and specific beliefs (e.g. self-efficacy, mastery, self-esteem)
- problem solving skills (e.g. intellectual skills, cognitive flexibility and complexity and analytic ability).

In most discussions of coping the assumption is made that coping is an organised activity and that ‘coping strategies’ are employed. Some authors suggest that the transactional model of stress, as proposed by Lazarus and Folkman, provides the most adequate explanation of how people deal with potentially adverse life events (Nolan et al., 1996). The transactional model of stress can be used to explore individual circumstances and therefore provides a framework for assessing carers’ needs on a one-to-one basis.

The stress process model

Pearlin et al. (1990) describe a similar but slightly different conceptual framework, which they developed in the context of carers of Alzheimer’s patients.

The components of the proposed model are:

- Background and context – SES characteristics, caregiving history, family and network composition, program availability
- Primary stressors – Objective indicators (cognitive status, problematic behaviour, ADL, IADL dependencies), Subjective indicators (overload, relational deprivation)
- Secondary role strains – family conflict, job-caregiving conflict, economic problems, construction of social life
- Secondary intrapsychic strains– Global (self -esteem, mastery), Situational (loss of self, role captivity, competence, gain)
- Mediators – Coping, social support
- Outcomes – Depression, anxiety, irascibility, cognitive disturbance, physical health, yielding of role.

The authors argue that the stress process is made up of four domains: the background and context of stress; the stressors (primary and secondary); the mediators of stress; and the outcomes or manifestations of stress (Pearlin et al., 1990). They divide stressors into primary and secondary stressors. Primary stressors drive the process that follows. The demands of caregiving are seen as encompassing primary stressors that in turn lead to other problems and hardships, referred to as secondary. Primary stressors include both objective measures such as a care recipient’s need for assistance, and subjective measures, such as overload or burnout experienced by the caregiver. An underlying premise of the model is that one set of stressors can lead to another.

The Resiliency Model of Family Stress, Adjustment and Adaptation

Developed by McCubbin, Thompson and McCubbin (1996), the focus of the Resiliency Model is on understanding those family strengths and capabilities which buffer the family from the disruptions associated with normative family transitions and non-normative stressors (Lustig, 1999).

In this model, the level of adjustment in response to changes is determined by the interaction of the following factors:

- the pile-up of family demands related to specific stressors, the normative family transition, prior family strains, the consequences of the family’s efforts to cope, contextual difficulties and intrafamily and social ambiguity associated with the situation

- the family's resources related to personal traits of family members, family system resources and social support
- the family's appraisal of the demands on the family
- the family's problem solving and coping responses (Lustig, 1999).

Antonovsky's concept of the sense of coherence, particularly family sense of coherence, is an important element in this approach. The sense of coherence comprises three aspects:

- comprehensibility, the ability to understand and comprehend the situations of life
- manageability, the ability to manage demands
- meaningfulness, the ability to derive meaning from the situations and demands that one confronts (McCubbin et al., 1994).

The concepts of this approach have been used to develop a typology model of family adaptation and adjustment (Failla & Jones, 1991; Lustig, 1997)

Service Delivery Models

Carers' relationship with formal services

Four ways of thinking about carers and their relationship with formal services have been characterised by Twigg and Atkin (1994):

- (1) carers as resources in which carers are seen as a means to an end of meeting the care recipient's needs;
- (2) carers as co-workers with whom the formal care providers work in parallel with the outcome being focused on the welfare of the care recipient;
- (3) carers as co-clients where the focus is on relieving the carer of strain or stress; and
- (4) the superseded carer in which the aim is not to support the care-giving relationship but to transcend or supersede it (Twigg & Atkin, 1994).

Each of these approaches has inherent problems, and none take the family care situation as the starting point for considering intervention and support (Department of Health and Community Services, Victoria, 1996). The third approach has been recommended as it enables important elements of the family care relationship, such as reciprocity, interdependence and mutuality to be maintained as long as possible (Department of Health and Community Services, Victoria, 1996).

Family support approach

The family support approach to service delivery focuses on how services are provided, giving a central role to family-centred helpgiving and the empowering of families. While the principles of this approach were intended for families with a person with disabilities, it is possible to apply them to many situations involving a carer.

Dunst, Trivette, Starnes, Hamby & Gordon (1993) describe the distinctive characteristics of family support programs:

- "Treating adults as capable and competent persons who have different developmental needs at different life stages
- Building on family strengths rather than focusing on what the family cannot do (i.e. deficits or weaknesses)

- Employing health promotion and competency enhancement rather than treatment models for guiding provision of support to families
- Treating families as partners and active participants in developing and procuring needed supports and resources rather than as clients or passive recipients of aid and assistance
- Employing a broad-based definition of support that recognises the diverse needs of families and the full range of supports and services necessary for meeting needs
- Building programs within the context of supportive communities that enhance the integration of the family into the mainstream of society
- Promoting the independence of the family in making informed decisions and the interdependence of the family and community in ways that produce health and growth” (p. 4).

Dunst et al. (1988) provide the following guidelines for enabling and empowering families:

- Be both positive and proactive in interactions with families.
- Offer help in response to family-identified need.
- Permit the family to decide whether to accept or reject help.
- Offer help that is normative.
- Offer help that is congruent with the family’s appraisal of its needs.
- Promote acceptance of help by keeping the response costs low.
- Permit help to be reciprocated.
- Promote the family’s immediate success in mobilizing resources.
- Promote the use of informal support as the principle way of meeting needs.
- Promote a sense of cooperation and joint responsibility for meeting family needs.
- Promote the family members’ acquisition of effective behaviour for meeting needs.
- Promote the family members’ ability to see themselves as an active agent responsible for behaviour change (Dunst et al., 1988, p. 97).

