A CAMEO OF RE-CREATION

The Caregiver Recreational Respite Program

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Executive Summary

1. The Caregiver Recreational Respite Program provided 39 caregivers with the opportunity to take part in a seven week course of drawing, relaxation, walking, or activities of their own choosing. The research team organized classes and transport for caregivers and offered respite care for their dependants. In most cases, caregivers preferred to make their own respite arrangements through their informal network. The majority of caregivers indicated that they would not have participated in courses of the kind offered by the Program if the research team had not organized it for them.

2. The viability of the Caregiver Recreational Respite Program depended on caregivers being interested in pursuing activities outside caregiving, and once enrolled in the Program, attending on a regular basis. The Program met these objectives and attracted high quality staff who were successful in bringing their expertise to caregivers.

3. The effectiveness of the Caregiver Recreational Respite Program was supported by reports from caregivers of (a) a restoring of spirits, (b) the acquisition of new interests and skills, (c) social engagement through the classes, and (d) motivation to pursue their interests. The majority of caregivers reported little disruption to the relationship between caregiver and care receiver as a consequence of their participation in the Program.

4. The effectiveness of the Caregiver Recreational Respite Program was also evaluated through comparing before and after measures on physical health, life satisfaction, burden, minor psychiatric symptoms, feared possible selves and hoped-for possible selves. Two changes were observed that could be linked with Program effectiveness. Participants recruited from the community showed a significantly larger drop in feared possible selves after the Program. Participants who were recruited through the Carers

Association reported a significantly larger drop in minor psychiatric symptoms after the Program.

5. The research undertaken in conjunction with this Program revealed that the major determinant of well-being among caregivers was the quality of the relationship between the caregiver and the care receiver. The intervention was overshadowed in its impact on well-being by the caregiver's perceptions of the care receiver's capacity to relate to and show regard for the feelings of the caregiver. Relationships that were degenerating were characterized by the care receiver becoming hostile, demanding and unappreciative of the caregiver's efforts.

6. The caregivers who regarded the Program most positively were caregivers experiencing degeneration in their relationship with the care receiver. Positive responses were also characteristic of caregivers who were committed to care on a number of dimensions: Caregiving made them feel useful and busy, they enjoyed the companionship of the care receiver, they provided emotional care as well as physical care, they had little backup support, and they had not taken steps to arrange a hostel or nursing home placement. In other words, most benefit from the Program was reported by those who were most committed to caregiving and on the verge of loss.

7. This finding provides one possible explanation for why caregivers praise support services while showing no improvement in independent measures of well-being. Well-being is shaped by factors that are far more important to the caregiver than the use of respite. Respite is the crutch when well-being falters.

8. In spite of the effectiveness of the Program, caregivers were hesitant to come forward to take advantage of it. Recruitment through GP surgeries, community support groups, and local newspapers all resulted in a very slow take up rate.

9. The explanation offered for this resistance is the caregiver's reluctance and slowness to accept the identity of "caregiver" alongside wife, daughter, husband, or son. Recruitment to the Program was most successful through the Carers Association, where caregivers were given maximum support in understanding the changes that were occurring in their lives and the steps that they might take to cope with new circumstances. A significant aspect of this awareness is the legitimacy of taking time out and accepting respite support.

10. It is of note that where recruitment was successful, caregivers from the community benefited as much from the Program as caregivers from the Carers Association. The workload and burden of caregivers recruited from these different populations did not differ, providing no basis for assuming that the needs of "non-networked" caregivers are less. These findings reinforce the view that extra effort needs to be made to inform those outside caregiving networks of the options for support that are available to them. Other community networks need to be accessed to improve take up rates among carers who need a break.

11. Very few caregivers reported disruption to the caregiver-care receiver relationship, but the findings demonstrate that this is a possibility even in a group of volunteer participants. Respite services should be offered to caregivers with full recognition that their use may adversely affect relationships between caregivers and care receivers, and care receivers must be recognized as active participants in the respite decision.

12. The research did not identify a specific social demographic group that is likely to benefit more from the Program. The findings highlight the importance of empowering caregivers to make their own decisions regarding respite after being offered information, options, and role models to explain how respite can be used beneficially for both the caregiver and the care receiver.

13. Being able to benefit from respite is more a function of attitude than workload. This report introduces two concepts warranting further research. Both concepts describe enmeshment in caregiving, that is, an involvement in caregiving in terms of one's thoughts and actions to the virtual exclusion of everything else. Enmeshment entails a loss of balance in one's life. The two types of enmeshment identified in this study were relationship enmeshment in which the caregiver's identity faded into insignificance in the shadow of the person receiving care, and role enmeshment, in which the caregiver singlemindedly pursued the role of being a caregiver, without stopping to think about different ways of providing care. Relationship enmeshment shows signs of being most damaging to the caregiver as she/he tries in vain to find a sense of worth in the eyes of the care receiver. Role enmeshment threatens harm to both caregiver and care receiver through excluding others from participating in the caregiving process.

Recommendations

These findings suggest that the Caregiver Recreational Respite Program has the potential for bringing about change in the coping capabilities of caregivers. Following are our recommendations for improved implementation.

1. The Caregiver Recreational Respite Program should be trialed on a larger scale, preferably in conjunction with a carers' association or other community association that can provide education, counselling and practical advice for those who may need further support.

2. The Caregiver Recreational Respite Program ran for 7 weeks. Comments from participants and instructors, and the observations of the research staff suggest that a longer time frame may be needed to receive maximum benefit from such a program.

3. Recruitment for Caregiver Recreational Respite Programs should be planned at three levels. First, information should be available in the community for those who can benefit from respite, but who have no connections with caregiving support networks, and may not even see themselves as caregivers. Second, the Program should be promoted by respite care agencies as an opportunity to expose caregivers to ways of using respite constructively as part of a care plan: Respite clients will be familiar with respite care, but not necessarily with using respite for a recreational activity for themselves. A promotion of this kind may involve referrals to the association sponsoring the Recreational Respite Program. Finally, community associations need to take a leadership role in educating caregivers to use respite not only to relieve stress, but enhance well-being, to reconnect with past interests and create new identities.

4. GPs, and to some extent health care workers, need to be assisted in identifying caregivers who have unmet needs as a result of caregiving and who would benefit from links with caregiver support associations. The screening instrument used in this project proved ideal for quickly identifying caregivers whose lives were seriously disrupted by their caregiving responsibilities. The instrument assesses psychological and physical caregiving pressures, and can be completed quickly and easily by clients. GPs can use the responses to enquire further about the problems faced by caregivers and advise contact with support agencies where appropriate. Caregivers can be advised that if they ticked yes to more than half the questions in the Threat to Basic Needs Burden Scale, it is in the long term interest of both caregiver and care receiver to find additional support. The benefits to GPs of using the instrument when dealing with stress related illness are expected to be greater than the time required for its completion.

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Chapter 1

The value of respite care to caregivers

The contribution of unpaid carers in the community to maintaining the quality of life of those experiencing frailty in old age, long term illness, or disabilities is substantial and now widely recognized. Informal carers, either spouses, other relatives, friends or neighbours, provide support for 74% of the activities for which persons with a disability living in an Australian household need help (Australian Bureau of Statistics, 1993). How carers are best supported in this work is a question that is far from resolved. While de-institutionalization promised economic efficiencies and improved quality of life for those formerly supported in long term care facilities, governments were unprepared for the costs that were to be felt by families and friends, who, as they provided care to others, developed their own needs for support. The provision of help with household and personal care tasks, which are the forms of assistance that were initially anticipated, represent the tip of the iceberg. It is well established that the social and emotional costs borne by carers and their families are high (Braithwaite, 1990; Cantor, 1983; Commonwealth /State Ministers Conference for the Status of Women, 1994; Gilhooly, 1984; Gilleard, 1984; Grad & Sainsbury, 1963; Kinnear & Graycar, 1982; Schultz, Smyrnios, Schultz, & Grbich, 1993; Schulz, Visintainer, & Williamson, 1990). In a bid to reduce, or at least contain pressures on families, governments have directed substantial resources to initiatives that give carers a break from caregiving (Commonwealth Department of Health and Family Services, 1996). These initiatives, referred to broadly under the rubric of respite services, have been endorsed as a first order priority by caregiver associations (Carers Association of Australia, 1994).

Widespread commitment to respite care has given rise to a variety of forms of delivery, including the provision of care at home or in a facility, on a regular or occasional basis, for anything from a few hours to a number of days or weeks. Finding effective ways of providing respite services has emerged as a pressing issue for policy makers and professionals alike, as government resources diminish and public demand increases (Callahan, 1989; Knight, Lutzky, & Macofsky-Urban, 1993). The Caregiver Recreational Respite Program represents an example of an innovative response to this challenge. The analysis of the quantitative and qualitative evaluation data gathered during the course of the Program provides encouragement and direction for future programs of this kind, in spite of difficulties in satisfying some of the criteria that we had initially specified for its viability and effectiveness.

The Caregiver Recreational Respite Program

The Caregiver Recreational Respite Program provided at-home respite to caregivers for three to four hours a week for seven weeks, so that caregivers could take part in recreational activities offered through the Program or pursue alternative recreational activities of their own choosing.

The research objectives in trialing such a program were two-fold. The first was to evaluate the viability of the Program and its effectiveness in providing relief to those who had primary responsibility for providing home care to an adult.

The second objective was broader in scope. The Caregiver Recreational Respite Program was designed to provide new insights into three policy questions that loomed large at the time of the Respite Care Review (Commonwealth Department of Health and Family Services, 1996):

(a) Why are respite services wanted by caregivers, but not always fully utilized?

(b) What kinds of respite care provide the most effective relief for caregivers?

(c) How is respite care perceived by caregivers in the context of their caregiving situation?

High demand, low usage

The Respite Care Review found that Australian carers, like others in the western world, are enthusiastic supporters of respite programs, especially those that are flexible and are delivered at home (Commonwealth Department of Health and Family Services, 1996). Yet the Review noted that respite services were not accessed to the extent expected. In particular, supporting evidence revealed that respite services are not used by those in the community who appear to have the greatest need, those identified through Australian census data as vulnerable caregivers (Gibson, Butkus, Jenkins, Mathur, & Liu, 1996) .

In Australia, a sizeable 62% of principal carers of persons with a severe or profound handicap say that they neither need nor have used respite services. A substantial proportion rely on a fall-back carer from their informal network when they require someone to take their place (Gibson et al., 1996). Having such support, however, is not the whole story behind the low use of formal respite. An even more striking finding from these data is that highly vulnerable carers (those who have little support and were expecting increases in care receiver dependency) were also low users of respite services (20%). When non-users were asked why they didn't seek this type of assistance, 46% saw no need, and a further 15% said that they would prefer to do without outside help (Gibson et al., 1996). The picture that emerges from the Australian Government's Respite Care Review and its supporting research is that the vast majority of carers in Australia shoulder the load alone for a considerable period of time, often in extraordinarily demanding circumstances (Commonwealth Department of Health and Family Services, 1996). This pattern of high need, low usage is not peculiar to Australia, and has been observed consistently in the United States and Britain (Lawton, Brody, & Saperstein, 1989; Montgomery & Borgatta, 1989; Pollitt, Anderson, & O'Connor, 1991; Rudin, 1994; Smith, Smith, & Toseland, 1991) .

The mismatch between caregiving demands on the one hand and actual respite use on the other continues to puzzle policy analysts world-wide. Do respite programs need fine-tuning to bring them further in line with caregiver and care receiver needs or are there other more fundamental impediments to the use of respite care?

Fine-tuning respite services

Some of the reasons for not using respite services can be dealt with quite effectively through fine-tuning delivery systems. Caregivers report many respite services as unsuitable and not sufficiently flexible (Commonwealth Department of Health and Family Services, 1996; Clark, Bond, Nankivell, & Jarrad, 1995; Coopers & Lybrand, 1996; Rhys Hearn, Hewitt, Lindsay-Smith, Barratt, Hendrie, & McCarthy, 1996). In other cases, information is a stumbling block. Caregivers often do not know that respite care is available, or they don't know what it is and how it can be used (Clark et al., 1995; Gibson et al., 1996; Rhys Hearn et al., 1996; Schofield, Murphy, Nankervis, & Friedin, 1996). These problems can be dealt with reasonably effectively through educating and informing carers and those who are part of their network about the respite options available, and through ensuring that respite services are set up in such a way as to cater for individual needs (Clarke & Finucane, 1995).

A further step toward improving the effectiveness of respite services has been to link them formally with educational and psycho-social support programs (Berry, Zarit, & Rabatin, 1991; Knight et al., 1993; Monahan, 1993). Caregivers are often unprepared for the experiences ahead of them (Braithwaite, 1990; Fengler & Goodrich, 1979; Robinson & Thurnher, 1979), and find themselves on the outside in medical settings, receiving insufficient information about both diagnosis and prognosis in relation to the person who needs their care (McGown & Braithwaite, 1992). If caregivers don't know what is ahead, it's not surprising that so few plan for their future needs (Horowitz, 1985; Sorensen & Zarit, 1996). Through dealing with some of these fundamental problems that are known to contribute to caregiving burden, caregivers should be better equipped to use respite services in a way that relieves their own stress and recharges their batteries.

Social-psychological impediments to respite use

Fine-tuning delivery systems can only go so far in supporting caregivers, particularly those low users who have been classified as highly vulnerable. Caregivers can find it difficult to leave the person they are caring for, sometimes for fear of upsetting them, sometimes because they do not want to be parted from them (Braithwaite, 1998; Clark et al., 1995; Montgomery & Borgatta, 1989; Schofield et al., 1996; Smith et al., 1991). Braithwaite (1998) has argued that respite care is seen by some caregivers as the security they need in an emergency. Under normal circumstances, caregivers who have a loving and positive relationship with their care receiver are unwilling to hand over their responsibilities to a respite service provider. A break from chores is not an attractive option when caregivers risk a break in their social bonds, albeit temporarily.

The widespread nature of commitment to caregiving by family members has been interpreted by some as a manifestation of a cultural system of care that is embedded in our society (Albert, 1990). Focusing on parents and their children, Albert observed that ideas about "dependency" and "obligation" go together. When individuals see their parents losing competencies, they take on the role of the caretaker who is now responsible for ensuring the well-being of the parent. Albert explains this process in terms of the dimensions of intimacy and identity. Where the parent-child relationship is intimate, children see their parent as a child in his or her dependency and they view caregiving more as care for someone who is part of themselves. Where the child does not have an intimate relationship with the parent, the dependency is seen as an illness and children view their caregiving as a repayment for the parent's past support. Either way, dependency elicits a caregiving response that takes the form of an obligation.

Other researchers explain the relatively low utilization of respite care differently. They observe that family members often protect themselves from recognizing increased dependency in another and invest considerable effort in "normalizing" the dependency long after it is apparent to outsiders (Boss, Caron, Horbal, & Mortimer, 1990; Pollitt, O'Connor, & Anderson, 1989). As such, those whom we call caregivers often don't see themselves as caregivers at all, but rather as husbands, wives, sons and daughters who are helping in ways that are quite normal. Difficult or unusual behaviours in the care receiver are not singled out as signs of marked deterioration, but are minimized and accommodated in perceptions of how it has always been and what is normal for someone of that age.

Effectiveness of Respite

Low usage is not a problem for policy makers unless it can be shown that respite breaks the cycle that leads to breakdown in caregivers and of the caregiving relationship. Caregiver characteristics that lead to decisions favouring the institutionalization of the care receiver include burden, and poor psychological and physical well-being (Colerick & George, 1986; Deimling & Poulshock, 1985; McFall & Miller, 1992; Pruchnow, Michaels, & Potashnik, 1990). Analyses based on the Survey of Disability, Ageing and Carers (ABS, 1993) raise concerns that carers who don't use respite risk developing such characteristics. These analyses revealed that those with unmet respite needs were more likely to be facing further deterioration in the person they were caring for, their own social and emotional support network had constricted, they were more likely to report strain in their relationship with the care receiver, and their economic, emotional and physical well-being had suffered (Gibson et al., 1996). All these factors have been linked with caregiving burden (Braithwaite, 1990). Clark et al. (1995) reported that those with unmet respite needs reported greater depression and illness.

Such data, however, are at best suggestive of causal associations. To date, it remains unclear how respite can or does protect caregivers from these risk factors.

Although carers repeatedly express satisfaction with respite and ask for more, there has been a marked absence of quantitative studies demonstrating beneficial effects on key outcomes such as burden, life satisfaction, mental and physical health (Brodaty & Gresham, 1992; Callahan, 1989; Flint, 1995; Gallagher, 1985; Homer & Gilleard, 1994; Lawton et al., 1989; Montgomery & Borgatta, 1989; Commonwealth Department of Health and Family Services, 1996). Furthermore, with the exception of the work of Kosloski & Montgomery (1995), there has been little evidence to support the case for delayed institutionalization through respite services (Gilleard, Gilleard, & Whittick, 1984). In some cases, this failure has been attributed to methodological and statistical problems with the research, for example, samples of insufficient size, inappropriate statistical tests, and insensitive outcomes (Haley, 1991; Whitlatch, Zarit, & von Eye, 1991; Zarit, Anthony, & Boutselis, 1987). More recent studies that have sought to overcome these problems have produced more encouraging findings, but the size of the effect remains small (Knight et al., 1993; Kosloski & Montgomery, 1995)

Further evaluations of programs that are combining respite with caregiver education and counselling may offer a more optimistic picture of the effectiveness of respite care in alleviating stressful caregiving situations. At the present time, there is some evidence that respite is not being used as part of a caregiving plan, but rather as a means of caregivers gaining relief when on the brink of relinquishing care. Wells and Kendig (1996) found that respite use predicted loss of motivation to continue caregiving. Recognition of problems of this kind has led to an interest in integrated care packages that may enable caregivers to make use of respite more effectively (Monahan, 1993). How respite breaks are used may be a more critical determinant of their effect on caregiver well-being than frequency of use (Berry et al., 1991).

Respite means time out from care and makes no assumptions about the caregivers' activities when they are "off-duty". Respite may be a way for caregivers to meet their other obligations (paid work, household chores, family commitments), it may be used for leisure, or to do absolutely nothing. For some, it may be a form of crisis management, for occasions when they can no longer deal with their situation. The way in which respite use impacts on respite effectiveness is poorly understood. It is reasonable to suppose, however, that respite for crisis management is less likely to be accompanied by improved caregiver well-being than respite for leisure and recreation.

The benefits of recreation and doing something different

The positive effects of recreational activities on well-being have been discussed in a number of literatures. Within the field of gerontology, activity was once considered to be the essence of successful ageing (Havighurst, 1963) until recognition was given to those who maintained a sense of well-being, in spite of being incapacitated and unable to pursue active lives. While the contribution of activity toward well-being was qualified to make room for the ways in which individuals reframe their goals and priorities and compensate for their losses (Baltes & Baltes, 1990), the concept remains important in the health literature.

Defined broadly as the process of being involved in doing something, whether it be physical, cognitive, affective or social, activity is widely regarded as central to physical well-being, interpersonal relations, personal development, and mental well-being (Bond & Feather, 1988; Lilley & Jackson, 1993). Activities, particularly leisure activities, can allow individuals to exercise competence (Iso-Ahola, 1980). Activities which are structured can shift the focus of attention away from problems that heighten anxiety and depression, and can involve actions that induce relaxation, or offer distraction from life's troubles (Landgarten, 1983; Sallis & Lichstein, 1982).

While caregiving gives the caregiver ample opportunity to be active, it invariably results in reduced activities outside the home (Biegel, Sales, & Schulz, 1991; Clark & Bond, 1997). The contribution to well-being of outside activities and interests has been explained through both the social support and self-concept literatures.

As outside activities are relinquished by caregivers, so too are opportunities for social interaction. Isolation from friends and the loss of a social life are among the problems most often mentioned by caregivers (Grad & Sainsbury, 1963; Jones & Vetter, 1984; George & Gwyther, 1986), and such problems have been linked with burden and depression (Braithwaite, 1990; Clark et al., 1995; Poulshock & Deimling, 1984). Thompson, Futterman, Gallagher-Thompson, Rose and Lovett (1993) have found that the kind of social support that is most likely to reduce caregiving burden involves social interaction for fun and recreation. These researchers argue that with increased dependency, caregivers who lack the opportunities for reducing tension through recreation and social participation may well find themselves becoming less emotionally caring, more resentful, and looking for answers in the wrong place, for example, in the ritualistic provision of assistance.

One useful approach to understanding why social activities outside caregiving are so important to caregivers is through the self-concept literature. Social identities are acquired through our role relationships and define who we are, how we should behave, and give us meaning and purpose in life. Most people have a number of social identities, and considerable research has been devoted to understanding how many is too many, or whether multiple identities preserve well-being through ensuring that not all our eggs are in the one basket (Moen, Robison, & Dempster-McClain, 1995; Stephens, Franks, & Townsend, 1994; Thoits, 1983). For caregivers, there seems to be some evidence to suggest that the rewards found in roles outside caregiving can be helpful in compensating for some of the losses experienced in the caregiving role (Hong & Seltzer, 1995; Scharlach, 1994).

This is not to suggest that the caregiving role does not offer its own rewards. A significant literature has emerged to demonstrate the pleasure and satisfaction caregivers find in their role (Kinney & Stephens, 1989; Motenko, 1989; Walker, Martin, & Jones, 1992), and it is not impossible for caregivers to hold on to these perceptions to the end, finding meaning in their experiences, good and bad (Antonovsky, 1987). The vast literature on caregiving burden, however, alerts us to the fact that this is not the experience for the majority of caregivers. Aspects of the caregiving role threaten caregiver identity in ways that adversely affect psychological well-being and may ultimately defeat a caregiver's capacity to cope.

The threat to well-being comes from two directions. As the care receiver becomes more dependent and is less able to engage with the world outside, the caregiver's world also shrinks. Loos and Bowd (1997) studied how caregivers construed their role and noted a common theme of becoming subservient to the needs of the person in care. This diminution of self has been noted in quantitative research as well. Aneshensel, Pearlin, and Schuler (1993) map "the gradual absorption of a person into a caregiving role" (p. 55) through their concept of role captivity. During this process, the caregiver discards other roles or relegates them to the category of "things I'll do later" or "when I have time". As a consequence, the role of caregiver dominates and defines the identity of the person almost to the exclusion of everything else. Without the caregiving role, caregivers feel insecure and at a loss as to what they can and should do: Their gradual dislocation from other social roles leaves them uncertain as to how to re-connect with old social identities.

These deleterious effects may be felt keenly and quickly by those who thrive on multiple roles and high levels of engagement with the outside world. For those who can find contentment within their shrinking world, harmful consequences of role loss may not be felt until the care receiver's condition deteriorates to the point where the caregiver is no longer recognized, valued, and no longer feels needed by the care receiver. Aneshensel et al. (1993) have found that the loss of important elements of attachment in the caregiver - care receiver relationship can exacerbate feelings of captivity, and that role captivity is implicated in decisions to institutionalize. Braithwaite (1990) also identified distance in the relationship, enmeshment in the caregiving role, and low levels of social interaction as contributors to burden, anxiety and depression in caregivers.

People who are socially isolated and not receiving positive affirmation from their primary social role of caregiver are not necessarily helpless to change their situation. It is in this context that caregivers are expected to make use of support services, such as respite care, so that they can counteract the adverse effects of social isolation and role loss. Role accumulation offers possibilities for restoring well-being (Hong & Seltzer, 1995; Thoits, 1983), and respite for the care receiver can provide the perfect opportunity, if caregivers use their time away to engage in other social roles.

The observed reluctance of caregivers to seek other social roles, for whatever reason, places them at risk of having reduced opportunities for finding ways to buffer themselves from the blows that caregiving may bring. Possibly the loss of roles and eventually of positive identities is a gradual and invisible process for caregivers. Perhaps the adverse consequences are exaggerated. Thoits (1983) found that isolated individuals were not as adversely affected by role loss as those with multiple identities. According to Thoits, having multiple identities often means that roles are interconnected, and as one unravels, so too do others, magnifying the possible identity loss and decrements in well-being. This argument works in the reverse as well. Those with multiple identities from interconnected social roles will reap the benefits of identity gain more dramatically than isolated individuals: Individuals in detached and unfulfilling social roles must start from scratch in finding new roles that they hope will produce positive social identities. Isolated caregivers may recognize this task as energy sapping and risky. The gains for the time and effort invested may be considered too small, particularly if the demands of caregiving are high (Worcester & Hedrick, 1997).

One explanation for how the accumulation of social roles can rebuild social identities is provided by the concept of possible selves. These are the images that we carry with us as we consider our future, our ideas about what we would like for ourselves (hoped-for selves) and what we do not want (feared selves). Markus and Nurius (1986) have proposed that possible selves help motivate us to act in certain ways, as we steer our minds toward how we should achieve the things we desire, and how we should avoid the things we fear. Oyserman and Markus (1990) conceive of feared and hoped-for selves working together such that the feared self provides the motivating force to pursue the hoped-for self. Hoped-for and feared selves seem particularly relevant to the caregiving situation where caregivers risk the loss of key identities as they sideline other roles, and endeavour to realign goals and expectations with their current situation. While possible selves are likely to change on entry into the caregiving relationship, they might also be expected to change as the care receiver's situation deteriorates. Adaptation should still be possible, providing caregivers believe it is possible. Belief in one's own capacity to act on the motivational force of the feared and hoped-for selves is an important aspect of actual behavioural change (Hooker & Kaus, 1994).

The question then is whether caregivers, after a period of enmeshment in the caregiving role, have sufficient belief in themselves to allow them to adjust their roles and re-gain positive social identities. Skaff, Pearlin, and Mullan (1996) raise doubts about how realistic this expectation is. They found that role captivity brought with it a loss of mastery, the sense that one has control over the salient areas of one's life. The loss of mastery persisted even after the institutionalisation of the care receiver and continued up to his or her death. To the extent that these findings can be generalized to other contexts, it is likely that prolonged caregiving may damage caregivers' capacities to initiate the changes in lifestyle necessary to ameliorate the deleterious effects of enmeshment in caregiving.

Against this background, the Caregiver Recreational Respite Program was set up to encourage caregivers to take the opportunity to re-engage with past interests or develop new ones outside the world of caregiving. For this reason it stood apart from other respite programs. Instead of being offered to caregivers as time out from tiredness and frustration, this program was offered in the spirit of self-fulfilment and personal development. There was no suggestion that the program was put in place to counsel carers who were not coping. While at all times acknowledging the difficulties inherent in the caregiving role, the Program encouraged carers to leave their troubles at home and immerse themselves in a different kind of activity.

This differentiating feature also points to an important drawback. The Caregiver Recreational Respite Program neither helped carers get their tasks done nor provided opportunities to catch up. It involved doing something extra, albeit pleasurable, but it was unmistakably an additional commitment.

At the same time, the aim of the Caregiver Recreational Respite Program was to give something back to carers in recognition of their enormous contribution, and oftentimes sacrifice, in providing home care. The research team organized classes, taxis, and at-home respite according to the wishes of the caregiver. All costs were met by the research project. Every effort was made to free carers from as many organizational hassles as possible so that they could take advantage of an opportunity to engage in a pleasurable activity just for themselves.

While extra commitment was one disincentive of the Caregiver Recreational Respite Program, there were others as well that are commonly recognized in relation to the under utilization of respite services (Monahan, 1993; Smith et al., 1991; Worcester &

Hedrick, 1997). Accepting formal respite requires trust in the care provider, not always easy despite the efforts made to assess the suitability of potential carers and to introduce them and get to know them beforehand. Accepting respite care also means being able to walk away from caregiving responsibilities, even if it is just for a little while, and coming to terms with a separation that may not be welcomed by the care receiver.

Criteria for assessing viability and effectiveness

The viability of the program was assessed in terms of the availability and continued attendance of interested caregivers and of the suitability of the instructors engaged.

Effectiveness was assessed in two ways. First, caregivers were asked to rate their perceptions of the program in terms of five criteria:

(a) capacity to restore spirits
(b) capacity to spark new interests and impart knowledge
(c) capacity to integrate the caregiver socially into the group
(d) capacity to motivate caregivers to generate activities for themselves
(e) respectfulness of the caregiver- care receiver relationship.

Second, effectiveness was assessed by comparing scores on measures of well-being prior to the commencement of the Program and after its completion. Improvement in well-being was expected on the following six outcomes:

(a) self-reported physical health
(b) life satisfaction, that is, self-reported satisfaction assessed overall and in relation to five facets of life (health, finances, personal/emotional life, respect and independence)
(c) burden, that is, subjective assessment of whether or not caregiving frustrated basic needs of a physiological, security-related, social or psychological kind
(d) minor psychiatric symptoms, that is, anxiety and depression
(e) number of hoped-for selves
(f) number of feared selves.

Wherever possible, both quantitative and qualitative data were collected for cross-method validation of findings, and to provide a sound base for acquiring a deeper understanding of the meaning of respite to carers. Through using these as complementary methodologies, we hoped to move a step closer to understanding the impediments to using respite services.

Chapter 2

Caregivers, courses and respite

The Caregiver Recreational Respite Program was based in Canberra, Australia. Prior to the commencement of the project, we were well aware of the reluctance of caregivers to use respite services, and past research had convinced us that there was no empirical basis to expect what Montgomery and Borgatta (1989) called the "the woodwork effect", whereby all eligible clients would come out of the woodwork to take part, thereby overloading the system. Rather, we recognized that the challenge would be to identify needy families early enough in the caregiving experience.

Yet the thought of offering a program that included free tuition, free respite care and free transport to and from the venue gave rise to concerns that we would have more people wanting to enrol than we could handle. With this in mind, we spent many hours deciding what our criteria for inclusion should be so that we could prioritize those who had high responsibility in terms of personal care, who reported experiences of caregiving burden, and who had little support of either a formal or informal kind. As the project got under way, our concerns could not have been more misplaced. We had been blinded by the underlying assumption that caregivers would be attracted to a Program that was set up with the express purpose of catering to their self-interest.

It took six months to recruit the 39 caregivers who participated in the program. They came from an initial list of 103 possible recruits, and this 103 came from an unknown number of individuals who were approached by doctors' receptionists, health care professionals and health care workers, or who had heard of the Program through talks by research staff at various support group functions, picked up pamphlets at respite centres or carers' support centres, or read about the program in the free local area newspaper (see Appendix A for examples of the approaches we used to contact caregivers).

