

Family caregivers of people with dementia

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Family caregivers of people with dementia, often called the invisible second patients, are critical to the quality of life of the care recipients. The effects of being a family caregiver, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill-health, and financial hardship. Caregivers vulnerable to adverse effects can be identified, as can factors which ameliorate or exacerbate burden and strain. Psychosocial interventions have been demonstrated to reduce caregiver burden and depression and delay nursing home admission. Comprehensive management of the patient with dementia includes building a partnership between health professionals and family caregivers, referral to Alzheimer's Associations, and psychosocial interventions where indicated.

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Who are informal caregivers?

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here are an estimated 30 million people with dementia worldwide currently,¹ and this figure is likely to double every 20 years.² People with dementia generally require high levels of care, most of which is provided by informal or family caregivers. Without caregivers, people with dementia would have a poorer quality of life and would need institutional care more quickly, and national economies would be swept away by the advancing demographic tidal wave. However, this support comes at a cost of caregiver distress and poorer quality of life.

The majority of people with dementia live in the community (USA estimates vary between 70% to 81%)³⁻⁶ and for approximately 75% of these individuals, care is provided by family and friends.⁵ In 2007 approximately 10 million Americans were caring for a person with Alzheimer's disease or another dementia.⁷ The largest proportion of those caregivers was spouses, followed by children and children-in-law, mostly female. The typical profile of a dementia caregiver is a middle-aged or older female child or spouse of the person with dementia.^{3,8-10} In the US, at least 60% of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives,^{3,11} although male caregivers are becoming more frequent. In 2008 men made up 40% of family caregivers in the US, an increase

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of 21% from a 1996 study by the Alzheimer's Association.¹² In the UK, men aged over 75 are more likely than women to be caring for their spouse.⁴

More than 60% of people with dementia live in developing countries.¹ The 10/66 Dementia Research Group assessed the care arrangements of people with dementia in South-East Asia, China, India, Latin America and the Caribbean, and Nigeria. While the typical profile of the principal caregiver was similar to those in the USA, the proportions of female caregivers tended to be higher (mean of 78%, range from 59% in China and SE Asia to 95% in Nigeria), spousal caregivers were as common as child caregivers (mean of 40% in both cases across the groups), and daughters-in-law comprised a mean of 11% of caregivers overall (influenced by India where 24% of caregivers were daughters-in-law). One of the main differences between caregiving in the developed and developing world is the living arrangements, whereby persons with dementia in the developing world live in much larger households with extended families.¹⁰

Why do family caregivers care?

Family caregivers may be motivated to provide care for several reasons: a sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, social pressures, or in rare instances, greed.¹³ Caregivers who are motivated by a sense of duty, guilt, or social and cultural norms are more likely to resent their role and suffer greater psychological distress than caregivers with more positive motivations.¹⁴ Caregivers who identify more beneficial components of their role experience less burden, better health and relationships, and greater social support.¹⁵ The negative aspects of caregiving for people with dementia tend to receive most attention, but caring has also been associated with positive feelings and outcomes.^{15,16} Sanders¹⁷ reported that between 55% and 90% of caregivers experienced positive experiences such as enjoying togetherness, sharing activities, feeling a reciprocal bond, spiritual and personal growth, increased faith, and feelings of accomplishments and mastery. Gender, age, education, and ethnicity can also influence the way caregivers view their role. Feeling more positively towards caregiving has been associated with lower educational level, greater social resources, satisfaction with social participation and better physical health status, being non-Caucasian, and being older.¹⁸⁻²⁰ Race appears to mediate effects of caregiving. Compared with white Americans, African-Americans have

been found to identify more strongly with traditional values, to score more highly on a scale of "cultural justifications" for caregiving, including perceptions of "duty," setting an example to children, religious or spiritual beliefs, family teachings and expectations, and to provide care in collectivist rather than individualistic caregiving systems.^{14,21} Also, barriers to providing formal institutional care may be more prevalent in the African-American community.²²

How do family caregivers care?

