Informal Caregiving and Its Psychological Implications:

A brief Review of Research

Rukhsana Kausar

Caregiving has become an issue of universal importance in the past few years. Carers, particularly those who provide help in the community did not receive much attention unttil quite recently. The phenomena of caregiving has received more attention from policy makers and researchers for the reasons, such as political, financial factors, demographic changes and the feminist movement. Demographic changes, such as the increased number of dependent people in the community due to medical advances that help prolong the life span of severely disabled and elderly people (Eisdorfer, 1991; Pervin et al., 1990), and the decreased number of potential carers due to changed employment pattern have made caregiving a topic of general concern for researchers and policy makers. Another influence has come from the feminist movement, which was concerned about the uneven burden placed on women as carers (Brown & Smith, 1989; Smith, 1991; Twigg, 1992; Parker, 1990). Furthermore, the WHO's (1976) emphasis on the need to support elderly people in the community and Government policy which advocate the care for mentally handicapped and disabled people within their families have brought the topic of care to the forefront of research attention (Hirst, 1982; Parker, 1990; Twigg, 1992; Twigg, Atkins & Perring, 1990).

The Office of Population Census Survey (OPCS) made a distinction between 'informal caregiver' and 'main caregiver'. The former refers to the person who provides help in self-care activities, whereas the 'main carer' is the person who spends most of their time helping the disabled person. Stone, Cafferata and Sangel (1987) defined the primary caregiver as a person who has total responsibility for the provision of care. Caregiving in general refers to the activities and experiences involved in providing help and assistance to relatives and friends who are unable to meet his or her own physical, psychological, or social needs (Killeen, 1990; Pearlin, Mullan, Semple & Skaff, 1990). Besides this definition, there are various other definitions of caregiving in the literature. Caregiving has been defined in terms of relationships (Brody & Schoonover, 1986; Scharlach, 1987), living arrangements (Soldo & Myllyluoma, 1983), job description and job satisfaction (Silliman & Sternberg, 1988), and styles of caregiving (Matthews & Rosner, 1988). Thus, the definitions provided are almost as broad as the number of studies carried out, and they range from great specificity to varied flexible categories. The range of meanings attributed to the term 'caregiver' have resulted in diverse ways of identifying caregivers, and it has made the task of generalizing findings and comparing results from different studies very difficult.

As a result of the current trend to develop more community oriented services, caregivers' needs are likely to be of greater priority (Morris, Morris & Britton, 1988). In UK, the National Health Service and Community Care Act (1990, Atkins, 1992) facilitated research to help planners and practitioners make community care more effective. Research emphasis is now on identification of the carer's needs and on designing interventions accordingly. In UK, recognition of the importance of informal care began after 1988 when the General Household Survey (OPCS, 1988) published statistics about carers who helped in non professional settings. In 1985, the GHS asked respondents for the first time if they were providing any help for mentally ill, elderly or handicapped persons. The results produced an alarming figures of six million carers in Great Britain, amongst which 1.7 million carers were caring for someone in the same household. The peak age to be carer was 45-64 years, and 24 percent of women in this age range were carers, compared to 16 percent of men carers. Most households with a dependent person contained one carer looking after the person (72%), and only 18 percent of such households had two carers looking after the same person. Nearly three quarters of the carers (73%) were looking after someone who had a physical rather than a mental disability.

An increasing number of disabled and chronically ill people depend on family members for care (e.g. Schulz et.al, 1987; Kausar, 1994, 2000; Kausar & Jabeen, 1997). Geriatric research shows a consensus that when an elderly person needs care, it is mainly the family who provides care for him or her (Eagles et al., 1987; Jones, & Vetter, 1984). Likewise, many stroke survivors who are left with a disability remain at home for months or years (e.g. Anderson, 1992; Silliman, Earp, Fletcher & Wagner, 1987; Wade, Leigh-Smith, Langton-Hewer, 1986; Kausar, 1994). Similarly, the majority of individuals with traumatic brain injury when discharged from hospital, are cared for by their families (Willer, et al., 1990; Kausar, 1994).

