

One of the major issues in social gerontology is the nature of family support for older people (Chappell 1996). This is not surprising given that the family is the most basic social institution in our society. Much of the earlier research in this area was carried out to investigate the extensiveness of social ties during later life.

Some of the questions asked were: If caregiving links exist between adult children and their elderly parents, what do the children do? Who are the family caregivers? What are the personal, social and economic costs of caregiving? What is the influence of social and demographic trends on the respective roles of family carers and service providers? What are the implications for these changes on social policy and service provisions? (Aroni and Minichiello 1992).

This research has increased our knowledge about changes in kinship structure over time, the status of the elderly within the family, marital relations over the family life cycle, adjustment to

the ageing process within the family context, and the onset of and adjustment to family-related role transitions, such as the empty nest, widowhood, divorce and childlessness.

Implicit in these earlier studies is the idea that values based on filial and moral obligations dictate what families should do for their dependent elderly parents. However, in a review of the caregiving literature, Chappell (1996) notes that during the early 1990s research on caregiving had become politicised for two main reasons.

First, the family as a caregiving unit was being investigated by feminists as a potentially inherently oppressive institution for women because it confines them to domestic and caring roles. According to these critiques, community care services are built upon the assumption that care in the community by women already exists and simply needs to be activated on a much larger scale. The role of such policies is to create the moral imperative to care, imposed upon women to whom nature and chance



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have assigned a frail or handicapped relative.

Second, the political rhetoric which has given recognition to caregivers as players in a restructured health care system resulted in researchers building more theoretically rigorous and empirically relevant models of caregiving (Wenger, Grant and Nolan 1996).

This paper will first review some of the political context surrounding community care and highlight several issues arising from the tightening and streamlining of residential care on providing care in the community and, second, raise awareness on providing care to relatives and friends who have dementia.

Community care: political rhetoric?

In 1985, the Home and Community Care (HACC) program was established to consolidate a variety of existing programs which provided home nursing, home help, meals, and paramedical assistance

principally to elderly people. The main objective of the program remains to provide services to reduce the risk of premature or inappropriate admission to residential care by increasing 'the capacity of members of the target groups to remain in their own homes in the community' (House of Representatives Standing Committee on Community Affairs 1994:3).

This involved the integration of four Acts which had previously covered the area of home and community care into the Home and Community Care Act 1985. It is unlikely that any government would engage in such a major reformulation of policy as that embodied by the HACC legislation without good reason (for a detailed discussion of this issue see Courtney, Minichiello and Waite 1997; Minichiello 1995; Minichiello, Russell and Swerissen 1992).

Apart from the program's stated intentions, in the early 1980s the Commonwealth Government was concerned about the rapid escalation in the number of nursing home beds that had occurred as a result of financial incentives offered to nursing homes through a system of benefits introduced in 1963. From 1963 to 1985 the number of nursing home beds per 1000 people aged over 65 increased from 29 to 47. In the same period, nursing home benefit costs increased from \$6.6 million to \$940.16 million. Costs-per-bed-day in nursing homes increased substantially above the rate of inflation (Minichiello, Russell and Swerissen 1992).

While a range of social and demographic factors (such as the increasing participation of women in the labour force) influenced these trends, the system of financial incentives for establishing nursing homes was the major cause. Ten times as much money was spent on institutional services as on community services (Healy 1990). In a review of aged care policies in Australia, Courtney and her

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Given the changes in our population structure, the need to re-examine social and political thought on the issue of caring for older people in the community is becoming increasingly urgent. The evidence suggests that caregivers will face complex challenges in the years to come and that current policies do not go far enough in supporting older people and their families.

community

I N G S O C I E T Y

colleagues (1997) suggest that, in part, the government's reforms have been successful in as much as they have reduced the admission of older people into nursing homes. For example, it has been estimated that the aged care assessment teams are responsible for maintaining in the community up to 40 per cent of clients who would previously have been assessed as requiring residential accommodation (Otis 1992). Such saving can properly be described a landmark achievement since expenditure per head is substantially greater in residential accommodation than for community service users.

However, such achievements have been criticised for not necessarily promoting the most appropriate or best case options for older people or their carers. The criticism has centred around the debate over what is and what should be included in community care, and who pays for it (Minichiello 1995).