Archbold's²³ concept of care providers and care managers is useful. Care providers provide hands-on care, dressing, assisting with finances and other daily activities, and care managers arrange for others to provide care, for example a nurse for personal care, an accountant to assist with finances. Spouses tend to be care providers, and adult children and other relatives, care managers. Care providers tend to be more stressed than care managers.²³ Dementia is associated with long care hours and physically demanding caregiving. Many studies have found that caregivers of those with dementia (particularly care providers) have higher levels of burden than other caregivers.^{7,24,25} A 2003 survey of 227 US dementia caregivers found that nearly one quarter provided 40 hours of care or more per week (compared with 16% for nondementia caregivers). This included personal care such as bathing, feeding, and assisting with toileting for 65% of caregivers. Over two thirds of caregivers sustained this commitment for more than 1 year and one third for 5 or more years.⁷ Caregivers in developing countries spend a median of 3 to 6 hours a day with the person with dementia, and 3 to 9 hours assisting with activities of daily living. Eleven to 25% of caregivers spend more than 11 hours per week providing informal additional support.¹⁰ As people are more likely to live in large households, care is distributed among a greater number of individuals, and there is some evidence that the main caregiver experiences less strain.¹⁰ However, the effect is small and only applies only for cohabitating primary caregivers.¹⁰ Additionally, while there may be a number of care managers involved, most of the hands-on day-to-day caring is still likely to be left to an individual.⁵

Effects of dementia on caregivers

Caregivers face many obstacles as they balance caregiving with other demands, including child rearing, career, and relationships. They are at increased risk for burden,

stress, depression, and a variety of other health complications.²⁶ The effects on caregivers are diverse and complex, and there are many other factors that may exacerbate or ameliorate how caregivers react and feel as a result of their role. Numerous studies report that caring for a person with dementia is more stressful than caring for a person with a physical disability.^{25,27,28}

Two models of factors leading to caregiver stress are useful. In the Poulshock and Deimling²⁹ model, dementia leads to a burden of care which can manifest as strain in a number of ways that can be exacerbated (eg, by behavioral disturbance, physical or psychological ill-health in caregiver) or ameliorated (eg, by support, mature coping mechanisms) (*Figure 1*). Pearlin and colleagues³⁰ model of caregiver stress outlines four main areas that contribute to caregiver stress: the background context (such as level of support and impact of other life events), the primary stressors of the illness (such as the level of help required by the patient and behavioral and psychological problems in dementia [BPSD]), secondary role strains (such as family conflict and social life), and intrapsychic strains such as personality, competence, and role captivity of the caregiver (*Figure 2*).^{30,31} In Campbell and colleagues³¹ review of the model, the strongest predictors of caregiver burden were sense of “role captivity” (carer feelings of being “trapped” in their role), caregiver overload (eg, fatigue and burnout), adverse life events outside of the caregiving role and relationship quality.

Objective burden

Objective burden reflects the dependency of the person with dementia and the level of behavioral disturbance.

Subjective burden or strain

Subjective strain is the appraisal of burden by the caregiver, including their evaluation of the physical and emotional impact, their psychological state, and resources.^{17,32} Subjective strain is only loosely correlated with objective burden.³¹ Caregivers generally report experiencing some form of strain, including all the 85 caregivers in the Sanders (2005) study.^{17,33}

Psychological morbidity

Strain can manifest as psychological morbidity, including depression and anxiety. A robust relationship between

dementia caregiving and negative effects on psychological health has been demonstrated in numerous studies.^{31,34,35} Rates of depression vary between 23% and 85% in developed countries,^{33,36} and of anxiety between 16% and 45%.^{34,37-39} In the developing countries psychiatric morbidity range from 40% to 75%.¹⁰

Levels of psychological distress and stress are significantly higher, and levels of self-efficacy, subjective well-being, and physical health significantly lower, in dementia caregivers than in other caregivers; these differences are even larger when compared with noncaregivers.⁴⁰ Many factors may moderate the presence of symptoms: being female, being a spousal caregiver, additional stressful life events, physical health, family history of mental health issues, quality of relationship between caregiver and care receiver, life satisfaction, low levels of self esteem and mastery, high neuroticism, and levels of behavioral and psychological symptoms of BPSD.^{31,39,41} (*Table 1*).