Thus, the literature provides strong evidence supporting caregiving as a family affair. The major impact of caregiving is felt by those members of the immediate family who assume the responsibility for the disabled person (e.g. Pilisuk & Parks, 1988; Stone, 1991; Kausar, 1994, 2000). This could be the spouse (if they are married); or the children; sometimes parents; and occasionally, friends. Stroke studies have found that two thirds of the main carers comprise spouses, and a further third comes from the younger generation, mainly the children (Drummond, 1988). Although the family is considered the main source of support for disabled people, it appears that the concept of 'shared care' between family members is uncommon. When one person formally takes on the responsibility of care, the rest of the family tends to stop helping the dependent relative (Gilhooly, 1984).

Usually the major burden of care falls on the shoulders of the closest female relative (Brown & Smith, 1989; Smith, 1991:

Kausar, 1994, 2000; Kausar & Jabeen, 1997). In most cases, it is the wife, daughter, daughter in law, sister, or mother who assume the role of carer (Gilhooly, 1984; Schultz et al., 1987; Silliman et al., 1987; OPCS, 1988; Kausar & Jabeen, 1997). Kausar and Powell (1996) in a longitudinal study carried out in UK with carers of patients with neurological problems reported that it was mainly either female member of the family or female friends who had assumed responsibility of care (70% and 68% for the first and second follow-ups, respectively).

There is a consensus in findings of researches that relatives play a major role in maintaining dependent people in the community (Twigg, Atkins & Perring, 1990; OPCS, 1988; Kausar, 1994, 2000). Since informal caregivers constitute the backbone of community care and are the principal source of support for dependent relatives (DHSS, 1983), it is important to consider the emotional costs the caregiving job may demand.

Psychological impact of informal caregiving

The strain suffered and the difficulties encountered by relatives who care for their dependent elderly family members have been acknowledged since the 1950s (Klein, Dean & Bogdonoff, 1967; Townsend, 1957). In their early studies of home care of mentally ill patients, Grad and Sainsbury (1963) pointed out strain in relatives. There are various adverse effects of caregiving on caregiver such as financial, social, emotional and physical impact (Johnson & Catalano, 1983; Sheldon, 1982).

By assuming the role of a carer, a high price has to be paid in that being a carer may affect the quality of life, physical and mental well-being of the carer. The symptoms related to the carer's strain which are often reported by carers themselves include guilt (Cohen & Eisdorfer, 1988), somatic complaints, fatigue, anxiety, depression, sleep disturbances (e.g. Mayou, Foster & Williamson, 1978), withdrawal from social activities and disturbed marital relationships (Kinsella & Duffy, 1979; Kausar & Jabeen, 1997).

Research on caregiving has identified a variety of effects on carers of disabled children, elderly people, head injured and stroke patients. Caring for a dependent relative has been regarded as a stressful role and an emotionally distressing experience. The following section briefly reviews the literature on the impacts of caring for disabled children, demented elderly people, head injured people and stroke patients.

Caring for a disabled child

The effects of caring for a disabled child have been examined and described in detail in the past (Baldwin, 1977, 1985; Baldwin & Glendining, 1983; Thompson, 1990; Thompson et.al., 1992). Disability of a child almost invariably causes practical problems for the parents. Baldwin and Glendining (1983) identified different types of costs of caring for a disabled child such as opportunity costs (e.g. restricted social life), financial costs (loss of earning, extra spending) and psychological costs (e.g. increased strain level).

The available literature on handicapped children reports high levels of depression, anxiety, sleep disturbances, nightmares, increased smoking and excessive use of tranquillizers by the parents (e.g. Shapiro, 1983). Hirst (1985) in a comparative study on mothers of disabled and normal children found that mothers of disabled children reported high levels of psychological distress. Similar findings have been reported by other studies carried out on parent carers (Hallum & Krumboltz, 1993; Mullin, 1987; Singhi et.al., 1990). Studies on mothers of physically disabled children have indicated a very high proportion of mothers of disabled children being judged to be depressed when compared to mothers of non-disabled children (e.g. Breslau, Staruch & Mortimer, 1982). Hence, the parents experience significant strain because of psychological and social problems they may face while caring for a disabled or handicapped child.