Prior to the introduction of HACC, local governments assisted older people to remain at home through the provision of 'domiciliary services', such as providing 'home' help, 'home' maintenance, and delivering meals to the home. While the term 'domiciliary' has been replaced, community care still means being cared for at home.

For example, in a study evaluating the Victorian Linkages and Community Options Projects – established to provide 'innovative' community care for individuals who have complex and intense needs and high risks of 'inappropriate' entry to residential care – Kendig and his associates (1992) found that the viability of community care is dependent upon unpaid care provided by family and friends. Slightly less than half of the Linkages clients lived with a primary carer, while 35 per cent received support from a non-resident carer. The study also found that despite the services provided through the Linkages program, carers found it stressful to maintain the older person at home. Half of the carers in this study reported that they 'very often' or 'frequently' felt that they were unable to cope. The benefits of the program to the government were more obvious. As of 1990, for clients apparently eligible for both forms of care, Linkages was much less expensive to government than a nursing home. Twenty-eight per cent of clients had dependencies equivalent to a Residential Classification Index score of 1 to 4. Their costs of \$293 per week in Linkages compared to an estimated \$550 for their care in a nursing home (Kendig et al. 1992: 15–16).

The current reality of *where* most of the care occurs and *who* provides it is in sharp contrast to the intention behind the term 'community care'. The two words together suggest a positive service concerned with meeting the shared needs of individuals living together within a geographical area. Some feminist writers argue that 'community' should read 'family' and, in turn, 'family' should read 'women'. Not surprisingly, many women have become suspicious of the attempts of politicians to increase 'community' care provision, perhaps correctly interpreting such initiatives as part of a political agenda of getting women out of the labour market and back into the home to provide unpaid health and welfare services for members of their own fam-

ilies. The issue of gender injustice has only recently begun to be incorporated in community care policies.

Hidden issues associated with caregiving

In reviewing the Australian research literature on ageing between 1990 and 1997, Minichiello and his colleagues (1999) note that the research agenda in the latter part of the 1990s began increasingly to focus on exploring some of the hidden issues associated with providing care in the community to older persons by family and friends.

For example, the topic of elder abuse has surfaced as a public issue, and the Australian medical profession raised the profile of this emerging and growing social issue through the publication of case studies of elder abuse in the *Medical Journal of Australia* (Kurle et al. 1991). Elder abuse may be related to inadequate support for carers. Consider the following argument: if the community is being asked to bear a greater responsibility to provide informal care to older persons, and if community care is being used to offset the escalating cost of residential care (as it has been above), then perhaps the phenomenon of what the literature now refers to as 'caregiving stress', and the lack of adequate resources to support community care, may be playing a contributing role in the occurrence of abuse. One of the few prevalence studies which have attempted to establish the rate of occurrence and patterns of elder abuse in Australia has estimated that 46 per 1000 of the geriatric and rehabilitation service community patient population aged 65 and over were victims of elder abuse, with carer stress identified as one of the causes for the abuse (Kurle et al. 1992).

Recent Australian studies which have studied aggression in caring relations are revealing some interesting challenges.

First, few people associate the issue of violence with the provision of care. Yet studies reveal that violence does occur. For example, Cahill and Shapiro (1993) found that over three-quarters of carers looking after a relative suffering from dementia in the community reported verbal aggression, and over half claimed to be victims of physical aggression, including threatening gestures, hitting, kicking, shoving, being struck by flying objects and sexual aggression.

Second, the same researchers argue that current legislation and services dealing with domestic violence are totally inappropriate in terms of meeting the needs of this client group, making it more difficult to address the issue at a public level.

Third, caregiving is not always a positive experience. Braithwaite (1996) identified a dimension of caregiving which she labelled as 'dysfunctional caregiving'. This is a situation where the caregivers do not see themselves 'as being in control of the situation, and they had low life satisfaction and poor mental health. Furthermore, the caregiver-care relationship was a destructive one, and institutionalisation occurred within two years' (Braithwaite 1996: 50). This finding has a significant policy relevance because, as Braithwaite argues, nursing home admissions are usually dependent

on high levels of objective disability rather than high levels of social need. Yet her findings reveal that 'dysfunctional caregiving has its origins in social relationships rather than disability type, and [that] problems of elder abuse and caregiver breakdown may be slipping through the welfare net' (Braithwaite 1996: 51).

