

# LIVING WITH LOSS: DEMENTIA AND THE FAMILY CAREGIVER

*Dr Wendy Moyle, RN, PhD, is Senior Lecturer, Faculty of Nursing and Health, Griffith University, Nathan Campus, Queensland, Australia*

*Associate Professor Helen Edwards, RN, PhD, is Head of School of Nursing, Queensland University of Technology, Queensland, Australia*

*Professor Michael Clinton, RN, PhD, is Professor, School of Public Health, Curtin University, Western Australia*

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## ABSTRACT

Two focus group interviews with 15 relatives, investigated family caregivers' perceptions of having a relative in a dementia care unit. Data analysis revealed the significant theme of living with loss. The results demonstrate that the burden of care giving creates growing stress and tension that continues even when the family member is placed into a residential care setting. The findings suggest that health professionals must be prepared to assist family members with the anticipatory grieving of losses that accrue with the changing relationship with the relative and health care staff. Furthermore, there is a need to look for a means of helping and supporting family caregivers so that they can develop a sense of satisfaction and accomplishment in their care giving role.

## INTRODUCTION

Loss is often a very real issue as people age. Friends, family members or a spouse may die; there may be a loss of bodily functions to face, a fear of loss of functioning, or a loss of autonomy as one's health declines as a result of a disease process. It is not difficult to comprehend loss and the grief experienced as a result of the death of a loved one. However, it is not only death or a loss of one's own body function that may result in a feeling of loss and grief. There is also evidence that the family caregivers of persons with Alzheimer's disease also experience stress and 'predeath grief' as a reaction to the 'nondeath' losses which arise from the deterioration of the person as a result of the dementing syndrome (Lindgren et al 1999; Hooker et al 1998; Collins et al 1993; Theut et al 1991). Family members have described their predeath grief as 'raw, overwhelming, and wrenching', and related to the loss of the person as they were once known (Collins et al 1993). Furthermore, the stress and burden of caring for a family member with dementia may result in caregivers feeling helpless and hopeless about their current life and about the future (Acton and Wright 2000).

## Dementia

There are approximately 135,000 Australian people over 60 years of age who have moderate to severe dementia (Woods 1997). These numbers are expected to increase because of the ageing of the Australian population, with the prevalence rates for dementia expected to rise by 65% by the year 2016 (Cummings 1995). Many of these people will be cared for in the home setting by family caregivers, at least in the early stages of the disease process.

As the disease progresses a number will be placed in an institution often unwillingly by family members who have been unable to cope with the crippling demands of the

disease progress. Family caregivers have reported that the decision to place a relative with dementia in a nursing home is one of the most difficult and painful decisions that they will ever make (Fink and Picot 1995).

While many caregivers face the decision of whether to place a loved one in a nursing home the insidious progression of the disease generally means that most caregivers must face not whether to place the person in a nursing home but when is the best time for this to occur.

However, there have been a number of changes and challenges created for family caregivers as western society has moved rapidly towards de-institutionalisation of people with disorders such as dementia, resulting in family members being pressured into taking on informal care giving in the community (McMurray 1995). Such changes have resulted in an increase in caregivers' research over the last decade as a means of facilitating community care giving that is sensitive to the needs of the caregiver and to the individual with dementia. Such research (eg Almberg et al 1997; Buck et al 1997; Noonan and Tennstedt 1997; Naleppa 1996; Ponder and Pomeroy 1996; Adams 1994; Gilhooly et al 1994) has emphasised the rational and functional aspects of care giving at home for relatives with dementia. This research has demonstrated the loss and grief experienced by spouses and families in caring for family members with dementia, and the significant burden that can lead to a breakdown of family care arrangements if not managed appropriately. Furthermore, a key variable in preventing institutionalisation appears to revolve around the family member's willingness to assume and continue the caregiver role (Robinson 1990).

The majority of this research has investigated care giving while the dementia sufferer is in the family home. There is a paucity of research, which explores the family care giving experience once the family member is placed in an institution. The research available indicates that even though placement relieves caregivers day-to-day care of relatives, it engenders sources of stress associated with the institutional setting (Aneshensel et al 1995; Zarit and Whitlatch 1992; King et al 1991; Townsend 1990). It is important that such research is carried out in the Australian setting and that health care providers understand this experience so that they may provide appropriate support for family caregivers of people who have been institutionalised.