Caring for a demented elderly relative

A substantial body of data shows that caring for a demented elderly relative is likely to have a negative impact on the carer. Caring for a close relative, especially a demented spouse, has been described as one of the most demanding situations that can be encountered (Rabins, 1984; Teusink & Mahler, 1984). Demented elderly people suffer from a number of physical, cognitive, and emotional deficits. Carers may have to help them with dressing, feeding, bathing and management of incontinence, and the patient may require constant supervision. The strain on relatives of demented elderly people is severe enough to place caregiving relatives at high risk of mental and physical illness (Gilhooly, 1984; Gilleard, et.al, 1984a; Gilleard, et.al., 1984b). Several clinical and empirical studies bear witness to a wide range of somatic, emotional and social problems among carers (Baumgarten, et.al., 1992; Brodaty & Hadzi-Pavlovic, 1990; George & Gwyther, 1986; Pagel, Becker & Coppel, 1985; Poulshock & Deimling, 1984; Zarit, Reever & Bach-Peterson, 1980).

The most common complaints reported by the relatives, include anger, depression, anxiety, guilt, worry, hypochondriasis, marital stress and emotional strain (Brodaty & Hadzi-Pavlovic, 1990; Fitting, et.al, 1986; Horowitz, 1985; Johnson & Catalano, 1983; Morris, Morris & Britton, 1988). Mace and Rabins (1984) reported that 87% of the primary caregivers had suffered from chronic fatigue, anger and depression. In another study, Eisdorfer and colleagues (1983) reported that 55% of those relatives who served as a primary caregivers to Alzheimer patients met DSMIII criteria for clinical depression. Thus, caring for frail or demented elderly person exerts adverse effects on physical as well as psychological well-being of a carer.

Caring for a head injured person

Traumatic head injury may leave a person with a variety of sensorimotor, cognitive and psychosocial deficits, and the broader effects of these deficits must be realised by the person who provides care for an injured person (Brooks, 1991; Kausar, 1996; Kausar & Powell, 1996). As early as 1967, London drew attention to the distressing effects of severe damage on personality of an injured person and the heavy burden imposed on the family. Stress among relatives of patients following traumatic head injury is often appreciable, and usually family members are far more distressed than the patient (Jennett, 1975).

There are several studies, which indicate that relatives of head injured people experience psychiatric and social impacts of caregiving (Livingston, Brooks & Bond, 1985; Novack, et.al., 1991, Kausar & Powell, 1996). Rosenbaum and Najenson (1976) in their study of injured soldiers concluded that the wives of injured patients faced more social and sexual problems, and experienced greater disruption of lifestyle and depression than spouses of persons with paraplegia. Oddy and Humphrey (1980) in a longitudinal study of closed head injured patients found that many relatives reported stress as a result of having to deal with the injured patient, and their feelings of stress did not diminish over time. Other longitudinal studies with varying periods of follow ups, have identified high levels of psychosocial disability in the relatives even 15 years after the injury (Livingston, Brooks & Bond, 1985; Rappaport, et.al., 1989; Thomsen, 1974). Novack, Bergquist, Bennett and Gouvier (1991) found that anxiety was a major problem for primary caregivers, with almost one half of their sample having at least some anxiety and a third of it exhibiting a clinically significant level of anxiety. Kruetzer, Gervasio, and Complair (1994a, 1994b) demonstrated that one half of the caregivers of head injured patients met the criteria for psychiatric 'caseness'; that is, these individuals experienced elevation on two or more subsets of a brief symptoms inventory. One third showed elevation in the anxiety scale and one fourth demonstrated elevation on the depression subscale. Some of the carers also indicated elevation in scores on paranoid ideation and psychoticism. In summary, the existing studies suggest that caregivers of head injured people experience an enormous amount of strain even several years after the onset of head injury.