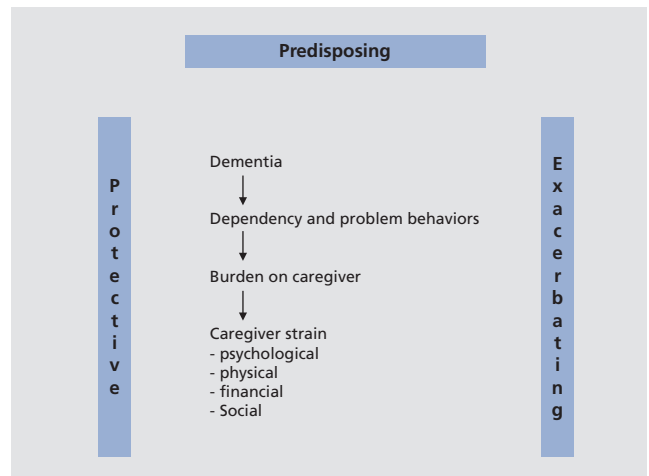


Figure 1. Poulshock and Deimling model of caregiver strain (modified).²⁹

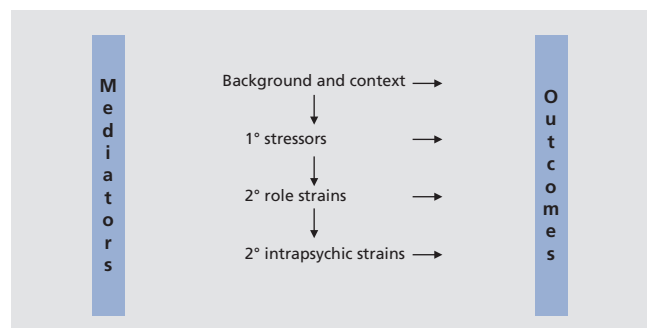


Figure 2. Pearlin et al model of caregiver strain.³⁰

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Physical morbidity

Dementia caregivers are at an increased risk of various health problems including cardiovascular problems, lower immunity, poorer immune response to vaccine, slower wound healing, higher levels of chronic conditions (such as diabetes, arthritis, ulcers, and anemia), more doctor visits and use of prescription medications, poorer self-rated health, decreased engagement in preventative health behaviors such as exercise, and greater likelihood of smoking, drinking alcohol, and poor sleep patterns.^{5,7,42,72-78} Caregivers report a greater number of physical health problems and worse overall health compared with noncaregiver controls.^{28,42} Those with psychological morbidity and greater strain are even more likely to have poor physical health and a higher risk of mortality.^{41,79}

Social isolation

Caregivers often lack social contact and support and experience feelings of social isolation.^{41,80} Caregivers tend to sacrifice their leisure pursuits and hobbies, to restrict time with friends and family, and to give up or reduce employment.^{41,81} Caregivers who are more satisfied with their social interactions show fewer negative psychological symptoms.⁵³ Interventions may assist. One psychosocial intervention significantly increased the number of support persons for caregivers, their satisfaction with their support network, and the assistance they received with caregiving, compared with controls.⁸²

Financial

Costs of dementia are high. The worldwide direct costs of dementia, estimated in 2003 to be 156 billion USD, representing over 5000 USD per demented person, are but a fraction of the total costs.⁸⁴ Direct costs include medical consultations, investigations, pharmaceuticals, provision of personal and nursing care, and often residential care in the later stages. In 2005 the care provided by caregivers of people with Alzheimer's disease and other dementias cost the US at least 83 billion USD.⁷ Comparative figures for Australia were approximately 3.2 billion AUD (approximately 2.6 billion USD) in 2002.⁸⁵

Cost estimates may omit or underestimate the substantial hidden unpaid costs borne by caregivers, which are substantial. Indirect costs include loss of earnings by patients and family caregivers as they relinquish or

reduce employment, hours of informal care and mortality burden.^{85,86} The US Alzheimer's Association⁷ estimated that direct and indirect costs total 148 billion USD annually based on 2005 estimates. In Australia total costs reached 7 billion AUD, or over 40 000 AUD in total costs for each individual with dementia.⁸⁵ An important issue is balancing caregiving and work responsibilities. Almost 60% of US family caregivers of people with dementia are also employed, of whom two thirds reported that they missed work, 8% that they turned down promotion opportunities, and up to 31% that they had given up work to attend to caregiving responsibilities.^{3,7}