Reasons for why recruitment was so difficult remain unclear. Undoubtedly some problems were peculiar to this project, but the similar experiences of others who have done research in this area suggest that in our failure to reach deep into the community, we were following a well-trodden path. Previous researchers have attributed their lack of success to the fact that many caregivers do not see themselves as caregivers (Montgomery & Borgatta, 1989; Pollitt et al., 1991), and that using outside services can be more trouble than it's worth for caregivers who are already working on a tight schedule to keep a routine in place (Worcester & Hedrick, 1997).

Difficulties of recruitment, however, had a silver lining. We did not turn anyone away from the Program who wanted to take part. This raises the important question, however, of how those who took part differed from those who did not. Our objective, after all, was to deliver a service to those who were most in need and possibly falling through the cracks of current service provision. The next section examines how well we were able to reach caregivers with high task demands, high burden and low support.

Caregivers

Recruitment followed two main paths. Because we were interested in making contact with caregivers who were not receiving support, we wanted to advertise outside the network of caregiver services as well as within this network. We therefore commenced recruiting through seven doctor's surgeries[1] and the local newspaper (see Appendix A). Practice staff in the surgeries were required to identify potential caregivers through asking those who came for a consultation whether they or anyone in their family provided care to someone over the age of 18. If they answered yes and identified

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[1] The number of doctors participating in the project was limited by the fact that a large scale Coordinated Care Trial was being conducted in Canberra at the same time as this project.

themselves as the carer, they were handed a screening questionnaire to fill out while they waited for their appointment. Completed questionnaires were placed in a sealed box in the waiting room and were collected by the research staff on a regular basis. If the person identified someone else in the family as the primary caregiver, that person was asked to pass on the screening instrument to the caregiver. The questionnaire was placed in an envelope with a reply paid addressed envelope. During the recruitment period, we became aware that staff sometimes forgot to ask patients about caregiving. We therefore placed a question on the front of the collection box with an accompanying information sheet (see Appendix A) so that patients could ask staff for a screening questionnaire if they were interested.

The screening questionnaire comprised five parts (see Appendix B). Caregivers were asked if they were the primary caregiver and to specify their relationship to the person receiving care (eg. daughter, husband).

Following was the personal care requirements scale which assessed caregiving workload through asking caregivers if the care receivers needed help with any of the following: (a) walking, (b) shopping, (c) housework, (d) laundry, (e) movement, (f) bathing, (g) eating, and (f) toileting. Responses to each item were made on a scale from 0 to 2 where 0 represented no help, 1 represented some help, and 2 represented substantial help. This scale was a modified form of the CAMDEX (Cambridge Mental Disorders of the Elderly Examination) (Roth, Tym, & Mountjoy, 1986). Responses to the items were summed to give a total personal care requirements score for each care receiver. The third set of questions related to the supervisory workload of the caregiver (Braithwaite, 1990). The supervisory requirements scale involved asking caregivers if the care receiver could summon help in an emergency (yes = 0, no = 1), be left alone unsupervised for a couple of hours during the day (yes = 0, rarely = 1, no = 2), and be left alone unsupervised for a couple of hours at night (yes = 0, rarely = 1, no = 2). Responses were aggregated over these three items to give a total score.

The fourth set of questions were the Threat to Basic Needs Burden Scale (Braithwaite, 1990). Burden was defined as the degree to which caregivers believed that caregiving threatened their basic needs for rest, order, love and belongingness, and self-worth. This 17 item instrument asked caregivers whether or not (no = 0, yes = 1) they experienced disruption and feelings of loss and inadequacy in their role as caregiver. Responses to these items were summed to give a burden score. Psychometric details about the scales are provided in Appendix C.

Finally, caregivers were asked to provide their name and phone number if they wished to be contacted in relation to the Caregiver Recreational Respite Program. The screening instrument was used to identify possible recruits and ascertain the level of dependency of the care receiver and the level of burden of the caregiver.

The second path for recruiting caregivers was through organizations that offered services of various kinds to caregivers and care receivers. In some cases, health workers gave screening questionnaires to caregivers, in other cases, they just gave them the advertisements that we distributed through the community regarding the Program (see Appendix A). Reply paid addressed envelopes were provided so that caregivers could return the enrolment form to us with their name and address, so that we could contact them directly regarding the Program. By far the most successful recruitment strategy involved personal "hand overs". Our main source of recruits was the Carers Association. They actively searched for participants on our behalf, talked with them about the Program extensively, and then gave us the names of those who were interested in participating, so that we could immediately make contact. Assistance of this kind was also provided by a health worker who had strong links with people from diverse linguistic and cultural backgrounds.

The burden scale and the personal care requirements scale were completed by those who had filled out a screening questionnaire or had agreed to a first interview. This meant that we could compare those who progressed to being a participant in the program and those who withdrew at an earlier point to find out if we retained those with the heaviest caregiving load. The different levels of participation were defined as follows: (a) those who completed the screening instrument, but did not proceed any further (the screen only group), (b) those who were considering the Program, agreed to an interview, but for one reason or another withdrew (the ambivalent group), (c) those who were more committed, did not take part in the Program, but agreed to be part of a comparison group (comparison group), and (d) the Program participants.

These four groups were compared in terms of the average personal care requirements of the care receiver, supervisory requirements, and caregiving burden (see Table 2.2). Also included is the percentage of each group caring for a spouse.

Table 2.2: A comparison among four groups of caregivers in terms of average personal care requirements of care receiver, supervisory requirements, caregiving burden, and percentage of each group caring for a spouse

Caregiving load	Screen only (n=29)	Ambivalent (n=18)	Comparison (n=17)	Participant (n=39)
Personal care	7.54 (3.28)	8.28 (3.63)	6.46 (3.46)	7.99 (3.48)
Supervisory care	2.34 (1.80)	2.17 (2.18)	1.71 (2.11)	2.05 (2.05)
Burden	9.98 (4.74)	10.17 (4.41)	8.67 (3.65)	9.10 (4.49)
% Spouse	45%	22%	65%	41%

Recruitment through the Carers Association was notably more successful than any other method. Most participants were recruited through this source, and the percentage who dropped out after initial contact was minimal for this group. Table 2.1 provides a summary of attrition from first contact, through the initial interview, to course participation. First contact involved a phone call from us to explain the Program and to ask caregivers if they were interested in taking part in an interview (see interview schedule in Appendix D). From Table 2.1, half of the GP recruits did not progress to the first interview, either because they had not given a phone number (n = 19) or because they were not interested (n = 11). Of those who agreed to an interview, less than half wanted to participate in the Program. Some were not interested in any courses, some were no longer caregivers, and others were too busy with other commitments including work. Half of those recruited through other organizations, the newspaper and personal referrals also dropped out after the initial interview. In contrast, the majority of referrals through the Carers Association stayed in the Program until the end.

While Program take up rates were low among first contacts, caregivers who began the Program stayed with us and attended most sessions. Two caregivers were not available for interview after course completion, giving a final participation rate of 36% (N =37).

Table 2.1: The number of caregivers following through to each consecutive stage by recruitment source

Recruitment source	Initial contacts	First interview	Program participant
GP practices	56	28	10
Carers Association	23	23	18
Other services, personal referrals, newspaper responses	24	22	11
TOTAL	103	73	39

The burden scale and the personal care requirements scale were completed by those who had filled out a screening questionnaire or had agreed to a first interview. This meant that we could compare those who progressed to being a participant in the program and those who withdrew at an earlier point to find out if we retained those with the heaviest caregiving load. The different levels of participation were defined as follows: (a) those who completed the screening instrument, but did not proceed any further (the screen only group), (b) those who were considering the Program, agreed to an interview, but for one reason or another withdrew (the ambivalent group), (c) those who were more committed, did not take part in the Program, but agreed to be part of a comparison group (comparison group), and (d) the Program participants.

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Burden	9.98 (4.74)	10.17 (4.41)	8.67 (3.65)	9.10 (4.49)
% Spouse	45%	22%	65%	41%

These data do not reveal any significant trends toward losing caregivers who were most in need of support in terms of the responsibilities they carried. We do not know, however, about the caregiving load of those in the community who did not complete a screening questionnaire or who did agree to an initial interview. When the burden statistics for this sample of caregivers were compared with those reported in an earlier study (Braithwaite, 1990), the level of distress was found to be a little lower in the present sample. (The mean (standard deviation) in the 1990 study was 11.38 (4.11).) Nevertheless, any score above the midpoint of 7 was taken to indicate a serious threat to the well-being of caregivers. If respondents answered randomly, one would expect a score of 7. Given that all items reflect a threat to basic needs, endorsement of any items above chance is cause for concern in a civilized society.

While the data in Table 2.2 do not distinguish the participant group in any particular way, the qualitative data suggested that there was something extra happening to those who agreed to participate. We called this "the tip factor". We conceive of this as a critical shift in identity which moves individuals from seeing themselves in a normative role (as a daughter, wife, husband carrying out the duties of the relationship) to seeing themselves as "carers" (and thus occupying an exchange role that carries rights and entitlements to service support and possibly financial benefits). A major problem for research on caregiving is that many of those looking after dependent elderly people do not define themselves as caregivers, and thus neither know of available assistance nor see it as relevant in their particular case. The shift in self-definition occurs either through the worsening of the care receiver's condition or through intervention by an outside agent such as a GP, friend, or relative who causes them to see that what they are doing exceeds the normal requirements of the relationship. Once the shift to "carer" status is accomplished, the likelihood of their accepting help from others is greater. The next step is to recognise and acknowledge their own needs. For this to occur, they may need an outside body such as the Carers Association or the Alzheimers' Association or, again, their GP, to push them in this direction.

The 37 caregivers who participated in the Program seemed to have made this transition. As can be seen from Table 2.3, they were predominantly women (95%) with an average age of 59 years. The age distribution was spread over a wide range from 13 to 76 years, suggesting that the Program was able to accommodate all age groups. The mean age of the care receivers was 73 years, 57% of the care receivers were female, and on average, the caregiving relationship had continued for 7 years. About half (51%) had used formal respite previously. Most care receivers lived with their caregivers (70%), but it is of note that 3 care receivers had been placed in residential care when the Program started. Interviews with these caregivers revealed that they still spent considerable time administering care, a pattern that has been well documented in the literature (Tilse, 1997). On this basis, these caregivers were included in the study. By the end of the Program, another 8 care receivers had been institutionalized and 1 had died. In total, 31% of caregivers were not providing home care by the time the Program finished.

The profile of the comparison group did not differ markedly (see Table 2.3), perhaps because more than half (53%) had originally indicated interest in taking part in the Program. Most of this group were co-residents (82%), they had been caring on average for 6 years, just under half had used respite before (47%), and most were women (71%). The ages of caregivers ranged from 39 to 80 years, with a mean of 58 years. The mean age of care receivers was 70 years and 71% of them were men. This was higher than the percentage of men receiving care in the participation group, 43%. By the end of the Program, 4 care receivers had been institutionalized, that is, 24% of caregivers were no longer providing home care.

Table 2.3: Sociodemographic characteristics for the participant and comparison groups, and a 1990 caregiving sample

Sociodemographic characteristics	Participant (n = 37)	Comparison (n = 17)	Braithwaite (1990)
% women caregivers	95	71	75
Average age caregivers (years)	59	58	58
% women care receivers	57	39	61
Average age of care receivers (years)	73	70	77
% caring for spouse	40	65	43
Average length of caregiving (years)	7	6	6
% co-resident	70	82	86
% using respite before	51	47	30
% relinquishing home care	31	24	-

When the profiles of the participant and comparison groups were compared with the statistics describing another sample of caregivers interviewed in an earlier survey, few notable differences emerged. There was no evidence that the recruitment process for the Program had appealed to one sociodemographic group rather than another. From these data, the Program appears to have the potential to reach a broad cross-section of caregivers.

The courses

Courses and instructors were not finalized until we had undertaken a number of initial interviews with caregivers. The intention was to find activities that appealed to caregivers and to orient the Program to caregivers' interests. We conducted the early interviews with the drawing class as our flagship, but we took the opportunity to talk with caregivers about other courses that might appeal them. In this way, there was room for responsiveness in the courses that we ran. During these interviews, we found that some caregivers were missing activities that they used to be able to do and could no longer do, such as volunteer work or gym work outs. We also found that some caregivers had very specific interests and goals, such as learning about computing. Wherever possible, we accommodated these needs, and such caregivers engaged in an independent activity. Our only restriction was that the activity had to be outside the house, it had to be something that the caregiver could not do without respite help, and it had to have a recreational and non-caregiving focus. We decided not to support unfocused activities such as meeting friends for coffee or looking after the grandchildren, as highly valued as these activities were by both caregivers and the research staff.

The instructors were hand picked for the courses, and from all reports (see Chapter 6), they lived up to our expectations. One selection criterion was essential, being able to share a positive attitude to practising their craft or leisure activity. Instructors were chosen who communicated a belief in the receptiveness of others to new ideas and experiences, and in the prospect of enhancing well-being for participating caregivers.

Five people were involved in teaching the classes. The instructor who was initially employed for the relaxation course and who had had previous experience with caregivers unfortunately had to resign through ill health. The class was taken over, on recommendation, by someone without prior experience of working with caregivers. She quickly learned what was required and very successfully conducted the second course. The drawing class instructor had trained both as an artist and as a psychologist, and so was particularly well placed to recognise the problems the participants might be having. The walking course was conducted by a married couple who have run "Walking for Pleasure" programs in the ACT for many years.

Courses were planned with a sensitivity to gender and age differences in the caregivers who expressed interest in the Program. The broad age range of participants reflected a willingness to expand options through the individual activities programs. Younger caregivers, in particular, preferred this option. So too did male caregivers.

The courses took place one morning a week, and were planned for six weeks. In response to popular demand, they were extended to seven weeks. Caregiver interest was such that they could have been longer. A member of the research team participated in each of the courses to observe how caregivers were responding to the programs, and to provide an extra pair of hands where necessary so that all ran smoothly.

Respite care

The major respite care services in the ACT were contacted early in the project to explain the Recreational Respite Program and to prepare them for the fact that participating caregivers would need respite care for a few hours a week at a set time for several weeks. At the first interview with caregivers, we asked about their respite care needs and their transport needs, explaining that we would organize all this for them. Much to our surprise, only 5 accepted the offer of respite care. Some preferred to organize someone from their informal network to stay with or keep an eye on the care receiver, while others already had respite or Day care in place. Respite was organized well in advance in consultation with the caregiver. The caregiver and care receiver had the opportunity to meet with the respite providers prior to the commencement of the Program so that all parties could get to know each other first.

Interestingly enough, the taxi service proved more popular than the respite service. Twelve caregivers relied on this form of transport to and from courses. Research staff made bookings, took responsibility for cancellations and changes in plans, and arranged payment through providing caregivers with vouchers. All caregivers had to do to participate in the Program was to be ready to be collected at the agreed time at the place of their choice.

Chapter 3

What did caregivers think of the Program?

A few weeks after the completion of the program, participants were re-interviewed to assess levels of social-psychological well-being, to catch up on changes that may have occurred in their lives since the last interview, and to learn of their reactions to their program (see Appendix E). The programs offered participants the opportunity to step out of their caregiving role and become involved in an alternative enjoyable activity for a couple of hours a week. To varying degrees, the programs also offered opportunities to acquire new skills and engage socially with others. The hope was that participants would be encouraged to use respite for recreational purposes without disruption to the caregiver-care receiver relationship. This chapter uses both quantitative and qualitative data to analyze participants' reactions to the programs in terms of whether or not these objectives were achieved.

Evaluation Method

The quantitative evaluation was based on participants' ratings of 20 statements compiled to reflect the degree to which the programs achieved their objectives. Each of the 20 statements was accompanied by an 11 point scale ranging from 0 to 10. Participants were asked to indicate their level of agreement or disagreement, where 0 meant no agreement at all, 10 meant that they agreed wholeheartedly, and 5 meant they half agreed. The statements are listed in Table 3.1. In this chapter, these evaluations are described for the group as a whole and are subsequently compared for participants (a) who attended different programs, (b) who were recruited from different sources, (c) whose caregiving circumstances differed, and (d) whose well-being varied prior to the course.

The qualitative evaluations were based on participants' answers during their second interview to an open-ended question about what they thought of the program. In two cases, participants later provided written comments on what the program had meant to them.

Quantitative findings

Means and standard deviations were calculated for each of the 20 statements listed in Table 3.1. The statements are presented in order from the most strongly endorsed to the least strongly endorsed. The mean scores show that participants had an overwhelmingly positive response to the programs. Scores were very high for statements that reflected the effectiveness of the program as a break for carers, and very low for statements that reflected unintended consequences, such as damage to the caregiver-care receiver relationship and loss of self-esteem. Of particular interest was the finding that few participants felt guilty or worried about leaving their care receiver. Possibly those who agreed to take part in a program had already worked through their concerns, while those who were unable to feel comfortable at the prospect of being away had decided not to participate.

Table 3.1: Mean scores (standard deviations) reflecting level of agreement among participants with 20 program evaluation statements (N=37)

Program Evaluation Statements	Mean (SD)
I enjoyed the social atmosphere of the course.	8.95 (1.62)
I wouldn't have gone to such a course if the staff of the research project hadn't organized it for me.	8.76 (3.05)
Attending the course gave me an opportunity to get involved in something other than caregiving.	8.75 (2.05)
Attending the course recharged my batteries.	8.43 (1.99)
I would do this course again.	8.43 (2.98)
Attending this course gave me time to look after my own needs.	8.16 (2.80)
Attending this course gave me a complete break from caregiving.	8.16 (3.02)
I will try to continue … in my spare time.	7.94 (3.11)
I plan to enrol myself in another course.	6.58 (4.00)
Attending the course reminded me of things I had been missing in my life.	6.27 (3.23)
Attending the course introduced me to skills that I didn't have before.	5.78 (4.02)
I have found a new interest through this course.	4.92 (4.02)
I was scared about starting this course.	1.38 (2.74)
I was worried about being away from the person I was caring for when I started this course.	1.35 (2.88)
There were times when I felt guilty about leaving my caregiving responsibilities to go to the course.	.89 (2.23)
The course added to my frustration with life.	.70 (2.05)
My attendance at the course upset the person I was caring for.	.57 (1.76)
The course made me feel inadequate as a person.	.54 (1.84)
My attendance at the course made the person I am caring for feel resentful.	.49 (1.84)
The course interfered with my caregiving responsibilities.	.27 (1.15)

In order to provide a more in-depth analysis of the quantitative evaluations and the ways in which they varied across groups, items were combined to represent four desired outcomes (a-d) and one undesirable outcome (e):

(a) the restoring of spirits in caregivers
(b) the acquisition of new skills and interests
(c) social engagement for caregivers
(d) motivation among caregivers to initiate program activities
(e) intrusion of program on the caregiving relationship

Restoring of spirits

All programs were expected to improve the emotional well-being of participants by providing them with a pleasurable experience outside the caregiving role. Five of the statements were relevant to this outcome and responses to them were added to give each participant a score on the restoring of spirits scale:

The Restoring of Spirits Scale

(1) Attending the course gave me an opportunity to get involved in something other than caregiving.
(2) Attending the course recharged my batteries.
(3) Attending this course gave me time to look after my own needs.
(4) Attending the course reminded me of things I had been missing in my life.
(5) Attending this course gave me a complete break from caregiving.

Four stages accompanied the development of each scale:

(a) Appropriate items were selected and scores were intercorrelated to ensure that participants were responding to the items in a similar way. The items that maximized the Kuder-Richardson alpha reliability coefficient were retained as scale items.

(b) Participant's responses to the selected items were summed and divided by the number of items in the scale to give each person a score out of 10.

(c) A mean and standard deviation were calculated for each scale, with special note taken of the number of cases falling below the midpoint of 5.

(d) The scale scores were compared across programs (drawing, movement and relaxation, walking, and other independent activities) and for caregivers who entered the program through different sources (GP surgeries, the Carers Association, community contacts). In addition, scale scores were related to variables representing sociodemographic background, caregiver well-being and caregiving circumstances to find out if the programs were tailored to the needs of some caregivers more than others (see Table 3.2 for list of variables). It is of note that the caregiver's gender is not included in these analyses because there were so few men in the sample. Future work should focus on obtaining a substantial sample of male caregivers to evaluate the suitability of the Program for this group.

Details concerning the ways in which the variables in Table 3.2 were measured are provided in Appendix F. The statistical analyses on which the following findings are based are summarized in Appendix G.

Table 3.2: Variables tested for their relationship with program evaluation scales

Sociodemographic background	Caregiver well-being
carer's age *(in years)*	self-reported physical health scale
spousal care *(no = 1, yes = 2)*	life dissatisfaction scale
co-resident *(no = 1, yes = 2)*	burden scale
reduction in paid work *(no = 1, yes = 2)*	minor psychiatric symptoms scale
option of institutional care *(no = 1, yes = 2)*	number of hoped-for selves
length of time caregiving *(in years)*	number of feared selves
Circumstances: work demands	Circumstances: relational quality & rewards
personal care requirements scale	sole responsibility scale
supervision requirements scale	conflict scale
emotional care scale	relationship investment scale
behavioural problems scale	the reciprocity scale
change in care receiver scale	companionship *(no = 1, yes = 2)*
backup scale	being useful *(no = 1, yes = 2)*
use of formal respite *(no = 1, yes = 2)*	being busy and occupied *(no = 1, yes = 2)*

The mean for the restoring of spirits scale was a high 7.93, with a standard deviation of 1.78. With a few exceptions (5 participants scored below the midpoint of 5 on the scale), participants believed that the program had been effective in restoring their spirits through providing them with an activity outside caregiving.

Scores on the restoring of spirits scale were high for all programs (drawing, movement and relaxation, walking, and other independent activities) (see Figure 3.1). Being away doing something that one enjoyed seemed more important than the actual activity one was engaged in. The statistical tests reported in Appendix G showed no program producing a better outcome than another on this criterion.

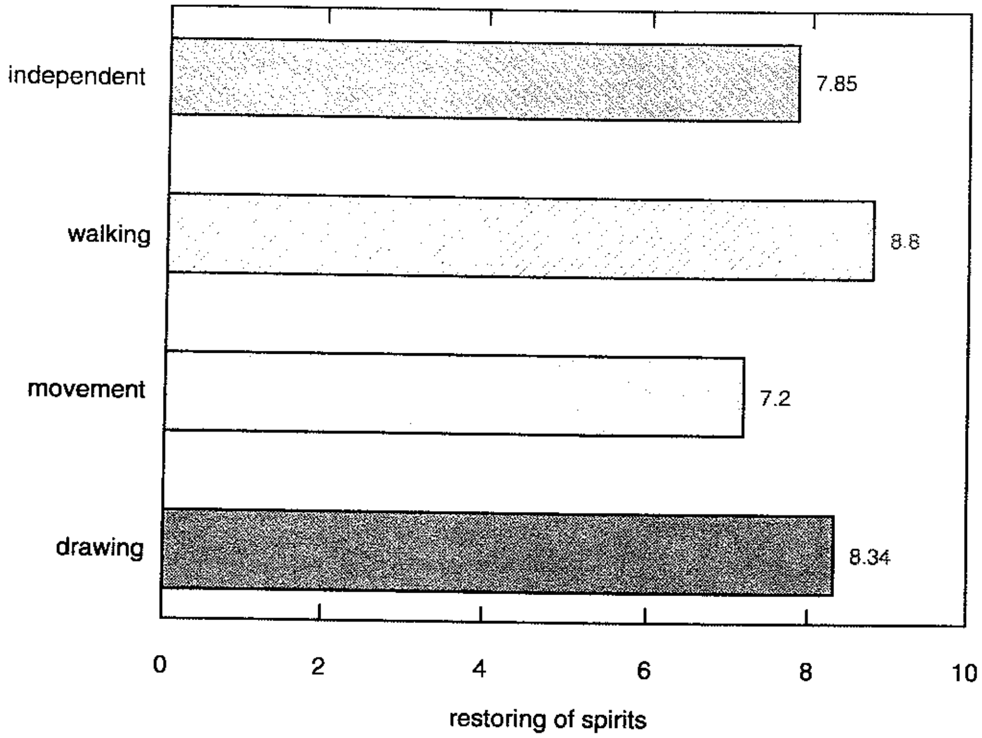

Figure 3.1: Scores on the restoring of spirits scale by program type

Furthermore, feeling restored by the Program did not differ significantly for groups recruited from different sources (see Figure 3.2). Participants contacted through GP surgeries, the Carers Association and the community all reported beneficial effects from taking part in their chosen activity.

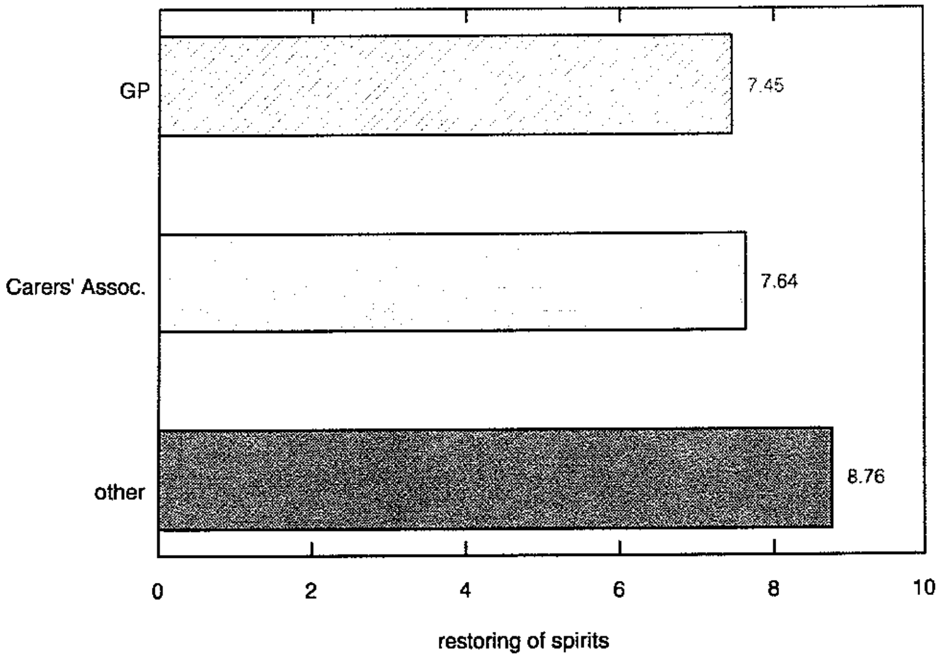

Figure 3.2: Scores on the restoring of spirits scale by recruitment source

When caregiving circumstances were examined in relation to the restoring of spirits scale, some interesting findings emerged. Caregivers who were co-resident with the care receiver reported significantly higher scores on the restoring of spirits scale than caregivers who lived apart (see Figure 3.3). Furthermore, those who felt most restored by their programs were those who reported having less backup care (see Figure 3.4), who valued the companionship of their care receiver while caregiving (see Figure 3.5), and who appeared to be the most committed to staying with home care by virtue of not making inquiries about nursing home or hostel accommodation (see Figure 3.6). Interestingly, caregivers who admitted to having more hoped-for selves were less restored by the program. It seems likely that in these cases too much was being asked, and too little provided.