Caring for a Stroke Patient

Relatively few studies have investigated caregiving within the context of stroke. Stroke has an acute and definite onset, and is characterized by a broad range of physical, social, emotional, Personality and cognitive disabilities (Jongbloed, 1986; Silliman, Earp & Wagner, 1987; Kausar & Powell, 1996). Survivors may have different combinations of motor, cognitive and psychological problems depending upon the extent and the anatomical location of the stroke (Caughlan & Humphrey, 1982). Accordingly, they may need assistance in performing everyday activities.

Over the past few years, it has been realised that the relatives of stroke patients experience an immense amount of strain. As one might expect, the major impact is felt by the members of the immediate family who have to care for the stroke patient, particularly by patients' spouses (Drummond, 1988; Mulley, 1985; Brocklehurst et al., 1981).

In order to look after their partners, spouses of stroke patients encounter a variety of problems, such as having to give up their jobs and interests and often they get isolated from friends and other relatives and have social problems and (Carnwath & Johnson, 1987). On top of this, their relations with their affected partner often change radically, in particular if the patient is aphasic (Holland & Whalley, 1981; Kinsella & Duffy, 1979). Spouses are very frequently reported to experience depression (Kinsella & Duffy, 1979; Tompkins, Schulz & Rau, 1988; Kausar, 1994), decreased life satisfaction (Caughlan & Humphrey, 1982) and anxiety (McNamara, Gummow, Goka & Gregg 1990; Wahrborg, 1988; Kausar, 1994). There seems to be a significant increase in psychiatric illness generally and in the amount of antidepressant medication and tranquillizers issued to carers (Holland & Whalley, 1981).

Brocklehurst and colleagues (1981) noticed a considerable increase in the number of primary carers who regarded their health as poor. Physical problems, tiredness, irritability and confusion were the most commonly reported problems among carers in this study. By the end of the first year, some of the carers had been treated either for anxiety or depression. Similarly, Holbrook (1982) found that one third of the family members in her study had not yet adjusted to the new life circumstances 2-5 years after the stroke. Subsequent research provides further support for these results (George & Gwyther, 1986; McNamara et al., 1990; Silliman et al., 1987; Tompkins, Schultz & Rau, 1988). Above mentioned studies are based on patients selected by age or the presence of aphasia, those referred to for rehabilitation, or those recruited through newspaper advertisement. Very few studies are based on community samples.

Longitudinal studies with varying lengths of follow-ups, have confirmed that spouse carers of stroke patients often experience depression. Carnwath and Johnson (1987) interviewed spouses of stroke patients and found more depression in carers 3 years after the stroke than after the first year. Findings regarding the significant prevalence of depression in their study is striking, given that the study dealt with all types of stroke, including those leaving minimum disability. Wade, Leigh-Smith and Langton-Hewer (1986) conducted a longitudinal study with a follow-up period ranging from 3 months to 2 years. Their study was the first to include all carers of all patients derived from a defined population. They examined the emotional distress caregivers experienced, and reported that 11-13% of carers became depressed over a two years period. Eagles and colleagues (1987) compared spouses of stroke patients and those of normal counterparts on a depression scale and found that the spouses of stroke patients were more disadvantaged.

Hence, stroke affects carers in parallel with the patient. The above literature review suggests that caregiving for a disabled or ill family member has a variety of personal, social and physical effects on carers and may therefore predispose them to psychological distress. A high proportion of carers experience negative effects of caring on their own physical and emotional well-being. In a longitudinal study carried out in UK with carers of patients having neurological disorders, Kausar (1994) found that majority was experiencing burden in relation to caregiving. In another study, with 112 carers of Patients recruited from different disabled Units and Neurology Wards of Different Hospitals in UK, Kausar (1994) reports that 67% were female carers and majority was experiencing anxiety and depression.