The economic disadvantage associated with caregiving in the developing world is significant.¹⁰ Wimo and colleagues estimated that direct costs of dementia in emerging markets and developing countries totaled 13 billion USD in 2003.¹⁰ Total costs, including those borne by families are likely to be much higher. On average, 32% of caregivers in the countries surveyed cut back on paid work to care for a family member with dementia (including 84% in Nigeria). Compensatory financial support was lacking, very few people received government pensions, and 45% to 80% received no informal support. While health care services are cheaper, in relative terms these families spend a greater proportion of their income on health care for the person with dementia. Moreover, caregivers from poorer countries tend to use the more expensive services of private doctors due to unsatisfactory public services.¹⁰

Predictors of and protectors from caregiver distress

Evidence regarding which variables are associated with greater and lower levels of strain and psychological morbidity experienced by caregivers (*Table I*) sometimes conflicts. For example, greater caregiver strain has been linked to both shorter and longer duration of dementia, as explained by three theories. The adaptation hypothesis posits that over time caregivers adapt to the demands of their role.^{54,55} Alternatively, the "wear and tear" hypothesis proposes that the longer a caregiver remains in his or her role, the more likely negative outcomes are to occur.^{56,57} A third theory, the sequestration hypothesis, proposes that caregivers experiencing greater stress are more likely to admit their demented relative to a nursing home, thus removing these individuals from cross-sectional research correlating caregiver morbidity and dementia duration.⁸⁶

Variables associated with:	Greater strain and psychological morbidity	Lower strain and psychological morbidity	Comments
Demographic	Female gender Spousal caregivers, particularly those of younger patients Cohabiting with the care recipient ^{38,41,42,43} Lower income or financial inadequacy ⁴⁴⁻⁴⁸	Male gender Nonspousal (eg, child or child-in-law) caregivers Living separately to the care recipient Better financial position/resources ^{41,42,47-49}	Gender may have no effect when allowance is made for the increased likelihood of behavioral disturbances in men ⁴¹ Evidence about the relationship between age, gender and psychological morbidity is inconclusive ³⁹
Dementia variables			
Dementia type	FTD ⁵⁰	Types of dementia other than FTD ^{50,51}	Most research indicates that caregivers of people with different types of dementia experience similar levels of stress ^{52,53} It is important to control for patient and caregiver age, duration of dementia, and level of BPSD
Duration	Shorter duration ^{50,54,55}	Shorter duration ^{56,57}	Other studies have found no relationship between duration of caring and caregiver distress ³⁷
Severity	More neuropsychiatric disturbances and behavioral problems ^{40,52,58,59} Impairment in basic activities, particularly incontinence in the developing world ⁶⁰	Fewer neuropsychiatric disturbances and behavioral problems ^{38,39,61} Preservation of basic functions in the developing world ⁶⁰	Most studies in the developed world have found no significant relationship between cognitive decline and caregiver psychological health ^{39,86,52}
Relationship factors	Poorer relationship quality and low levels of past and current intimacy ^{38,41,62,63}	Positive current and previous relationship between caregiver and care receiver ³⁹	Cultural differences may mediate these associations ^{64,65}
Caregiver variables			
Personality	High level of neuroticism ³¹ High expressed emotion ⁶⁵ Less secure (or avoidant) attachment style ⁶⁶	More secure attachment style ⁶⁶ Higher self-esteem ⁶⁷	Depression levels can predict neuroticism levels ⁶⁸
Perception and experience of caregiving role	A low sense of confidence in the caregiver role ³¹ High "role captivity" —caregivers feelings of being trapped in their role ^{30,31}	Increasing caregivers' confidence in their competence as caregivers, reduced burden levels ⁶⁹	
Coping strategies	Emotion-based coping strategies ^{37,70} Confrontative coping strategies ³⁷	Problem-focused coping strategies ^{70,71} Positive reappraisal (reframing) ³⁷	Coping style may be more associated with anxiety than depression, which is related to factors such as burden and poor health ^{34,37} Cooper and colleagues ³⁷ found inconsistencies in the evidence regarding problem-based versus emotion-based coping strategies.