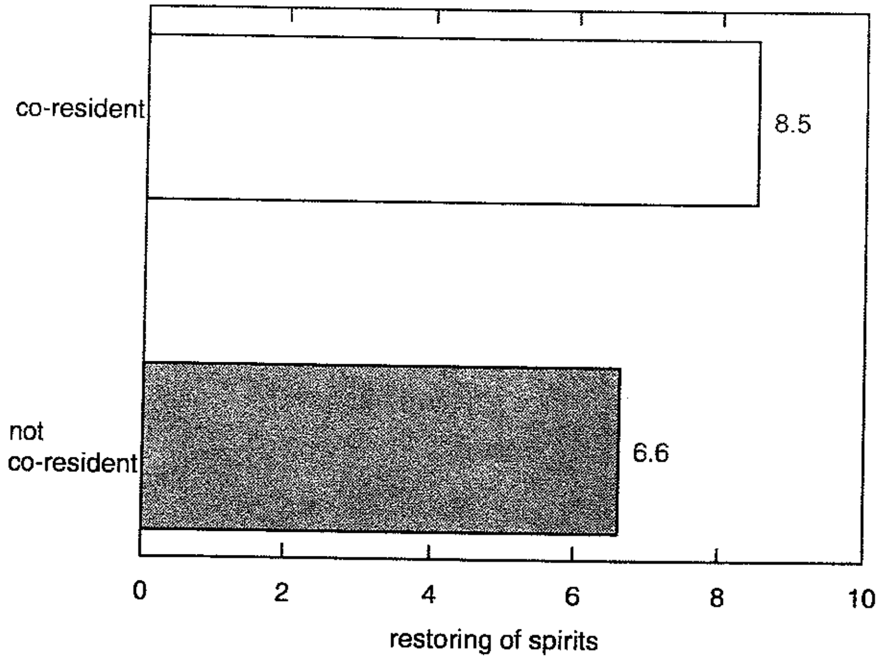

Figure 3.3: Scores on the restoring of spirits scale by co-residency

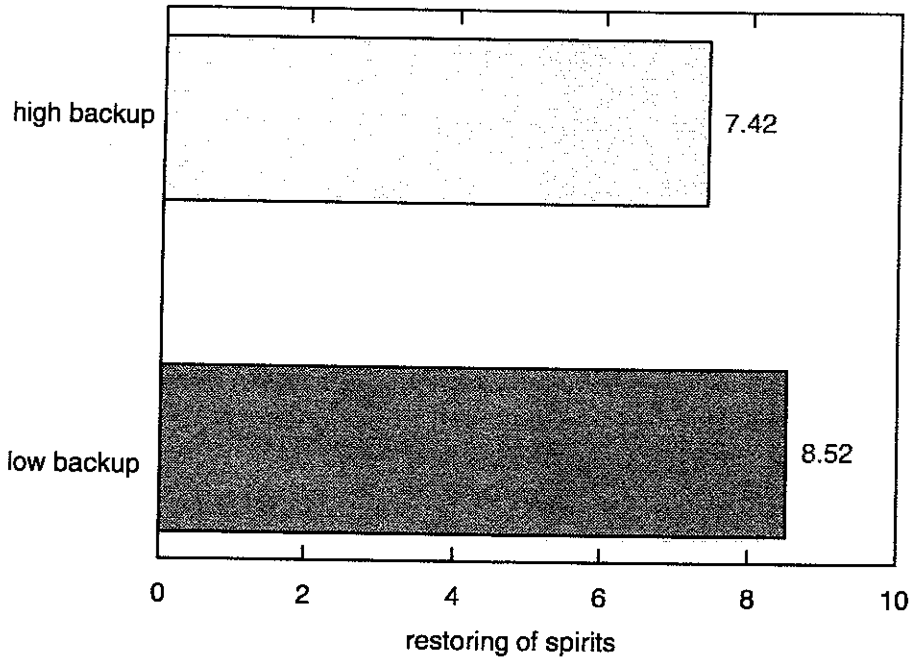

Figure 3.4: Scores on the restoring of spirits scale by having backup for caregiving

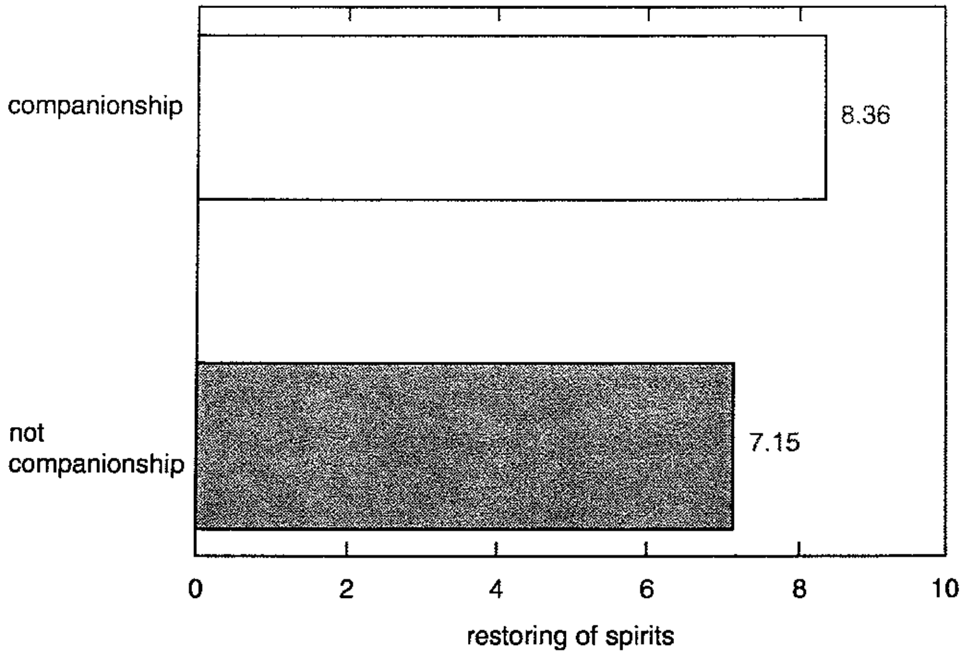

Figure 3.5: Scores on the restoring of spirits scale by companionship in caregiving

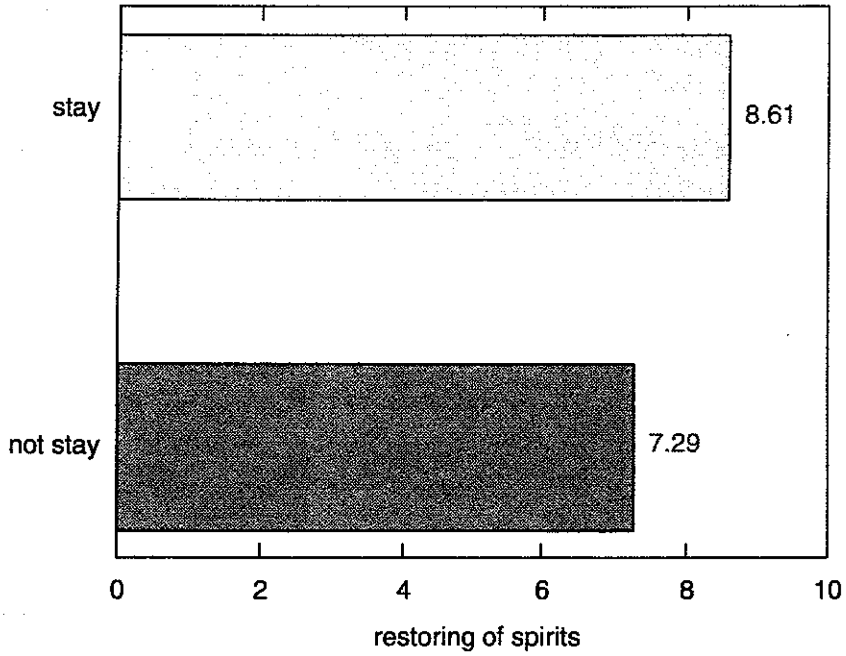

Figure 3.6: Scores on the restoring of spirits scale by staying with home care

The results of the statistical analyses comparing programs, sources of participants, and types of caregivers on the restoring of spirits scale are presented in Appendix G. The scale had a satisfactory alpha reliability coefficient of .65.

Acquiring skills and interests

This aspect of participation was assessed using four program evaluation statements, two measuring success in learning new things, and two measuring failure to master and/or enjoy the activities on offer. Responses to the items measuring failure to master and/or enjoy the activities were reverse scored for the purposes of calculating scale scores. This meant that on each of the items and on the scale as a whole, a high number could be interpreted as a sign of greater learning, a low number of greater frustration.

The Skills and Interest Scale

(1) Attending the course introduced me to skills I didn't have before.
(2) I have found a new interest through this course.
(3) The course added to my frustration with life. *(reverse score)*
(4) The course made me feel inadequate as a person. *(reverse score)*

The mean for the skills and interest scale was 7.36 and the standard deviation was 2.08. As with restoring of spirits, most participants were positive, adopting the view that they had acquired skills and interests through taking part in the program. Only three participants scored below 5, feeling that the program had detracted more from their sense of competence than it added.

Scores on the skills and interest scale did not differ significantly across courses although the trends in the data are worthy of comment. From Figure 3.7, participants involved in the walking program were less likely to report acquiring skills and interests than those in drawing or independent activities. This undoubtedly reflects differences between the programs in their balance between teaching new skills and enjoying familiar activities.

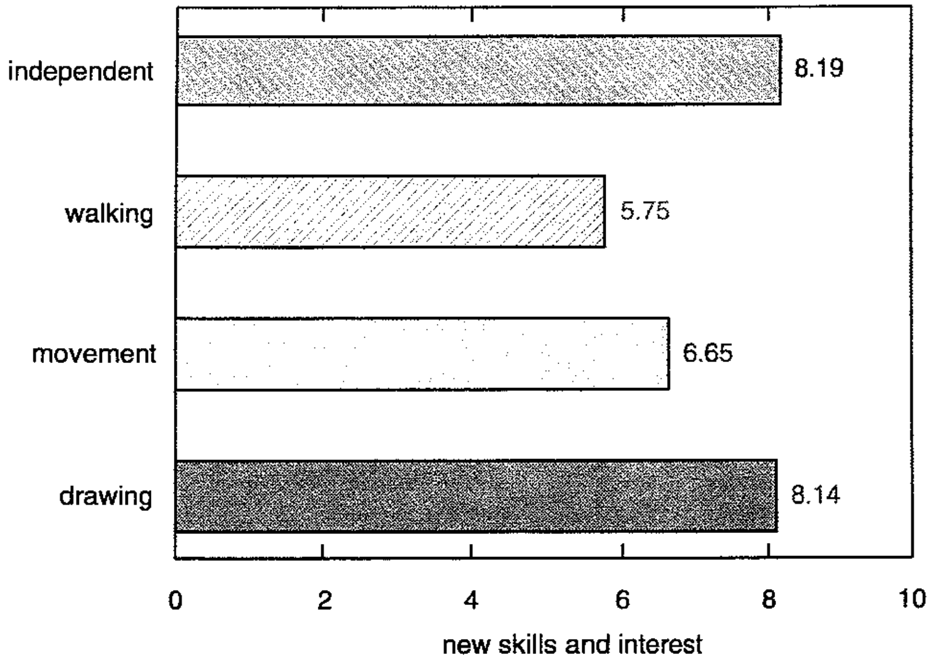

Figure 3.7: Scores on the skills and interest scale by program type

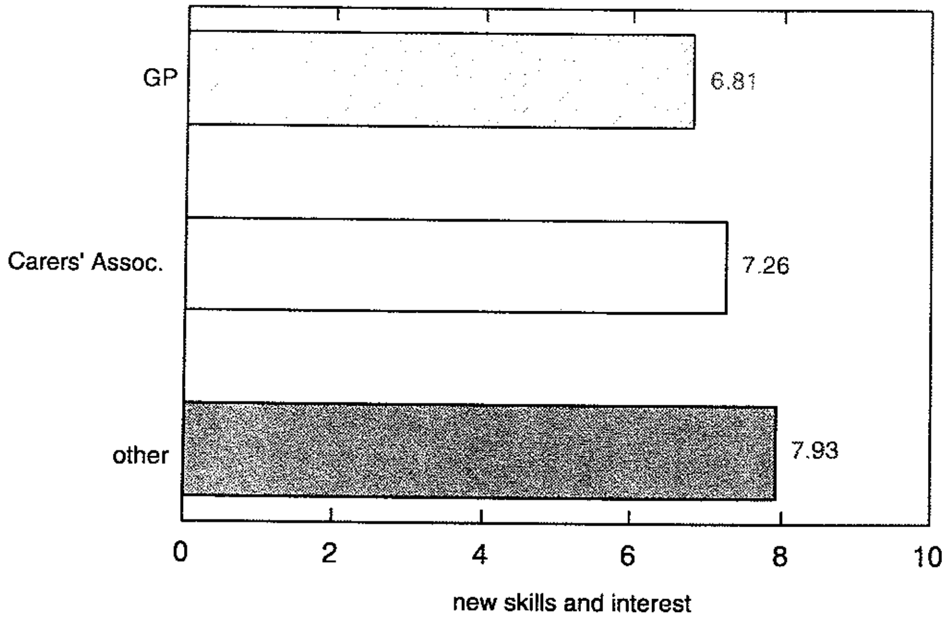

Figure 3.8: Scores on the skills and interest scale by recruitment source

The degree to which participants acquired skills and interests through their program wasn't statistically related to source of recruitment (GP surgeries, Carers Association, community contacts) (see Figure 3.8) or other caregiving characteristics. Only two significant findings emerged when the skills and interest scale was related to sociodemographic background variables, caregiver well-being and caregiving circumstances. Those who were committed to staying with home care endorsed the value of new skills and interest more strongly (see Figure 3.9). Spouses were less likely than non-spouses to report having acquired skills and interests. This may have been due to differences in the program choice of spouse and non-spouse caregivers. Spouses were well represented in the independent activities category (3 out of 4), but were notably underrepresented in the drawing program (2 out of 16).

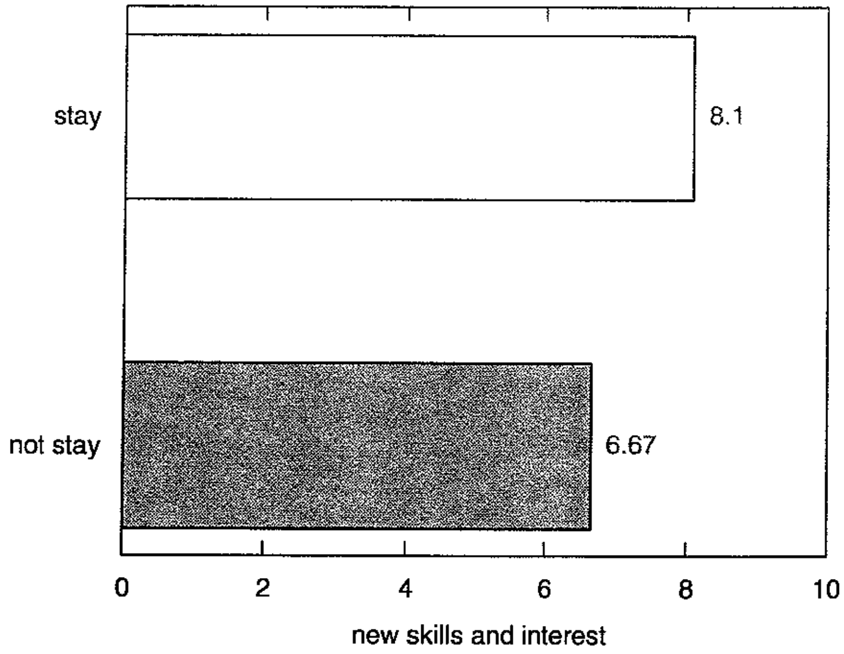

Figure 3.9: Scores on the skills and interest scale by staying with home care

The skills and interest scale had an alpha reliability coefficient of .56. The statistical analyses on which the above discussion is based are presented in Appendix G.

Engaging socially

The drawing and movement and relaxation programs explicitly encouraged the social engagement of participants with each other. In walking and independent activities, participants chose the level of social engagement that suited them. The degree to which participants valued the social aspects of their program was measured through one evaluation statement:

The Social Engagement Scale

(1) I enjoyed the social atmosphere of the course.

Across all programs, enjoyment of the social aspects was high (see Figure 3.10). The mean across programs was 8.95 with a standard deviation of 1.62. No one scored below 5. Furthermore, it did not matter how participants were recruited. The social benefits were felt as strongly by those already linked with the Carers Association as those less well networked (see Figure 3.11).

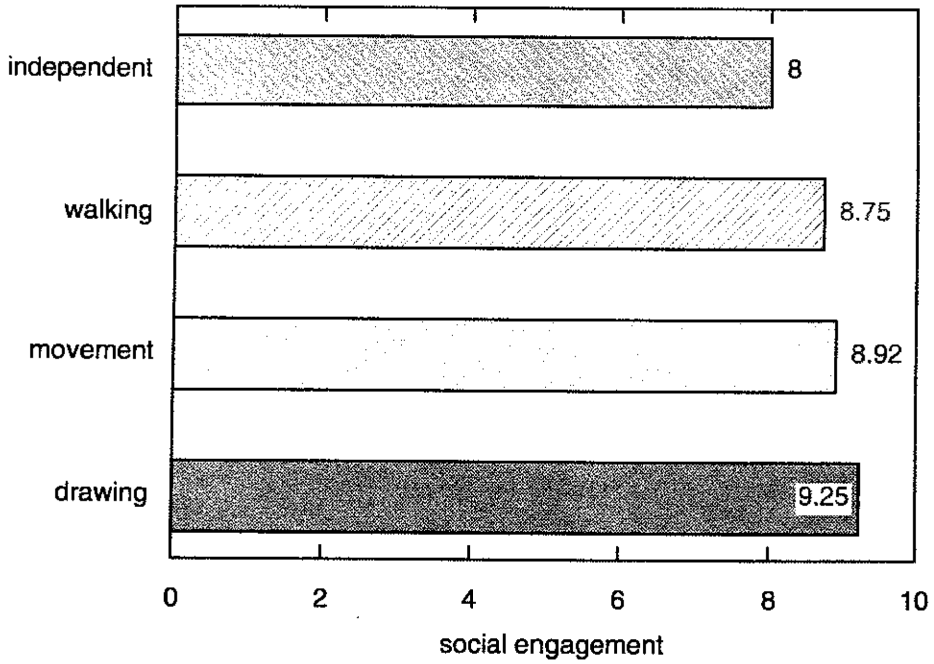

Figure 3.10: Scores on the social engagement scale by program type

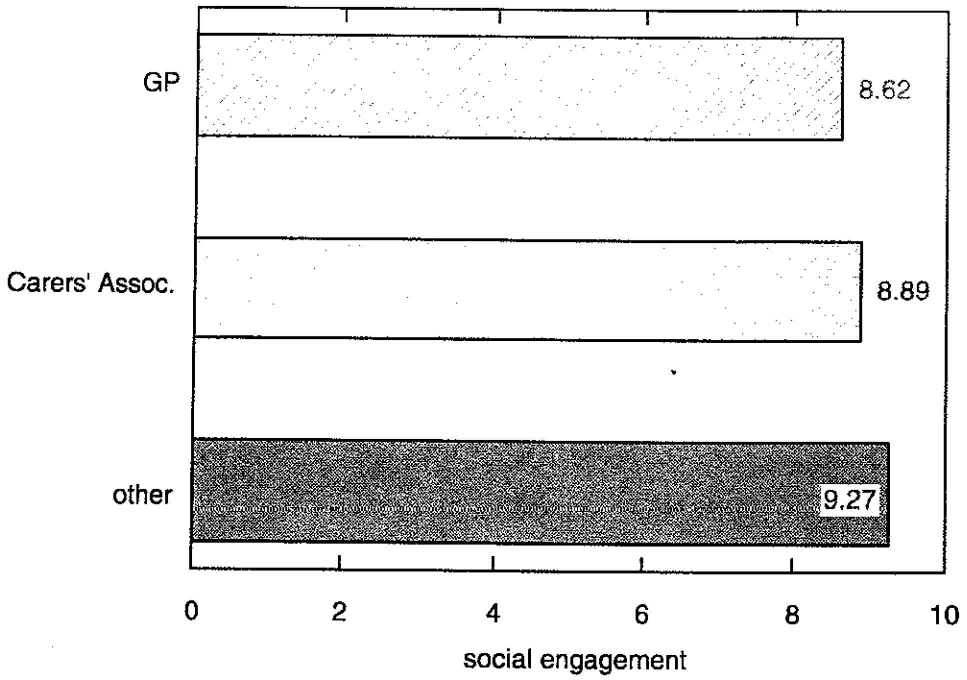

Figure 3.11: Scores on the social engagement scale by recruitment source

Social engagement was related significantly to four caregiver characteristics. Those who enjoyed the social atmosphere most were those committed to staying in the caring role: That is, they were less likely to have taken the first step of inquiring about other accommodation (nursing home or hostel) for the person in their care (see Figure 3.12). Furthermore, those who most enjoyed the social aspects of the programs were those who reported providing high emotional care to the care receiver (see Figure 3.13), and who found that the caregiving role made them feel useful (see Figure 3.14), busy and occupied (see Figure 3.15). Statistical details are presented in Appendix G.

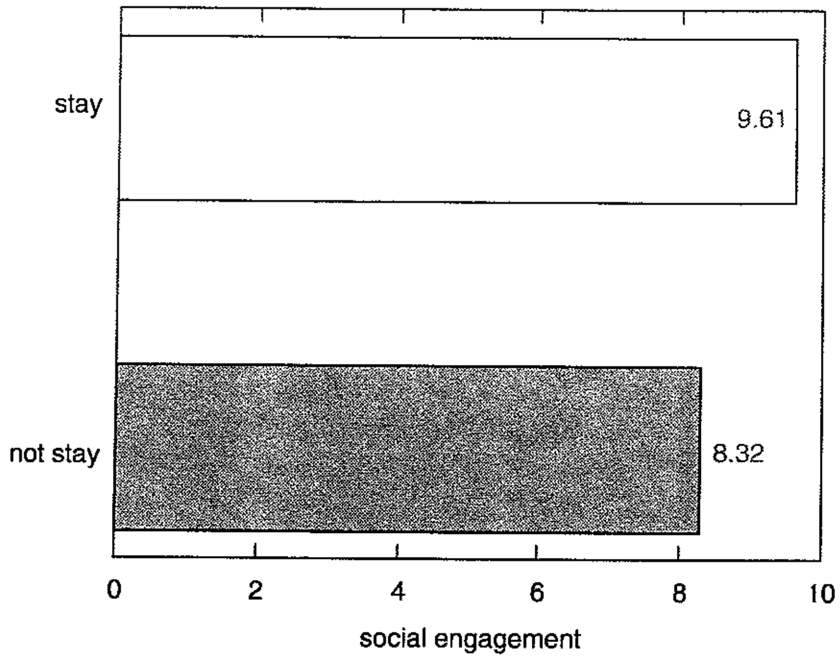

Figure 3.12: Scores on the social engagement scale by staying with home care

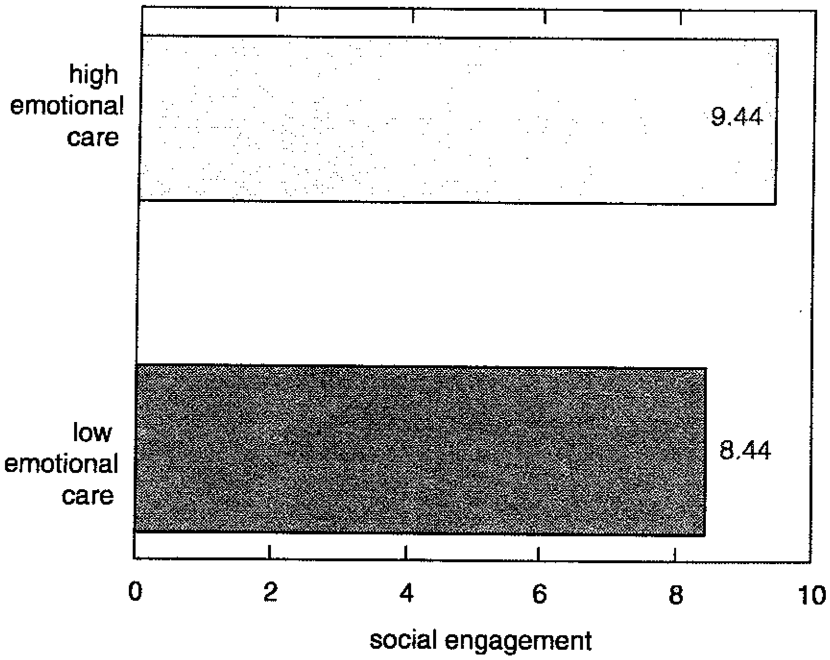

Figure 3.13: Scores on the social engagement scale by providing emotional care

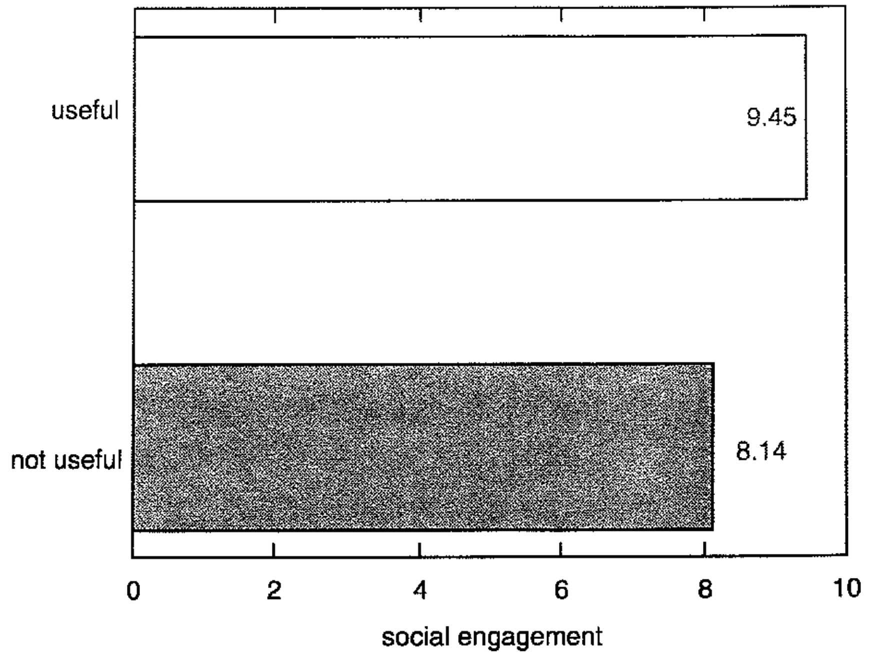

Figure 3.14: Scores on the social engagement scale by usefulness in caregiving

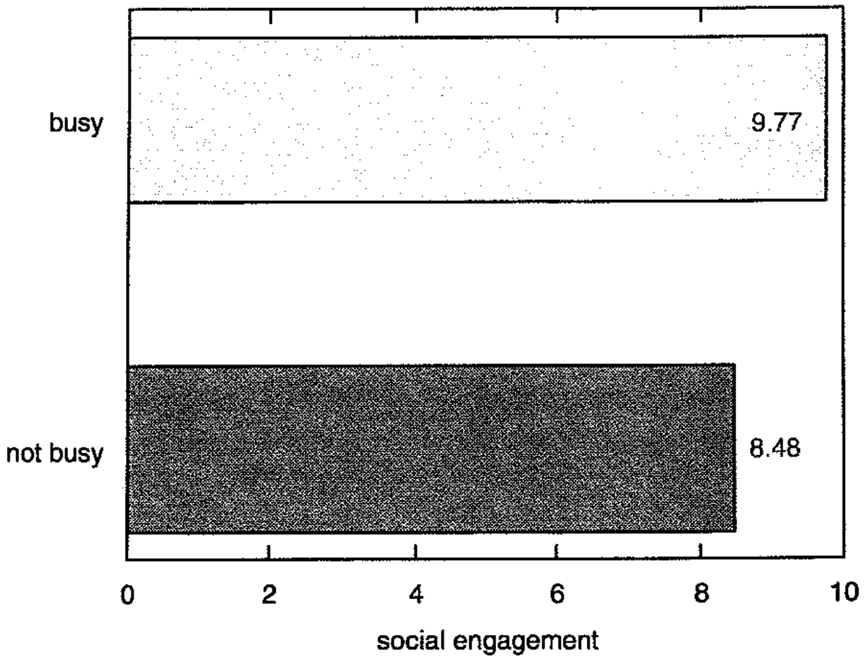

Figure 3.15: Scores on the social engagement scale by being busy and occupied through caregiving

Self-starting

One hope for the project was that carers would see and feel the benefits of using respite for pleasurable activities and would continue to seek out opportunities after the programs had finished. Three program evaluation statements tapped the extent to which participants were motivated to pursue the activities of their chosen program:

The Self-starting Scale

(1) I will try to continue ... [drawing] in my spare time.
(2) I would do this course again.
(3) I wouldn't have gone to such a course if the staff of the research project had not organized it for me. *(reverse score)*

Overall, carers were not as highly motivated to pursue the activities as might be expected from the very positive program endorsements presented above. The mean for the self-starting scale was 5.84 with a standard deviation of 2.29. Seven cases fell below the mean. The relatively low mean is attributable primarily to one item: Most course participants agreed that they "wouldn't have gone to such a course if the staff of the research project had not organized it" (see Table 3.1). This is one of the most important findings of the study. In line with the positive evaluations of the programs reported previously, participants sounded positive about continuing their activities and said that they would do the course again (see Table 3.1). Whether or not good intentions to continue afterwards became a reality in the lives of the participants is a question for the future.

Self-starting scale scores did not vary by either program type or caregiver characteristics when means were compared statistically (see Figure 3.16). They did vary by recruitment source, however (see Figure 3.17). Those recruited through community contacts were more highly motivated to pursue the activities than those recruited through the Carers Association. It is possible that participants who came to the programs through the community were more likely to be acting on their own initiative and, therefore, more likely to be self-starters. Participants recruited through the Carers Association may have enrolled in the Program because of their affiliation with the caregiving network rather than interest in the activities per se.

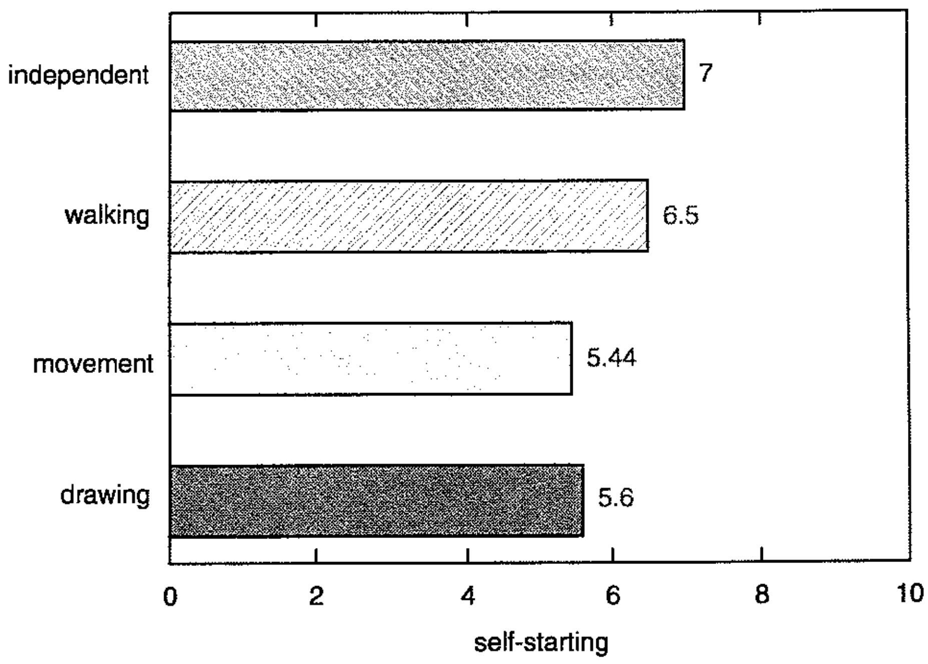

Figure 3.16: Scores on the self-starting scale by program type

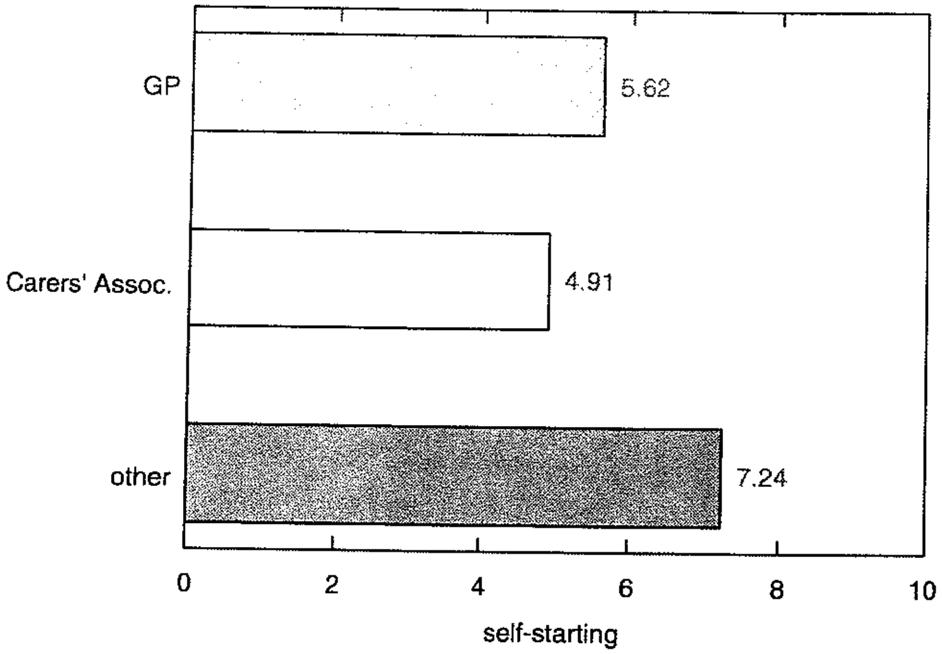

Figure 3.17: Scores on the self-starting scale by recruitment source

The alpha reliability coefficient for the self-starting scale was a satisfactory .61. The statistics on which the above discussion is based are reported in Appendix G.