In Pakistan the concept of caregiving has not received much attention by the policy makers and researchers alike. Kausar (2000) conducted a study with 120 informal carers of physically disabled people in Pakistan and found that all of them were family members and the vast majority of them were females (92%). In another study with carers of cancer patients, Kausar and Jabeen (1997) report that 89% providing care to cancer patients were close family members and about half of them were experiencing depression (49%), anxiety (42%), somatic complaints (48%), whereas 38% reported social dysfuntioning. The given empirical evidence highlights importance of issue of caregiving in Pakistan, and draws attention to the fact that caring in Pakistan is left to the female family members.

To summarize, studies carried out in different cultures in the context of caregiving show consensus that it is mainly the family members or closer relatives, in particular a female who either herself assumes the role of caregiving or is expected to provide care whenever needed. Specifically in our culture the burden of caregiving is left usually on the shoulders of a female member who also has the added responsibilities of running the house and other obligations to meet. Caregiving is an exhaustive job and carers experience immense burden and stress in form of various psychological problems. This issue of uneven and unshared added burden of caregiving needs to be addressed and the concept of shared care should be introduced. Furthermore, psychological services and Counseling facilities should be provided to those who provide care in order to alleviate their stress.

References:

Anderson, R. (1992). The aftermath of stroke: The experience of patients and their family. Cambridge: Cambridge University Press.

Atkins, K. (1992). Similarities and differences between informal carers. In J. Twigg (Eds.), Carers: Research and Practice London: HMSO.

Baldwin, S.W. (1985). The Costs of Caring. London: Routledge and Kegan Paul.

Baldwin, S. (1977). Disabled Children-Counting the Cost. London: Disability Alliance.

Baldwin, S., and Glendinning, C. (1981). Children with disability in their families. In A. Walker & P. Townsend (Eds.), Disability in Britain (pp. 119-141). Oxford: Martin Robertson.

Baumgarten, M., Battista, R.N., Infante-Rivard, C., Hanley, J.A., Becker, R., and Gauthier, S. (1992). The Psychological and physical health of family members caring for an elderly person with dementia. Journal of Clinical Epidemiology, 45(1), 61-70.

Breslau, N., Staruch, K.S., and Mortimer, F.A. (1982). Psychological distress in mothers of disabled children. American Journal of Diseases of Children, 136, 682-686.

Brocklehurst, J., Morris, K., Andrews, B., Richards, and Laycock, P. (1981). Social Effects of Stroke. Social Science and Medicine, 15, 35-39.

Brody, E.M., and Schoonover, C.B. (1986). Patterns of parent-care when adult daughters work and when they do not. the Gerontologist, 26, 372-381.

Brodaty, H., and Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers of living with persons with dementia. Australian and New Zealand Journal of Psychiatry, 24(3), 351-361.

Brooks, D.N. (1991). The head-injured family. Journal of Clinical and Experimental Neuropsychology, 13(1), 155-188.

Brown, H., and Smith, H. (1989). Whose "ordinary life" is it anyway? Disability, Handicap and Society, 4(2), 105-119.

Carnwath, T.C.M., and Johnson, D.A.W. (1987). Psychiatric morbidity among spouses of patients with stroke. British Medical Journal, 294, 409-411.

Cohen, D., and Eisdorfer, C. (1988). Depression in family members caring for a relative with Alzheimer's disease. Journal of the American Geriatrics Society, 36(10), 885-889.

Caughlan, A., and Humphrey, M. (1982). Presenile Stroke: Long Term Outcome for patients and their families. Rheumatology and Rehabilitation, 21, 115-122.

DHSS (1983). On the State of the public health for the year 1983. London: HMSO.

Drummond, A.E. (1988). Stroke: The impact on the family. British Journal of Occupational Therapy, 51(6), 193-194.