Assessment of Carers’ Needs

One clear finding from the literature reviewed is the importance of careful assessment of individual carers’ needs. The need for this is supported in many areas of the literature:

- The inconsistent findings of the empirical studies examining a range of interventions to support carers may be explained by their failure to take account of the individual responses of carers to their situation. It is clear from the research that no one way of supporting carers will benefit all carers, but that some carers will be assisted by each approach.
- The theoretical models highlight the role of individual circumstances and characteristics of the individual or family, and how the individual appraises their situation in explaining the impact of caregiving on the carer.
- Individual assessment can include the identification of caregiver strengths and satisfactions gained from caregiving which can be built on to empower the carer.
- The needs of carers change at different stages of the caring trajectory (Bigby & Ozanne, 1999; Nolan et al., 1996).
- With careful individual assessment it is possible to take account of ethnic or cultural factors which may be important in the caregiving situation.

- When Victorian carers have been surveyed about the services currently available to them, a consistent finding is the need for greater flexibility in service provision, suggesting a need for more attention to individual needs (McVicar & Reynolds Pty Ltd, 1993).
- Carers have themselves identified the particular nature of their needs (e.g. Rook, 2000).
- The fact that individual carers and persons with disabilities have unique needs which require a flexible response from service deliverers has been recognised in government policy papers (Department of Human Services and Health, 1996; Department of Human Services, Victoria, 2001).
- Services which have responded to the individual needs of families with a child with significant disabilities have been well received (McVicar & Reynolds Pty Ltd., 1996).

Possible Assessment Instruments

There are several instruments which can be used for assessing the needs of caregivers. Appendix B provides a summary of several of these. Only instruments which include some measure of rewards or the positives of caregiving are included in Appendix B.

Case studies of how two of the instruments can be used successfully with carers show case managers or interviewers using the instruments with an individual carer and discussing responses to items (Berg-Weger & Tebb, 1998; Grant, Ramchara, McGrath, Nolan & Keady, 1998). It appears that how the assessment instruments are used, that is, the process, is extremely important. While most can be used as self-administered tools, an individualised approach with a skilled person who is able to relax and draw the carer out will be most beneficial. Carers are then prompted by the instrument to reflect on their situation. A preference for an interactive form of needs assessment interview was expressed by participants in a Carers Association Victoria project (Pierce & Nankervis, 1998). An examination of the available instruments indicates a need for further work in this area in the development and refinement of a single, streamlined instrument that can be applied across many caring situations.

Research Proposals Developed

Two research proposals have been developed and submitted to appropriate bodies for funding. The Executive Summaries of these projects are presented below.

Caring For Carers: An Enrichment Orientation

This research represents a paradigm shift in the approach to supporting carers – from a deficit model, where the focus is the ‘burden’ of caring, to an enrichment model, focusing on the positive aspects of caring.

Our key aim is to enhance the sustainability of providing care to another individual in a rural location, in the areas of aged care, disability and mental health. Our aim will be achieved by developing a systematic analytical tool to determine the genuine and broad-based health-related needs of carers and their need for support services. In contrast with current assessment methods, which tend to be reactionary, focusing on the burden of care, and weighted towards respite services, this analytical tool will be

based on an enrichment model that describes a positive, pro-active approach encompassing social, psychological and physical needs.

Caring for carers is a significant issue for our industry partner, the Department of Human Services (DHS) (Barwon South-Western region), as it is the major funding body for many support service providers in the areas of aged care, disabilities and mental health across this rural region of Victoria. Although substantial financial resources are allocated to these services, there is no evidence to confirm that current spending is optimally efficient and effective. Anecdotal evidence suggests that available funding may be too heavily weighted towards providing respite care, at the expense of other possible options.

The outcome of this project will be an analytic tool that will allow the physical, social and psychological needs of individual carers to be more readily identified. This analytical tool will reinforce positive aspects of caring, while being respectful of diverse concerns. The tool will be tested and evaluated.

The benefits of this project extend beyond the needs of our industry partner, and include:

- an enrichment model (encompassing the analytic tool) which can be utilised by service providers other than our industry partner
- more effective use of funds for supporting carers
- improved health and well-being of carers
- more sustainable caregiving relationships
- indirect benefits for care recipients - as they will be positively affected by the enhanced health and well-being of their carers.

Enhancing The Coping Skills Of Carers

The impact of care-giving is well documented. Some carers cope well, maintain personal self-esteem, well-being and positive family functioning. However, other carers do not cope so well, and experience a considerable negative health impact as a result of their caring role. Carers living in rural areas face additional problems due to isolation, distance, and a lack of access to some services. ‘Enhancing the Coping Skills of Carers’ is a health promotion project that aims to identify and describe useful coping skills for people caring for a child with a disability, and to apply this information to improve the well-being of carers who would benefit from the development of positive coping strategies. The project is important, first, because the possession of appropriate coping strategies positively impacts on the caring role, possibly decreasing the need for crisis interventions or other service provision. It is also important because it will provide a model for developing coping strategies that may be implemented across other sectors such as aged care and mental health.

This project will involve three stages. Firstly, experienced carers will be invited to participate in a structured interview with the aim of identifying useful and effective coping strategies. Secondly, a “Skills for Carers Kit” will be developed, in both print form and as a web site, based on the findings from the interviews. The kit will provide information to carers on effective coping strategies to use for particular situations, as well as information about how to deal with particular problems they experience as carers. Finally, the kit will be distributed to a group of carers and methodically

evaluated. Following this evaluation, the kit will be distributed to as wide a population of carers as possible throughout the Barwon and South Western region.