Intrusiveness

Interventions which remove the caregiver from the caregiving situation, particularly for purposes of recreation, run the risk of offending the care receiver and/or disrupting the caregiving relationship to the detriment of one or both partners. This unintended consequence of the intervention was a major consideration in discussions surrounding the ethics of the project, and every effort was made in recruitment to be sensitive to the interdependency of caregiver and care receiver and to respect their relationship. Nevertheless, the intervention demanded some kind of check on our ability to offer such programs to caregivers without jeopardizing the caring relationship. Four program evaluation statements correlated with each other sufficiently well to form an intrusiveness scale:

The Intrusiveness Scale

(1) My attendance at the course made the person I am caring for feel resentful.
(2) I was worried about being away from the person I was caring for when I started this course.
(3) There were times when I felt guilty about leaving my caregiving responsibilities to go to the course.
(4) My attendance at the course upset the person I was caring for.

The intrusiveness items were the least supported in Table 3.1 and consequently it is of no surprise that the mean was a low .82 with a standard deviation of 1.57. One participant, however, scored above the midpoint of the scale, showing that in spite of our best efforts, an invitation to caregivers to take part in a recreational program could have unintended negative side effects.

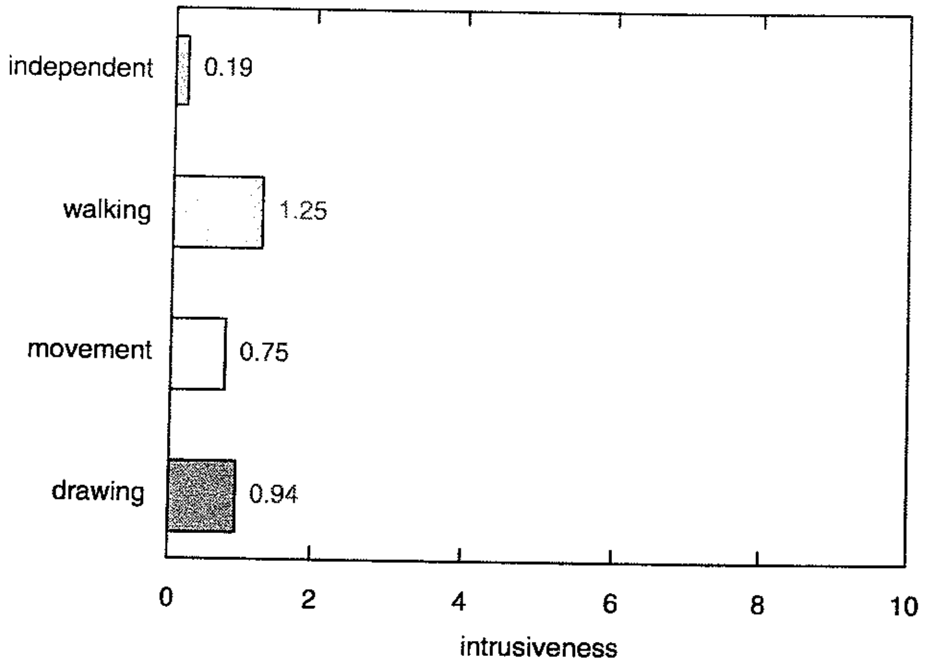

Figure 3.18: Scores on the intrusiveness scale by program type

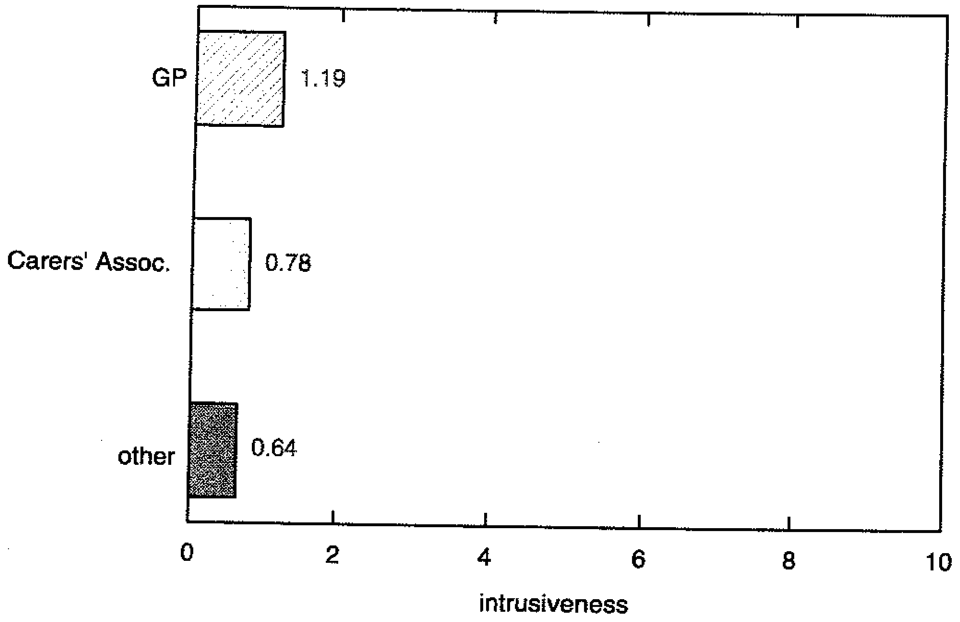

Figure 3.19: Scores on the intrusiveness scale by recruitment source

Intrusiveness scale scores did not differ significantly across programs (see Figure 3.18), sources of recruitment (see Figure 3.19) or caregiver characteristics with two exceptions. Intrusiveness was more likely to be felt by caregivers with poor physical health (see Figure 3.20) and few ideas about other possible selves (see Figure 3.21). Possibly, such caregivers' coping capacities had been stretched beyond their limits.

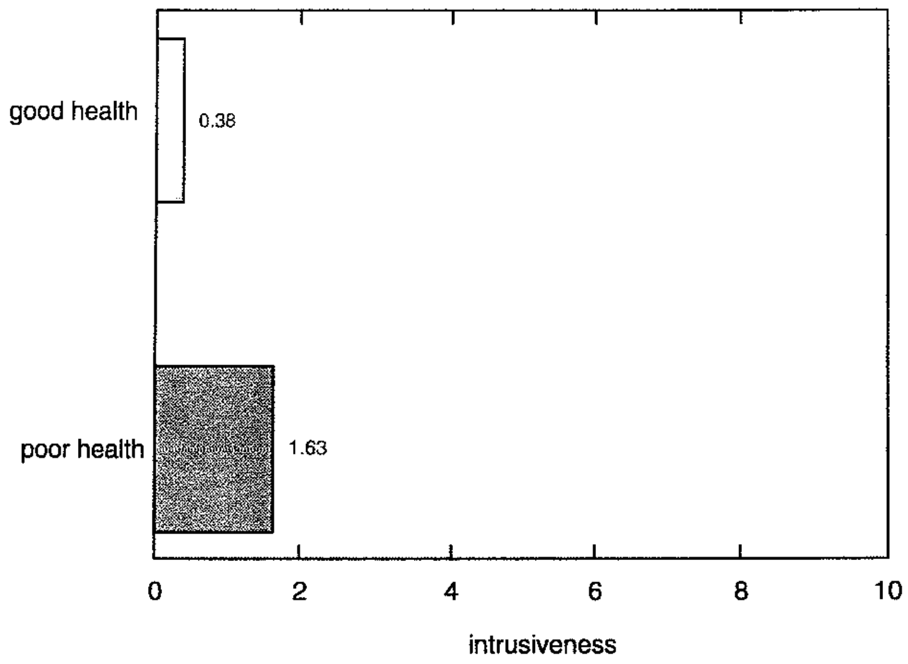

Figure 3.20: Scores on the intrusiveness scale by physical health

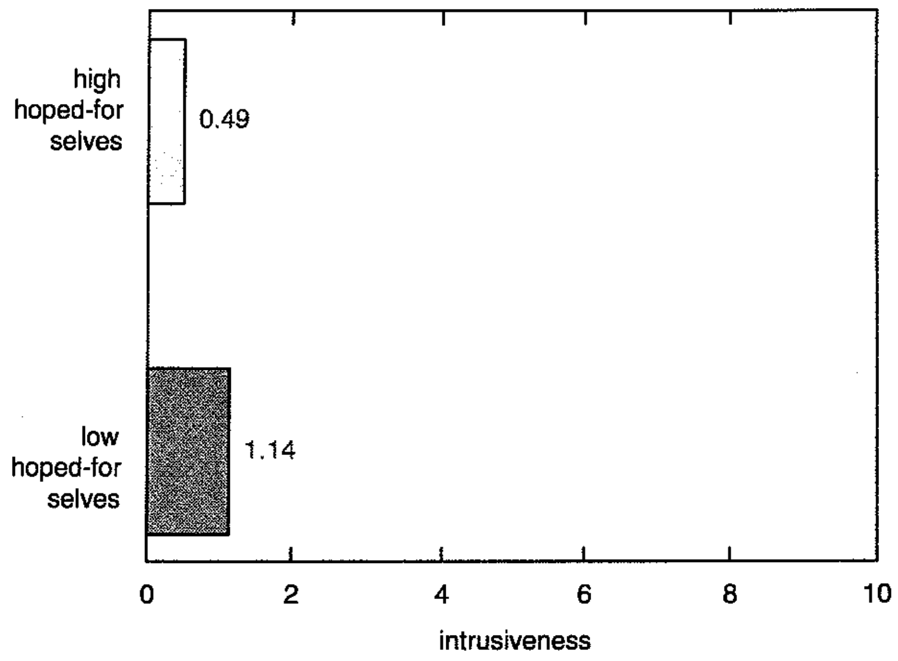

Figure 3.21: Scores on the intrusiveness scale by hoped-for selves

The intrusiveness scale had a satisfactory alpha reliability coefficient of .67. Details of the statistical analyses appear in Appendix G.

Qualitative findings

The open ended question asking carers how they felt about the program elicited positive responses overall ranging from the global to the specific. At the global end of the spectrum were positive comments such as "a wonderful course, looked forward to it every Thursday" and "completely enjoyed the course, wouldn't change a thing about it". In the case of one participant: "I liked everything even though I don't speak English".

The specific aspects of the program that appealed were remarkably diverse. One participant had never been in a taxi before by herself and marvelled at the experience. Others appreciated the quality of the courses, commenting that they were well thought out, well run and well organized. Some participants paid tribute to the staff involved in teaching the courses, finding them understanding and approachable, kind, and excellent instructors. Participants mentioned that they valued being treated with respect and as individuals with different needs. One was particularly impressed by the respite service, appreciating the way in which the agency coordinated their service so that the care receiver had a familiar face visit each week. In another case, the respite carer encouraged the care receiver to do little things for herself that the caregiver thought she could never do again. Furthermore, the caregiver was delighted to find the care receiver looking forward to respite visits.

The specific impacts of the programs on individuals also varied enormously. Some focused on having "time to explore new skills" and "learning a new way of looking at tangible things", others were drawn to internal pleasures such as time to relax, time to oneself, the pleasure of listening to music, the enjoyment of relaxation and of learning how it is done, the enjoyment of a challenge and of trying to do something new, and the self-discovery of doing things that one had never thought about doing before. One participant commented that she found the class "totally absorbing", "mentally stimulating" and "requiring a lot of concentration". As a result she "didn't think about things that were bothering [her]". At the same time, this respondent observed that "there was no pressure, no expected outcomes, just enjoyment for self".

Others focused on rewards and encouragement from the external environment. On these issues, however, praise from one tended to be offset by criticism from another. One caregiver welcomed structured activities at specific times with a taxi arriving to provide transport, because it prevented her from getting tied up with something else. Others found the times unsuitable, particularly those with school aged children. On the topic of venue, some commented on the pleasant surroundings and the enjoyable drive there, while others felt that they spent too much time driving and not enough time on their chosen activity. Having time to talk during coffee breaks was appreciated by some, but again others preferred to spend all their time on their activity. Conversations about caregiving were discouraged in the programs, but needless to say such conversations occurred. For some this was a good thing as they realized that others were in situations similar to their own, indeed sometimes worse. One caregiver commented that " it cheered [her] up seeing women worse off than [her]self who were cheerful and laughed a lot". Others didn't like hearing distressing stories, particularly when they related to events that might be ahead, such as nursing home admission. Some enjoyed the variety of people in the programs, some wanted more, and others felt uncomfortable because their problems were different. One participant mentioned feeling excluded because her situation was so different.

The courses themselves also drew a variety of responses. Walking was considered gentle and pleasurable, drawing was at times difficult and frustrating, while movement and relaxation ranged from relaxing to embarrassing and uncomfortable. Specific mention was made of the occasional snag. The most dramatic of these was losing an instructor midway through the first movement and relaxation class due to illness. A replacement was found immediately, but the change was an unwelcome disruption to some.

In the midst of this array of responses, one criticism occurred with greater regularity than any other. Eleven participants considered the seven week programs too short. In the words of one, "I was just getting comfortable with the activities and then I had to stop". Another commented that a few hours was just not enough to make a difference to stress levels, "a few days would be necessary for that".

The positive reaction to the Caregiver Recreational Respite Program was probably most evocatively conveyed through two letters, the first written for us to promote the Program among other caregivers (see Box 3.1), the second unsolicited and appearing in the Carers Association newsletter (see Box 3.2).

Box 3.1: Letter of support for the Caregiver Recreational Respite Program

As a carer of a husband with dementia and being partially blind myself, I am always on the look-out for ways to keep fit and healthy to help cope with all the demands on me.

I was particularly interested to learn of the ANU Research as it seemed to me to be exploring an in-depth understanding of the role of the carer at home and in the community.

When a six week course was offered which would allow me to participate in a two hour activity right away from my usual caring role I was most happy to accept.

I chose the 'relaxation through music and movement group' and was so pleased to be introduced to some quite different movements and exercises.

My previous experience had been through aquarobics, gentle exercises of the aerobic variety, tai chi and yoga but this course seemed to be quite different. 'Psycho-physical exercise' it was called.

Unfortunately I was not able to attend the last 2 sessions as I had to go into hospital for significant surgery but would have liked to have been able to attend more sessions and perhaps have been able to have got to know the other participants more fully. Sadly, it was only the beginning of a winding down process but I did begin to feel the beneficial effects.

On reflection, I think I would have liked a greater component of the sessions to have been more of the free-flowing creative movement to music and some more time for 'visualisation' (if that is the right word for quietly imagining a wonderful place in nature for deep relaxation) but I realise that that may be determined by the composition of the group.

It would be good to be aware of an ongoing group of this nature - perhaps publicised through the Carers Association or its Newsletter. Venue to be at a convenient central location - preferably on a bus route.

In the meantime, thank you to all who made it possible for me to be part of this little cameo of re-creation.

M.F. 24.10.97

Box 3.2: Letter of support for the Caregiver Recreational Respite Program

I recently attended seven free "Drawing on the Right Side of the Brain" classes, conducted at Weston through the ANU Research Program for Carers.

Our small group all assured our teacher we couldn't draw, but after the classes were finished and we laid out the best of each week's work, we were all amazed at what we had achieved and were disappointed it had come to an end.

Just goes to show what hidden abilities we all have if we are given the opportunity to explore them.

Carers are funny people, we will do anything to make sure the ones we care for are healthy and happy, but WHY are we so hard on ourselves?

The course organisers were happy to arrange transport, respite, just about anything, so we carers could attend one of the three courses offered. So WHY don't we jump at the chance to have a break. WHY are we so reluctant to let someone care for us?? Are we really so indispensable?

As a reluctant carer who was persuaded to give it a try, I can't speak highly enough. There was no pressure or stress, in fact the two hours each week were wonderfully mind relaxing. You are so busy concentrating on drawing that you don't think or worry about anything or anyone for two wonderful carefree hours.

So if you get a chance to do something for yourself DON'T think of why you can't, just give it a try, who cares if it's something you've never thought you were capable of, or something you don't really think you're interested in.

The company and morning tea are worth the effort to go, and let's face it, the only way we can continue to give 110% is to give ourselves an occasional dose of R&R.

Beryl "just another carer"

(Reproduced with the kind permission of the Carers Association of the ACT Newsletter)

Conclusion

The programs that were offered to participants were well received, achieving the objectives of providing a complete break from caregiving, offering opportunities to acquire new skills and giving participants the option of social engagement. The qualitative data confirmed these quantitative findings and uncovered the variety and richness of responsiveness to the Recreational Respite Program. For the vast majority of participants, involvement in the programs was not accompanied by negative side effects either in the form of disruption to the caregiver-care receiver relationship or through placing strain on the limited resources of the caregiver. The most commonly and freely offered criticism related to the shortness of the courses that were offered. For many, two hours a week for seven weeks was not enough. These positive outcomes seem inconsistent with the reluctance of caregivers to initiate such activities themselves. Caregivers needed someone else to invite them to participate and organize things for them. Part of the explanation for this finding is undoubtedly the priority placed on care, with little time or energy for organizing other things. Part of the explanation also seems to be legitimation. Caregivers needed assurance that it was all right to take a break, and that the Program would not only be good for them, but also could be good for their care receiver. In some cases, taking the break was justified on other grounds entirely. Some participants came to the Recreational Respite Program as much to help us, and, as several suggested, to help others like them, as to help themselves.

Chapter 4

Changes in caregiver well-being

Interventions of the kind described in this report are expected to impact positively on the lives of caregivers: to make them feel less burdened, more satisfied with life, less stressed, and generally speaking, more positive and in better health. It has been widely accepted that unless intervention programs can deliver such outcomes, they should not be making claims on the public purse. Consequently, evaluations are routinely built into intervention projects, most commonly taking the form of client satisfaction surveys (Gallagher, 1985). This methodology, however, has increasingly come under scrutiny, as interventions with favourable outcomes exceed the funding resources available and sometimes conflict with more objective measures of change (Callahan, 1989; George & Gwyther, 1986). More stringent evaluation involves going beyond client satisfaction surveys of the kind reported in the previous chapter to support the case for positive outcomes. Evidence from more objective before and after measures is required to enable policy makers to judge the relative effectiveness of competing interventions (Callahan, 1989; Lawton et al., 1989; Knight et al., 1993).

This chapter and the next address these questions in relation to the Caregiver Recreational Respite Program. Due to the small numbers in each activity group, participants in drawing, movement and relaxation, walking and other independent programs were pooled for the analyses presented in this chapter and the next. The appreciation that caregivers expressed in relation to their programs, described in Chapter 3, was expected to coincide with a number of quantifiable positive changes in the lives of caregivers. In order to index these changes as objectively as possible, the following five measures of well-being were taken before the program started and a few weeks after its completion:

(a) physical well-being

(b) life dissatisfaction

(c) burden

(d) minor psychiatric symptoms

(e) number of hoped-for selves

(f) number of feared selves

These measures are described in detail in Appendix F. The Threat to Basic Needs Burden Scale is described in Chapter 2.

Methodology

In order to quantify the changes taking place in caregivers' lives as a result of an intervention, four design features were desirable in the evaluation:

(a) measures of outcomes prior to program commencement

(b) measures of outcomes after program completion

(c) a control group for comparison with the intervention group so that change can be attributed to the intervention and not to other external events that affect the outcomes over the period of the intervention

(d) random assignment of the caregivers to the control group or the intervention group so that groups could be regarded as equivalent before the intervention started.

The present evaluation did not meet requirements (c) or (d) because of low rates of recruitment within a restricted time frame (6 months) and because of the commitments and timetables of caregivers. Ethical considerations led us to find a place for caregivers as soon as possible that best suited their personal circumstances (some wanted to do the program on the second round, others could only do it on the first round), and in so doing, we departed from the design that we first envisaged for this project. The original intention was to use randomly assigned participants in round 1 as the intervention group, while participants who were randomly allocated to the later program could serve as a control group for the period of the first round.

In the absence of a control group, we sought a comparison group among those caregivers who had volunteered for the Caregiver Recreational Respite Program, but who, for one reason or another, did not or could not enrol in a particular program. For these caregivers we had collected information for the pre-program outcome measures. We asked them if they would agree to a follow-up interview after the program finished, explaining to them our need for a comparison group. Of the 35 caregivers who had completed the pre-program interview but who had not participated, 17 agreed and were available to take part in a second interview. We will refer to this comparison group below as the "non-participant" group.

Those who participated in the programs were divided into two groups depending on how they had been recruited. Caregivers who were recruited through the Carers Association were separated from caregivers recruited through other means. Qualitative interviews suggested that participants from the Carers Association had been exposed to another intervention that was possibly more powerful than our own. The majority had received counselling and/or belonged to carers' support groups. Through the staff of the Carers Association and through the reports of caregivers themselves, we found that they were quite sophisticated in thinking about how to take care of their own needs at the same time as meeting the needs of their care receiver. These two groups are defined below as "participants" and "participants with Carers Association support". Of the 37 participating caregivers who completed their pre- and post -program interviews, 19 comprised the first group and 18 the second group.

The design of the evaluation is summarized in Table 4.1. It is of note that regardless of the group to which caregivers belonged, all received a visit from a member of the research team during the course of the program. Part of the purpose of this visit was to keep in touch with the caregivers involved in the project and check on how things were going. This visit was also used to conduct a qualitative interview with the caregivers to find out how they perceived their caregiving situation. It will be recalled that caregivers' perceptions were considered to lie at the heart of understanding why so many are reluctant to use respite care even though the caregiving load that they carry is high.

Table 4.1: The measures and design for assessing changes in well-being associated with the Caregiver Recreational Respite Program

Group (size)	Stage 1	Stage 2	Stage 3
Participants (n=19)	Pre-program measures (a) physical well-being (b) life dissatisfaction (c) burden (d) symptoms (e) hoped-for selves (f) feared selves	Recreational Respite Program Qualitative interview	Post-program measures (a) physical well-being (b) life dissatisfaction (c) burden (d) symptoms (e) hoped-for selves (f) feared selves
Participants + CA (n=18)	Pre-program measures (a) physical well-being (b) life dissatisfaction (c) burden (d) symptoms (e) hoped-for selves (f) feared selves	Recreational Respite Program Qualitative interview	Post-program measures (a) physical well-being (b) life dissatisfaction (c) burden (d) symptoms (e) hoped-for selves (f) feared selves
Non-participants (n=17)	Measures identical to pre-program measures (a) physical well-being (b) life dissatisfaction (c) burden (d) symptoms (e) hoped-for selves (f) feared selves	Qualitative interview	Measures identical to post-program measures (a) physical well-being (b) life dissatisfaction (c) burden (d) symptoms (e) hoped-for selves (f) feared selves

Did the intervention work?

For the intervention to work as hoped, mean scores on the scales measuring life dissatisfaction, burden, minor psychiatric symptoms and feared selves should be lower on post-test than pre-test. Furthermore, the decline in scores should have been significantly greater for those in the intervention groups (participants and participants with Carers Association support), than for those in the comparison group (non-participants). In the case of physical well-being and hoped-for selves, the opposite effect was sought. Both participant groups should have higher scores after they had completed the program than before, and their gains should have been greater than those of non-participants.

The means of the pre-program and post-program scores for each of the groups on each outcome measure are presented in Table 4.2. Overall, the trend was for all groups, participants and non-participants, to improve their psychological and physical well-being scores at post-test. There were four exceptions. All groups expressed fewer hoped-for selves after the program than before. Possibly at the first interview, anticipation of the program and the fact that we were searching for ideas for subject matter unleashed a host of responses that we would not have received otherwise, and that we were unlikely to receive after the program. The three other exceptions involved only non-participants. Non-participants had more feared selves at post-test than pre-test, they reported their health as being slightly poorer, and their life dissatisfaction showed signs of increasing.

Table 4.2: Pre- and post-program means for non-participants, participants, and participants with Carers Association support on the well-being outcomes

Well-being outcomes	Time of interview	Non-participants	Participants	Participants + CA
Physical well-being	Pre	3.29 (1.10)	2.79 (1.18)	3.22 (1.35)
	Post	3.18 (1.07)	2.90 (1.20)	3.28 (1.13)
Life dissatisfaction	Pre	15.29 (3.90)	15.63 (4.58)	14.72 (3.75)
	Post	15.35 (4.02)	14.16 (4.32)	13.94 (2.82)
Burden	Pre	8.68 (3.65)	10.28 (4.16)	8.50 (4.58)
	Post	7.35 (4.24)	8.33 (4.16)	6.94 (4.88)
Minor psychiatric symptoms	Pre	21.41 (6.16)	23.30 (9.82)	23.78 (8.68)
	Post	20.35 (5.17)	21.53 (6.71)	19.28 (6.58)
No. hoped-for selves	Pre	4.31 (2.02)	4.47 (1.87)	4.44 (1.72)
	Post	4.00 (1.63)	4.10 (1.41)	3.67 (1.53)
No. feared selves	Pre	2.00 (.73)	2.56 (1.20)	1.78 (1.17)
	Post	2.25 (1.48)	1.89 (1.02)	1.67 (.97)

The critical question that needs to be answered before interpreting these findings is whether or not the changes we observed are statistically significant, or are they merely chance phenomena. Furthermore, a perusal of the pre-program mean scores for the three groups (participants, participants with Carers Association support, and non-participants) reveals non-equivalence among them before the programs started. Participants with Carers Association support, for instance, had fewer feared selves than the other groups, non-participants had fewer symptoms, and participants reported poorer health. A statistical procedure is needed to examine whether the differences are large enough to be statistically significant and to test whether change was significantly greater in the participation groups than in the non-participant comparison group. The procedure chosen was repeated measures analysis of variance with time being the within subject factor (pre-program and post-program) and the intervention being the between-subjects factor (non-participant, participant and participant with Carers Association support). This 3x2 analysis was performed for each of the outcomes and the statistical results are reported in Appendix H. The text below summarizes the findings for each of the outcomes.

Physical well-being

Significant differences were not found between the groups at the outset nor was there evidence of significant change in the health status of any group over time. The health of caregivers remained much the same for the duration of the study.

Life dissatisfaction

The findings for life dissatisfaction followed the same pattern as for physical well-being. The groups did not differ significantly on life dissatisfaction at pre-test and these levels had not changed significantly for any group at post-test.

Burden

A somewhat different pattern of results emerged when mean scores on caregiving burden were compared statistically. The groups could not be differentiated on their burden scores at pre-test. At post-test, all groups (non-participants, participants, participants with Carers Association support) had improved on their pre-test scores. Carers reported significantly less burden when they were re-interviewed, regardless of whether they had taken part in the respite recreational programs or not. There was no evidence of the intervention groups experiencing a greater reduction in burden than the comparison group of non-participants. The scores are represented graphically in Figure 4.1.

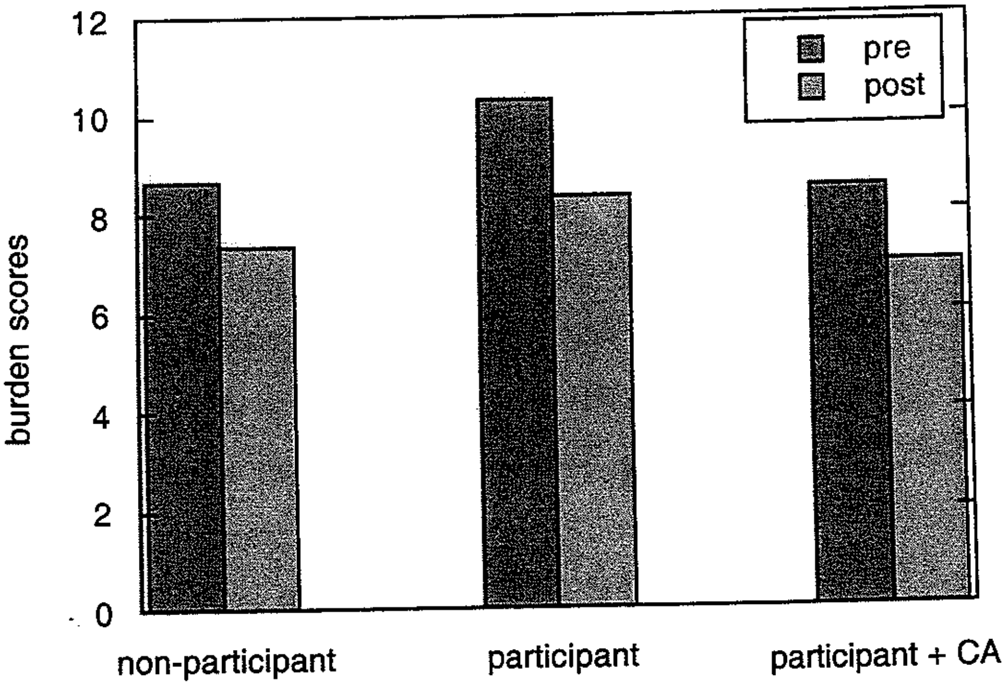

Figure 4.1: Pre- and post-test burden scores for non-participants, participants and participants with Carers Association support

Two explanations of these findings warrant consideration. One line of argument dismisses the effect as measurement artefact. Epidemiological studies have shown that psychopathology often declines when assessments are made on two separate occasions. The appearance of fewer symptoms on re-test has been attributed to a tendency to respond in a more socially desirable way second time round or to respond more mechanically, not thinking too deeply about the response alternatives, and choosing the one that is the more common. Jorm, Duncan-Jones and Scott (1989) investigated the circumstances in which this drop in psychopathology was observed and concluded that the types of measures most susceptible to the re-test artefact were those involving the assessment of negative self-characteristics and those administered orally by an interviewer. The Threat to Basic Needs Burden Scale meets both these criteria.

A second explanation is that caregivers genuinely did feel less burdened by caregiving at the post-test interview. At the beginning, some caregivers were waiting on nursing home placement, and by the end of the program, offers had been made and accepted. Furthermore, all caregivers were receiving support of some kind for the duration of the program. Even those who were not participating were visited by one of our staff who talked with them extensively about their caregiving and how it affected their lives. This is not to suggest that talking with our interviewers solved problems, nor to belittle the time they so generously gave to our research team. The qualitative interviews, however, did provide caregivers with an opportunity to tell their story to someone who would listen, affirm the substantial nature of their responsibilities, and the importance of their contribution. A number of studies in the workplace have shown attention and recognition can improve both task performance and morale (Lana, 1969; Roethlisberger & Dickson, 1939).