Eagles, J.M., Beattie, G.W., Blackwood, D.B., Restall, D.B., and Ashcroft, G.W. (1987). The mental health of elderly couple: The effect of a cognitively impaired spouse. British Journal of Psychiatry, 150, 299-303.

Eisdorfer, C. (1991). Caregiving: An emerging risk factor for emotional and physical pathology. Bulletin-Menninger Clinic, 55(2), 238-247.

Eisdorfer, C., Kennedy, G., Wisnieski, W., and Cohen, D. (1983). Depresion and attributional style in families coping with the stress of caring for a relative with Alzheimer's disease. The Gerontologist, 23, 115-116.

Equal Opportunities Commission. (Ed.). (1982). Caring for the Elderly and Handicapped: Community care policies and Women's lives Equal Opportunities Commission. Manchester:

Fitting, M., Rabins, P., Lucas, M., and Eastham, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. The Gerontologist, 26(3), 248-252.

George, L.K., and Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. Gerontologist, 26(3), 253-259.

Grad, J., and Sainsbury, P. (1963). Mental illness and the family. Lancet, i, 544-547.

Gilhooly, M. (1984). The impact of caregiving on caregivers: Factors associated with the psychological well-being of people supporting dementing relative in the community. British Journal of Medical Psychology, 57, 35-44.

Gilleard, C.J., Belford, H., Gilleard, E., Whittick, J.E., and Gledhill, K. (1984a). Emotional distress amongst the supporters of the elderly mentally infirm. British Journal of Psychiatry, 145, 172-177.

Gilleard, C.J., Gilleard, E., Gledhill, K., and Whittick, J. (1984b). Caring for the elderly mentally infirm at home: A survey of the supporters. Journal of Epidemiology and Community Health, 38(4), 319-325.

Hallum, A., and Krumboltz, J.D. (1993). Parents caring for young adults with severe physical disabilities: Psychological issues. Developmental Medicine and Child Neurology, 35, 24-32.

Hirst, M. (1985). Young adults with disabilities: health, employment and financial costs for family carers. Child: Care, Health and Development, 11, 291-307.

Holbrook, S.E. (1982). Strokes: Social and emotional outcome. Journal of the Royal College of Physicians of London, 16, 100-104.

Holland, L.K., and Whalley, M.J. (1981). The work of the psychiatrist in a rehabilitation hospital. British Journal of psychology, 138, 222-229.

Horowitz, A. (1985). Family caregiving to the frail elderly. New York: Springer.

Jennett, W.B. (1975). Who cares for head injuries? British Medical Journal, iii, 267-270.

Johnson, C.K., and Catalano, D. (1983). A longitudinal study of family support to impaired elderly. The Gerontologist, 23(612-618).

Jones, D.A., and Vetter, N.J. (1984). A survey of those who care for the elderly at home: their problems and their needs. Social Science Medicine, 19(5), 511-514.

Jongbloed, L. (1986). Prediction of function after stroke: a critical review. Stroke, 17, 765-776.

Kausar, R. (2000). Cognitive appraisal, coping and psychological distress in carers of physically disabled people in Pakistan. Pakistan Journal of Psychological Research. Submitted for Publication.

Kausar, R. (1996). Head injury and its Psychological Consequences: A Literature Review. Pakistan Journal of Neurology, 2 (1). Pp. 17-20.

Kausar, R. (1994). Cognitive appraisal, coping and psychological adjustment of those who provide care to physically disabled people. Ph.D. Thesis, Psychology Department, Surrey University, England.

Kausar, R. and Powell, G. E. (1996). Subjective burden of carers of patients with neurological problems as a consequence of precise objective symptoms (objective burden). Clinical Rehabilitation, 10(2), 159-165.

Kausar, R. and Powell, G. E. (1996). Personality and Behaviour Changes in Stroke Patients. Pakistan Journal of Neurology, 1 (1). Pp. 20-32.

Kausar, R. and Sumira Jabeen (1997). Psychological Health and Coping Strategies used by Family Carers of Cancer patients. M.Sc thesis, Department of Applied Psychology, University of the Punjab, Lahore, Pakistan.