The impetus for research into having a relative with dementia living in an institution, came not only from the paucity of research but also from a group of family caregivers whose relatives resided in a long-term dementia care unit in Brisbane, Australia. During information sessions explaining research being undertaken of nurses' experiences of caring for people with dementia (Clinton et al 1995) the relatives asked if they could 'tell their story'. They believed their contribution would strengthen the

researchers' exploration of care in dementia units. With this in mind and at a later date, the researchers set out to investigate family caregivers' perceptions of having a relative with dementia living in an institution.

## METHOD

### Study design

A qualitative exploratory framework was adopted for the conduct of this research. This design was chosen to enable exploration of an area that had not previously had extensive exploration. Focus groups were chosen as the data collection method to enable a reasonable size number of participants to be interviewed and to also provide the opportunity for discussion and collaborative information sharing within the group.

### Participants

Following ethics approval from the Queensland University of Technology's Human Research Ethics Committee and the Institution's Bio-Ethics Committee a mailed open invitation to attend a focus group interview was extended to individuals identified on resident care plans as next of kin of residents in the long-term dementia unit. Information and consent forms were included with the invitation to allow potential participants the opportunity to read the aim of the research and to be assured that their participation was voluntary and that participation or non-participation would not change the care given to their relative. Furthermore, the information sheet also included what was required of their participation in the research and cited contact people if they wanted to discuss the research further. Potential participants were also informed data would be collected through focus groups which were described as 'a semi-structured group setting, with the purpose of collecting information on a designated topic' (Carey 1994, p.226).

### Focus group format

Two focus group sessions were arranged during the unit's scheduled 'relative meeting times' to ensure interview times were convenient for relatives. Interviews were held in a comfortable room away from the dementia unit and presence of nursing staff to provide participants with the opportunity to express their experience without fear of reprisal. Nine wives and two daughters attended one focus group, and three daughters and one son-in-law attended the other. Although 15 is a small number of relatives when compared to the number of residents in the unit (n=36), this participation figure was not surprising given that many of the residents in the unit did not receive visitors or any indication of people expressing an interest in them. In contrast all of the research participants were

found to visit their relatives on a regular basis and expressed to staff a desire to be involved in the care provided.

In a group situation the relatives were asked to respond to the following open-ended question: *'Can you tell us what it is like to have a relative here?'*

Probing questions were kept to a minimum to give participants every opportunity to comment as fully as possible on the issues raised. The participants freely discussed a variety of issues related to having a relative in a dementia care unit. Although the interviewers came with a list of possible questions with which to explore the topic, it was found that participants quickly covered the areas once they found that they were being given the opportunity to tell their story.

At each of the focus group interviews one of the researchers facilitated the discussion while another observed and participated in the process to ensure that all participants were given the opportunity to be involved in the discussion. The focus interviews were approximately one and a half-hours in length and were audio taped to facilitate analysis. The interviews were transcribed verbatim and the transcripts were content analysed to identify common emergent themes and category codes. Content analysis identified the major theme of 'Living with loss' and within this theme the following six sub-themes:

1. Relief versus burden of loss.
2. Loss from observation of the cognitive decline.
3. Loss of companionship.
4. Loss creating fears and frustration.
5. Loss of personhood.
6. Losses - the anticipation of death.

These sub-themes are discussed below.

## FINDINGS

### 1. Relief versus burden of loss

The participants recalled positive aspects of placing their relative in the dementia unit. They suggested the placement *'relieved their stress'*, had *'made a difference to their family life'* and *'that it was good to see their relatives in a safe, secure and loving environment'*. They commented that they had found caring for their relative at home had become more difficult and stressful as the disease progressed and that this had been the impetus for finding placement.

These findings are supported by research suggesting that the caregivers' relationship with the dementing

relative may deteriorate because of psychological, physical, social and financial stress (Almberg et al 1997; Brodaty and Hadzi-Pavlovic 1990; George and Gwyther 1986).

Furthermore, poor mental health has also been identified in carers who live with the dementia sufferer (Brodaty and Hadzi-Pavlovic 1990; Fitting et al 1986). Burden amongst caregivers has been shown to be related to variables such as age (Fitting et al 1986); for example, looking after an elderly person when the caregiver is also elderly is burdensome, and gender (Almberg et al 1997; Gilleard et al 1984) where women are frequently the ones left to manage their male spouse or father. Further stresses have been identified as a result of such things as the caregivers' reluctance to go out of the house for fear of the sufferer's dysfunctional behaviour, incontinence or immobility, as well as the dependency of the dementia sufferer on the carers ability to socialise (Brodaty and Hadzi-Pavlovic 1990). Thus, it is not surprising that when the family caregiver is relieved of such constant stress that they would feel less burdened.