Minor psychiatric symptoms

The results for minor psychiatric symptoms mirrored those for burden. The three groups did not differ significantly on the pre-test, and they all reported fewer symptoms on the post-test, regardless of whether or not they had participated in the recreation respite programs. No group improved significantly more than any other. The scores are represented graphically in Figure 4.2.

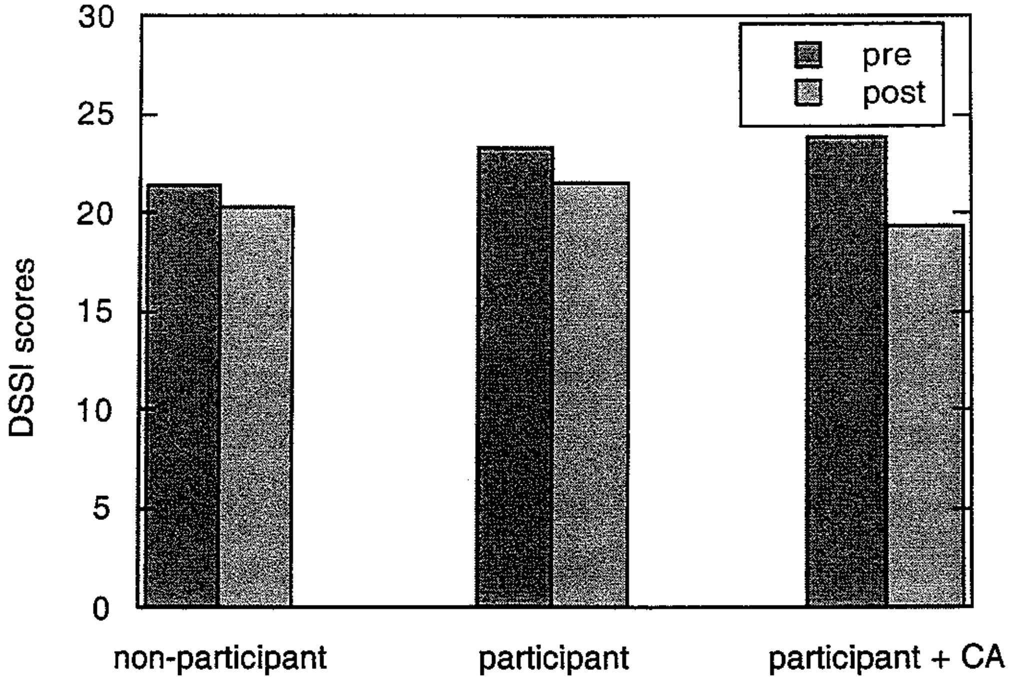

Figure 4.2: Pre- and post-test DSSI/sAD scores for non-participants, participants and participants with Carers Association support

Symptoms were measured by the Delusions-symptoms-states Inventory (DSSI/sAD) developed by Bedford et al. (1976) and used extensively in epidemiological work to assess anxiety and depression. It was one of the measures that Jorm et al. (1989) identified as being sensitive to the re-test artefact. The re-test artefact explanation gains plausibility in the light of the findings in Figure 4.2. Improvements may still have been due to offers of nursing home placements, but it seems unlikely that lending a sympathetic ear and recognition would influence symptoms of anxiety or depression.

Hoped-for selves

The decrease in the number of hoped-for selves from pre-test to post-test was not sufficiently great to produce a statistically significant difference in the analysis of variance. Hoped-for selves were relatively stable across groups and across time. There was no evidence that the intervention affected this variable in any way.

Feared selves

The number of feared selves behaved quite differently from the number of hoped-for selves. The differences between groups were not significant at the pre-test, but the changes from pre-test to post-test differed significantly across groups. The intervention had the effect of reducing the number of feared selves for the participant group, while the non-participants acquired more feared selves. The graph in Figure 4.3 shows the different patterns of change for participants and non-participants. The change for participants with Carers Association support was in the same direction as the participants, but was not of sufficient magnitude to be significantly different from the non-participant group.

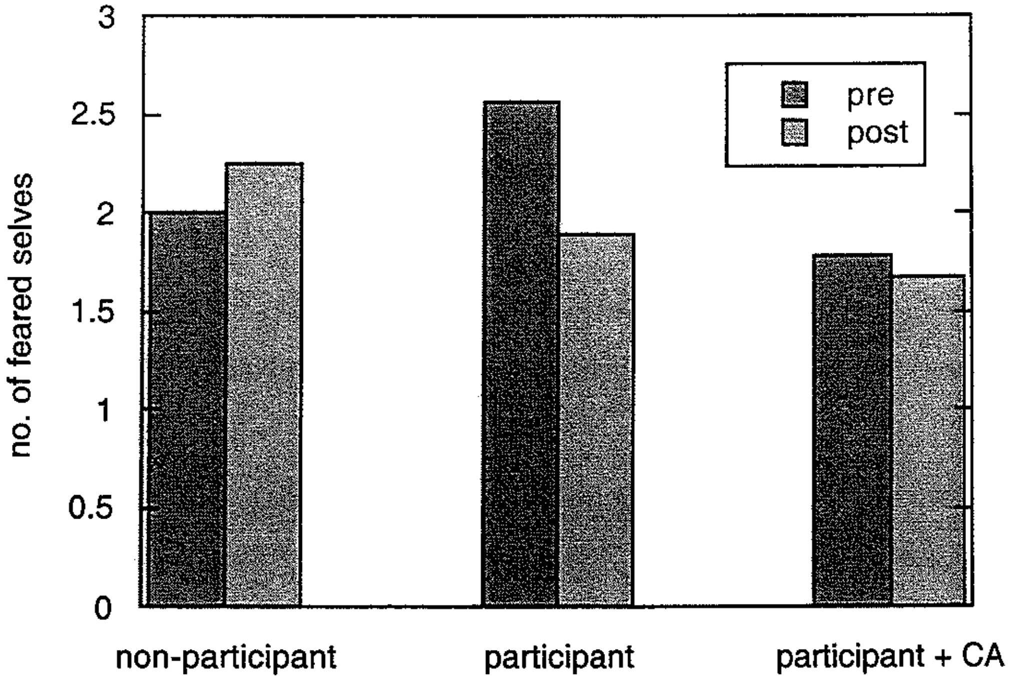

Figure 4.3: Pre- and post-test number of feared selves for non-participants, participants and participants with Carers Association support

Conclusion

Overall, these analyses provide little support for the hypothesis that the Caregiver Recreational Respite Program improved levels of well-being in caregivers. The findings of this chapter stand in stark contrast to those of the previous chapter. How can they be reconciled? Are caregivers' experiences in the programs irrelevant to the concept of well-being, or are the measures of well-being too far removed from the site of the intervention to detect the benefits of the Program (Zarit, Anthony, & Boutselis, 1987).

Perhaps there is some truth in both interpretations. There is no reason to discount caregivers' expressions of appreciation and delight in taking part in the programs. Post-test interviews were conducted by paid interviewers who had not been involved in any way in the courses. As a consequence, caregivers did not need to spare the interviewer's feelings when reporting their experiences. A more fruitful avenue for understanding these results is to focus attention on the criticisms. A significant number of carers found something specific that displeased them. Even though the sources of their displeasure varied, one attracted notable support: Eleven of the 37 participants complained about the program being too short and offering too few hours per week. One caregiver explicitly linked the limited time to issues of well-being, claiming that a longer period of recreational respite was required to make an impact on well-being (see Box 3.1 and Box 4.1). The Caregiver Respite Recreational Program may have been offering too little too late to turn around a group of people who were feeling acutely the stresses of providing home care.

A second way of reconciling the enthusiastic responses of Chapter 3 with the absence of change in well-being in Chapter 4 starts with questioning the relevance of the outcomes. They were chosen because they constitute standard, reliable, well-validated measures of well-being. As such, they cover a broad spectrum of human activity. Measures of life satisfaction, and psychological and physical symptoms tap into domains that go well beyond the caregiving role. The most focused of the well-being measures is the Threat to Basic Needs Burden Scale which assesses the extent to which caregiving threatens needs of a biological, social and psychological kind. Taking part in a two hour a week recreational respite program for seven weeks is only a very small part of even this restricted domain of activity.

The notion that the outcomes may have been too grandiose for such a cameo intervention gains some credibility when we consider the outcome that was affected by the intervention in the way we expected, the number of feared selves. The number of feared selves a person has at any one time is a potent, yet very specific measure. The fact that this aspect of well-being changed suggests that the program's point of impact on the well-being of the individual was in making them think a little differently about the sort of person they were and were likely to become. This is not a trivial accomplishment. As pointed out in Chapter 1, conceptions of the self are by no means unimportant and are implicated in the quest for physical and mental health. The fact remains, however, that the Recreational Respite Program does not appear to have shaped caregiver well-being directly: It seems to have merely touched the outer layer of the relevant psychological processes.

Box 4.1: The case of CL

CL has been looking after her co-resident mother for several years. Although forgetful and easily confused, her mother's major problems are physical: difficulties with breathing, eating and mobility. She is also incontinent. CL's caregiving is constant which impinges on her other roles and relationships. "The biggest difficulty - aside from stress, is mental exhaustion. Not being able to go out for the evening without major planning. Or to be able to go away for a weekend, it's too involved to move Mum to a hostel because she has to take so much stuff with her. It's not worth it, and also it makes her tired"...

CL has a helpful GP and good support from formal services except in times of crisis which occur fairly frequently because of the nature of her mother's illness. CL finds the personal care at such times difficult while her mother has problems with the loss of dignity that is involved. Despite this, CL wants to continue looking after her mother with whom she has and has always had an extremely close relationship. "I find [caring] stressful. I hate to see her in pain. .....because I know that I'm hurting her. Because it's someone you care for, it's that much harder to hurt them."

CL was very self effacing in the drawing class and barely mixed with the others. She said she enjoyed the course, however, and was sorry that it didn't go on for longer: "I was just getting into it when it stopped" She would have preferred a later starting time because of having to get her children to school. She hoped to do more courses in art and craft.

Another way of understanding the gap between the presumed benefits of the Caregiver Recreational Respite Program and the measures of global well-being is to consider the factors that are likely to be causing burden, symptoms and life satisfaction in caregivers. Interventions and their evaluations often seem to proceed with the unspoken assumption that the program is the most important thing in the life of the caregiver and that all else remains either in the background or stationary. This is not the situation, and the case study presented in Box 4.1 illustrates the complex pattern of factors that go to the heart of well-being for a lot of caregivers. Rapid deterioration in the care-receiver's condition, tension in the relationship between caregiver and care-receiver, and other family concerns are likely to have a far greater impact on well-being than recreational respite programs.

From a methodological perspective, outside events, particularly of a traumatic kind, are expected to affect all groups in a similar way, so that, in theory, the effects of an intervention can still be detected. These outside events, however, add to the variance in the data for each group, thereby making it difficult to detect significant differences between groups. The problem is exacerbated in an evaluation such as this where the sample size is small.

In spite of these difficulties, the path of discovery with these data does not end here. The above analyses provided no statistical controls for the outside events that one would expect to shape well-being in caregivers. To state the expectations of the Caregiver Recreational Respite Program more precisely: Having a regular break to pursue an enjoyable activity would increase the psychological and physical well-being of caregivers, providing there were no further decrements in the capacities of the care-receiver and providing the quality of the caregiver-care-receiver relationship was not compromised. To assume stability in events outside the Caregiver Recreational Respite Program is unrealistic. In the next chapter, the patterns of change in the lives of the three groups of caregivers will be examined to identify the outside events that have the greatest influence over changes in well-being, and to pit the intervention as a source of change against them.

Chapter 5

Changes in well-being: How important are outside events?

The case study of CL presented at the end of the last chapter gives some appreciation of the factors external to the Caregiver Recreational Respite Program that may be influencing well-being. This chapter focuses on change outside and within the Program. The purpose is to explore the patterns of change that occurred in the lives of the 54 caregivers who comprised the intervention and comparison groups in the previous chapter. The question asked is whether change in the demands of caregiving and the relationship between the caregiver and care-receiver accompanied changes in the outcome measures, and is there any evidence of the Program having beneficial effects when external factors are taken into account.

The chapter is divided into two parts. Part 1 focuses on the five well-being outcome measures of physical health, life satisfaction, burden, minor psychiatric symptoms, hoped-for selves, and feared selves. Part 2 uses different outcomes, caregivers' program evaluations from Chapter 3. It will be recalled that the 37 caregivers who had participated in the program were asked to rate their experiences along five dimensions: restoring of spirits, new skills and interest, social engagement, self-starting motivations, and intrusiveness. The question asked here is whether these evaluations are coloured or shaped by the external factors that have taken place in people's lives while the Program was in progress.

Part 1: Can the Program compete with change in the caregiver's home situation?

Change scores between pre- and post-test for each individual on each outcome (physical health, life satisfaction, burden, minor psychiatric symptoms, hoped-for selves, and feared selves) were calculated as follows:

Change in Y = Post-test score - pre-test score.

The external factors that may be responsible for these changes are many. Pre-test and post-test measures were taken of a significant number of variables that were known to be related to caregiving burden (Braithwaite, 1990). From Table 3.2, the workload variables in this category include personal care, supervision, emotional care and behavioural problems in the care receiver (Measurement details for personal care and supervision are provided in Chapter 2, the remainder in Appendix G). The relationship variables include sole responsibility, conflict, relationship investment and reciprocity (see Appendix G for measurement details). With a relatively small sample of 54, an omnibus analysis that includes all of these variables is not feasible. Thus, we will focus on three of them, chosen for their theoretical relevance to the notion of enmeshment in caregiving, and because preliminary analyses suggested that they were the best representatives of workload demands and relationship constraints.

The first was the amount of help care receivers needed in order to function in everyday life. Based on the CAMDEX, the Personal Care Requirements Scale focused on the ability to perform certain basic tasks for independent living. Although the data were collected through the caregiver, and as such may be open to biases in perception of what the care receiver is and is not capable of doing, the Personal Care Requirements Scale represents the more objective aspect of caregiving workload in the present research.

The second measure was the Behavioural Problems Scale which asked caregivers to report on the levels of cognitive deterioration they were observing in the care receiver as well as losses in social functioning and emotional control. Previous research has shown that both the nature of the relationship and the condition of the care receiver play a role in determining caregivers' responses on this scale (Braithwaite, 1990). It is, therefore, a more subjective measure of caregiving demands than that provided by the Personal Care Requirements Scale.

The third measure was the Reciprocity Scale which focused on the caregiver - care receiver relationship. Caregivers indicated the extent to which they thought the care-receiver recognized their contribution and appreciated and respected them for their efforts, as opposed to expecting care and taking it for granted.

For these three variables, change scores were calculated in a manner similar to that specified above for the outcomes. For each individual on each variable:

Change in X = Post-test score - pre-test score.

Analyses

In this chapter, the statistical analyses are presented in the text rather than the Appendix, because the analyses are central to the process of developing a theoretical understanding of respite care use. For those readers wishing to transcend details of the analysis, summaries of findings are presented after each table.

Hierarchical multiple regression analysis was used to predict change in the well-being outcomes from (a) changes in the demands of caregiving (using the Personal Care Requirements Scale), (b) changes in the caregiver-care receiver relationship (using the

Behavioural Problems Scale and Reciprocity Scale), and (c) the recreational respite intervention.

In order to track the effects of external changes on well-being net of the Program, it was necessary to control for the initial levels of the workload and relationship variables. These were therefore entered at Stage 1.

Stage 2 involved entering the change in workload and the change in relationship variables into the equation. Ideally, the predictors in such an analysis correlate minimally with each other, otherwise one variable tends to rob its correlate of some of the effect it might have had, had the second variable been in the regression equation alone. Preliminary analyses revealed that change in Behaviour Problems and change in Reciprocity were negatively correlated ($r = -.37$, $p < .05$). Where behaviour problems had increased, reciprocity had dropped, and these effects overlapped in predicting change in well-being. As a consequence, a single measure of relationship quality was developed through summing scores after appropriate score reversal and scale standardization.

Once caregiving demands and relationship quality were included in the regression equation as external factors, the intervention was entered at the third stage in the form of two dummy variables representing membership in the "participant group" or membership in the "participant group with Carers Association support". The first dummy variable was created by assigning a score of 1 to "participants" not recruited through the Carers' Association and 0 to everyone else. The second dummy variable was created by assigning a score of 1 to "participants with Carers Association support" and 0 to everyone else. The third category of non-participation constituted the omitted category in the regression analysis, and as such, the benchmark for interpreting the effectiveness of the intervention. The question asked at this stage was whether or not the two dummy variables, representing the Program intervention, had an effect on well-being above and beyond that of the external factors.

Table 5.1: Beta coefficients and R^2 for the prediction of change in well-being from change in demands, relationship quality, and program participation (N = 54)

Predictor	Change scores					
	Physical health	Life dis-satisfaction	Burden	Symptoms	Hoped-for selves	Feared selves
initial demands	-.22	.01	.23	.14	-.15	.06
initial relationship	-.26	-.03	-.01	-.08	-.26	-.06
change in demands	-.14	-.04	.05	.07	.10	.12
change in relationship	-.45**	.55**	.47**	.42**	-.24	-.14
participants	.01	-.24	-.07	.06	-.07	-.45*
participants + CA	.10	-.14	-.05	-.34*	-.09	-.16
Step 1 R^2	.01	.06	.07	.06	.05	.01
Step 2 R^2	.18*	.34**	.24**	.20*	.10	.02
Step 3 R^2	.18*	.37**	.24*	.34**	.10	.15
Change R^2 Steps 2-3	.00	.03	.00	.14*	.01	.13*

* $p < .05$

** $p < .01$

The results of the hierarchical multiple regression analyses are presented in Table 5.1. They show that the external factors have an impact on changes in well-being for four of the six outcomes, physical health, life satisfaction, burden and mental health. As has been claimed and found in previous research, the change that appears to be most detrimental to caregivers is the loss of connectedness between caregiver and care receiver (Braithwaite, 1990, 1996a, 1996b; Morris, Morris, and Britton, 1988; Motenko, 1989; Smith et al., 1991; Walker, Martin, and Jones,1992; Whitbeck, Hoyt, and Huck, 1994; Williamson and Schulz, 1990). As the care receiver's condition declines so that cognitive impairment becomes more pronounced, conversation more difficult, social functioning less acceptable, and appreciation and respect for the caregiver less detectable, caregivers are likely to suffer a drop in well-being over a range of indicators. Equally important is the finding that relationship dominates physical dependency levels in this analysis. Caregivers' well-being appears to be protected from increases in the personal care needs of care recipients (assistance with bathing, eating, moving). This may reflect the effectiveness of formal services in helping meet such needs. It's also likely that caregivers are more resilient to the pressures of hard work, than they are to the loss of an affirming relationship with the care receiver.

The second major finding from Table 5.1 is that the Caregiver Recreational Respite Program was effective in changing some of the well-being outcomes after we had controlled for what was happening in the caregiving situation. First, those who belonged to the "participant" group were more likely to express fewer feared selves at the end of the program than at the beginning. This is consistent with the findings from the previous chapter in which we had not controlled for caregiving workload and relationship changes.

Furthermore, caregivers who were participants in the program with Carer's Association support were significantly more likely to show a drop in minor psychiatric symptoms than the other groups. Whether this drop is attributable to initiatives undertaken by the

Carers Association at this time or whether it is a function of a recreational respite program working with caregiving support services is unclear from these data alone. Informal conversations and data from the qualitative interviews supports the latter interpretation rather than the former. Caregivers' spontaneous reactions to the program suggest that there may be considerable advantage in running recreational respite programs alongside, but independently of, educational and counselling programs. If caregivers find it difficult to do something for themselves, even when they are aware that they might need it, a support service to advise on respite options and show how others are using respite as part of a high quality home care plan might be valuable. In a relatively early publication in this field, Zarit and Zarit (1982) observed not only reluctance on the part of caregivers to ask for help, but also the importance to caregivers of having others to follow who have found ways of dealing with caregiving difficulties effectively.

Part 2: Who benefits the most with a changing caregiving situation?

Chapter 3 provided some evidence that the evaluations that caregivers made of their programs were related to features of their caregiving situation. Caregivers with poor physical health at the beginning of the program, for instance, were more likely to register intrusiveness, that is, resentment about their participation from the person they were caring for and uneasiness about stepping out of the caregiving role. In contrast, caregivers who were highly committed to the caring role in that they were not considering institutionalization and were providers of high levels of emotional care, were most likely to report feeling restored, to appreciate gaining new skills, to value the social engagement the Program offered, and to report the intention to do more of their chosen activity. All of these measures were taken prior to the commencement of the Program. The question asked in Part 2 of this chapter is whether changes in the lives of caregivers outside the Program also influenced their evaluations. For instance, are the experiences of increased burden and caregiving demands so overwhelming, that they limit caregivers' capacity to benefit from a respite recreational program?

Participants' evaluations of their program along the dimensions of restoring of spirits, new skills and interest, social engagement, self-starting motivations, and intrusiveness were correlated with changes in the well-being measures (physical health, burden, life satisfaction, minor psychiatric symptoms, hoped-for selves, feared selves) and with changes in task demands (personal care requirements) and relationship quality (behavioural problems, reciprocity). The correlations, presented in Table 5.2, are partial correlations with the initial levels of the well-being and caregiving variables controlled in the statistical analysis.

Table 5.2: Partial correlation coefficients of caregivers' program evaluations with changes in well-being, caregiving demands and relationship quality (N = 37) controlling for initial measures of well-being, caregiving demands and relationship quality

Changes in ...	Restoring spirits	New skills & interest	Social engagement	Self-starting	Intrusiveness
physical health	-.07	.14	.00	-.10	-.10
life dissatisfaction	.32[a]	.04	.27	.10	.10
burden	.26	.18	.36*	.35[c]	-.16
symptoms	.54***	.34[b]	.20	.38*	.04
hoped-for selves	.03	.18	-.19	-.12	-.11
feared selves	-.21	-.23	.11	-.15	-.01
demands	.18	.16	-.14	.24	-.46**
behavioural problems	.14	.26	.16	.06	-.02
reciprocity	.05	-.02	-.17	-.51**	.10

[a] [b] [c] These coefficients just failed the .05 cut-off for statistical significance with values of .069, .055 and .056 respectively. These trends, however, are considered important theoretically and will be discussed in the text.

* $p < .05$

** $p < .01$

The significant relationships that emerged in Table 5.2 are interesting in what they reveal about who believes themselves to be the prime beneficiaries of respite care. One suspicion we held was that program evaluations would go up and down as satisfaction with life outside the program went up and down. This kind of effect has been recognized in a range of contexts. The phenomenon can prove quite powerful in discrediting client satisfaction ratings: General satisfaction with life clouds one's capacity to evaluate one specific aspect, that is an intervention program, as one's negativity spreads to other domains uncritically. The data in Table 5.2 do not support this expectation. Indeed, the trends in the data are in exactly the opposite direction. Positive reactions to the program were more likely to be associated with life becoming more difficult outside. Those who showed least improvement or a worsening of minor psychiatric symptoms reported feeling more restored by the Program, more appreciative of the activity, and more prepared to pursue their activity afterward. In addition, those whose burden had increased over the course of the Program were the most likely to appreciate the social atmosphere of the programs and to want to continue with their activity afterwards. A trend was also noteworthy in relation to increasing dissatisfaction with life as a whole, although the correlation coefficient just failed to reach statistical significance. These increasingly dissatisfied caregivers tended to appreciate the restorative aspects of the Program. The Program showed signs of being a haven for those with increases in burden and symptoms, and decreases in overall life satisfaction.

The suggestion that the Caregiver Recreational Respite Program may have been valued most when things were bad at home was supported further by the two remaining significant findings in Table 5.2. Those who declared an interest in continuing with their activity and being self-starters were those who experienced a drop in reciprocity over the duration of the Program. The converse was that where reciprocity had improved, caregivers were less inclined to want to continue by themselves. This finding sits well alongside others that have shown how central relationship quality is to the ways in which caregivers respond to the help that they are offered. The last significant finding from Table 5.2 adds yet another piece to this puzzle of when caregivers look favourably on using respite and when they do not. Where the care receiver's personal care requirements had increased, intrusiveness scores tended to be low, suggesting that both caregiver and care receiver were accepting of their time apart. Possibly, the increased caregiving workload, evident to both parties, was regarded by both as justification for a break. Interpreting these findings from the perspective of those few individuals who found the Program intrusive is also insightful. Intrusiveness was more likely to be seen as a problem by caregivers with a care receiver who was functioning more independently at the post-program interview than before. Improvement in the care receiver's condition in response to new respite care arrangements has been documented elsewhere as a positive outcome of respite interventions (Homer & Gilleard, 1994). But this change may come at a cost. Care receivers and caregivers may both feel insecure as one learns to function more independently with a new carer, and the other relinquishes control over the caregiving routine. Given that caregivers in the program were less likely to use formal respite than informal help, care receivers may have felt under pressure to do more things for themselves.

Conclusion

This chapter demonstrates the centrality of the relationship between caregiver and care receiver in shaping overall well-being. Compared with the loss of social connectedness and reciprocation between caregiver and care receiver, the offerings of the Caregiver Recreational Respite Program are indeed small. Yet, the findings of this chapter tell a positive story about the importance and value of using respite. Caregivers can use respite purposefully and profitably when they absolutely need it, and they recognize this kind of support as something that will help them through the difficult times. Respite use can be likened to a pain killer for caregivers. It does not go to the heart of the problem, and it cannot take away the problem or its negative consequences. It can only relieve the symptoms. Caregivers expressed this view themselves through their ringing endorsement of the Program's capacity to restore flagging spirits (Chapter 3). Furthermore, the pre- and post-program data revealed participants showing signs of fewer feared selves (Chapter 4) and psychiatric symptoms (Chapter 5) afterwards.

Finally, and most importantly, the data demonstrate that the primary beneficiaries of the Caregiver Recreational Respite Program are those who need it most: Those who are committed to continuing care at home, have little backup and gain satisfaction from their role (Chapter 3), but at the same time, are experiencing a loss of connectedness and value in the eyes of their care receiver (Chapter 5).

Chapter 6

What did instructors think of the Program?

To this point, the Recreational Respite Program has been evaluated in terms of the responses of caregivers. While this remains the major focus of the evaluation, the viability of such a Program in the long term depends on the availability and responsiveness of instructors to provide the kinds of courses that meet the needs of caregivers. This chapter reports the views of three of the five instructors. We chose to interview instructors from the drawing, and movement and relaxation classes because they had a broader base of experience on which to draw. Unlike the other instructors, they had taught their courses twice with the Program, and in the process had become acquainted with a wider variety of caregivers.

Gains and achievements of the classes

In the interviews, the instructors for the movement and relaxation classes spoke mostly in terms of the gains whereas the art class instructor focussed more on the problems. This was partly because of the difference in the aims of the courses. For those taking part in the movement and relaxation classes the benefits were very clearly and quickly felt, whereas in the drawing classes people found it quite difficult to get over the hurdle of unlearning beliefs. Most notable were the problems of overcoming old habits of seeing, and the self-defeating view that they "couldn't draw".

While LS, the instructor for the art class, felt that everybody had made progress in that they had produced some good drawings, it was sometimes difficult to persuade them of this:

> "B was very self-effacing but she did some quite delightful drawings. .. She was very anxious and this made it hard for her but I think she got quite a lot

> out of the class because she admitted, almost begrudgingly, that they were quite good drawings".

The less tangible effect that LS was striving for was a shift in perception: that is, learning to see things differently "which can subtly affect the quality of life, even in such simple ways as arranging flowers". This was where the real achievement lay:

> "When people could say, 'I look out the window and I just see that blue, and that little bit of pink and it is so magnificent'. People were saying that, they'd say 'I'm doing a job and I start looking at the colours and things' and that's exactly it, that's what its about.."

LS was also very sensitive to the complexities of individual situations. For example, she felt that one of the carers needed more classes because although "she'd been really breaking through to her feelings" and producing some good work, on the last day she had reverted to her earlier stereotypical images "where she didn't have to think or feel and it was a bit like, 'I've got to go back to that world and I need to put myself back to the way I was before I started here' ".

Some art class participants reported having done drawing or collage at home, and some purchased the book on which the course was based, *Drawing on the Right Side of the Brain*. Several people expressed a determination to continue drawing although without the structure of the course this may prove difficult to do.

For LS, what the course achieved overall was "an added positive experience or an increased capacity to seek out positive experience", the lack of which "as everyone knows, is one of the best predictors of depression".

MB, who took the movement and relaxation class, felt that in almost all cases the gentle exercise, stretching and meditation had helped to reduce tension and raise energy levels. These techniques had helped to achieve "a centring of self", an awareness of the body's "sense of grace", and an increased readiness to acknowledge distress:

> "you know how you can be... running all day, getting done what has to be done, and you're never actually experiencing what it is that you're feeling, in fact you're consciously trying to blot it out because it's too hard or too painful, especially in the case of people who are caring for others who aren't getting well".

The importance of touch was emphasised by both instructors for movement and relaxation. They felt that many of the participants were not accustomed to it. Touching - massaging hands, necks, backs - had an unwinding effect on the participants:

> "C just melts. ...she would be lying on her back and she'd have her arms up, stiff, and I would just touch her arm like this and gently bring it down and just feel her letting go. She was a very warm soul and I think she hasn't had a lot of touch in her life or not recently. So that's very healing in itself".

MB felt that overall the relaxation classes had provided a greater sense of well-being and that the basic objective of the class had been appropriate for everybody:

> "although they were from so many different backgrounds they were all in need of a similar time out .. and gentle unwinding... And they reported it, 'I feel much better', 'I feel wonderful!' and I could see it. I could see their energy levels change throughout the course".

At the end of the relaxation classes, notes on the exercises were eagerly requested and relaxation tapes (made by both the instructors) purchased. There was evidence that participants endeavoured to find time to practise the exercises at home.

Additional gains, particularly for those doing the movement and relaxation classes, lay in the way the more successful groups functioned as a whole. MB commented: "I began to think, halfway through the second group, that they were people who had known each other for a very long time" (In fact, they had all begun as strangers to one another).