The above discussion has not been put forward to portray the carers as 'villains' or to suggest that caregiving does not provide rewards and gratifications. But as the literature shows, in some instrumental care situations carers are also the 'victims'. Indeed, a host of studies have identified them as the invisible 'patients' (Chappell 1996). Feminist researchers have reported that not enough attention has been paid to the needs and services of carers, particularly older women. For example, a study which examined the impact of caring upon the health of older women reports

stresses of providing support in the community, few studies are evaluating the effectiveness of intervention programs to support caregivers, or demonstrate their impact on improving the care and quality of life of older people who are being maintained in the community rather than residential care. This is perhaps one of the most challenging issues facing a society that is attempting to recognise the rights of an ageing society in this International Year of Older Persons.

A positive sign is that increasingly innovative programs to support the work of caregivers are emerging. Murphy et al. (1995) reported the provision of a Carer Support Kit which includes fact sheets relating to home safety, respite care, self-care, financial help, disability specific information, a directory of services, an emergency care plan, a 'medi-list' for recording medications, a relaxation tape and a tape of discussion. Their study found



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that the short-term and long-term negative effects upon the physical health and emotional wellbeing of the older woman carer is great, with self-reported stress being a major predictor of several health problems, such as headaches, tension and nervousness, and symptoms associated with the musculoskeletal system (Rosenman et al. 1994). Yet assessment for access to residential care rarely takes into account the health and functional capacity of the carer. Other researchers have found that health professionals dealing with dementia sufferers and their families do not have a sound knowledge of the stress experiences of the carers, and that there is an urgent need to raise the awareness of health professionals about the impact of dementia on informal carers (Waltrowicz et al. 1996). More will be said about this later.

Yet the significance of providing support and resources to caregivers has emerged as an important factor in predicting more functional and beneficial caregiving relationships. For example, a study that attempted to predict admission to nursing homes and death in patients with dementia found that the training of caregivers was significantly associated with delayed nursing home admission and reduced mortality. The study also reported a reduction in caregiver distress with immediate caregiver training (Brodaty et al. 1993). This suggests that current policies which focus on community care need to allocate sufficient resources to support more extensive caregiver training programs. The political rhetoric of providing more cost-effective care for an ageing population must be weighted against the welfare of both the health and wellbeing of older Australians and their caregivers.

While to date much has been published on caregivers, with most of the literature documenting the

that carers who did not use the kit reported significantly more negative emotions and health problems than those who used it. An important issue raised by this study was that such kits needed to be disseminated to carers prior to their reaching a crisis point if the intervention is to be successful as an education prevention. This highlights the fact that community care may not necessarily be effective if appropriate resources are not made available to support effective care in the community.

Caregiving and dementia

A major challenge for caregivers is caring for a relative or friend who suffers from dementia. Dementia is a syndrome due to a disease in the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement (WHO 1990). According to the Australian Bureau of Statistics, the number of persons with dementia has risen dramatically in the last decade and will continue to rise into the next century (DHHCS 1992).

Estimates of the number of moderate to severe dementia cases in 1991 in the 65 years and over age groups ranged from 117,200 to 136,800. It has been projected that in Australia the total population is expected to grow 39 per cent to 65 per cent between the years 1987 and 2031. Of this there will be a 178–190 per cent increase in the aged over 65 years, and a 233–245 per cent increase in dementia cases diagnosed (DHHCS 1992).

However, the emotional costs to families are far greater than the millions of dollars spent each year by government. What is even more revealing is

that family caregiving in Australia is estimated to cost families approximately \$6 billion annually (Brown 1998). The increase in dementia cases and the devastating effects of the disease provides the mandate to continue to develop programs and services that support families who suffer from the effects of the disease.

Impact of dementia on family caregiving

Persons with dementia have a profound impact on family relationships and caregiving. The person with dementia is eventually no longer able to integrate, communicate and process information appropriately and this results in various psychological reactions from the caregiver. Feelings such as guilt, anger and hopelessness occur from a lack of patience in caregiving and an overwhelming sense of loss (Duijnste 1993). Potential negative effects experienced by family caregivers is often termed 'caregiver burden' (Duijnste 1993).