This project will positively impact on the health of persons in the rural and regional community who care for a child with a disability. It will provide a model that may be replicated for other groups of carers and reinforces our commitment to multidisciplinary and collaborative approaches to rural human services.

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Appendix A: Quantitative evaluations of the effect of interventions to support carers

<i>Authors and country</i>	<i>Participants / Relationship to care-recipient</i>	<i>Reason for care / Age of care-recipients</i>	<i>Intervention</i>	<i>Outcome Measures</i>	<i>Design</i>	<i>Findings</i>	<i>Limitations</i>
(a) Effect on care recipients: Respite							
Adler, Ott, Jelinski et al. (1993) US	37 patients and caregivers Caregivers: 92% female 81% spouse	Male veterans with dementia (AD or non-AD)	2 week in-hospital respite.	Caregivers: Physical Self-Maintenance Scale (PSMS), Behavioral Assessment Instrument (BA), Burden Interview (BI, Zarit), Geriatric Depression Scale (GDS).	Within subjects, repeated measures. Measures at 14 days and 7 days prior to admission, day of admission, at discharge, and 14 days after discharge.	Caregivers: Significant decrease in burden and depression in non-AD group on discharge, but improvement no longer present at 2 weeks follow-up. Improvements in AD group non-significant. Patients: Significant increase in PSMS dependence in AD group (not more than expected for disease progression) Little change in non-AD group.	No control group. Small sample size.

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Burdz, Eaton & Bond (1988) Canada	55 caregivers Intervention: 89% female 43% child Mean age 57 yrs Controls: 75% female, 50% spouse, Mean age 62 yrs	Elderly: dementia vs non-dementia	Facility-based respite care – mean of 15 days.	Assistance measure (ADLs), The Burden Interview, Memory and Behaviour Problems Checklist.	Comparison of intervention with controls (waiting list), with dementia and non-dementia patients in each group. Measures before and 2 to 3 weeks after respite (or 5 weeks apart for controls).	No effect on carers. Intervention patients (respite) showed significant improvements in problems (reported by carers) than waiting list (controls).	Non random group assignment, differences between control group and intervention group, heterogeneous sample, patient dementia diagnosis not validated.
Homer & Gilleard (1994) UK	77 carers (58 received respite, 54 interviewed at post-test) 56% female Mean age 66 yrs	Elderly	In patient respite care.	28 item General Health Q'aire, CAPE Behaviour Rating Scale (BRS).	Within subjects design.	Small but significant reduction in depression and increase in social dysfunction. Reduction in dependency in care recipients during respite.	No control group. Few details on respite care given, or details of carer's characteristics.
Howarth, Clarke, Bayliss et al. (1990) UK	474 patients	Aged 70 yrs or over, Unable to look after themselves	Admission to hospital for 2 to 3 weeks to provide respite for carer.	Mortality.	Comparison of death rates of persons admitted to hospital with those awaiting admission.	No significant difference in the death rates in those admitted to hospital for relief care compared with those waiting to be admitted.	

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Seltzer, Rheaume, Volicer et al. (1988) US		37 care-recipients with Alzheimer-type dementia Mean age 70 yrs 97% male	First-time, 2 week respite stay in AD ward.	MMSE, Blessed IMC (memory), PEA (ADL), MACC Behav. Adjustment Scale, BANS (Bedford Alzheimer Nursing Scale).	Pre-test on admission, and post-test at discharge.	Patients with most severe dementia showed some improvement on some of MACC and BANS measures. Patients with less severe dementia showed some deterioration.	Small sample. Possible lack of consistency in who scores measures.
(b) Effects on Carers: Respite							
Botuck & Winsberg (1991) US	14 carers 100% female 100% mothers	Adult children with severe disabilities Mean age 18 yrs	10 day overnight, out-of-home respite.	Bradburn Affect Balance Scale, Norwich Depressed Mood Scale, Activity Pattern Indicators.	Pre, during respite, and post test (3-4 days after respite) Intervention group only.	Increased feelings of well-being and less depressed mood during and after respite. Some changes in mothers' activities.	Small sample. No control group.
Caradoc-Davies & Harvey (1995) New Zealand	39 carers 72% female 72% spouses	People with disabilities – various 69% aged 65 yrs +	Social relief admission to long-stay or rehab. ward of hospital.	Barthel ADL, General Health Q'aire (GHQ), Zung (depression) Care-giver stress (Greene Scale), Social adjustment (SAS-SR) Index emotional support.	Pre – Post (1 week after discharge) measures.	Significant improvement only in personal distress subscale of stress scale, Significant improvement in care-giver GHQ scores after social relief.	Small sample. No control group. No details on length of admission.