In all courses, instructors attended to making each person feel special and welcome. Overall, they felt they had succeeded. For example:

> "during the coffee time, just chatting and acknowledging who <u>they</u> were on a personal basis was important, rather than just a group of people who came by for the class and off they went again. I think this added to the sense of belonging and of having had a good experience".

Problems for the instructors

These included incorporating late starters into the class, explaining difficult concepts, and integrating people from other language, cultural and social backgrounds; and perhaps most difficult of all, managing the depression, anxiety and, in some cases, hopelessness that the carers evinced. In this last respect, the instructors sometimes had to work hard to prevent the class from becoming a forum for discussing caring problems.

For the carers from non-English speaking backgrounds, there were, in addition to language problems, difficulties in explaining the concepts underlying the courses. For example, LS felt that the notion of brain and creativity "was a very western sort of conception" and that the problem was not simply one of language but of relevance. She worried that for people from NESB it was difficult to communicate what drawing could give: "I think for some people, culturally, it's not a relevant activity", particularly, she thought, for people who may have had to cope with the loss of personal safety and the trauma of exile.

The group dynamic as described above could be both helpful and hindering. For example, LS felt that the mix of people was not always the best, with those who worked hard at hiding their emotions sometimes feeling uncomfortable with those who were more open. Some carers were less able or willing to benefit from the activities and this could be distracting to the others.

The instructors felt that stress and depression levels were high compared to other classes they had run. However, they were concerned that what they saw as positive outcomes might be interpreted in more negative terms by others, because they involved acknowledging distress and learning to express feelings: "I remember thinking at the time that maybe this is going to make people look like they're worse because they are admitting to a lot of the difficulties, frustrations and sadness that they were denying at first" (MB).

Those who benefited most

In the view of the instructors, those who benefited most from the classes were those who made this transition from denial to acknowledgment of negative feelings, and were thus able to take advantage of what the courses had to offer.

Those who were already coping reasonably well with their level of distress were able to benefit immediately from the drawing activity and, in the relaxation classes, "were more able, willing, to move through the process of the gentle exercise, the relaxation, the meditation and therefore I think that they received the results, they embodied the results, better" (MB).

Those who benefited least

These were the people who failed to make the transition or who were too distressed to make the necessary effort the courses required. But these were few. LS mentioned G who "stayed where she was and she was determined to stay where she was and that was clear quite early on... She may have been so damned depressed and overwhelmed that it was just beyond her at that point". While MB mentioned R "who often didn't join in the exercises because she was too distressed. She wasn't willing to do the breathing, she wasn't willing to do the opening out. There wasn't much of a breakthrough there".

But these were exceptions. The instructors were strongly of the view that, in the words of LS:

> "just providing enhancing experiences is a great way of protecting people from depression. And then you've got the other possibility which is that they can continue. If you have a self that can continue to pursue enhancing experiences then you've got an ongoing kind of improver of quality of life. Some people in that class may just have had a good experience, or an OK experience, [but others] may have incorporated enough to continue, in which case you'd expect long-term changes not just a short-term 'Oh, it was quite good' type of change. ... In my view either of them is going to be helpful".

Chapter 7

Enmeshment: in the role or the relationship?

The Caregiver Recreational Respite Program aimed to assist individuals take on a new role or resume an old role that they could enjoy outside of caregiving. The reports of the instructors and our own observations suggested that the transition was easier for some caregivers than others. The qualitative data pointed to the issue of time as a critical factor in determining whether or not caregivers were able to take on a new role with any prospect of permanency. The observation from an instructor in the last chapter that one carer reverted to her old self in the last class of the program in preparation for what lay ahead reflected how deeply entrenched caregivers can be in their caregiving role. It also raises the issue of whether seven weeks gave sufficient time for the Program to achieve its objectives.

This chapter uses the qualitative data from interviews with 46 caregivers from the participant and comparison groups to examine the way in which the Caregiver Recreational Respite Program affected those enmeshed in the caregiving role. Enmeshment refers to over-involvement in caregiving in terms of one's thought and actions, to the virtual exclusion of everything else. Enmeshment entails a loss of balance in one's life. In the first chapter, enmeshment was regarded as damaging to caregivers, if the caregiving role fails to provide a positive self identity, particularly as the care receiver's condition deteriorates. In the course of the project, our attention focused on enmeshment, with the qualitative interviews providing valuable insights and sources of information. We recognized two types of enmeshment that had been separated empirically in co-dependency research (Wright, 1985; Wright & Wright, 1997). Wright and Wright (1997) distinguished defensive and over-protective care taking from enmeshment in the relationship. Gillies (1995) has argued that this distinction is relevant to the caregiving context. We observed that caregivers who were preoccupied with the caregiving role to the exclusion of everything else often dominated the care receiver and the prospective helpers. As the caregiver bec~~ame indispensable, others became increasingly irrelevant.~~ We refer to this as role enmeshment. The other type of enmeshment appeared to be qualitatively different in that caregivers lost all sense of boundary between their needs and their care receiver's needs. Their identity and the care receiver's identity seemed inextricably connected, creating tension when goals were not compatible and leaving caregivers frustrated and hostile. This we refer to as relationship enmeshment, since the driving force for caregivers seems to be the approval of the care receiver rather than the execution of a duty of care.

Transcriptions of the qualitative interviews were reviewed and each caregiver was assigned two scores, one on role enmeshment and the other on relationship enmeshment. The coding frame used to assess caregivers is outlined below.

Role enmeshment

Role enmeshment was defined as pre-occupation with fulfilling the role of caregiver to the exclusion of all other roles and with the exclusion of other people. The concept was operationalized by classifying the caregiver on the following 1 to 4 scale:

1 = Caring role does not dominate other roles, help is provided in a manner that is an extension of a normal supportive role, disruption to self and others is minimized, solutions to problems are found with full recognition of one's limitations. The objective burden may be low (not much help required) or high (a lot of help is required).
26% of caregivers were judged as belonging to this category.

2 = Care is provided as above but there is a need to compete with other care providers, sometimes re-creating the tasks that others are doing, and there is a need to control the way in which care is provided (insistence that routines are followed etc).
30% of caregivers were located in this group.

3 = A more intense desire to control the way in which care is provided to the point where the wishes of the care receiver, even when they seem reasonable, are not accommodated, and there is evidence of a more intense desire to take over caregiving tasks that others are doing. Also apparent is role overload, feeling one is not doing enough and not doing it well, pushing beyond one's limits, with health beginning to suffer.

31% of caregivers were classified in this group.

4 = Caregiver is consumed by the caregiving role, can't focus on, or apply oneself to other roles even within the family, has no time for self, and is incapable of standing outside the role. Caregiver cannot trust anyone else to provide the same quality of care, and must be there always.

13% of caregivers were given a score of 4.

Relationship enmeshment

Relationship enmeshment was defined as the subjugation of one's own desires and needs to win the approval of the care receiver. The concept was operationalized by classifying the caregiver on the following 1 to 4 scale:

1 = Perceives caring as a positive choice, feels that the gains outweigh the losses, enjoys caring, and speaks about the care receiver in positive terms (eg. affectionately, kindly, with good humour).

Only 2% of caregivers met these criteria.

2 = Perceives caring as a positive choice, and speaks about the care receiver in positive terms mostly, but the driving force is less obviously the expression of affection, and includes a desire to reciprocate or do one's duty.

48% of caregivers fitted this description.

3 = Perceives the care receiver positively and negatively, wanting to provide care, but resenting the demands that it involves. The caregiver shows signs of being overwhelmed by the care receiver's desires and needs and has difficulty in saying no. The result is an inconsistent pattern of bending over backwards one minute and refusing to do anything the next. There is evidence that the caregiver has in the past, or continues to want affection, approval or preferment over others from the care receiver.
34% of caregivers were located in this group.

4 = Perceives the care receiver positively and negatively, and with greater intensity. The caregiver is overwhelmed completely by the care receiver's desires and needs, real or assumed, has difficulty refusing to do things, over-empathizes with the care receiver to the point of sharing pain and frustration, does not want to disappoint the care receiver in any way, and becomes caught in cycles of guilt and resentment. The caregiver may not want to provide care at all, but feels compelled to do so.
16% of caregivers were best described in these terms.

This coding frame was applied by two researchers (one from the project, one outside) to the interview transcripts. They formed their judgements independently, and then met to discuss those cases for whom ratings differed. Their agreed rating was recorded for further analysis.

The enmeshment variables and their links with outcomes

The difference between role and relationship enmeshment rested heavily on the distinction between being task oriented, over protective and controlling and being relation oriented and subservient to the needs of the care receiver. It was not surprising, however, to find that the two had a significant amount of variance in common. Caregivers who were single minded and insistent on providing care to the exclusion of all else were also likely to be caregivers whose identity was entangled with and dependent on that of the care receiver. Role enmeshment correlated .33 ($p < .05$) with relationship enmeshment, suggesting that the two may not be as easy to unravel as we had supposed. Nevertheless, the measures were correlated first with the evaluations of the course by participants, and second, with the measures of well-being and change in well-being.

The first set of analyses answered the question of whether levels of enmeshment differentiated those who believed they benefited most from those who believed they benefited least from the Program. The second set of analyses addressed a broader question: Is role enmeshment or relationship enmeshment implicated in caregiver well-being and changes in well-being? The first chapter discussed the work of Aneshensel et al. (1993) and Skaff et al. (1996) which identified role captivity and a loss of mastery as critical components of caregiver stress. Role captivity and mastery may reflect either type of enmeshment. Knowing which type does harm, however, is critical to planning effective interventions. Interventions that deal with role enmeshment should be different from those that deal with relationship enmeshment. Role enmeshment might be contained through exposure to other interesting activities, providing caregivers have moved past seeing respite as a threat to their competence and to their caregiving identities (Gillies, 1995). The problem of relationship enmeshment, however, is unlikely to be effectively resolved through a recreational respite program, requiring instead a family oriented psychotherapeutic intervention.

Does enmeshment affect perception of benefits?

This question was answered by correlating role and relationship enmeshment with caregiver responses on the scales measuring restoring of spirits, acquiring new skills and interest, social engagement, self-starting motivations, and intrusiveness. As can be seen in Table 7.1 below, only two correlations were significant. As role enmeshment and relationship enmeshment increased, so too did the likelihood of caregivers finding the program intrusive, with caregivers feeling guilty and reporting resentment from their care receivers.

Table 7.1: Pearson product-moment correlation coefficients of role and relationship enmeshment with program evaluations (N = 37)

Evaluations	Role enmeshment	Relationship enmeshment
restoring of spirits	.32	.09
new skills and interest	-.15	-.22
social engagement	-.01	.02
self-starting	.03	-.24
intrusiveness	.40*	.49**

* *p*< .05
** *p*< .01

Does enmeshment have links with well-being?

Both role and relationship enmeshment were correlated with the well-being measures taken before the Program had started. Partial correlations were calculated between the enmeshment variables and changes in well-being, controlling for caregivers' initial well-being. The results appear below in Table 7.2.

Table 7.2: Correlation coefficients of role and relationship enmeshment with well-being at pre-test, and with change in well-being controlling for pre-test levels (N = 46)

Well-being measure	Role enmeshment	Relationship enmeshment
physical health	.12	-.02
physical health change	.17	-.04
life dissatisfaction	-.15	.12
life dissatisfaction change	-.15	-.19
burden	.19	.21
burden change	.09	-.01
minor psychiatric symptoms	.21	.37*
symptom change	.06	-.08
hoped for selves	-.31*	.05
hoped-for selves change	.02	.17
feared selves	-.18	.10
feared selves change	.19	.16

* *p*< .05

Neither role enmeshment nor relationship enmeshment correlated significantly with the change in well-being measures. Two significant relationships emerged, however, with pre-program scores. Role enmeshment was significantly related to the number of hoped-for selves reported prior to the commencement of the Program. Caregivers who were highly enmeshed in their role articulated fewer possible selves than those who could put themselves outside it. Relationship enmeshment was linked with well-being in quite a different way. Those who reported high levels of relationship enmeshment were more likely to report high levels of anxiety and depression before the Program started. This finding is consistent with a growing literature that identifies caregivers as being at risk of psychiatric morbidity if they have a history of insecure attachment to the care receiver

(Albert, 1990; Braithwaite, 1990; Cicirelli, 1993; Morris et al., 1988; Whitbeck et al., 1994; Williamson & Schulz, 1990).

Conclusion

The distinction between role and relationship enmeshment appears promising, with the present analysis identifying both as factors that result in caregivers experiencing tension and discomfort when they enter a recreational respite program. For enmeshed caregivers, the Caregiver Recreational Respite Program presented a conflict of interest. Caregivers who were enmeshed in their roles felt torn between doing caregiving and doing their chosen activity. Caregivers who were enmeshed in their relationship felt torn between pleasing the care receiver and their chosen activity. In both cases, caregivers had difficulty leaving caregiving behind them, even for a couple of hours a week.

While role enmeshment and relationship enmeshment affected caregivers' evaluations of the Program similarly, their links with well-being differed. Not surprisingly, caregivers who were enmeshed in the caregiving role were less able to identify a range of hoped-for selves prior to the commencement of the Program. Of greater importance was the finding that caregivers who were identified as being enmeshed in the caregiving relationship were more likely to report symptoms of anxiety and depression. These data are consistent with the thesis that some caregiving relationships, because of their history, are dysfunctional, causing enormous anguish to caregivers and the institutionalization of the care receiver (Braithwaite, 1990, 1986b).

Chapter 8

Conclusion

The Caregiver Recreational Respite Program proved to be both viable and effective in three important respects. First, caregivers found the Program restorative, stimulating, and motivating, with minimum disruption to caregiving. Second, our instructors considered the exercise to be beneficial to caregivers, as well as finding it personally rewarding and a challenging context in which to apply their skills. Third, the Program was viable because of the commitment given to it by the Carers Association, and more particularly, by one counsellor who believed in the Program and the benefits it could offer her clients. This is not to suggest that caregivers associated with the Carers Association were the prime beneficiaries. They were not. There is no reason to withdraw from the initial position that reaching caregivers who are not linked up with support services is a priority. The reality, however, is that such caregivers are difficult to contact, and are reluctant to accept the role of caregiver, preferring instead to hold on to the image of themselves as husband, wife, son, daughter, partner, relative or friend. Caregivers outside the formal support networks need to come forward in their own time as they re-define their role. In the case of the Caregiver Recreational Respite Program, this occurred in dribs and drabs. The caregivers recruited through community contacts were few in number at any one time, and our success in placing them in programs quickly was due to the Carers Association supplying participants in sufficient numbers to make running the course viable. This problem did not arise for those who wished to pursue independent activities.

Claiming the Program to be an overall success requires further justification. We did not meet our objective of improving the well-being of caregivers from pre-test to post-test with regard to physical and mental health, burden, life satisfaction, and hoped-for and feared selves. There were encouraging findings emerging in relation to feared selves and minor psychiatric symptoms. The number of feared selves dropped for participants who were not recruited through the Carers Association and not receiving counselling support. Anxiety and depression dropped for those participants who were with the Carers Association, once we had taken account of adverse changes in the quality of the caregiver-care receiver relationship. Partial successes of this kind, as welcome as they are, signal the need for significant qualifications to claiming the Caregiver Recreational Respite Program as an effective innovation.

Current thinking surrounding the efficacy of support for caregivers has moved away from expecting to demonstrate substantial improvements in caregiver well-being if intervention X is implemented and offered universally. Research is progressing on the premise that some caregivers will be assisted in some circumstances by some types of support, or some combinations of support (Brodaty & Gresham, 1992; Clarke & Finucane, 1995; Knight et al., 1993; Kosloski & Montgomery, 1995). Needless to say it will take time for researchers to identify the key parameters that should guide the implementation of a successful intervention. By the same token, knowledge will accumulate more quickly if we can integrate our learning and on this basis, engage in cautious speculation about how caregivers regard respite now and how they might in the future.

The research conducted as part of the Caregiver Recreational Respite Program produced some important findings which are listed below:

(1) Caregivers are not comfortable taking the initiative to look after their own needs through a recreational respite program.

(2) Caregivers need someone to encourage their participation.

(3) The majority of caregivers respond positively when the opportunity is created for them to enjoy recreational activities outside the caregiving role.

(4) Caregivers need more than 7 weeks of a recreational respite program to feel the full benefits.

(5) A minority of caregivers reported intrusiveness from the program on caregiving, and a minority were perceived by the instructors as unable to engage with the Program sufficiently well to reap benefits. Intrusiveness was more likely to be a problem among caregivers who were enmeshed in the caregiving role or the caregiving relationship. Those who were enmeshed in the role entered the Program with fewer hoped-for selves than those who were not. Caregivers enmeshed in the relationship with the care receiver were more likely to enter the Program suffering from anxiety and depression.

(6) The caregivers who reported the greatest benefits from the Program were not those who were dealing with the highest levels of physical dependency, nor were they those who did not take their caregiving responsibilities seriously.

(7) Those who felt restored by caregiving, who appreciated acquiring new skills, enjoyed the social aspects of the Program, and intended to continue with their activity were most likely to be caregivers who were committed to providing care, but whose mental health, life dissatisfaction, and burden increased over the course of the Program as their relationship with the care receiver became increasingly difficult to sustain.

(8) A change for the worse in the relationship between caregiver and care receiver was the most salient factor in the lives of caregivers, contributing to a lowering of caregiver well-being across a number of measures. The impact of the intervention to improve caregivers' state of health faded in importance in comparison with the relationship variables. Relationship changes were assessed on two correlated dimensions. The first was the degree to which the care receiver engaged in problematic behaviour with the caregiver, behaviours that reflected a loss in cognitive capacities, a loss of emotional stability, and an increase in anti-social behaviours. The second was the degree to which the caregiver perceived the care receiver as being disrespectful and unappreciative of her efforts and of taking her care for granted. Together these factors captured distancing in the relationship between caregiver and care receiver. This distancing damaged something that is at the heart of caregiver stress. At this point, we can only speculate as to what this something is.

In Chapter 1, a person's identity was postulated as being placed at risk as the caregiver abandons social roles to put more time and effort into the caregiving role. As the caregiving role fails to provide caregivers with positive affirmation of their contribution, caregivers suffer a loss of identity that threatens their well-being. The process of giving up social roles to provide care is explained by Albert (1990) in terms of a deeply entrenched and longstanding caregiving culture. The culture that leads to feelings of obligation to give care when dependency is recognized, however, does not always proceed in a way that benefits caregiver and care receiver (Albert, 1990; Strawbridge & Wallhagen, 1992) as a substantial body of research has demonstrated. The second aspect of this process described by Albert that is striking is that caregivers need have no self-insight into the process that is engulfing them. In following cultural norms, caregivers do not have a personalized understanding of what is happening: Responding to the care receiver's needs is just something that they have to do. Add to this resistance to recognizing and accepting dependency in a loved one, and the human capacity to re-interpret unusual behaviour to make it seem normal and/or transient, and we have a firm basis for predicting ineffective low respite usage among spouses caring for their partners and children caring for their parents.

The findings of the Caregiver Recreational Respite Program can be interpreted fruitfully within this framework. Our initial problems in recruitment can be understood as both resistance to accepting the role of caregiver and difficulty leaving caregiving because of enmeshment. Enmeshment in the role is consistent with the prescripts associated with a caregiving culture: Dependency elicits obligation, and leaving to pursue pleasurable activities is not always seen as a legitimate use of time within the framework of a caregiving culture. Relationship enmeshment, separated in this research from role enmeshment, intensifies the problems posed by a caregiving culture and a shrinking social world. Relationship enmeshment involves the loss of self in the identity of another, a phenomenon that is far more likely to become salient when the caregiver is becoming engulfed by the role of caregiver. Role enmeshment exacerbates the likelihood of intimate relationships moving to a state of relationship enmeshment. There is some evidence to suggest that relationship enmeshment gains a foothold through earlier patterns of interaction. A caregiver who recalls the care receiver as an emotionally distant and over-controlling parent or spouse is at risk of burden, anxiety, depression, life dissatisfaction and of seeking institutional placement (Braithwaite, 1990). Through this report we can add relationship enmeshment as yet another aspect of a highly dysfunctional caregiver-care receiver relationship.

Future policy?

If this analysis captures the impediments to effective respite use, what are the levers for change? The analysis supports four central propositions to guide caregiving policy.

First, caregivers are the ones best placed to recognize their own needs and to choose options that will suit their personal caregiving circumstances.

Second, a range of options need to be available so that caregivers can readily access different alternatives and compare them for their suitability.

Third, caregivers need to be in a position to make informed and planned choices. Informed choice means recognizing dependency, understanding the harm that can be caused by caregiving enmeshment, and seeing possible solutions at work in the community. As Zarit and Zarit (1982) so astutely pointed out over a decade ago, caregivers need to learn from other caregivers. So too must policy makers.

Fourth, a better understanding of enmeshment is critically important to the learning process that results in policy makers finding creative options and caregivers making informed choices. Enmeshment prevents the sharing of care and engagement in society. Problems of role enmeshment can be understood at a cultural level and can change with public discussion and innovative policy. In contrast, relationship enmeshment is a personal issue and poses a problem for caregivers and care receivers that they can not readily resolve for themselves. Consequently, caregiving options need to be packaged and assistance may be required to give people the appropriate tools for coping with their situation.

In this complex process of finding ways to use respite effectively, provision also needs to be made for the perspective of care receivers. This report has not focused on the needs of care receivers, but others have, with warnings that should be heeded. As Edwards (1996) has so persuasively argued, caregivers unwittingly can gain well-being at the expense of care receivers. Care receivers' wishes and hopes must be respected, therefore, at all times.

Finding ways to meet the needs of both caregivers and care receivers is not always going to be easy, and has to involve discussion, negotiation and understanding from all parties. Too often, these matters are pushed aside as private affairs. But as this report shows through its analysis of respite usage, the impediments to caregivers and care receivers finding solutions to their difficulties are enormous. Significant others, be they family members, doctors or health care workers, must assume some responsibility for moving caregivers to a position where they can provide loving care without experiencing a loss of self. This is, after all, the essence of a caring community.

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Appendix A

Recruitment strategies and information sheets

Strategies and recruitment materials are presented in the following order:

(i) Letter to doctor, further information, instructions for practice staff, information for patients

(ii) Letter to other professionals, information sheet for professionals

(iii) Information sheet: Are you looking after an older person?

(iv) Newspaper article and advertisement

(v) Course descriptions

Carers' Project
Fax 06-247 8522
Direct line 06-249 3138
E-Mail Gina.Roach@anu.edu.au

24 April 1997

Dear Dr ....,

The Carers' Project at the Australian National University has received funding from the Commonwealth Department of Health and Family Services to undertake a study of "vulnerable" carers in the community. An outline of the project is attached. As a general practitioner with an interest in aged care issues, we hope you may be willing to talk to us, with a view to assisting us in providing a point of contact for the identification of such carers.

Our usual practice in GPs offices has been to leave screening questionnaires (a copy is attached) and a box for receipt of the questionnaires in a prominent place in the practice waiting room, and to ask practice staff to point out the questionnaire to patients as they arrive. We know that practice staff are often very busy, so we are not asking any further involvement from them; the sign attached to the questionnaire box asks patients whether they provide care for someone, and thus indicates whether they would be eligible to complete a questionnaire.

I'm sure that your time during working hours is limited, but I would be happy to talk to you by phone to answer any further questions you may have about the project. I can be contacted from Monday to Thursday on 249 3138.

With thanks for any assistance you may be able to provide,

Yours sincerely,

Gina Roach
Project Coordinator.

Carers' Project
Fax 06-247 8522
Direct line 06-249 3138
E-Mail Gina.Roach@anu.edu.au

Additional information on the proposed conduct of the Carer's Project

- The literature on caring suggests that the carers we are particularly interested in finding out about are vulnerable to severe levels of burden in their daily lives, mostly through a combination of the level of care they undertake, their feelings about their caring role and their lack of contact with informal networks or formal networks of service providers. In addition, it is suggested that many of the carers who fit this profile do not identify themselves in a caring role - the situation of a husband or wife caring for a spouse "because it's just what I'm there to do and it's what the relationship is all about" for example - so that they don't feel able to, or don't feel that it is appropriate to seek help such as respite care. Such people often do not receive a carer's benefit, and thus do not form part of official figures or databases.

- This lack of self-identification to others means that we initially want to try to find people who fit this profile through their own statements about their situation, rather than through asking GPs or other health professionals whether they know of patients who are carers. We hope to be able ask all people attending a sample of practices to fill in the screening form; we fully expect that we will get a large proportion of non-carers, and a proportion of carers who don't fit the vulnerable profile, as well as some who do. From this screening instrument, we hope then to identify vulnerable carers and ask them to take part in the survey proper.

- In practical terms, we are asking that the reception and office staff in each practice hand out a copy of the screening instrument to all adult patients (or where the patient is a child, to the accompanying adult) and collect the returned forms and store them for collection by us. Filling in the form is of course voluntary, and we will provide office staff with information to answer queries or refer queries to us. Patients may take away the form to fill in and return, but we would prefer it to be filled in while they wait, to maximise response. All materials such as pens and envelopes will be provided by the project. I know that office staff in busy practices experience hectic times during each working day, but we are hoping that the additional set of tasks suggested for this project will not be too much of a burden. I'd appreciate any comments your staff may have on this matter.

- As I indicated in my original letter, this project is being sponsored by the Commonwealth Department of Health and Family Services, and the proposed methodology of the project has gone through an ethics review at the ANU. Part of the project also involves feedback to GPs specifically about their patients, as well as some general information at the end of the project about ways of identifying vulnerable carers in the future. You will see that we seek permission to share information at the end of the screening instrument.

Care in the Community Survey

Instructions for Practice Staff

- The first stage of this project is particularly concerned with locating people who provide care to others in the community. We are hoping to locate these people through the information they themselves provide about their situation, rather than by asking doctors and other professionals to identify people who fit this profile. We are asking practice staff to ask **all adult patients coming in for a consultation (or if the patient is a child, then the accompanying adult)** a couple of screening questions to determine whether they are then eligible to complete a questionnaire.

A suggested introduction to the project may be something like:

The practice is participating in a survey run by the Australian National University (ANU) and the Department of Health and Family Services. Would you mind answering a couple of brief questions?

(Question 1)
Do you or anyone in your family care for someone aged 18 or over?

If the answer to this question is **No**, then add one box to the patient log we have provided. Thank the patient - you don't need to ask this patient any more questions.

If the answer is Yes, then you will need to ask

(Question 2)
Who does the caring - is it you, or another family member?

If the answer is **another family member**, then please ask the patient whether they would pass on a copy of the questionnaire in a sealed envelope to this family member to complete and send back to us. The envelope contains the questionnaire as well as a reply paid envelope.

If the answer is **the patient her/himself** then say

The project team is asking that we give you this questionnaire to complete. Have you filled out a copy of this questionnaire before? (IF NO) I'll give you one now; you should be able to complete it while you wait, and you can put it in this box when you are finished. Thanks.

If the answer is "both" - for example, a patient saying "I care for my mother but my sister also cares for her" - then only give a copy of the questionnaire to the patient. Do not also provide a copy in an envelope for the other family member mentioned.

There are some important points to note here.

- For the purpose of this study, caring for someone means taking the main responsibility for the care of someone who is aged, or who is over the age of 18 and has a long term illness, disability or other problem.

- We need you to ask these two questions at the beginning, because we want to ensure that **only the person providing care** completes the form. We particularly want to avoid the situation where someone who **receives** care for example, fills in the questionnaire on behalf of their carer, if that carer happens to be a member of their family. The survey form contains questions which require individual responses which can't really be filled in satisfactorily on someone else's behalf.

- In order to get a rough baseline measure of the extent to which care in general is being provided, we need an indication of who is **not** providing care. Although it may seem a bit pointless to keep filling in one box if the answer to Question 1 is "No", it is important to us that we have this level of information.

- It is important to check that the patient has not filled in a questionnaire before. We want to make sure that we only receive one questionnaire per patient. This will be of particular importance as the days pass and patients may possibly return for another consultation, but the question should be asked even at the beginning, in case the patient has been to another practice where this survey is being run.

- The questionnaire should be filled in while the patient waits - this is our preferred way of collecting the information. If a patient does come back to you and says that they don't have time, or they don't feel well enough to fill it in, or they haven't brought their reading glasses for example. then offer them a reply paid envelope so that they can fill it in at home and return it to us. Don't offer an envelope when you first hand out the questionnaire.

- **Participation in this survey is voluntary**, and this is made clear on the questionnaire. If you encounter a patient who is opposed to answering any questions or filling in the questionnaire from the very beginning, then don't make any attempt to force them to answer or to take a copy. If a patient is not opposed to filling in the questionnaire however, but is reluctant because of the time or other considerations, then you could repeat that it can be filled in while they wait.

- If the patient wants to know more about the project, please hand out a copy of the information sheet we have provided, which also gives information on how to contact project staff if necessary.

- **Completed questionnaires may contain information which identifies patients. For this reason it is most important that patients see clearly that the completed questionnaires are being put securely in the box provided; for anyone who may ask questions about this, please stress that staff in your practice will not have any contact with the completed questionnaires, and that they will be collected personally by staff from the project.**

If you have any queries or any problems arise during the conduct of the screening phase of the survey, please contact Gina Roach on 249 3138. The office may occasionally be unattended, so please leave a message. If the matter is urgent and the general office is unattended, then please call Dr Valerie Braithwaite on 249 4601.

Care in the Community

A Project Sponsored by

the
Commonwealth Department

of Health and Family Services

and

the
Australian National University

This survey project is being run by a team from the Australian National University, and is being sponsored by the Department of Health and Family Services. The main aims of the project are to gain an idea of the care being provided by family and friends to others in the community, to be able to pass some of the general findings about such care on to other professionals in the community such as doctors, and give the government some idea of the kinds of programs which would best help those who provide care, to continue in their caring role. Your general practitioner has agreed to assist us in this research, by providing a location through which we may be able to contact people who do provide care.

Dr Valerie Braithwaite is the project leader at the ANU. Dr Penny Pollitt is the other member of the project team, and Gina Roach is the project coordinator. If you have any questions about the project, please feel free to call Gina Roach on 249 3138. The office may occasionally be unattended; please leave a message on the answering machine and we will get back to you as soon as possible.