However, despite the caregivers' initial positive thoughts and contrary to popular belief, the placement of a dementing relative into a residential care setting did not result in an absolute relief of the family caregiver's burden or stress. This move created the reality of further loss as a result of being away from the family member and raised other concerns that were not evident while the relative was at home. The placement of the relative resulted in the beginning of another potentially difficult and stressful situation. This type of situation was far removed from the relative's thoughts when they had admitted the family member.

Having a relative in the unit caused the participant's great anguish. The wives showed the most visible distress and expressed concern in relation to their coping with a new situation where they were no longer the caregiver the relative relied on for constant support. All of the participants described difficulty with knowing how to redefine their new role from one of being a constant caregiver to one of being *'a family caregiver at home'*, or in other words a caregiver from afar who was no longer totally responsible for the care situation. They had imagined that their new role would be easier once the family member was institutionalised, but they found their new situation was just as difficult, if not more difficult than when they were with their loved one at home. Townsend (1990) supported the participants' concerns as she also found that institutionalisation created new family tensions such as conflict over family members' obligations and unclear expectations about the caregivers' involvement in the residents' care.

## 2. Loss from observation of the cognitive decline

Participants noted that the relative's cognitive limitations continued to be of concern whether the individual was institutionalised or was in-home care. Participants described their situation as *'devastating', 'difficult to watch the decline', 'depressing to remember them as they were', 'it tore you apart', 'you reminisce and are desperate for them to be normal and to do normal things'*. Reflection on the past was a constant reminder of not only the changes to the family member but also changes to the caregivers' role. Without the distraction of providing care for the relative, family caregivers found that they concentrated on and wanted to recall *'their previous life'*, a life without the complications of dementia; whereas previously they had been too busy to give this more than a passing thought. The anguish of watching their loved one deteriorate may help to account for some of the reason why some relatives stop visiting once the family member is institutionalised.

In particular, caregivers expressed their anguish and guilt in relation to making the decision to admit the relative as well as remembering how the family member once was. Their reflection on past life experiences with the family member was far from stress relieving but rather captured the enormity of the situation, which was now seen as a different stage in their life, and one that they had never thought would eventuate. They now felt they had no control over the situation which they believed they had been managing well while the individual was at home.

The caregivers craved support as well as distraction for their guilt and anguish. Although one would imagine that health professionals would be there to help family caregivers work through their concerns participants did not recall health professionals helping them to overcome their grief. It appeared that nursing staff in particular catered for the sufferer's needs but did not extend their practice to include relatives. The family caregivers felt lost and alone as they tried to adjust to their new role where they felt they were no longer the essential person in the family member's life. Concern also arose with how to manage their relationships with staff and with the family member. They felt the need to avoid conflict with staff so that staff would approve of their relative and provide them with the best possible care.

Thus, it appears that family caregivers have to cope not only with their relative's deterioration but also with an adjustment in their relationship with the relative, as well as the establishment of a new relationship with staff members. Conflicts with staff members are common in such situations where time is not given to discussion of the issues (Rosenthal et al 1992; Townsend 1990).

## 3. The loss of companionship

The family caregiver deliberated between their perceived loss of companionship with their loved one and lost opportunity. They thought they were no longer able to demonstrate to the sufferer the extent of their love via their care giving. In spite of the stress of providing on going care at home, relinquishing this role was difficult for the caregiver to suddenly give up. The family caregiver had initially believed that once the relative was institutionalised that they would have more time to concentrate on other things in their life. However, the time taken up with care giving was now filled with other burdens concerning the family member. Family caregivers became constantly concerned with practical issues such as when to visit, difficulties with travelling to and from the institution, financial and legal issues, and dealing with household maintenance, particularly when this had previously been the role of the dementia sufferer.

Whereas communication and care for the dementia sufferer had been difficult for sometime, the family caregiver had felt comfortable doing what they believed was best for their loved one in the confines of their home. They now felt that their lives were always on display and no longer their own as their relationship had been intruded upon by another stranger - nursing staff who were always around to watch and observe their performance. This is supported in previous research where Townsend (1990) reports on caregiver difficulty with having enough time and energy for visiting and Hertzberg and Ekman (1996) report on relatives' concerns about what to do or talk about during visits with the family member.

## 4. Loss creating fears and frustration

Participants pondered between knowledge that on the one hand the care provided in the residential care setting was considered as *'good'* and on the other, their concerns with the care. They acknowledged that *'staff were flexible with residents'*, staff were perceived to *'have the knowledge and techniques on how to handle the residents and their behaviours'*, and *'residents were taken on outings and activities were organised for them'*.