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Deimling (1991) US	78 carers 59% spouse 59% Black	Alzheimer's disease	Various types of respite care over 4 mth period.	CES-D scale Symptoms of health problems, Relationship strain, Caregivers reports of activity restriction, ADL competency & cognitive functioning (care recipients).	Comparison of declining with non-declining participants. Measure at pre-test and 4 – 6 months follow-up.	No improvements in caregivers overall. In caregivers of patients with stable condition, significant improvement in depression. In caregivers of patients with stable cognition, significant decline in health problems, and relationship strain.	No details given on the amount of respite care received. No control group.
Johnson & Maguire (1989) Australia	46 carers 50% male Mean age 75 yrs	Geriatric and psychogeriatric clients	Day care over 4 mths, 1-3 times a week.	Carer Stress Scale, Katz R. Scale for clients.	Pre and post test.	Reduction in anxiety and suspiciousness in clients.	Small sample. No comparison group.
Kosloski & Montgomery (1993) US	92 carers Intervention: (<u>n</u> = 47) 77% female 60% spouse Controls: (<u>n</u> = 25) 68% female 68% spouse	Alzheimer's disease or related condition	In-home or day care of various duration and frequency.	Subjective burden, objective burden, morale (all by authors).	Comparison of intervention group with waiting list control group. Pre-test and 6 mths follow-up.	Intervention group significantly lower subjective burden, and significantly higher morale at 6 mths follow-up.	Small control group. Non-random controls. Control group higher minority representation and lower income.

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Lawton, Brody & Saperstein (1989) US	642 carers E = 317 81% female 50% spouse Mean age 60 yrs C = 315 78% female 40% spouse Mean age 60 yrs	AD patients Mean age 76 yrs	Over 12 mths: Case management by respite service social worker, Offer of range of respite services, Regular contact (each 2 mths min.), Caregiver education and transportation.	Pre-post measures: Use of respite, Caregiving attitude scales, Physical Health scale, CES-D, Bradburn Affect Balance Scale, Nursing home placement.	Controlled trial, random assignment.	Treatment group patients stayed longer in the community (22 days).	Treatment group was offered respite – not all used it (analysis with only users non-significant also).
Rimmerman (1989) Israel	53 mothers (28 intervention, 25 controls) Median age 29 yrs	Developmental disabilities (75% mental retardation, 25% multiple disabilities) 75% severely handicapped Aged 18 mths to 5 yrs, median 3.2 yrs	Home-based respite for at least 6 hrs per week over 18 mths.	Questionnaire on Resources and Stress (short form – Friedrich).	Comparison between intervention and controls. Measures at pre-test, 6 mths, 12 mths, 18 mths.	Reduction in maternal stress in intervention group compared with controls. Reduction was not consistent over time. Reduction peaked at 6 mths for perception of child's characteristics and at 12 mths for maternal pessimism, maternal family problems, and maternal perception of child's physical incapacitation.	Small sample size.

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Rimmerman, Kramer, Levy & Levy (1989) US	78 mothers Mean age 46 yrs	Mentally retarded children and adults Mean age 25 yrs 58% male	Use of respite care services – home-based and centre-based.	Coping Resources of Stress (QRS-F), Self-esteem component of Interpersonal Support Evaluation List (ISEL), FACE-III (measures family system).	Cross-sectional.	Respite most benefitted mothers with high self-esteem and young, low-functioning child.	Few details of results provided. No control group.
Skelly, McAdoo & Ostergard (1993) US	30 carers, “mostly” wives, mean age	Elderly veterans	Participation in facility-based respite care program over past 2 years.	The Burden Interview, Memory and Behaviour Problem Checklist, Zarit’s ADL scale.	Quasi-experimental: Intervention group compared with control group (waiting list), measures at pre- and post-test.	Suggests that respite reduces burden related to memory and behaviour problems.	Few details provided on results or carer characteristics.
Zarit, Stephens, Townsend & Greene (1998) US	At 3 mths: 324 carers, 81% female, 44% spouse 12 mths: 193 carers, 77% female, 43% spouse	Dementia	Day care – at least 2 times per week for 3 mths (first measure), 12 months (2 nd measure).	Role Captivity (from Pearlin), Overload (new), Worry and strain (new), CES-D (depression), Anger (from Brief Symptom Inventory), Positive affect (from PANAS).	Quasi-experimental, comparison of intervention and control groups (latter recruited from States not offering day care). Measures at pre-test, 3 mths and 12 mths.	Intervention group had significantly lower levels of overload, worry/strain, depression and anger at 3 mths, and lower levels of overload and depression at 12 mths than control group.	High attrition rate – many in intervention did not continue using day care. Restrictive inclusion criteria (must not have used day care before, use twice weekly etc).

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(c) Effect on Carers: Other & mixed							
Brodaty, Roberts & Peters (1994) Australia	81 co-resident primary caregivers: 76% female 75% spouses	Alzheimer's Disease	Total of 18 hours training within support groups, over 4 months. Topics included: disease process, communication problems and behavioural disorders, impact on the carer, stress management, problem-solving, and management of specific behavioural problems.	Problem Behaviour Check List, Family Burden Interview, General Health Questionnaire, Satisfaction with Life Scale, Positive and Negative Affect Scales, Happiness Scale, Knowledge questionnaire.	Quasi-experimental prospective controlled intervention trial. Support groups as intervention or control groups. Three groups: Completers – finished program, Non-completers, started but attended fewer sessions, Controls – waiting for training.	No significant findings.	No consent rate reported, but appears low given the large number of support groups involved. Small sample size. Some support group co-ordinators uncomfortable with structured educational package.
Chang (1999) US	65 caregiver dyads Carers: 100% female 89% spouses	Dementia	Cognitive-Behavioural intervention group received videotapes demonstrating assisted modeling behaviour (eating and dressing) and Nurseline support program to reinforce video and explore caregiving	Ways of coping (Moos), Caregiver Appraisal tool (burden – Lawton et al), Brief Symptom Inventory, Strength of intervention, Care recipients – Functional Rating Scale.	Two-group randomised trial. Measures at baseline, 4, 8, and 12 weeks.	Time by group interaction for depression – intervention group's depression scores stable over time, control group's increased. Both groups showed decrease in anxiety. Both groups showed decreased	Effect on control group of weekly telephone calls. Impossible to separate effect of video from that of telephone calls.