The Australian National University

The Research School of Social Sciences
Carers' Project
Fax 06-247 8522
Direct line 06-249 3138
E-Mail Gina.Roach@anu.edu.au

Canberra, ACT 0200
Telegrams & cables NATUNIV Canberra
Telex AA 62694 SOPAC
Telephone 06-249 5111

Monday 10 February 1997

Dear Ms ....,

We are writing to you to ask if you would be interested in cooperating in a study which we are conducting with caregivers of elderly persons or those with age-related disorders. Our objective is to evaluate a program which organizes recreational classes for caregivers to give them an opportunity to find other interests as well as have a break from caregiving. We organize respite care and provide transport where it is required. Our funding comes from the Department of Health and Family Services, and the study is based at the ANU.

If you have contact with any caregivers in the course of providing residential respite care, whom you think might benefit from the program, we would be very interested in talking briefly with you, and making contact with them. We have a screening instrument that assesses the tasks that caregivers are doing, as well as the degree to which caregivers are having basic needs frustrated by caregiving. If caregivers tick the highest categories for at least half of the items in either measure, they fit our criterion of a vulnerable caregiver and, therefore, are eligible for the program. We have been leaving this instrument with other health professionals and in doctors' surgeries, and would be happy to bring some to you should you be able to assist us.

I am enclosing a copy of this screening instrument, a summary of the objectives of the project, an information sheet for professionals, an information sheet for caregivers, and a flyer for the course we are currently running. Other courses are also planned to run in the next couple of months.

I will contact you by phone in the next few days. We appreciate any assistance you may be able to provide with this project,

Yours sincerely,

Gina Roach

INFORMATION SHEET FOR PROFESSIONALS

You may have clients who are interested in a research project that we are running over the next few months. Our project is based at the Australian National University and is sponsored by the Department of Health and Family Services. We are trying to contact co-resident caregivers of elderly people and invite them to take part in some recreational courses such as drawing, reading groups, and bird watching, which we will organize, and for which we provide respite care. The courses will run for 6 to 8 weeks and our task is to evaluate how well they are received by caregivers, and whether they ease some of the pressures that are often associated with providing care at home.

Who are we targetting? We have a brief questionnaire that asks caregivers about the help they provide to another and about the effects of providing care on their own lives. If caregivers tick approximately half of the high task demand categories OR approximately half of the statements that show that carers are not having their basic needs met because of caregiving, we would be very interested in interviewing them and including them in our project if they are willing to take part. We can send you this screening instrument, if we have not already done so.

What to do? Please ask interested clients to ring us on 2494601 (Valerie Braithwaite) or 2493138 (Gina Roach and Penelope Pollitt) so that we can arrange a time to talk with them. Alternatively, if you could give us their name and phone number, we will call them. We are also able to supply some stamped addressed envelopes and expression of interest forms for those caregivers who would prefer to contact us that way.

Many thanks for your cooperation. We look forward to de-briefing you on our findings at the end of the project.

Gina Roach
Penelope Pollitt
Valerie Braithwaite

INFORMATION SHEET: ARE YOU LOOKING AFTER AN OLDER PERSON?

If you are looking after a person at home who is no longer able to do some of the basic things that need to be done on a day to day basis, please consider asking for our screening instrument and taking part in our Caregiving Enrichment Project.

We are an Australian National University research team, funded by the Department of Health and Family Services, and we are setting up a number of recreational courses for carers including topics like drawing, bird watching, nature walks, reading groups and so on. Our flyer for drawing which is a course that we are currently running is attached.

Our funding enables us to provide these courses to you free of charge and cover any costs that would be associated with the respite care that you might need for the person you are looking after while you attend the course. You will be consulted about your respite care needs, you will have an opportunity to meet the respite care people, and we can supply you with transport to and from the course.

This is a pilot project that we are asking you to participate in. Our objective is to offer new forms of respite for carers and evaluate the usefulness of such programs. To this end, we would like to interview you before, after and during the course.

We hope you find this option both useful and interesting. If you are willing to talk with us, please detach and complete the sheet of paper at the back, and send it to us in the stamped addressed envelope. If you would rather phone us, please do so on the following numbers:

Gina Roach & Penelope Pollitt	2493138
Valerie Braithwaite	2494601

I am interested in hearing more about the Caregiving Enrichment Project.

Please phone me at the following number..

The most suitable time is ....

Name and address ....

....

....

Care in the Community

A Project Sponsored by

the Commonwealth Department of Health and Family Services

and

the Australian National University

Caregivers need a break from caregiving, but too often they don't take one. Sometimes there's just too much to do, other times they feel that it's impossible to leave the person they are caring for at home.

An ANU research team, headed by Dr. Valerie Braithwaite from the Research School of Social Sciences, is evaluating a new program that gives ACT caregivers the opportunity to experience the benefits of having a break from caregiving in order to pursue other activities. Caregivers of the frail aged and those with age-related disorders are spending one to two hours a week in classes on drawing, relaxation and movement, or "environmental" walks.

The findings of the study will not be known until October, but results so far are encouraging. According to Dr. Penelope Pollitt, who has interviewed many of the participants, caregivers feel revitalized by the break: "It helps them unwind, adds something completely different to their lives, and gives them an opportunity to meet new people".

There are still places available for courses in July. Arrangements for transport and home-based care from a respite care service are made by the research team, and costs are covered by a grant from the Department of Health and Family Services. Caregivers who are interested should ring Gina Roach or Penelope Pollitt on 2493138.

Advertisement and article for The Chronicle

Look for a break

CAREGIVERS need a break from caregiving, but too often they don't take one. Sometimes there's just too much to do, other times they feel that it's impossible to leave the person they are caring for at home.

An ANU research team, headed by Dr Valerie Braithwaite from the Research School of Social Sciences, is evaluating a new program that gives ACT caregivers the opportunity to experience the benefits of having a break from caregiving in order to pursue other activities.

Caregivers of the frail aged and those with age-related disorders are spending one to two hours a week in classes on drawing, relaxation and movement or "environmental" walks.

The findings of the study will not be known until October, but results so far are encouraging. According to Dr Penelope Pollitt, caregivers feel revitalised by the break: "It helps them unwind, adds something completely different to their lives, and gives them an opportunity to meet new people".

If you are interested in courses to be held in July call 249 3138.

Are you providing care for an older person?

Do you find it difficult to take a break from caregiving to do something for yourself?

The Carers' Project at the ANU would like to talk to you about your experience of looking after another person.

As part of the Project, we are also organising recreational courses for carers which are free of charge. If you need respite care or transport to be able to go to a course, we can arrange that too.

For more information on the Project, call *Gina Roach* or *Penelope Pollitt* at the ANU on 249 3138.

AOA99429/#6010/2

RELAXATION

The course: Each session will include relaxation exercises, with music or with guided imagery, as well as movement to music, and exercises which gently help to improve flexibility, posture and ease of movement. Exercises and movement will be tailored to meet the needs of the individuals taking part. Each session will aim to leave people feeling relaxed and refreshed, as well as provide a basis for learning to use relaxation techniques in everyday life.

The venue: The course will be held on Monday mornings in Room 1 at the Om Shanti College, 2a Barker Street, Griffith (at the Griffith shops, paking available behind the shops) from 10am to 12pm. The course will run for six weeks, and will begin on Monday 12 May. Room 1 is a quiet, comfortable and carpeted room which is ideally suited to relaxation classes. Please wear comfortable, loose clothing.

The teacher: Jane Murray is an experienced private relaxation and dance consultant, who has run workshops and classes for many different groups over past years.

WALKS FOR PLEASURE

About the walks: Join us in a walk once a week, starting Monday 19 May, for six to seven weeks. Each walk will be over flat, level ground, in different locations around suburban Canberra, and will last for about and hour and a half. At the end of each walk, we will be getting together for morning tea.

Where: The first walk will be around the Lakeside and Commonwealth Park, starting from the Carillon carpark, Wendouree Drive, Parkes at 9.30 am Monday 19 May 1997 (map reference : Gregory's map 10th edition Map 52, B11). The location of walks for the following weeks will be arranged at this first walk, and this information provided to participants before the next week.

What to bring: Wear comfortable clothes and comfortable, sturdy shoes. Bring a hat and some sort of outer wear for cool mornings, as well as sunscreen and a water bottle if you want. The leaders of the walk will carry a first aid kit and a mobile phone.

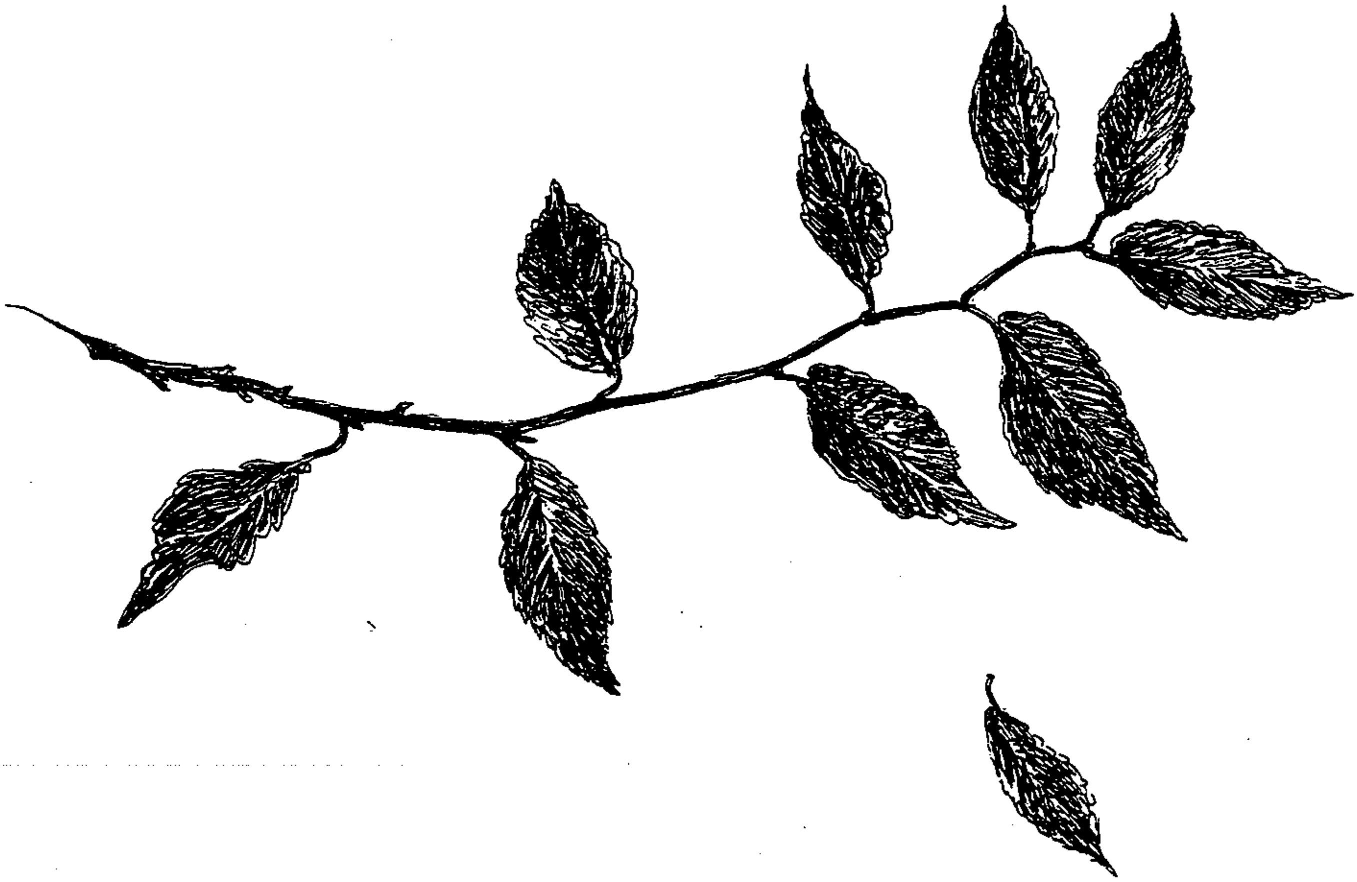
The leaders: Ivan and Rosemary Gilchrist, who have been involved with the Walking for Pleasure group for a number of years, will be coordinating and leading the walks. They both know Canberra well and are looking forward to taking a new group to some of the places they in which they enjoy walking.

DRAWING * COLLAGE

The course: The six week course explores drawing as ways of describing the world around us, describing inner worlds of thoughts and feelings, and/or as ways of creating beauty and decoration. Learning to draw is essentially about learning (or relearning) to see. Drawing is a creative medium that can be done anytime and virtually anywhere . No prior drawing skills are required for this course. Developing drawing skills are the starting point of the course - with a focus on learning to use 'drawing on the right side of the brain' techniques. Participants are encouraged to bring in with them personal projects or favourite images that they wish to draw, or express. While much of the focus will be on developing drawing skills, using paper collage to create or enhance drawing will also be included.

The venue: The course will be held at ORANA school Weston (old AME buildings), Thursday mornings from 9.30 to 11.30. The course runs for six weeks, starting Thursday the 8th of May. Morning tea, easels, paper and pencils, ink etc will be provided. Please wear old clothes or bring an overshirt as working with charcoal or ink can sometimes get messy!

The teacher: Lyndall Strazdins has a degree in Fine Art with majors in drawing and printmaking. Lyndall is also a clinical psychologist.



Appendix B

Caregiver Screening Instrument

Care in the community

A Project sponsored by the Department of Health and Family Services and The Australian National University

We are working to better understand the levels of care that families and friends provide for each other in the community. As part of this project, we are asking people to complete the following questionnaire. When you have finished, please place the questionnaire in the box provided in the surgery for collection by us.

Completing this questionnaire is voluntary and results will remain confidential. We greatly appreciate any assistance you can provide.

(Please tick the correct box)

1. Do you care for someone aged 18 or over?

No ☐ **(if no, please stop here)** Yes ☐ **(if yes, please go to question 2)**

2. Who is receiving the care?

Spouse / Partner	☐	Father / Mother	☐	Son/Daughter	☐
Sister/Brother	☐	Friend or Companion	☐		
Other Relative	☐	....		(please specify)	

Questions 3 to 13 are about **the person you care for**, and the sorts of tasks they may be able to do for themselves. Please circle the number that indicates how well this person manages these tasks.

3 .Can he / she get to places outside walking distance :	Without help (travels alone) 0	With some help 1	Unable to travel without special arrangements 2
4 .Can he / she go shopping for groceries :	Without help 0	With some help 1	Completely unable to do any shopping 2

5. Can he / she do any housework:	Without help 0	With some help 1	Completely unable to do any housework? 2
6. Can he / she do his / her own laundry :	Without help 0	With some help 1	Completely unable to do laundry at all 2
7. Does he / she get around the (house/unit/room)	Without help of any kind (except for a cane) 0	With some help (from a person, walker, crutches etc) 1	Doesn't get around unless someone moves him / her 2
8. Does he / she bathe - that is, take a bath, shower or sponge bath	Without any help 0	With some help 1	Only when someone bathes him / her 2
9. Does he/ she eat :	Without any help 0	With some help 1	Someone feeds him /her 2

10. About how often does he / she wet or soil him/herself during the day or night?	Never 0	About once or twice a week 1	Three times a week or more 2

11. Can he / she summon help in an emergency, like using a telephone, ringing a bell, signalling a neighbour in some way?	No 1	Yes 0

12. Can he / she be left alone unsupervised for a couple of hours - during the day?	Yes 0	Rarely 1	No 2
13. during the night?	Yes 0	Rarely 1	No 2

14. Caring for a friend or relative can give rise to feelings that are difficult to cope with. Could you please circle the number which indicates whether any of these problems apply to you .

	Have experienced this	*Never had to cope with this*
Not being able to do your job as well as you would like	1	0
Having to constantly be on call to assist the person you are caring for	1	0
Being unable to get enough sleep	1	0
Having health problems as a result of caregiving	1	0
Being unable to get your household chores done	1	0
Feeling divided loyalties between the person you are caring for and other members of your family	1	0
Feeling that you are not doing anything as well as you should	1	0
Feelings of resentment that this has happened to you	1	0
Feeling that you don't understand the nature of the other person's illness	1	0
Feelings of resentment at what has happened to the person you are caring for	1	0
Being unable to rest when ill yourself	1	0
Feeling that you cannot get on top of all the things you have to do	1	0
Feeling guilty about what you have or have not done for the person you are caring for	1	0
Feeling that you have lost control over your life	1	0
Losing patience with the person you're caring for	1	0
Not having a regular daily routine	1	0
Having to change plans at the last minute	1	0

PLEASE TURN OVER TO THE LAST PAGE

Would you be willing to be contacted further by one of our project researchers? If you are, please provide us with your name, telephone contact number and a time and/or day of the week which is convenient for us to call you in the box below.

NAME:	**PHONE NO:**	**CONTACT TIME:**

THANK YOU FOR YOUR TIME AND CO-OPERATION IN COMPLETING THIS QUESTIONNAIRE.

Appendix C

Psychometric details for the personal care requirements scale, the supervisory requirements scale and the burden scale

Scale	Screen (N = 59)			Initial interview (N = 74)		
	alpha reliability	Mean	Range (SD)	alpha reliability	Mean	Range (SD)
personal care	.82	8.49	1-15 (3.73)	.82	8.49	0-16 (4.04)
supervisory	.76	1.93	0-5 (1.92)	.76	2.00	0-6 (2.07)
burden	.87	10.99	0-17 (4.26)	.84	9.26	0-17 (4.27)

Appendix D

Pre-Program Interview Schedule

Care in the community

Sponsored by the Department of Health and Family Services
&
The Australian National University

ID Number ....

Date of Interview: ....

Please complete the following by circling the number or writing on the dotted line.

1. Would you say that you are the main person involved in providing assistance to [EP] or do you share the responsibility?

no	1
yes	2

If no, who is?

....

If another person is seen as primary caregiver, have an informal chat about how this has come about, who does what, and ascertain for yourself who is the primary caregiver. If you decide this person is not the primary caregiver, terminate the interview. If you decide this person is the primary or joint caregiver, continue.

2. Who are you caring for?

Father/Mother	1
Spouse	2
Aunt/Uncle	3
Sister/Brother	4
Son/Daughter	5
Grandmother/Grandfather	6
Other Relative / Friend	7
....	(please specify)

3. Is the person being cared for

male	1
female	2

4. How old is [EP]? .... years

5. What are the major health problems of the person being cared for?

....

....

....

6. Now I would like to ask you about the help that [EP] needs.

Circle the number that indicates how well [EP] manages these tasks.

Note the options continue on adjacent page.

	How well does [EP] manage....	
a) Can he / she get to places outside walking distance:	Without help 0	With some help 1
b) Can he / she go shopping for groceries:	Without help 0	With some help 1
c) Can he/she do any housework:	Without help 0	With some help 1
d) Can he/she do his/her own laundry :	Without help 0	With some help 1
e) Does he / she get around the house/unit/room:	Without help of any kind 0	With some help 1
f) Does he/she bathe - that is, take a bath, shower or sponge bath	Without any help 0	With some help 1
g) Does he/she eat:	Without any help 0	With some help 1
h) About how often does he/she wet or soil him/herself during the day or night?	Never 0	About once or twice a week 1
i) Can he/she be left alone unsupervised for a couple of hours - during the day?	Yes 0	Rarely 1
j) during the night?	Yes 0	Rarely 1

k) Can he/she summon help in an emergency, like using a telephone, ringing a bell, signalling a neighbour in some way?	No 1	Yes 0

Continue on adjacent page.

6.. (continued)

Circle the number that best describes the situation.

Write answers on the dotted line.

	Who usually provides the help? **(Name/relationship)**	Do you have a backup?	Who is it? **(Name / relationship)**
Unable to travel without special arrangements 2	....	no 1 yes 2	....
Completely unable to do any shopping 2	....	no 1 yes 2	....
Completely unable to do any housework? 2	....	no 1 yes 2	....
Completely unable to do laundry at all 2	....	no 1 yes 2	....
Doesn't get around unless someone moves him / her 2	....	no 1 yes 2	....
Only when someone bathes him / her 2	....	no 1 yes 2	....
Someone feeds him /her 2	....	no 1 yes 2	....
Three times a week or more 2	....	no 1 yes 2	....
No 2			
No 2			

7. How long have you been involved in helping EP ? ....(years & months)

8. Do you live in the same house as EP, attached dwelling or separate dwelling?

same house	1
attached dwelling	2
separate dwelling	3

9. How much did you know about [EP's] condition when you first became involved in caring?

not much	1
a little	2
quite a lot	3

10. In the time that you have been a carer, has there been very much that you have had to learn about caregiving?

not much	1
some	2
quite a lot	3

11. Caring for a friend or relative can give rise to feelings that are difficult to cope with. Have a look at this list. Could you please circle the number which indicates whether any of these problems apply to you as a result of caregiving. **[Self completion if desired]**

	Yes	*No*
a) Not being able to do your job as well as you would like	1	0
b) Having to constantly be on call to assist the person you are caring for	1	0
c) Being unable to get enough sleep	1	0
d) Having health problems as a result of caregiving	1	0
e) Being unable to get your household chores done	1	0
f) Feeling divided loyalties between the person you are caring for and other members of your family	1	0
g) Feeling that you are not doing anything as well as you should	1	0
h) Feelings of resentment that this has happened to you	1	0
i) Feeling that you don't understand the nature of the other person's illness	1	0
j) Feelings of resentment at what has happened to the person you are caring for	1	0
k) Being unable to rest when ill yourself	1	0
l) Feeling that you cannot get on top of all the things you have to do	1	0
m) Feeling guilty about what you have or have not done for the person you are caring for	1	0
n) Feeling that you have lost control over your life	1	0
o) Losing patience with the person you're caring for	1	0
p) Not having a regular daily routine	1	0
q) Having to change plans at the last minute	1	0

12. In relation to looking after [EP], how often do you find yourself................

	hardly ever	sometimes	regularly	all the time
a) Feeling that you have total responsibility for the well-being of another person?	1	2	3	4
b) Fearing what will happen if you are unable to look after the person you are caring for?	1	2	3	4
c) Wondering if the person you are caring for is alright e.g. has not fallen over while you were not there?	1	2	3	4

13. Have you found the following difficult to cope with as a result of caregiving?

	no	yes
a) Missing out on outings and holidays	1	2
b) Having to plan any outing or holiday well in advance	1	2
c) Having less time to spend with the rest of the family	1	2
d) Having so little time to yourself	1	2
e) Giving up interests, leisure activities or hobbies	1	2

14. In the time you have been caring for [EP], have you observed the following in [EP]?

	no	yes
a) Worries unnecessarily	1	2
b) Wants to be the central concern of your life	1	2
c) Goes on and on about certain things	1	2
d) Constantly demands assistance	1	2
e) Gets very upset, may cry	1	2
f) Is irritable	1	2
g) Gets deeply depressed	1	2
h) Has sudden changes of mood	1	2
i) Is overly critical	1	2
j) Tends to expect the worst all the time	1	2
k) Becomes angry and threatening	1	2
l) Does strange things	1	2
m) Gets off the subject when having a conversation	1	2
n) Gets mixed up about the day, the year	1	2
o) Does not understand what is said	1	2
p) Is not interested in news of friends or relatives	1	2
q) Fails to recognize familiar people and places	1	2
r) Does not respond sensibly when spoken to	1	2
s) Endangers her/himself	1	2
t) Wanders outside the house	1	2

15. Think about the answers you have just given me. Do you think [EP] is now very different from how he/she used to be, much the same, or somewhere in between?

[Show answers to question 14 if necessary]

much the same	1
in between	2
very different	3

16. How often does a difference of opinion arise between you and [EP] that upsets one or both of you? Choose the answer that comes closest on average. **(Show list)**

more than once a day	8
once a day	7
a few times a week	6
once a week	5
a few times a month	4
once a month	3
every now and again, less often than once a month	2
hardly ever	1

17. When you are involved in looking after someone, tensions can arise on both sides of the relationship. The next set of questions asks you about the things you might do to build or maintain your relationship with [EP]. Tell me if you do these things all the time, regularly, sometimes, or hardly ever.

	hardly ever	sometimes	regularly	all the time
a) How often do you share your thoughts and feelings with [EP]?	1	2	3	4
b) How often do you ask about the thoughts, feelings or well-being of [EP]?	1	2	3	4
c) How often do you initiate 'play' e.g. jokes, games, humour with [EP]?	1	2	3	4
d) How often do you do things to protect [EP] from becoming stressed?	1	2	3	4
e) How often do you do things to soothe or calm [EP]?	1	2	3	4
f) How often do you listen attentively to the problems or worries of [EP]?	1	2	3	4
g) How often do you try to change or compromise in order to improve your relationship with [EP]?	1	2	3	4
h) How often do you try to talk about any problems in your relationship with [EP]?	1	2	3	4
i) How often do you act as a third party to resolve conflict between [EP] and someone else?	1	2	3	4
j) How often do you try to persuade [EP] to stop doing something that is harmful?	1	2	3	4
k) How often do you point out to [EP] that they may be upsetting or offending others (not just yourself) ?	1	2	3	4
l) How often do you stop [EP] from doing something that could be harmful?	1	2	3	4
m) How often do you show verbal affection e.g. speak warmly to [EP]?	1	2	3	4

18. These questions have been about keeping relationships positive with [EP], helping him/her and giving guidance. How much does [EP] ...

	not at all	somewhat	a great deal
a) Expect you to do these things	1	2	3
b) Recognise your efforts	1	2	3
c) Respect you for your efforts	1	2	3
d) Show appreciation for your efforts	1	2	3

19. Is there someone who would take care of [EP], if you were out of action for....

	no	yes
a) A few hours of a day	1	2
b) Most of a day	1	2
c) Overnight	1	2
d) 2 or 3 days	1	2
e) 2 or 3 weeks	1	2

20. If you were unable to care for [EP], would you miss ...

	no	yes
a) Companionship	1	2
b) Being useful	1	2
c) Being busy and occupied	1	2
d) His/her being there	1	2
e) Don't know	1	2
f) Nothing	1	2

21. How long do you intend to continue to look after {EP}?

....

....

22. Do you have a breaking point that you are aware of? Is there something that you know you just couldn't cope with?

no	1
yes	2

23. Have you made enquiries about other accommodation for [EP] or yourself?

no	1
yes	2

24. **If yes.** What sort?

....

25. **If yes.** Are you on a waiting list?

no	1
yes	2

26. **If hostel or nursing home.** If you got a phone call today saying that there was a place in this hostel or nursing home, what would you do?

decline it at this point	1	
accept it	2	
don't know	3	**(only use if truly undecided)**

27. The next set of questions are about yourself. First of all.....

male	1	female	2

28. Could you please tell me your age? .... years

29. In general, would you say your health is:

excellent	5
very good	4
good	3
fair	2
poor	1

30. Are you employed outside the home?

full-time	3
part-time	2
not at all	1

[If employed full-time or part-time ask Question 31(a)]

31(a). What kind of job do you do?

....

[If not currently employed, ask Question 31(b).]

31(b). Have you ever been employed outside the home? **[If yes]** What kind of job did you do? **[Note length of time worked and kind of work.]**

....

32. Have you changed your work status as a result of caring?

no	1
yes	2

33. **[If yes to Question 32]** How has it changed?

From:...

To: ....

[If partner is the carereceiver, code Question 34 without asking.]

34. Do you have a partner who is part of your household?

no	1
yes	2

[If partner is carereceiver, code 1 for Question 35 and go to Question 36(b)]

35. Is your partner in the workforce?

full-time	3
part-time	2
not at all	1

[If employed full-time or part-time ask Question 36(a)]

36(a). What does he/she do?

....

[If not currently employed, ask Question 36(b).]

36(b). Has he/she ever been employed outside the home? **[If yes]** What kind of job did he/she do? **[Note length of time worked and kind of work.]**

....

37. How many children do you have living at home with you? How old are they?

Total number:...........

Ages:...

38. Here is a list of questions about how some people feel from time to time. Please circle the number that most nearly represents how distressing you have found each of these things <u>in the past few weeks</u>. **[Self-completion if desired]**

	not at all	a little	a lot	almost unbearably
a) Recently I have worried about every little thing.	1	2	3	4
b) Recently I have been so miserable that I have had difficulty with my sleep.	1	2	3	4
c) Recently I have been breathless <u>or</u> had a pounding of my heart.	1	2	3	4
d) Recently I have been so "worked up" that I couldn't sit still.	1	2	3	4
e) Recently I have been depressed without knowing why.	1	2	3	4
f) Recently I have gone to bed not caring if I never woke up.	1	2	3	4
g) Recently, for no good reason, I have had feelings of panic.	1	2	3	4
h) Recently I have been so low in spirits that I have sat for ages doing absolutely nothing.	1	2	3	4
i) Recently I have had a pain <u>or</u> tense feeling in my neck or head.	1	2	3	4
j) Recently the future has seemed hopeless.	1	2	3	4
k) Recently worrying has kept me awake at night.	1	2	3	4
l) Recently I have lost interest in just about everything.	1	2	3	4
m) Recently I have been so anxious that I couldn't make up my mind about the simplest thing.	1	2	3	4
n) Recently I have been so depressed that i have thought of doing away with myself.	1	2	3	4

39. This part of the questionnaire is concerned with how you see yourself in the future. We all think about our futures to some extent. We think about the kinds of experiences that are in store for us and the kinds of people we might possibly become. We also think about what we hope we will be like. That's what I would like to talk with you about now - what you hope for yourself in the future.

I expect you will need a few minutes to think about this. Some questions that might help you define what you hope for yourself are these:

- What are my hopes for the future?
- Are there any hobbies that I would like to be better at?
- Is there anything that I haven't become that I would like to become?

List hoped-for possible selves: ....

....

....

....

....

....

....

....

40. What is the most important thing that you hope for yourself?

....

41. To what extent are you like this most important hoped-for self right now?

1 2 3 4 5 6 7

not at all very much

42. In addition to having hoped-for selves, we may have images of ourselves in the future that we fear, dread, or don't want to happen.

Take a few minutes and think about the things you fear for yourself. When you are ready, tell me what they are. Some questions that might help you define what you fear for yourself are these:

- What would happen if I was in bad health in the future?
- What would happen if I had to give up my hobbies or interests?

List feared possible selves:

....

....

....

....

....

....

....

43 What is the thing you fear most for yourself?

....

44. To what extent are you like this most feared self right now?

1	2	3	4	5	6	7
not at all						very much

45. Now I'd like to read through a list of phrases that describe different aspects of your life. For each phrase I would like you to tell me how satisfied you are with that aspect of your life.

Are you very satisfied, satisfied, dissatisfied or very dissatisfied with ...