Killeen, M. (1990). The influence of Stress and Coping on family caregivers' perception of health. International Journal of Aging and Human Development, 30(3), 197-211.

Kinsella, G.J., and Duffy, F. D. (1979). Psychosocial readjustment in the spouses of aphasic patients: A comparative study of 79 patients. Scandinavian Journal of Rehabilitation Medicine, 11, 129-132.

Klein, R., Dean, A., and Bogdonoff, M. (1967). The impact of illness upon the spouse. Journal of Chronic Diseases, 20, 241-248.

Kreutzer, J.S., Gervasio, A.H., and Camplair, P.S. (1994a). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. Brain Injury, 8(3), 211-230.

Kreutzer, J.S., Gervasi,o A.H., and Camplair, P.S. (1994b). Primary carergivers' psychological status and family functioning after traumatic brain injury. Brain Injury, 8(3), 197-210.

Lezak, M.D. (1986). Psychological implications of traumatic brain damage for the patient's family. Special Issue: Traumatic head injury. Rehabilitation Psychology, 31(4), 241-250.

Livingston, M.G., Brooks, D.N., and Bond, M.R. (1985b). Three months after severe head injury: Psychiatric and social impact on relatives. Journal of Neurology, Neurosurgery and Psychiatry, 48(9), 870-875.

Mace, N.L., and Rabins, P.V. (1984). The 36 hour day. New York: Warner Books.

McNamara, S.E., Gummow, L.J., Goka, R., and Gregg, C.H. (1990). Caregiver strain: Need for late poststroke intervention. Rehabilitation Psychology, 35(2), 71-78.

Matthews, S.G., and Rosner, T.T. (1988). Shared filial responsibility: The family as primary caregiver. Journal of Marriage and the Family, 50, 185-195.

Mayou, R., Foster, A., and Williamson, B. (1978). Psychosocial adjustment in patients one year after myocardial infarction. Journal of Psychosomatic Research, 22(5), 447-453.

Morris, R.G., Morris, L.W., and Britton, P.G. (1988). Factors affecting the emotional well-being of the caregivers of dementia sufferers. British Journal of Psychiatry, 153, 147-156.

Mulley, G.P. (1985). Practical Management of Stroke. Bechenham: Croom Helm.

Mullin, J.B. (1987). Authentic voices from parents of exceptional children. Family Relations, 36, 30-33.

Novack, T.A., Bergquist, T.F., Bennett, G., and Gouvier, W.D. (1991). Primary Caregiver distress following severe head injury. Journal of Head Trauma Rehabilitation, 6(4), 69-77.

Oddy, M., and Humphrey, M. (1980). Social recovery during the year following severe head injury. Journal of Neurology, Neurosurgery and Psychiatry, 43, 798-802.

Office of Population Census & Surveys (1988). General household Survey, 1985. London: HMSO.

Pagel, M.D., Becker, J., and Coppel, D.B. (1985). Loss of control, Self blame, and depression: An investigation of spouse caregivers of Alzheimer's disease patients. Journal of Abnormal Psychology, 94(2), 169-182.

Parker, G. (1990). With Due Care and Attention: A Review of Research on Informal Care (Second ed.). London: Family Policy Studies Centre.

Pearlin, L.I., Mullan, J.T., Semple, S.J., and Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30(5), 583-591.

Pilisuk, M., and Parks, S.H. (1988). Caregiving: Where families need help. Social Work, 33(5), 436-440.

Poulshock, D.W., and Deimling, G.T. (1984). Families caring for elders in residnece: Issues in the measurement of burden. Journal of Gerontology, 39(2), 230-239.

Rabins, P.V. (1984). Management of dementia in the family context. Psychosomatics, 25, 369-373.

Rappaport, M., Herrero-Backe, C., Rappaport, M.L., and Winterfield, K.M. (1989). Head injury outcome up to ten years later. Archives of Physical Medicine and Rehabilitaion, 70, 885-892.