Table I. Predictors of and protectors from caregiver distress. FTD, frontotemporal dementia; BPSD, behavioral and psychological problems in dementia

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Support

Support can come in the form of instrumental support (helping with daily living needs and housework), emotional support, and informational support (information and knowledge from both health professionals and from those who have experienced similar situations). A positive relationship between social support and psychological well-being has generally been found.^{41,87} Support provides a buffer against burden and stress for caregivers by increasing the perception that resources are available to handle stress.⁸⁷ The relationship is complex. There are differences between actual and perceived support, formal and informal support, and instrumental and emotional support.⁸⁸ Unwelcome support may be more stressful than helpful.⁸⁹ Gender, race, individual preference, neuroticism levels, and culture affect how support is used and perceived.^{88,90,91}

Nursing-home admission and caregivers

The variables most associated with an increased risk of institutionalization are demographic (caregiver relationship to care recipient, employment, financial resources, and age), and psychosocial (caregiver burden, caregiver's reaction to care recipient problem behaviors, "desire to institutionalize," quality of the relationship and caregiver health).^{92,93} Being employed and balancing too many demands, or being unemployed and financially unstable are associated with institutionalization, as are feeling burdened by the caregiver role, difficulty dealing with behavioral manifestations of dementia, poorer relationship and poorer physical and psychological health.^{94,95} Findings are inconsistent regarding the effect of age.^{93,96,97}

While nursing home placement helps to reduce the direct care obligations on caregivers, it does not necessarily reduce caregiver distress. Relief and reduced stress may follow institutionalization,^{41,98} but so can guilt, anger, anxiety and depression, and financial problems.^{99,100}

Caregiver interventions

Our review here focuses on family caregiver interventions and does not address formal services such as respite care, day centers, and community services. Psychosocial interventions may improve outcomes for caregivers and reduce the likelihood of institutionalization for care recipients.¹⁰¹ Caregiver interventions have been success-

ful at increasing caregiver knowledge, improving mood, reducing stress and depression levels, and delaying nursing home placement.¹⁰²⁻¹⁰⁴ The evidence for reductions in caregiver burden is mixed, possibly because of methodological differences in categorizing interventions and in defining burden.^{5,32,102,103}

Factors associated with more successful interventions are the extent to which they are tailored to the needs of the individual and address issues to do with subjective burden; whether they involve the caregiver and care recipient as active participants; and whether they are long-term as opposed to short-term.¹⁰²⁻¹⁰⁴ One systematic review concluded that individually tailored behavior management therapy over at least six sessions successfully reduced caregiver distress and burden in both the short and longer term, but support for the effectiveness of group therapy teaching general principles of behavior management was lacking.¹⁰⁴ Mittelman and colleagues¹⁰⁵ demonstrated that individually tailored individual, family, and ad-hoc counseling sessions covering topics specific to individual caregivers successfully reduced caregiver depression scores over 2 years. Pinquart and Sorenson¹⁰³ determined that longer interventions were more successful at reducing depression and the risk of institutionalization than shorter or "one-off" support or information sessions. A meta-analysis by Brodaty et al¹⁰² reported that the strongest predictor of success for an intervention was involving the patient in addition to the caregiver in a structured program, such as teaching the caregiver how to manage problem behaviors. The meta-analysis by Brodaty et al¹⁰² found a small significant overall effect of intervention on caregiver burden in addition to effects on knowledge/abilities, psychological health of caregivers, subjective wellbeing, and care receiver symptoms due to the inclusion of more recent studies which were found to have stronger effects on burden.

The Seattle Protocols provide a systematic, structured yet individualized approach to training family caregivers to reduce behavioral and psychiatric disturbances in people with Alzheimer's disease by teaching caregivers to monitor problems, identify possible events that trigger disturbances, and develop more effective responses.¹⁰⁶ It has been successfully used to improve caregivers' quality of life, reduce subjective burden and reactive responses to dementia care recipients' problem behaviors,¹⁰⁶ and to reduce dementia-related problems including depression,¹⁰⁷ agitation¹⁰⁸ and sleep disturbance.¹⁰⁹ The Resources for Enhancing Alzheimer's Caregiver Health (REACH)

multi-site, multicomponent intervention included information provision, didactic instruction, role-playing, problem-solving, skills training, stress management techniques, and telephone support.¹¹⁰ The randomized, controlled trial involving 642 caregivers in ethnically diverse populations in the US resulted in significantly lower depression, burden, and care recipient problem behaviors, and higher self-care and social support in Caucasian and Hispanic caregivers as compared with controls but not for African-American caregivers, apart from better spousal caregiver quality of life.¹¹⁰