On the other hand participants raised their concerns and frustration with the care provided. They often thought that they wanted to inform nursing staff that they knew better ways to provide care, but they felt that this would create unwanted conflict. They voiced fears about making demands on staff by stating that *'relatives don't like to complain'*, but they *'want[ed] residents to do more and more normal things'*.

They could not accept that relatives were left in chairs or beds, rather than participating in activities they used to enjoy such as gardening, shopping, cooking or walking. They wanted *'staff to talk with them more'* and for them to be offered the opportunity *'to be involved in decisions made*

- especially when the relative was first placed as [they viewed that] carers [are] reluctant to give over the care’.

The family caregiver compensated for the loss of their loved one by shifting the blame for their relative's condition onto the staff and facility. Underneath their apparent contentment they were seething with anger at their lack of control of the situation. The researchers contend that staff need to encourage relatives' involvement in resident's care as this may assist family caregivers to adjust to their new role and provide a means of retaining their value in the care giving of their family member.

5. Loss of personhood

Participants expressed their need to retain control of the situation and to keep their relative as they remembered them. These concerns may help us to understand the most frustrating issue voiced by participants. All participants raised concern with the clothes their relatives wore as they said they were not dressed in clothes of their own, or in clothes brought in by the family. The clothes which they had purchased with great care and attention were worn by other residents or simply seemed to disappear from their relative's wardrobes. The clothes given to relatives to wear were commonly either too big or too small, or not the type of clothing they knew their loved one would like to wear. The participants stated they believed that *‘clothes are a way of keeping your loved one as much as possible as they were’*. Furthermore, they stated that *‘buying their clothes was often the only thing that relatives can do’* and that *‘clothing gives people dignity’*.

When consulted about this issue the nurses had not considered that this might be of concern to relatives. They attempted to place individuals' clothes in wardrobes but were frustrated that sometimes clothes brought in by relatives were not considered suitable for an incontinent resident, or they were either too big or too small.

There was also the problem of clothes being removed by residents and placed in someone else's wardrobe. Nurses stated they found it easier to dress residents in tracksuits that could be pulled down or removed quickly for toileting or changing. They found dresses or tailored trousers that needed belts were difficult to get residents in and out of and they believed that some materials would not tolerate the frequency of washing required. They had forgotten that many of these residents might never have worn a tracksuit, loose clothing, or have gone out of their house without make-up on or their hair done. Thus, rather than considering residents as individuals with individual needs they had objectified residents, treating their condition from the nurses' perspective of *‘saving time’* rather than from an individual need and one that required that they knew something about the person's past life.

While clothing was obviously important to these family caregivers Gilhooly et al (1994) on the other hand found

when examining the predictors of breakdown of family care of the dementing elderly that physical appearance of family members was considered by the caregivers to be of reduced importance. The fact that Gilhooly et al investigated family homecare may help to explain this difference. Whereas, at home the family caregiver had many things to be concerned about, when the family member was placed in an institution concerns appear to change to activities that the family caregiver no longer has direct control over. This area is certainly worthy of further investigation.

6. Losses - The anticipation of death

In spite of the perception that the family member was already in a sense dead, because they no longer resembled the person they once were, the anticipation of planning for the event of death was summed up as *‘planning for the worst’*. The anticipated death of the loved one was longed for, considered as a blessing and as a means of relieving the stress of living with loss. But, the anticipation of death was also perceived to be another fear that the participants had to fight to stay on top of.

The anticipatory grief experienced by participants is supported by research (Laitinen 1993) that suggests the belief that residential care settings are *‘houses of death’* and encourages the view that the move into a residential care setting is one step closer to losing this person altogether. Furthermore, when nursing staff objectify care to the disease process rather than a holistic approach to practice, the worthlessness of the individual further encourages this concern.

Living with loss

The losses incurred by participants continued despite the relative being placed into a residential care setting. The family caregivers described their reactions and thoughts towards the situation as stages similar to a grieving process (Kubler-Ross 1986). These are outlined in Table 1.

| Table 1: Stages of loss and grief experienced by the family caregivers |   |
|--|---|
| Stage 1  | Grief and guilt   |
| Stage 2  | Anger and hurt at loss of control   |
| Stage 3  | Having to adjust to situation   |
| Stage 4  | Resignation of decline and their inability to provide the type of care needed |
| Stage 5  | Acceptance - <i>‘cannot go on grieving forever’</i>                           |

They described the initial phase of institutionalisation as *‘devastation’*, and *‘grief and guilt about having to place their loved one [in an institution]’* and one of concern at *‘watching the decline in their relative’s abilities’*. This was followed by feelings of anger and hurt with the situation as

they felt that they were often not in control of (eg, the clothing issue). The third stage was described as having to adjust - *'some things you learn are important and [others] unnecessary'*.