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			strategies (telephone calls), Control group received weekly telephone calls only (not discussing strategies).			use of emotion-focused coping strategies. Both groups decrease in satisfaction.	
Chiverton & Caine (1989) US	40 co-resident spouses: 20 intervention group: 50% male 20 in control group: 45% male	Alzheimer's Disease	3 group educational sessions covering the disease process, communication skills, behavioural management, strategies re. ADLs, resources available, group discussion.	Health Specific Family Coping Index for Non-Institutional Care (HSFCI).	Comparison of intervention group with control group. Measures taken pre- and post educational program.	Intervention group improved significantly more than control group on overall coping score. Significant differences in 3 categories of HSFCI: Therapeutic competence, Knowledge of condition, Emotional competence.	Small sample size. Measured only short term effects.
Gammon & Rose (1991) US	42 carers 100% mothers Mean age 38 yrs	Children with developmental disabilities	Coping Skills Training Program: 2 hrs per week x 10 weeks in small groups. Training comprised: cognitive restructuring, problem solving,	Problem-Solving Inventory (PSI), Role-play test, POMS, Questionnaire on Resources and Stress (QRS), Self-ratings on goal attainment	Comparison of intervention group with control, random assignment. Measures at pre-test and post-test	Intervention group reported greater problem-solving skills on 2 of 3 sub-scales and total PSI score. Intervention group obtained significant treatment gains in	Small sample size. Multiple treatment interference.

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			individual goal attainment, interpersonal skills training.			2 of 5 situations and total score for interpersonal communication skills, 1 of 3 positive self-regard situations, on 1 of the POMS subscales only, and 4 of 11 subtests of the QRS, and improved perceptions of goal achievement.	
Greene & Monahan (1989) US	289 caregivers All screened – experiencing substantial stress. 86% female 77% co-resident 208 in intervention 81 in control group	Frail elderly persons	Support and Education Program – 8 weeks x 2 hrs Comprised: guided group discussion, education in techniques and information, relaxation training.	SCL-90 – anxiety, depression, hostility, Caregiver burden (Zarit). Care-receivers: ADL, IADL, cognitive and behavioural dysfunction.	Non-random assignment to treatment or control group. Measures at pre-test, post-test and 6 mths.	Significant decrease in anxiety and depression in intervention group. These effects still present at later test but attenuated over time.	Non-random assignment. Self-selection – control group comprised individuals unable to find suitable group. Participants screened – all high levels of stress, could be just regressing to mean (reductions observed).

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Greene & Monahan (1987) US	As above	As above	As above	Nursing home placement.	As above.	After controlling for a number of factors, those who attended program significantly lower institutionalisation rate than non-attenders.	As above.
Goodman & Pynoos (1990) US	66 family caregivers Peer telephone network group: 68% spouse 77% female Taped lectures group: 66% spouse 83% female	AD or Dementia	Peer telephone network: Groups of 4-5 caregivers call each other in rotating pattern over 12 weeks, each call and receive call for 15 minute supportive conversation. Taped lecture group: Caregivers access by telephone 12 taped lectures about AD over 12 weeks.	Memory and Behavior Problem Checklist, Burden Interview (Zarit), Caregiver-Elder Relationship Scale, Mental health scale (Veit & Ware), Social Network measure (Vaux & Harrison), Percieved Social Support for Caregiving , Knowledge.	Random assignment to two intervention groups. Pre and post measures.	Both groups gained significantly in satisfaction with social supports, perceived social supports for caregiving and information. Taped lectures group – greater information gain and increased contact with family and friends for emotional support.	No control group. Participants in taped lectures group knew about peer network group and were told they could participate in one later – may have caused them to be more aware of using friends and relatives for support.
Kaasalainen, Craig & Wells (2000) Canada	46 caregivers 100% female Intervention group: 78% daughter Control group: 78% daughter	Aged	Caring for Aging Relatives Group: 8 weeks X 2 hr sessions. Provide information and support.	Profile of Mood States (POMS)- (morale), Personal Resource Questionnaire (PRQ) – social support, Knowledge, Visual analogue	Quasi-experimental pre-test, post-test design with a matched comparision group.	Significant increase in knowledge within intervention group. Participants reported that the group provided them with social support.	Small sample size. Convenience sample, no randomisation. Approx. half of participants in full-time employment. Participants obtained high

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				scale of perceived social support.			morale, information and social support scores on pre-test.
Mohide, Pringle, Streiner et al. (1990) Canada	60 caregivers at baseline (42 at 6 mths) Co-resident Experimental group: 70% female 70% spouses Control group: 73% female 83% spouses	Dementia – progressive and irreversible.	Intervention: Caregiver-focused health care, education about dementia and caregiving, problem-solving assistance, regular in-home respite, self-help family caregiver support group. Control group: conventional community nursing care.	Depression (CES-D), Anxiety (STAI), Caregiver Quality of Life Instrument (CQLI), Self-rated health, Life satisfaction (Cantil Self-Anchoring Striving Scale), Day-to-day impact scale (developed by authors).	Randomized trial with control group. Measures at baseline, 3mths, 6 mths.	Improved CQLI in experimental group (reported as clinically, not statistically, significant), Day-to-care impact decreased in experimental group.	High attrition rate – 30% did not complete trial. Small sample size.
Montgomery & Borgatta (1989) US	541 primary carers 79% female 59% adult children 31% spouses	Impaired elderly persons Median age 82 yrs	1 – seminars, support group, family consultation, respite. 2 – seminars, support group, consultation. 3 – support group. 4 – consultation. 5 – respite.	Health ratings, OARS, ADL & IADL, Care inventory, Subjective & objective burden, Nursing home placement.	Random assignment to control or one of five treatment groups. Measures pre, after 12 mths, after 20 mths.	Results at 12 mths: Service eligibility associated with decrease in subjective burden for all groups except controls. Services delayed placement among adult child carers but encouraged placement by spouse carers.	Many carers did not use services offered. High attrition rate, especially at 20 mths. Difficult to recruit people earlier in caregiving role.