Caregiver interventions can delay nursing-home placement. A 10-day structured caregiver intervention program delayed institutionalization of care recipients over 7 years without sacrificing the psychological health of caregivers or increasing usage of health services and dementia drugs, and with significant cost savings within 3 years.¹¹¹⁻¹¹³ In a 17-year longitudinal study of 406 spousal caregivers, an intervention program involving individual and family counseling, encouragement of support group participation and availability of ad-hoc telephone counseling was found to significantly delay time to nursing home placement by a median of 1.5 years.¹⁰¹ The intervention was also successful at improving caregiver well-being, as demonstrated by fewer symptoms of depression, improved reaction to memory and behavior problems and greater satisfaction with support networks.¹⁰¹ Other studies have demonstrated up to 9 months' delay in institutionalization.^{114,115} Interventions that were flexible, varied, and involved follow-up and an ongoing relationship between helper and caregiver were considered key to delaying nursing home placement.¹⁰² External factors may impinge on the efficacy of interventions. A randomized controlled trial of five sessions of family counseling conducted in Manchester, New York, and Sydney did not increase time to nursing home placement across the whole sample compared with usual care, but did so at the Australian site. Possible reasons are differences in aged care systems and financial disincentives to institutionalization, and differences in the amount of counseling provided (more ad hoc counseling was provided in Sydney).¹¹⁶ Pinguart and Sorenson⁴⁰ identified that multicomponent interventions were more likely delay time to nursing home placement. However, in the REACH trial, despite other positive outcomes, institutionalization of care recipients did not statistically significantly differ between the control and intervention groups.¹¹⁰

Recently, researchers have begun to examine the effectiveness of technology-based interventions for caregivers using computers, telephones, e-mail, and the Internet to provide support and information to informal caregivers. Interventions include conference calling among family members of dementia patients; telephone support systems with automated messages; stress monitoring and advice; respite calls for care recipients; online discussion groups; electronic reminder services; computer based forums and question and answer sessions (Internet and non-Internet based networks); e-mail; electronic encyclopedias and libraries; and computer-based decision support modules.^{26,117} Eisdorfer and colleagues¹¹⁸ found that having access to technology-based interventions resulted in a decrease in depression at 6 and 18 months for both white and Cuban-Americans compared with more traditional forms of support only. In a review of 15 papers describing five technology-based interventions for dementia caregivers, despite inconsistent outcomes and small studies, there were moderate effects on improving caregiver stress and depression.¹¹⁷ The obvious benefit of such interventions is that they can usually be accessed at all times of the day and night, at the caregiver's convenience. Further research in this area would prove useful.

Caregivers in the developing world face a different set of challenges that need to be considered in intervention programs. Dementia is often perceived to be part of normal aging, and families are less likely to present to health services, which in any case are often ill-equipped to meet their needs.^{119,120} Awareness and understanding about dementia are lacking and stigma is rampant. A randomized controlled trial evaluated a home-based intervention in Goa, India consisting of basic education about dementia and common behavior problems, strategies for managing problem behaviors, support to caregivers in activities of daily living, referral to psychiatrists or other medical professionals for assistance with BPSD, networking to assist the caregivers to form support groups, and advice on government provisions for the elderly. The intervention led to significant improvements in caregiver mental health and perceived burden. There were also reductions in the behavioral disturbances and improvements in the functional abilities of the dementia care recipients, but these were nonsignificant.¹¹⁹ The program used local health and human resources, making it affordable and easily accessible. The small sample size (41 caregivers received the intervention and 40 were controls) was a limitation, and possibly explained the lack of significance in the impact on

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the dementia patients' behavior. Additionally, the 6-month follow-up period may have been too short to demonstrate an effect, or to show whether the intervention had a long term impact on caregiver and care receiver well-being.

Special categories of caregivers

There are certain groups of caregivers who may experience additional challenges beyond those directly related to caregiving. Homosexual partners of people with dementia often feel that existing interventions and support services do not meet their needs, or address the issues they face (for instance next of kin rights). Moore¹²¹ reported that gay caregivers experienced prejudice and insensitivity in their interactions with health services, lacked social and emotional support due to efforts to maintain privacy in their relationship, were unable to use employee benefits to assist their partner with dementia, faced opposition from employers when attempting to take compassionate leave, and experienced legal difficulties with estate planning.¹²¹