It is not uncommon for the family caregiver to become responsible for all decisions and all activities of daily living, profoundly changing the interactions and lives of all concerned. In essence, the family caregiver bears the burden of understanding and managing their loved one's affairs, activities of daily living and property (Duijnste 1993; Hamdy et al. 1998).

Behaviours such as wandering, difficulty in sleeping, crying, combativeness and repetitive questions places an extraordinary amount of stress on the caregiver. Isolated and depressed caregivers who receive little or no support from other family members can experience feelings of frustration, anger and despondency.

One of the greatest concerns expressed by family caregivers is placement of their loved one in an aged care facility, and research confirms that families sometimes refuse aged care placement. For example, Aged Care Assessment Teams undertook a study in 1995 that included 71 of the 122 teams in Australia. The teams collected data which attempted to identify the reasons why people with dementia and difficult behaviours were remaining at home and not being placed in an aged care facility (nursing homes and hostels). At least 15 per cent of clients or their families were opposed to placing their loved one in an aged care facility. The data also showed that at least 11 per cent of clients with dementia were inappropriately placed because of insufficient home-based support (DHFS 1997).

What is perhaps more surprising is that caregivers of institutionalised family members have reported a more stable family network and more participation in recreation and social activities than do in-home caregivers (Hamdy et al. 1998). However, if and when the time comes that family caregivers can no longer provide adequate and safe care, and caregiving exceeds the personal resources of the family caregiver, it is not uncommon for families to experience a great sense of guilt and failure that they have abandoned their loved one following placement.

A consistent theme emerging in the clinical literature is an acknowledgment that a critical aspect to family caregiving is caring for oneself

(Hamdy et al. 1998). Caregiving often breaks down when the caregiver is not healthy, either physically or emotionally. Factors impacting on the caregiver's ability to provide care include loneliness and isolation, lack of transportation, lack of personal time out, poor finances, a poor physical environment to manage wandering and confusion, and a lack of education about caregiving and the disease process.

It is important that health care providers work closely with family caregivers to overcome the barriers to providing adequate and safe caregiving. For example, wandering is a common characteristic in dementia and there are now various innovative approaches for its management (Coulson 1993). Various state police agencies in Australia now have policies and procedures for handling an event involving a missing elderly person. For example, in Victoria the SAFE program was set up jointly with the Alzheimer's Association and the Knox Community Policing Squad. The purpose of the program is to assist in locating, identifying and returning persons with dementia to their loved ones (Rosewarne and Bruce 1998). When the program was initiated 20 people registered; today more than 100 people are registered with the program.

Another area that some health professionals rarely discuss with caregivers is the impact sexuality has on relationships when one of the partners has dementia. Aronson (1988) states that basic human needs for affection and intimacy persist well into the disease process. Weiner and Svetlik (1996:246) note that 'in most couples in which the onset of dementia is after the age of 70 years, sexual involvement has already diminished and does not present a problem'. But they suggest that if necessary a medical practitioner should be contacted and an assessment conducted on how sexual issues are impacting on the couple's relationship.

Counselling services are beginning to address some of the complex and multifaceted needs of caregivers, particularly the need for family caregivers to ease the guilt that is often accompanied when caring for a loved one with dementia (Coulson 1993). Persons with dementia may also live alone and may wish to remain in their home. The conflict between maintaining life and quality of life becomes an ethical issue that requires discussion with the person, professionals and other family members. Counselling may also be required prior to and after institutional placement.

These issues will become common discourses in the coming years and both older persons, their carers and the larger community must face up to the challenges they pose for building a caring and humane society.

Conclusion

One of the most important aspects to family caregiving is the promotion of quality of life for caregivers and their loved ones. For those with dementia quality of life can only be promoted if governments provide high quality, well trained staff, and easily located and arranged services within a system of well funded dementia specific resources. The enormous support families provide their loved ones to remain

at home is a resource that governments should not ignore, and in acknowledging their contribution governments must develop equitable policies which fully support their work in the community.

The challenges are not only for families to face but also for society. While governments have made great progress towards supporting older people in the community, the reality is that current policies are not enough. Minichiello (1995) has argued that policies have been created to satisfy what is politically achievable rather than what is community

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valued. Herein lies the contradictions behind much of Australia's and other countries' efforts in balancing residential care arrangements with state-funded community care programs to support an increasingly older population with complex social and health needs.

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