Rosenbaum, M., and Najenson, T. (1976). Changes in life patterns and symptoms of low mood as reported by wives of severely brain injured soldiers. Journal of Consulting and Clinical Psychology, 44(6), 881-888.

Scharlach, A.E. (1987). Relieving feelings of strain among women with elderly mothers. Psychology and Aging, 21(1), 9-13.

Schulz, R., Tompkins, C.A., Wood, D., and Decker, S. (1987). The soical psychology of caregiving: physical and psychological costs to providing support to the disabled. Journal of Applied Social psychology, 17, 401-428.

Shapiro, J. (1986). Assessment of family coping with illness. Psychosomatics, 27(4), 262-271.

Sheldon, D. (1982). Supporting the supporters: working with relatives of patients with dementia. Age and Ageing, 11, 184-188.

Silliman, R.A., Eaarp, J.L., and Wagner, E.H. (1987). Stroke: The perspective of Family caregivers. The Journal of Applied Gerontology, 6(4), 363-371.

Silliman, R.A., and Sternberg, J. (1988). Family caregiving: Impact of patient functioning and underlying causes of dependency. Gerontologist, 28(3), 377-382.

Singhi, P.D., Goyal, L., Pershad, D., Singhi, S., and Walia, B.N.S. (1990). Psychosocial problems in families of disabled children. British Journal of Medical Psychology, 63(2), 173-182.

Soldo, B., and Myllyluoma, J. (1983). Caregivers who live with dependent elderly. Gerontology.

Smith, H. (1991). Caring for everyone? The implications for women of the changes in community care services. Feminism and Psychology, 1(2), 279-292.

Stone, R. (1991). Familial obligations: Issues for the 1990s. Generations, 15(3), 47-50.

Stone, R., Cafferata, G.L., and Sangel, J. (1987). Caregivers of the frail elderly: A natural profile. The Gerontologist, 27, 616-626.

Thomsen, I.V. (1974). The patient with severe head injury and his family: follow-up study of 50 patients. Scandinavian Journal of Rehabilitation medicine, 180-183.

Thompson, R.J., Gustafson, K.E., Hamlett, K.W., and Spock, A. (1992). Stress, Coping and Family Functioning in the Psychological adjustment of mothers of children and Adolescents with Cystic Fibrosis. Journal of Pediatric Psychology, 17(5), 573-585.

Thompson, C.E. (1990). Raising a handicapped child: a helpful guide for parents of the physically disabled. New York: William Morrow.

Teusink, J.P., and Mahler, S. (1984). Helping families cope with Alzheimer's disease. Hospital Community Psychiatry, 35, 152-156.

Tompkins, C.A., Schulz, A., and Rau, M.T. (1988). Post-stroke depression in primary support persons: Predicting those at risk. Journal of Consulting and Clinincal Psychology, 56(5), 502-508.

Townsend, P. (1957). The Family life of old people. London: Routledge and Kegan Paul.

Twigg, J. (1992). Carers: Research and practice. London: HMSO.

Twigg, J., Atkin, K., and Perring, C. (1990). Carers and Services: A Review of Research. London: HMSO.

Wade, D.T., Legh-Smith, J., and Hewer, R.L. (1986). Effects of living with and looking after survivors of stroke. British Medical Journal, 293, 418-420.

Wahrborg, P. (1988). Behavioral changes in aphasic patients and their relatives following stroke: A review of the literature. Goteborg Psychological Reports, 18(5).

Willer, B., Abosch, S., and Dahmer, E. (1990). Epidemiology of Disability From Traumatic Brain Injury. In R. L. I. Wood (Ed.), Neurobehavioural Sequalae of Traumatic Brain Injury (pp. 18-33). New York: Taylor & Francis Ltd.

World Health Organization (1976). Disability prevention and rehabilitation (Reports of specific technical matters No. WHO Geneva, Seitzerland.

Zarit, S.H., Reever, K.E., and Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 649-660.