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Robinson & Yates (1994) US	33 Caregivers: 76% female 76% spouses	Dementia	6 x 90 minute training sessions. 2 types of training: Social Skills Development Program – network building skills, how to develop ties to others, encourage use of social support and community resources. Behavioural Management Skills Development Program – taught caregiving techniques and problem-solving.	Subjective and objective burden (Montomery et al. 1985), Attitudes toward using adult day care and asking for help, Satisfaction with the amount of help received.	Comparison of control group with 2 intervention groups.	Differences found only in small number (6) who participated in second (different) sessions months later.	Small sample size. Control group met twice to complete measures – acted as a support group.
Schultz, Smyrnios, Grbich & Schultz (1993) Australian	101 carers 33% adult children, 21% spouses, Intervention group: 86% female Control group: 93% female	Various, 99% aged 60 ys +	Regular group meetings for 2.5 hours – 9 meetings over 18 weeks.	State trait anxiety inventory (STAI), Affect Balance Scale (ABS).	Comparison of intervention group with non-random control group. Measures at pre- and post-test.	Reduction in state anxiety for the intervention group. Intervention group gained in positive affect.	Control group was waiting list – unable to arrange suitable time or venue to participate. Participants self-selected.
Toseland, Labrecque, Goebel & Whitney (1992)	N = 85 wives of veterans with high levels of burden:	Male, frail, ageing veterans (mean age 70 yrs)	6 Support groups (5-9 indivs in each) met 8 times	Caregiver's physical health status,	Randomised control group. Pre- and post-	Support group decrease in subjective burden,	Control group's comments that even interviews

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US	\underline{n} = 39 support group \underline{n} = 46 control group		for 2-hr sessions. 4 components: support, education & discussion, problem solving, stress reduction.	Care receiver's health and functional status, Burden scale, Beck Depression Inventory, Geriatric Depression Scale, Spielberger State-Trait Anxiety Inv. Perceived self-efficacy, Help Seeking Coping Index, Index of Coping Responses, Informal support network, Quality of marital relationship, Pressing problems, Personal Change, Satisfaction with program.	interviews.	greater use of active behavioural coping, knowledge of community resources, perceived independence in marital rel'ship, less perceived stress, and greater improvement in pressing problems, greater personal change.	may have made a difference (having someone to talk to).
Toseland, Rossiter & Labrecque (1989) US	52 adult daughters or daughter-in-law 100% female Peer-led group: \underline{n} = 16 44% co-resident Professional	Frail elderly persons	2 intervention groups, both 8 x 2 hr weekly sessions: Peer-led support groups: self-help approach, sharing concerns, information etc. Professionally-led	Extent of Caregiving Scale, Burden Inventory (Zarit), Problems with Caregiving Scale, Bradburn Affect Balance Scale, Brief Symptom	Random assignment to two intervention and one control group, pre and post-test.	Improvement in psychological functioning, increases in informal networks and positive personal changes in handling caregiver role in	

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	group: \underline{n} = 16 38% co-resident Control group: \underline{n} = 20 65% co-resident		groups: Structured sessions included education, discussion and problem solving.	Inventory, Community Resource Scale, Pressing Problem Index, Drug and Alcohol Use Scale, Personal Change Scale.		both groups. Peer-led group greatest increase in informal support network, prof-led group greatest improvement in psychological functioning.	
(d) Poorer quality							
Bland & Harrison (2000) Australia	15 carers 87% female 53% parent	Bipolar disorder	Family Support Program – education and support (adapted from Schizophrenia program).	Knowledge of Schizophrenia Scale, General Health Q'aire (distress), Level of Caregiver Support Scale, Coping, Attributions of Symptoms Scale, Life Skills Profile (patient community functioning).	Within subjects, pre-test (\underline{n} = 15) and post-test (\underline{n} = 11) with follow-up (\underline{n} = 8 only).	5 of 11 carers reliably improved in knowledge, 4 obtained lower distress scores at post-test, 6 improved in subjective coping, 6 less likely to attribute difficult behaviour to patient's personality.	Small sample size. High attrition rate. Difficulties in recruiting participants. Limited analysis possible due to small sample.
Conlin, Caranasos & Davidson (1992) US	15 carers, all co-resident Intervention (\underline{n} = 7): 100% female, 29% spouse, Mean age 50 yrs	Dementia	Respite care for 6 to 8 hrs, 2 days a week, over 10 week period. Respite either in adult-assisted facility (\underline{n} = 2), or in-home (\underline{n} = 5).	Relative's Distress Scale, Profile of Mood States (POMS), Institutionalisation.	Comparison of intervention with control group, measures at pre-test, 5 weeks and 10 weeks.	Time x Condition only effect for Relative's Stress Scale and confusion-bewilderment subscale of POMS (intervention group	Small sample. Differences between groups in age (Controls much older) and in relationship to care recipient. Two types of