	Very satisfied	Satisfied	Not sure	Dissatisfied	Very Dissatisfied
a) Your financial situation	1	2	3	4	5
b) Your health	1	2	3	4	5
c) Your independence or freedom	1	2	3	4	5
d) The respect or recognition you get	1	2	3	4	5
e) Your personal, emotional life	1	2	3	4	5
f) Your life as a whole	1	2	3	4	5

46. Let's turn our attention now to using respite care. Have you used formal respite care before?

no 1
yes 2

47. **If yes.** What type of respite have you used and how often have you used it? Would you say you are not satisfied, satisfied or very satisfied with the care?

Type of respite	No. times used	Satisfaction with respite

48. We have a number of programs for caregivers in mind that are to be used in conjunction with at-home respite. The first is a drawing class. Here is a flyer for it. Later on, we are thinking about organizing reading groups, bird watching and nature walks, photography, and self massage classes. What are your interests?

1st preference ....
2nd preference ....
3rd preference ....
4th preference ....
5th preference ....

49. Would you like us to book you in for a program?

no	1
yes	2

<u>If yes, seek the following information.</u>

50. We need you to sign a consent form for us. **(Can be left and collected later)**

51. We also need to know if you require us to arrange transport for you?

no	1
yes	2

52. We will arrange respite care for you. This will be for the duration of the class and half an hour travelling time each way. Our arrangements are made through accredited respite care agencies. Here is a pamphlet about the service. We will organize a visit before the course from the person that will be looking after [EP] for you.

The person responsible for making these arrangements for you is Gina Roach. Here is her number. If you have any queries, please don't hesitate to call. Otherwise, she will contact you to arrange a time for you to meet the person providing respite care and provide you with details about the course.

If yes or no, seek the following information.

53. Have you a carer's kit?

no	1
yes	2

If no, please supply.

Appendix E

Post-program Interview Schedule

This schedule was identical for the participants and the comparison group except that the participants were asked Questions 2 - 5 about the course while the comparison group was not.

Care in the community

Sponsored by the Department of Health and Family Services & The Australian National University

Second round interview

ID Number ....

Date of Interview: ....

1. It's been a few weeks since we first interviewed you. Since that first interview have there been any changes in your life as a whole or the way things happen on a daily basis?

(Prompt if necessary) For example, changes in your health or [EP's] health and wellbeing, the way your household functions.

Record descriptions of any changes in respondent's own words

Today I am going to ask you to complete a survey that covers some of the same ground as our first interview.

Before I do that however, I would like to ask you about the course you did with us.

2. I am going to read out a number of statements that someone could have made about the course. I'd like you to give each statement a score from zero (0) to ten (10).

Zero means that you don't agree at all and ten means that you agree wholeheartedly. Use the numbers between zero and ten to say how much you agree with the statement. Let us say that a five (5) means you half agree, for example.

a) Attending the course introduced me to skills that I didn't have before.	0	1	2	3	4	5	6	7	8	9	10
b) Attending the course reminded me of things I had been missing in my life.	0	1	2	3	4	5	6	7	8	9	10
c) Attending the course gave me an opportunity to get absorbed in something other than caregiving.	0	1	2	3	4	5	6	7	8	9	10
d) Attending the course recharged my batteries.	0	1	2	3	4	5	6	7	8	9	10
e) The course made me feel inadequate as a person.	0	1	2	3	4	5	6	7	8	9	10
f) The course added to my frustration with life.	0	1	2	3	4	5	6	7	8	9	10
g) The course interfered with my caregiving responsibilities.	0	1	2	3	4	5	6	7	8	9	10
h) My attendance at the course made the person I am caring for feel resentful.	0	1	2	3	4	5	6	7	8	9	10
i) My attendance at the course upset the person I was caring for.	0	1	2	3	4	5	6	7	8	9	10
j) I enjoyed the social atmosphere of the course.	0	1	2	3	4	5	6	7	8	9	10
k) I have found a new interest through this course.	0	1	2	3	4	5	6	7	8	9	10
l) I will try to continue drawing in my spare time.	0	1	2	3	4	5	6	7	8	9	10
m) I plan to enrol myself in another course.	0	1	2	3	4	5	6	7	8	9	10
n) I was scared about starting this course.	0	1	2	3	4	5	6	7	8	9	10
o) I was worried about being away from the person I was caring for when I started this course.	0	1	2	3	4	5	6	7	8	9	10
p) I would do this course again.	0	1	2	3	4	5	6	7	8	9	10
q) Attending this course gave me time to look after my own needs.	0	1	2	3	4	5	6	7	8	9	10
r) Attending this course gave me a complete break from caregiving.	0	1	2	3	4	5	6	7	8	9	10
s) I wouldn't have gone to such a course if the staff of the research project hadn't organised it for me.	0	1	2	3	4	5	6	7	8	9	10
t) There were times when I felt guilty about leaving my caregiving responsibilities to go to the course.	0	1	2	3	4	5	6	7	8	9	10

3. The list we've just gone through covers many specific aspects of the course you did. Overall though, how did <u>you</u> feel about the course? Is there anything else you'd like to add that this list didn't cover? Do you have any other comments to make about the course?

Prompt if necessary: for example, problems or gains we haven't already covered, the suitability of respite care while at the course, (if low scores on items m and p of Question 2), reasons for not enrolling in another course

Record answer in respondent's own words.

____

____

____

____

____

____

____

____

4. Can you refer us to anyone else who may be interested in doing a course?

If yes, note names and contact phone numbers.

____

____

____

____

5. Can we ring you in about a month's time to see how you are going?

no	1
yes	2

Next, I'd like to return to some of the questions I asked you in the first interview

Check response to Question 1

If changes noted in Question 1:

When we started this interview you mentioned that there had been changes in your life in the last couple of months. We're interested in seeing whether these changes make a difference to some of the information we collected at the first interview.

If no changes noted in response to Question 1:

As it is a few weeks since we first interviewed, we would like to repeat some of the questions we asked then to see whether there have been any changes to the information we collected at that time.

6. I would like to ask you again about the help that [EP] needs.

Circle the number that indicates how well [EP] manages these tasks.

	How well does [EP] manage....		
a) Can he / she get to places outside walking distance:	Without help 0	With some help 1	Unable to travel without special arrangements 2
b) Can he / she go shopping for groceries:	Without help 0	With some help 1	Completely unable to do any shopping 2
c) Can he/she do any housework:	Without help 0	With some help 1	Completely unable to do any housework 2
d) Can he/she do his/her own laundry :	Without help 0	With some help 1	Completely unable to do laundry at all 2
e) Does he / she get around the house/unit/room:	Without help of any kind 0	With some help 1	Doesn't get around unless someone moves him / her 2
f) Does he/she bathe - that is, take a bath, shower or sponge bath	Without any help 0	With some help 1	Only when someone bathes him / her 2
g) Does he/she eat:	Without any help 0	With some help 1	Someone feeds him /her 2
h) About how often does he/she wet or soil him/herself during the day or night?	Never 0	About once or twice a week 1	Three times a week or more 2
i) Can he/she be left alone unsupervised for a couple of hours - during the day?	Yes 0	Rarely 1	No 2
j) during the night?	Yes 0	Rarely 1	No 2

k) Can he/she summon help in an emergency, like using a telephone, ringing a bell, signalling a neighbour in some way?	No 1	Yes 0

7. In the time you have been caring for [EP], have you observed the following in [EP]?

	no	yes
a) Worries unnecessarily	1	2
b) Wants to be the central concern of your life	1	2
c) Goes on and on about certain things	1	2
d) Constantly demands assistance	1	2
e) Gets very upset, may cry	1	2
f) Is irritable	1	2
g) Gets deeply depressed	1	2
h) Has sudden changes of mood	1	2
i) Is overly critical	1	2
j) Tends to expect the worst all the time	1	2
k) Becomes angry and threatening	1	2
l) Does strange things	1	2
m) Gets off the subject when having a conversation	1	2
n) Gets mixed up about the day, the year	1	2
o) Does not understand what is said	1	2
p) Is not interested in news of friends or relatives	1	2
q) Fails to recognize familiar people and places	1	2
r) Does not respond sensibly when spoken to	1	2
s) Endangers her/himself	1	2
t) Wanders outside the house	1	2

8. Caring for a friend or relative can give rise to feelings that are difficult to cope with. Have a look at this list. Could you please circle the number which indicates whether any of these problems apply to you as a result of caregiving. **[Self completion if desired]**

	Yes	*No*
a) Not being able to do your job as well as you would like	1	0
b) Having constantly to be on call to assist the person you are caring for	1	0
c) Being unable to get enough sleep	1	0
d) Having health problems as a result of caregiving	1	0
e) Being unable to get your household chores done	1	0
f) Feeling divided loyalties between the person you are caring for and other members of your family	1	0
g) Feeling that you are not doing anything as well as you should	1	0
h) Feelings of resentment that this has happened to you	1	0
i) Feeling that you don't understand the nature of the other person's illness	1	0
j) Feelings of resentment at what has happened to the person you are caring for	1	0
k) Being unable to rest when ill yourself	1	0
l) Feeling that you cannot get on top of all the things you have to do	1	0
m) Feeling guilty about what you have or have not done for the person you are caring for	1	0
n) Feeling that you have lost control over your life	1	0
o) Losing patience with the person you're caring for	1	0
p) Not having a regular daily routine	1	0
q) Having to change plans at the last minute	1	0

9. In relation to looking after [EP], how often do you find yourself...............

	hardly ever	sometimes	regularly	all the time
a) Feeling that you have total responsibility for the well-being of another person?	1	2	3	4
b) Fearing what will happen if you are unable to look after the person you are caring for?	1	2	3	4
c) Wondering if the person you are caring for is alright e.g. has not fallen over while you were not there?	1	2	3	4

10. How often does a difference of opinion arise between you and [EP] that upsets one or both of you? Choose the answer that comes closest on average. **(Show list)**

more than once a day	8
once a day	7
a few times a week	6
once a week	5
a few times a month	4
once a month	3
every now and again, less often than once a month	2
hardly ever	1

11. When you are involved in looking after someone, tensions can arise on both sides of the relationship. Could I ask you again about the things you might do to build or maintain your relationship with [EP]. Tell me if you do these things all the time, regularly, sometimes, or hardly ever.

	hardly ever	sometimes	regularly	all the time
a) How often do you share your thoughts and feelings with [EP]?	1	2	3	4
b) How often do you ask about the thoughts, feelings or well-being of [EP]?	1	2	3	4
c) How often do you initiate 'play' e.g. jokes, games, humour with [EP]?	1	2	3	4
d) How often do you do things to protect [EP] from becoming stressed?	1	2	3	4
e) How often do you do things to soothe or calm [EP]?	1	2	3	4
f) How often do you listen attentively to the problems or worries of [EP]?	1	2	3	4
g) How often do you try to change or compromise in order to improve your relationship with [EP]?	1	2	3	4
h) How often do you try to talk about any problems in your relationship with [EP]?	1	2	3	4
i) How often do you act as a third party to resolve conflict between [EP] and someone else?	1	2	3	4
j) How often do you try to persuade [EP] to stop doing something that is harmful?	1	2	3	4
k) How often do you point out to [EP] that they may be upsetting or offending others (not just yourself) ?	1	2	3	4
l) How often do you stop [EP] from doing something that could be harmful?	1	2	3	4
m) How often do you show verbal affection e.g. speak warmly to [EP]?	1	2	3	4

12. These questions have been about keeping relationships positive with [EP], helping him/her and giving guidance. How much does [EP] ...

	not at all	somewhat	a great deal
a) Expect you to do these things	1	2	3
b) Recognise your efforts	1	2	3
c) Respect you for your efforts	1	2	3
d) Show appreciation for your efforts	1	2	3

13. How long do you intend to continue to look after [EP}?

....

....

14. Have you made enquiries about other accommodation for [EP] or yourself?

no	1
yes	2

15. In general, would you say your health is:

excellent	5
very good	4
good	3
fair	2
poor	1

16. Here is a list of questions about how some people feel from time to time. Please circle the number that most nearly represents how distressing you have found each of these things in the past few weeks.

[Self-completion if desired]

	not at all	a little	a lot	almost unbearably
a) Recently I have worried about every little thing.	1	2	3	4
b) Recently I have been so miserable that I have had difficulty with my sleep.	1	2	3	4
c) Recently I have been breathless or had a pounding of my heart.	1	2	3	4
d) Recently I have been so "worked up" that I couldn't sit still.	1	2	3	4
e) Recently I have been depressed without knowing why.	1	2	3	4
f) Recently I have gone to bed not caring if I never woke up.	1	2	3	4
g) Recently, for no good reason, I have had feelings of panic.	1	2	3	4
h) Recently I have been so low in spirits that I have sat for ages doing absolutely nothing.	1	2	3	4
i) Recently I have had a pain or tense feeling in my neck or head.	1	2	3	4
j) Recently the future has seemed hopeless.	1	2	3	4
k) Recently worrying has kept me awake at night.	1	2	3	4
l) Recently I have lost interest in just about everything.	1	2	3	4
m) Recently I have been so anxious that I couldn't make up my mind about the simplest thing.	1	2	3	4
n) Recently I have been so depressed that i have thought of doing away with myself.	1	2	3	4

17. Now what about how you see yourself in the future. Could you tell me again about what it is that you hope for yourself in the future?

Prompt with examples if necessary

- What are your hopes for the future?
- Are there any hobbies that you would like to be better at?
- Is there anything that you haven't become that you would like to become?

List hoped-for possible selves:

....

....

....

....

....

....

....

18. What is the most important thing that you hope for yourself?

....

19. To what extent are you like this most important hoped-for self right now?

1 2 3 4 5 6 7

not at all very much

20. In addition to having hoped-for selves, we may have images of ourselves in the future that we fear, dread, or don't want to happen.

Could I ask you again about the things you fear for yourself. When you are ready, tell me what they are.

Prompt with examples if necessary

- What would happen if you were in bad health in the future?
- What would happen if you had to give up your hobbies or interests?

List feared possible selves:

....

....

....

....

....

....

....

21 What is the thing you fear most for yourself?

....

22. To what extent are you like this most feared self right now?

1	2	3	4	5	6	7
not at all						very much

23. Finally I'd like to read through a list of phrases that describe different aspects of your life. For each phrase I would like you to tell me how satisfied you are with that aspect of your life.

Are you very satisfied, satisfied, dissatisfied or very dissatisfied with ...

	Very satisfied	Satisfied	Not sure	Dissatisfied	Very Dissatisfied
a) Your financial situation	1	2	3	4	5
b) Your health	1	2	3	4	5
c) Your independence or freedom	1	2	3	4	5
d) The respect or recognition you get	1	2	3	4	5
e) Your personal, emotional life	1	2	3	4	5
f) Your life as a whole	1	2	3	4	5

Thank you for your cooperation throughout the project.

We will be sending you an invitation to the launch of our report. I hope we see you there.

Appendix F

Key measures from quantitative interviews with caregivers

The following information provides the source of each scale, the items used to measure the scale, the response format, and basic statistical information on the scales collected before the program. The statistics are based on all completed questionnaires (including those who did not continue past the first interview).

Self-reported physical health scale (McCallum, 1995)

Q. 29 of the pre-program interview schedule for participants (Appendix D) is a single item health status measure.

In general, would you say your health is:

excellent	5
very good	4
good	3
fair	2
poor	1

Statistic	Pre-test N = 74	Comparator Leahan, 1995
mean	3.05	2.9
standard deviation	1.12	1.0

The life dissatisfaction scale (Headey & Wearing, 1992)

Presented as Q. 45 of the pre-program interview schedule for participants (Appendix D), we asked:

> Are you very satisfied (1), satisfied (2), not sure (3), dissatisfied (4), or very dissatisfied (5) with ...
>
> (a) your financial situation
> (b) your health
> (c) your independence or freedom
> (d) the respect or recognition you get
> (e) your personal, emotional life
> (f) your life as a whole

Responses (1 to 5) are summed over the 6 items to give a total score on life dissatisfaction.

Statistic	Pre-test N = 74	Comparator Schofield et al., 1997
mean	15.67	13.38[a]
standard deviation	4.15	na
alpha reliability coefficient	.73	.77

a Converted from the original for scale comparability

na not available

Minor psychiatric symptoms - DSSI/sAD (Bedford, A., Foulds, G. A., and Sheffield, B. F., 1976)

The Delusions-Symptoms-States Inventory (DSSI/sAD) is a self-completion instrument that includes two scales that measure anxiety and depression. The seven depression items and seven anxiety items (sAD) were presented to caregivers (see Q. 38 of the pre-program interview schedule for participants (Appendix D)) with the instruction to "circle the number that most nearly represents how distressing you have found each of these things in the past few weeks". Four response categories were provided: not at all (1), a little (2), a lot (3) and almost unbearably (4). Responses were summed over the 14 items to give a total score.

Statistic	Pre-test N = 74	Comparator Braithwaite, 1990
mean	23.30	21.05
standard deviation	8.33	6.94
alpha reliability coefficient	.91	.86 (anxiety) .84 (depression)

Hoped-for and feared possible selves (Hooker and Kaus, 1994)

Questions 39 - 44 of the pre-program interview schedule for participants (Appendix D) are based on the questionnaire constructed by Hooker and Kaus (1994). Piloting the questionnaire led us to shorten and simplify the opening instructions as follows:

> This part of the questionnaire is concerned with how you see yourself in the future. We all think about our futures to some extent. We think about the kinds of experiences that are in store for us and the kinds of people we might possibly become. We also think about what we hope we will be like. That's what I would

like to talk with you about now - what you hope for yourself in the future. I expect you will need a few minutes to think about this. Some questions that might help you define what you hope for yourself are these:

- What are my hopes for the future?
- Are there any hobbies that I would like to be better at?
- Is there anything that I haven't become that I would like to become?

The interviewer records the hoped for selves mentioned by the respondent.

Then the interviewer asks:

What is the most important thing that you hope for yourself?

To what extent are you like this most important hoped-for self right now?

Respondents answer on a 7 rating point scale from 1 meaning not at all like me to 7 meaning very much like me.

The interviewer follows up with matching questions on feared selves as follows:

In addition to having hoped-for selves, we may have images of ourselves in the future that we fear, dread, or don't want to happen. Take a few minutes and think about the things you fear for yourself. When you are ready, tell me what they are. Some questions that might help you define what you fear for yourself are these:

- What would happen if I was in bad health in the future?
- What would happen if I had to give up my hobbies or interests?

The interviewer records the feared selves mentioned by the respondent.

Then the interviewer asks:

What is the thing you fear most for yourself?

To what extent are you like this most feared self right now?

Respondents answer on a 7 rating point scale from 1 meaning not at all like me to 7 meaning very much like me.

These data were scored in terms of the number of hoped-for and feared selves and the types of hoped-for and feared selves. Types were coded using an 9 category system based on the work of Cross and Markus (1991):

1 = Personal development and general well-being
2 = Health, both mental and physical
3 = Abilities, focus on new skills or specific capacities
4 = Lifestyle
5 = Family relationships
6 = Social activities, spending time with friends
7 = Material and financial well-being, including social status
10 = Community and charitable work
11 = Leisure activities

In this report, the measures that we have used are the number of hoped-for and feared selves. The sample was not sufficiently large to analyze types with any degree of sophistication. The third type of measure, distance from the most important hoped-for self or the most feared self overlapped with well-being measures in some cases and are not discussed further in this report.

Statistic	Pre-test N = 74	Comparator Cross & Markus, 1991
mean number of hoped-for selves	4.76	6.1
standard deviation of hoped-for selves	2.35	na
mean number of feared selves	2.22	3.6
standard deviation of feared selves	1.20	na

na not available

The behavioural problems scale (Braithwaite 1990)

This scale measures emotional, social and cognitive degeneration and is a combination of two scales, one focusing on social-emotional loss of control, the other on cognitive loss of control. All behaviours represented in these scales represented deviation from mature adult behaviour and caregivers gave their views on whether each characterized the care receiver using a no (1) and yes (2) format (see Q. 14 of the pre-program interview schedule for participants (Appendix D)). Social-emotional loss of control encompassed (1) worries unnecessarily, (2) wants to be the central concern of your life, (3) goes on and on about certain things, (4) constantly demands assistance, (5) gets very upset, may cry, (6) is irritable, (7) gets deeply depressed, (8) has sudden changes of mood, (9) is overly critical, (10) tends to expect the worst all the time, and (11) becomes angry and threatening. Cognitive loss of control comprised: (1) does strange things, (2) gets off the subject when having a conversation, (3) gets mixed up about the day, the year, (4) does not understand what is said, (5) is not interested in news of friends or relatives, (6) fails to recognize familiar people and places, (7) does not respond sensibly when spoken to, (8) endangers her/himself, and (9) wanders outside the house. Because these two scales were correlated with each other ($r = .48, p < .001$) and showed similar patterns of relationships to other variables in Braithwaite (1990), they were combined in the present study. Responses were summed over the 20 items to give a total score.

Statistic	Pre-test N = 74	Comparator Braithwaite, 1990
mean	29.72	31.70
standard deviation	4.62	5.43
alpha reliability coefficient	.82	.87 (social-emotional) .86 (cognitive)

Changes in care receiver scale

This is an add on question to the behavioural problems scale designed to test whether such behaviours are seen by the caregiver as being normal for the care receiver or quite different from the way he/she use to be. The question (see Q. 15 on the pre-program interview schedule in Appendix D) is not used in the report although it is of note that 65% thought their care receiver was now very different.

Backup scale (Braithwaite, 1990)

This scale built on earlier work in which caregivers were asked if they had someone who would take care of the care receiver if they were out of action for:

(a) two or three days

(b) two or three weeks

Three additional categories were added:

(c) a few hours a day

(d) most of a day

(e) overnight

This scale appears in the pre-program interview schedule in Appendix D as Q. 19. Responses of no (1) and yes (2) are summed across the five items to give a total score.

Statistic	Pre-test N = 72
mean	7.97
standard deviation	1.97
alpha reliability coefficient	.88

Sole responsibility scale (Braithwaite, 1990)

The three item sole responsibility for care scale has been used as a measure of enmeshment in caregiving (see Q. 12 of the pre-program interview schedule for participants (Appendix D)) and asks caregivers how often they found themselves:

(a) feeling they had total responsibility for the well-being of another person

(b) fearing what would happen if they were unable to provide care

(c) wondering if the care receiver was all right when they were not with them.

The no/yes response format used previously was expanded to hardly ever (1), sometimes (2), regularly (3) and all the time (4). Responses were summed to give a total score.

Statistic	Pre-test N = 74
mean	8.16
standard deviation	2.31
alpha reliability coefficient	.49

The conflict scale (Braithwaite 1990)

The single item measure of conflict (see Q. 16 of the pre-program interview schedule for participants (Appendix D)) built on Braithwaite (1990) and asked:

> How often does a difference of opinion arise between you and the person you are caring for that upsets one or both of you.

The original three response categories were expanded to 8 options:

more than once a day	8
once a day	7
a few times a week	6
once a week	5
a few times a month	4
once a month	3
every now and again, less often than once a month	2
hardly ever	1

Statistic	Pre-test N = 74
mean	4.22
standard deviation	2.59

Reciprocity scale (Braithwaite, 1990)

This scale was a modification of an earlier scale which resulted in one item being subdivided into a number of sub-components (see Q. 18 of the pre-program interview schedule for participants (Appendix D)). Caregivers were asked:

How much does the person you are caring for...

(a) expect you to do these things (reverse score)

(b) recognize your efforts

(c) respect you for your efforts

(d) show appreciation for your efforts

Responses were made to each item in terms of not at all (1), sometimes (2) and a great deal (3). After reverse scoring (a), responses were summed to give a total score.

Statistic	Pre-test N = 74
mean	8.69
standard deviation	2.30
alpha reliability coefficient	.77

<u>The emotional care and relationship investment scale</u> (Strazdins, 1998)

Strazdins (1998) has developed a 21 item scale to measure emotional work in terms of providing companionship, help and guidance across a number of social roles. A subset of these items were trialled in the caregiving context in this study. A factor analysis produced two dimensions labelled emotional work and relationship investment. Emotional work captured the sentiment of looking after another, whereas relationship investment captured the desire to maintain the caregiver - care receiver partnership for as long as possible. The items appear in Q. 17 of the pre-program interview schedule in Appendix D). Responses were given in terms of hardly ever (1), sometimes (2), regularly (3), and all the time (4). Two scales were formed based on the factor loadings. The items comprising each scale are listed below. The scales correlated .16.

For the emotional work scale:

(a) How often do you ask about the thoughts, feelings or well-being of [EP]?

(b) How often do you initiate 'play' e.g. jokes, games, humour with [EP]?

(c) How often do you do things to protect [EP] from becoming stressed?

(d) How often do you do things to soothe or calm [EP]?

(e) How often do you listen attentively to the problems or worries of [EP]?

(f) How often do you act as a third party to resolve conflict between [EP] and someone else?

(g) How often do you show verbal affection e.g. speak warmly to [EP]??

For the relationship investment scale:

(a) How often do you share your thoughts and feelings with [EP]?

(b) How often do you try to change or compromise in order to improve your relationship with [EP]?

(c) How often do you try to talk about any problems in your relationship with [EP]?

(d) How often do you point out to [EP] that they may be upsetting or offending others (not just yourself) ?

Scale	Statistic	Pre-test N = 71
emotional work	mean	19.08
	standard deviation	4.07
	alpha reliability coefficient	.68
relationship investment	mean	8.27
	standard deviation	2.80
	alpha reliability coefficient	.64

Appendix G

Statistical analyses for Chapter 3

Restoring of spirits:

Program type	N	Mean	Standard deviation	*F*(*df* = 3,33)
drawing	16	8.34	1.70	1.39
movement and relaxation	13	7.20	2.04	
walking	4	8.80	.91	
independent activities	4	7.85	1.28	

Recruitment source	N	Mean	Standard deviation	*F*(*df* = 2,34)
GPs	8	7.45	1.89	1.82
Carers' Assoc.	18	7.64	2.08	
other	11	8.76	.64	

Care characteristics	Pearson correlation with restoring of spirits scale
Co-residency	.50**
Back-up for caregiving	-.35*
Companionship through caregiving	.33*
No. of hoped-for selves	-.34*
Stay with home care	.38*

Skills and interests:

Program type	N	Mean	Standard deviation	*F*(*df* = 3,33)
drawing	16	8.14	1.52	2.56
movement and relaxation	13	6.65	2.45	
walking	4	5.75	1.19	
independent activities	4	8.19	2.21	

Recruitment source	N	Mean	Standard deviation	*F*(*df* = 2,34)
GPs	8	6.81	2.04	.70
Carers' Assoc.	18	7.26	2.33	
other	11	7.93	1.65	

Care characteristics	Pearson correlation with the new skills and interest scale
Spouse care	-.40*
Stay with home care	.35*

<u>Engaging socially:</u>

Program type	N	Mean	Standard deviation	*F*(*df* = 3,33)
drawing	16	5.81	3.85	1.04
movement and relaxation	13	3.92	3.88	
walking	4	3.00	4.76	
independent activities	4	6.50	4.51	

Recruitment source	N	Mean	Standard deviation	*F*(*df* = 2,34)
GPs	8	8.62	1.51	.38
Carers' Assoc.	18	8.89	1.74	
other	11	9.27	1.56	

Care characteristics	Pearson correlation with the social engagement scale
Providing emotional care	.41*
Usefulness through caregiving	.40*
Being busy and occupied through caregiving	.38*
Stay with home care	.41*

Self-starting:

Program type	N	Mean	Standard deviation	*F*(*df* = 3,29)
drawing	16	5.60	2.27	.58
movement and relaxation	9	5.44	2.74	
walking	4	6.50	1.40	
independent activities	4	7.00	2.21	

Recruitment source	N	Mean	Standard deviation	*F*(*df* = 2,30)
GPs	7	5.62	.87	3.95*
Carers' Assoc.	15	4.91	2.74	
other	11	7.24	1.51	

A significant difference was found between the means for two of the groups, the Carers' Association and other.

Intrusiveness:

Program type	N	Mean	Standard deviation	*F*(*df* = 3,33)
drawing	16	.94	1.84	.33
movement and relaxation	13	.75	1.32	
walking	4	1.25	2.18	
independent activities	4	.19	.38	

Recruitment source	N	Mean	Standard deviation	*F*(*df* = 2,34)
GPs	8	1.19	1.98	.29
Carers' Assoc.	18	.78	1.77	
other	11	.64	.83	

Care characteristics	Pearson correlation with the intrusiveness scale
Physical health	-.36*
No. of hoped-for selves	-.33*

Appendix H

ANOVA results testing for group differences at pre-test, change over time and their interaction

Physical health

	SS	*DF*	*MS*	*F*
Between subject effect				
Within cells	116.42	51	2.28	
Groups (T1)	3.96	2	1.98	.87
Within subject effect				
Within cells	25.25	51	.50	
Change	.01	1	.01	.01
Groups X Change	.24	2	.12	.24

Life dissatisfaction

	SS	*DF*	*MS*	*F*
Between subject effect				
Within cells	1246.52	51	24.44	
Groups (T1)	17.30	2	8.65	.35
Within subject effect				
Within cells	344.39	51	6.75	
Change	14.39	1	14.39	2.13
Groups X Change	10.54	2	5.27	.78

Burden

	SS	*DF*	*MS*	*F*
Between subject effect				
Within cells	1440.46	50	28.81	
Groups (T1)	50.90	2	25.45	.88
Within subject effect				
Within cells	409.69	50	8.19	
Change	68.40	1	68.40	8.35**
Groups X Change	1.74	2	.87	.11

** $p < .01$

Minor psychiatric symptoms

	SS	*DF*	*MS*	*F*
Between subject effect				
Within cells	4586.40	51	89.93	
Groups (T1)	42.66	2	21.33	.24
Within subject effect				
Within cells	1013.61	51	19.87	
Change	160.93	1	160.93	8.10**
Groups X Change	58.63	2	29.31	1.47

** $p < .01$

Hoped-for selves

	SS	*DF*	*MS*	*F*
Between subject effect				
Within cells	206.92	50	4.14	
Groups (T1)	1.02	2	.51	.12
Within subject effect				
Within cells	83.48	50	1.67	
Change	6.23	1	6.23	3.73
Groups X Change	1.14	2	.57	.34

Feared selves

	SS	*DF*	*MS*	*F*
Between subject effect				
Within cells	97.94	49	2.00	
Groups (T1)	5.02	2	2.51	1.25
Within subject effect				
Within cells	24.39	49	.50	
Change	.80	1	.80	1.61
Groups X Change	3.65	2	1.82	3.67*

* $p < .05$