Some of the things they described as having to learn to adjust to were relatives wearing what they sensed were inappropriate clothing and their not wearing dentures or glasses. Thus, the family member no longer seemed to be the person they once knew. The fourth stage was described as resigning themselves to the ongoing decline as they recognised they could no longer provide the type of care they recognised their relative needed. The final stage described was acceptance of the situation, as they came to realise that they could not go on grieving forever, and they recognised that the relationship with the family member was no longer what it was previously. Thus, they come to the decision that they would have to continue on with their life, a life that did not include their loved one.

### Coping with the situation

The participants coped with the situation by seeking support from staff, family and other relatives who visited the units. Relatives spent time helping each other as they stated that this was important to them as *'we know what they're going through'*. As part of their adjustment they also started to reduce the number of times they visited and the time they took their relative out. Thus, they were preparing themselves for the final conclusion in their life - that of life without the family member.

The emptiness experienced by family caregivers did not appear to abate when the family member was institutionalised. The burden of caring for the family member at home had taken so much of their energy that they felt physically and emotionally drained when their loved one was admitted. Unfortunately, this energy had not been recouped once the family member was institutionalised. Instead the sapping of energy continued with the burden that endured.

### The need for change

The research findings highlight the need for family caregivers to continue to have community support even when their relative is institutionalised. Family caregivers with institutionalised relatives need support in helping them to adjust to their new role and assistance in planning for their future, without the true presence of the loved family member. Community organisations or even institutions could help with this task by facilitating family caregivers to get together to discuss their situation and to provide support to one another.

Support offered by such groups may help the caregiver to become empowered and to regain a sense of mastery and satisfaction. Such groups will also help both in-home caregivers and relatives of institutionalised individuals to

confront and cope with their difficult care giving situation (Spall and Smith 1996). Group members may be encouraged to reminisce about the good times they had together as a way of coming to terms with the tragedy. Education on the disease process may also unleash some of the guilt felt by family caregivers as they come to realise that there is nothing that they can do to stop the disease process.

Nursing staff, who form a therapeutic alliance with relatives, will encourage relatives' trust and respect. Thus, relatives' fears and frustration can be discussed and opportunities provided for relatives to be more involved in the care of their loved one. Nursing encourages a holistic perspective to practice. Yet, relatives in this situation have described stories in which they have not been involved with the care of the family member, and their needs and concerns have not been respected. To encourage a therapeutic situation nurses must involve not only the client but also relatives in order for mutual trust and respect to take place.

Grief therapy may also help the caregiver reframe the challenge of care giving as an opportunity for growth (Langner 1993). As many family carers are elderly and have few family support services they can call upon a variety of support services are required to provide both tangible and emotional support to the caregiver.

Furthermore, helping family caregivers to chose clothing for relatives that can be washed and removed easily and which still provides the wearer with a semblance of their previous clothing colour and style may help to prevent such concerns as raised by these participants. Moreover, nursing staff could assist further by ensuring the relative is dressed in a favourite piece of clothing for family visits.

## CONCLUSION

Ageing of the Australian population creates a challenge for society, as the number of people with dementia is likely to continue to rise. Care giving for family members with dementia has been found to be burdensome but it is frequently considered to be a family responsibility and one which may be done out of love or obligation.

The care giving role may result in poor physical and emotional health of the caregiver as providing care for a family member with dementia may set in motion a cycle of isolation, frustration and sadness as the family member's condition deteriorates.

Contrary to popular belief, placing of a relative into a care setting does not result in a lifting of the burden, but often results in the beginning of another potentially difficult and stressful situation. This area of research is

most important as the number of family caregivers with institutionalised family members is anticipated to grow.

It is essential that health professionals assess the family care giving situation so that appropriate support can be offered not only to the family caring for the member in the community but also to the family with an institutionalised member. Health professionals must also be prepared to assist family members with anticipatory grieving of losses that accrue with the changing relationship from a loving and close relationship to a difficult filial care giving relationship.

Finally, there is a need to respond to the caregiver research and to look for a means of helping and supporting caregivers of people with dementia so that the caregiver can develop a sense of satisfaction and accomplishment in their role, whether it be direct community caring or institutionalised care. This has the potential to improve upon not only the sufferer's but also the caregiver's quality of life. Finally, the authors consider that further research is needed that investigates caregivers' health status following the death of their family member.

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