<i>Authors and country</i>	<i>Participants / Relationship to care-recipient</i>	<i>Reason for care / Age of care-recipients</i>	<i>Intervention</i>	<i>Outcome Measures</i>	<i>Design</i>	<i>Findings</i>	<i>Limitations</i>
	Control (\bar{n} = 8): 75% female, 100% spouse, Mean age 69 yrs					decreased). No differences at individual times between groups.	respite evaluated at once.
Theis, Moss & Pearson (1994) US	130 carers at baseline 89% female 62% spouse Co-resident	Elderly, Various problems	Respite program – In-home by volunteers &/or short term stay in institution.	Family Inventory of Resource Management (FIRM), POMS, QOL, Response to Caregiving Inventory (Farren) Satisfaction.	Planned longitudinal – very low numbers at 6 mths and 12 mths so really only cross sectional.	High satisfaction reported with respite.	Very high attrition rates makes 6 and 12 mths measures meaningless. No control group. Does not report actual use of respite.
Scharlach, & Frenzel (1986). US	99 carers of veterans 100% female 80% wives	Range of impairments Mean = 72 yrs	Use of respite program – available for 3 to 28 days in Nursing Home Care Unit of VA Hospital.	Self-report from carers.	Cross sectional.	Carers reported improvements in their own health and sleeping, 56% reported improvements in caregiver-patient rel'ship. Equal % reported increased or decreased likelihood of nursing home placement in 12 mths.	No control group. No pre-post measures, purely self-report at single time.

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Robinson (1988) US	20 caregivers Few details given, not all co-resident, some hired carers	Mentally impaired elders	Caregiver Training Program – training in assertiveness, communication, social skills.	Rosenberg’s self-esteem scale, Gambrill & Richey’s assertion inventory, Objective & subjective burden (Montgomery), Norbecks’s social support q’aire (NSSQ).	Pretest-posttest randomized treatment and control group.	No significant differences between groups, but within intervention group burden reduced.	Participants changed treatment groups after randomisation. Small sample size. Few details about participants.

Appendix B: Summary of instruments for assessing carers' needs

The CADL, CAMI and CASI

Nolan, Grant and Keady (1998) provide three instruments which can be used as a basis for assessment and intervention with family carers. They argue that each assessment situation is unique and requires a skilled individual response by the assessor. As these instruments are based on the transactional model of stress, it is the carer's subjective appraisal that is most important. Each scale has good reliability coefficients.

CADI – the Carers' Assessment of Difficulties Index.

This is a 30-item index in which carers indicate if each statement applies to them, and if so, if they find it “not stressful”, “stressful”, or “very stressful”. Items cover:

- Carer-dependant relationships (7 items)
- Reactions to caregiving (7 items)
- Physical demands of caring (6 items)
- Restricted social life (3 items)
- Poor family support (2 items)
- Poor professional support (2 items)
- Financial consequences (2 items)

CASI – the Carers' Assessment of Satisfaction Index.

This is a 30-item index in which carers indicate if each statement applies to them, and if it does, does it provide them with “no real satisfaction”, “quite a lot of satisfaction”, or “a great deal of satisfaction”. The authors categorise items by beneficiary (person with disability, shared, or family carer) and the dynamic involved (interpersonal, intrapersonal or outcome). Lundh (1999) identified the following conceptual themes:

- Giving pleasure to the cared-for person (2 items)
- Maintaining the dignity and maximising the potential of the cared-for person (8 items)
- Enhanced relationships (2 items)
- Expressions of appreciation (3 items)
- Meeting perceived responsibilities (5 items)
- Mutual love and support (2 items)
- Personal development of the carer (8 items)

CAMI – the Carers' Assessment of Managing Index.

This is a 38-item index in which carers indicate if they use each way of dealing with the demands of caring, and if they do, do they find it “not really helpful”, “quite helpful”, or “very helpful”. Items cover three types of coping strategies:

- Managing events / problem-solving (14 items)
- Managing meanings / perceptions (15 items)
- Managing stress (9 items)

The Caregiver Well-Being scale

The Caregiver Well-Being scale was designed for use by social workers (Tebb, 1995).

It is based on the premise of the health-strength model described by Weick (1986, cited in Tebb, 1995), suggesting that: “By focusing on their regenerative capacity and resiliency, with support, caregivers can develop and expand their strengths and thus have a more positive experience in caregiving” (Tebb, 1995, p. 88). In the model, the social worker acts as a catalyst, empowering the clients to examine their inner knowledge of ways to best care for themselves in their role as caregiver.

In developing the Caregiver Well-Being scale, Tebb (1995) started with Weick and Freeman’s (1983, cited in Tebb, 1995) health menu, which lists nutrition, exercise, skills building, relaxation, personal growth, and social support. These items fall into two categories: basic human needs and activities of daily living. These two categories form the two subscales of the Caregiver Well-Being scale: 22 items address basic human needs, using Maslow’s hierarchy of needs; and 23 items address activities of daily living from a strengths perspective (using several sources for items).

The following factors have been described by Berg-Weger, Rubio and Tebb (2001):

Basic Needs Subscale

- Expression of feelings (7 items)
- Attendance to physical needs (4 items)
- Self-security / self-esteem (11 items)

Activities of Living Subscale

- Time for self / leisure activities (10 items)
- Maintenance of functions outside the home (3 items)
- Family support (3 items)
- Household maintenance (3 items)
- Household tasks (4 items)

The Victorian Carers Program instrument

Schofield, Murphy, Herrman, Bloch and Singh (1997) report the scale characteristics of a new generic instrument developed to assess the experience of caregiving, and the social and emotional well-being of caregivers. These measures were used in telephone interviews for the Victorian Carers Program research.