People from ethnic minorities, including indigenous groups, are less likely to have access to and to use mental health services.¹²²⁻¹²⁴ Contributing factors include a lack of understanding about dementia, language barriers, or other communication barriers, lack of GP knowledge of cultural differences in expression of mental illness and distress, distrust of Western medicine, ethnocentric attitudes and incorrect assumptions (for instance that certain ethnic groups will look after their relatives and do not require services).^{62,122}

People with younger-onset dementia and their caregivers face additional problems, as they are more likely to be working and to have dependent children and more financial responsibilities. Younger caregivers are often unprepared for the task and experience increased burden, will need to look after the care receiver for a longer period of time, have fewer appropriate services available to them and feel more isolated.¹²⁵⁻¹²⁸ Particular needs for this group are early referral to services, appropriate day care for younger people with dementia, more information and

support at diagnosis for caregivers.¹²⁹ One special group within this rubric are people with intellectual disability, who are doubly handicapped if they develop dementia. Down's syndrome confers a high risk of developing Alzheimer's disease by the sixth decade, leading to challenges in diagnosis and management.^{130,131}

When a care recipient is in a second (or later) marriage, particularly when he or she has children from a previous marriage, it is more likely that disputes will arise about financial, legal, and guardianship issues. When people marry close to the time that they begin to dement, further issues can arise regarding their capacity to marry, the motivation of their partner and possible issues to do with less well developed feelings of reciprocity and obligation.^{132,133}

Alzheimer's associations

A crucial part of helping family caregivers is linking them with local support, best done through local Alzheimer's Associations (see appendix for Web sites). Alzheimer's Associations provide information, emotional support, practical advice, support groups, training programs, help sheets, toll-free helplines, and useful Web sites. They are powerful advocates for people with dementia and for their families with governments and service providers, as well as funding research.

Conclusion

Family caregivers are integral to quality of life of people with dementia. The high levels of burden and psychological morbidity are well documented, as are factors that predict which caregivers are vulnerable to these. Interventions can ameliorate these effects and thereby improve the quality of the life of people with dementia. The management of the person with dementia requires a comprehensive plan that includes a partnership between doctors, health care workers, and families. Caregivers susceptible to negative effects can be identified and could be targeted for interventions. □

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Familiares que cuidan a personas con demencia

Los familiares que cuidan a personas con demencia, a menudo denominados los segundos pacientes invisibles, son determinantes para la calidad de vida de quienes reciben dichos cuidados. Las consecuencias para el familiar cuidador, aunque en ocasiones son positivas, en general resultan negativas; hay una alta frecuencia de carga y morbilidad psicológica, como también aislamiento social, enfermedades físicas y restricciones económicas. Se pueden identificar los cuidadores que serán vulnerables a los efectos adversos, como también los factores que reducen o aumentan la carga y la tensión. Se ha demostrado que las intervenciones psicosociales reducen la carga y la depresión, y retrasan el ingreso a residencias especializadas en el cuidado de estos pacientes. El manejo integral de los pacientes con demencia incluye la asociación entre los profesionales de la salud y los familiares cuidadores, la derivación a agrupaciones de pacientes con Enfermedad de Alzheimer y las intervenciones psicosociales cuando éstas estén indicadas.

Les aidants familiaux des patients atteints de démence

Souvent appelé « les seconds patients invisibles », les aidants familiaux, qui s'occupent des patients atteints de démence sont essentiels à leur qualité de vie. Les conséquences de la maladie sur cet entourage sont parfois positives mais généralement négatives avec une charge et une morbidité psychologique élevées, un isolement social, une altération physique et des difficultés financières. Il est possible d'identifier les aidants qui seront vulnérables de même que les facteurs qui améliorent ou aggravent leur charge et leur stress. Il existe des interventions psychosociales susceptibles de diminuer la charge et la dépression des aidants familiaux et de retarder l'admission du patient en institution spécialisée. La prise en charge globale du patient atteint de démence demande une collaboration entre les professionnels de santé et les aidants familiaux, une orientation vers les associations de patients atteints de la maladie d'Alzheimer et des interventions psychosociales lorsqu'elles sont indiquées.

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APPENDIX

Web sites

Alzheimer's Disease International: www.alz.co.uk

Alzheimer's Association USA: www.alz.org

Alzheimer's Europe: www.alzheimer-europe.org

Alzheimer's UK: www.alzheimers.org.uk

Dementia Advocacy and Support Network International (for people with dementia): www.dasninternational.org