The instrument includes:

- Life satisfaction – based on work by Headey & Wearing (1992), a 6 item scale was used.
- Positive and negative affect – Psychological well being was measured using the 20-item Positive Affect (PA) and Negative Affect (NA) mood scales (Watson et al., 1988).
- Health – Rates of major health problems, use of medication, number of visits to medical practitioners, number of nights in hospital, and respondents’ assessment of their overall health.
- Social Support – Seven items modified from the Provision of Social Relations Scale (Turner et al., 1983).
- Overload – Assessed by three of four items from a scale developed by Pearlin et al. (1990).
- Family environment – two 3-item scales designated ‘Closeness’ and ‘Conflict’.

- Caring role – Factual information such as duration of care, responsibility for household tasks. Also agreement with 15 statements, some drawn from Caring for Relatives Questionnaire (Greene et al., 1982) and the Caregiver Appraisal Questionnaire (Lawton et al., 1989).

Care recipient dependencies, disabilities and behaviour problems:

- Assistance with daily living – based on items used by Pearlin et al. (1990), the ABS, and Greene et al. (1988). Items produced two factor solution: ‘personal activities of daily living’ (PADL), and ‘instrumental activities of daily living’ (IADL).
- Severity of disability measures – carers were asked if their relatives were impaired in seven broad classifications of disability.
- Behaviour problems – carers were asked about the frequency of 21 behaviour problems (from several sources including Pearlin et al 1990).

The authors conclude that the scales demonstrate satisfactory reliability, and that this instrument advances on previous ones, while it is conceptually similar to some (e.g. Pearlin et al., 1990; Lawton et al., 1989) in that they assess the experience of caregiving, mediating factors and outcome, but this one is relevant to all ages and disabilities (previous ones focused solely on dementia carers). It also offers more opportunity for the expression of positive experiences and outcomes.

Assessing carers of persons with Alzheimer’s disease

Pearlin, Mullan, Semple and Skaff (1990) describe a measurement tool developed specifically for carers of persons with Alzheimer’s disease. This instrument is based on Pearlin et al.’s stress process model.

The measurement tool comprises:

Primary stressors - Objective indicators:

- Cognitive status of Alzheimer’s patient (8 items)
- Problematic behaviour of Alzheimer’s patient (14 items)
- ADL and IADL dependencies (Katz et al., 1963; Lawton & Brody, 1969), and a single question regarding the patient’s overall resistance to help.

Primary stressors - Subjective indicators:

- Overload (4 items)
- Relational deprivation (3 items on deprivation of intimate exchange, 3 items on deprivation of goals and activities).

Secondary stressors - Role strain:

- Family conflict (12 items)
- Job-caregiving conflict (5 items)
- Economic problems (3 items)

Secondary stressors - Intrapsychic strains:

- Self-esteem (Rosenberg, 1965 scale)
- Mastery (Pearlin & Schooler, 1978 scale)
- Loss of self (2 items)

- Role captivity (3 items)
- Caregiving competence (4 items)
- Personal gain (4 items)

Mediators:

- Coping (Management of the situation – 4 items; Management of meaning – 9 items; Management of distress (8 items)
- Social Support (Instrument support – items not specified; Expressive support – 8 items).

Aged care assessment

The Carers Association of Victoria has produced information on the process of assessing carer needs in aged care (Pierce & Nankervis, 1998). They suggest a range of domains that should be included when assessing needs, rather than using a pre-defined instrument. A cue sheet or checklist for exploring the carer's various life domains which may be affected by caregiving is presented.

The domains which should be included in needs assessment are:

- Domestic and family responsibility
- Family relationships
- Social sphere
- Employment
- Education
- Financial and other circumstances
- Physical health
- Emotional health
- View of future and overall quality of life

Assessment tool for families of children with disabilities

Deal, McWilliam, Cooper and Trivette (1989) briefly present an assessment tool which assesses strengths and needs of the five components of the total ecological system. This assessment tool is designed specifically for use with families with a child with disabilities. It assesses the family rather than the carer.

Based on a family-focused approach to assessment and intervention. The focus is on the exchanges between the child and the settings in which s/he participates and the significant individuals in their life. Each is rated as Not at all Supportive, Supportive, or Almost Always Supportive. Supportive is defined as “fostering and maintaining: (1) personal well-being for each family member as an individual (2) intra-family relationships; and (3) relationships of individual family members and the family as a unit with extended family, friends, social groups, and their community as a whole” (p. 270).

Components assessed include:

- Family (12 items)
- Child (9 items)
- Environment (7 items)

- Informal support network (6 items)
- Formal support network (7 items)

The first step in the assessment process is a mutual sharing of information between staff and the family. The case coordinator visits the home and gains information about the child and the family, their priorities, strengths and needs are assessed.

The next step is to ascertain how strengths and needs affect the day-to-day functioning of the family. Routine activities of the family are analysed, such as mealtimes, leisure time, bathing, bedtime etc. Where needs are apparent, the professional and parent engage in a partnership of problem-solving to examine all possible resources and alternatives for meeting needs. Strategies for intervention may be implemented at the level of the child, the family, the environment, other support systems or a combination.

The process of assessing regular family routines also allows for the identification and reinforcement of strengths and positive coping abilities already used by the family. Recognition of the family's strengths is a powerful intervention with families.

The assessment process culminates in the development of an intervention plan by the family members and professionals involved. This plan identifies the specific services to be received as well as specific interventions to be implemented. This is recorded in a matrix format specifying the routines when interventions will be implemented.