

Caregivers of the Elderly and Younger Adults with Disabilities: An Annotated Bibliography

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Caregivers of the Elderly and Younger Adults with Disabilities: An Annotated Bibliography

edited by
Lynn Sitsky



THE UNIVERSITY OF
NEW SOUTH WALES

International Section

- 129 Abel, Emily K. (1986), 'Adult daughters and care for the elderly', *Feminist Studies*, 12(3), 479-97.

'Enthusiasm for community care is growing at a time when feminists are debating both the shape of the welfare state and the meaning of nurturance in women's lives. this essay explores these interrelated issues.' Firstly, it examines the amount and nature of informal care that women provide for ageing parents and the costs they incur as a result. It analyses women's special role in parental caregiving. Finally, it discusses the dilemmas that feminists face in framing appropriate policies for the care of the frail aged.

DAUGHTERS; GENDER; POLICY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 130 Abel, Emily K. (1987), *Love Is Not Enough: Family Care of the Frail Elderly*, American Public Health Association, Washington, D.C., APHA Public Health Policy Series, v, 65pp.

'This monograph argues that caregiving is a women's issue and that a broad-based initiative must be adopted to support family members who choose to render care.' First it describes the consequences of various social and demographic trends on the ability of families to continue providing care. It delineates the burden caregiving places on many family members, paying particular attention to the ways in which factors of gender, class, and race shape the experience of caring for elderly relatives. Next it assesses the contrasting arguments of the major groups of policy analysts. Finally, it evaluates the central proposals for change and offers policy recommendations.

DEMOGRAPHIC ASPECTS; ETHNICITY; GENDER; POLICY; SOCIOECONOMIC STATUS; UNITED STATES

- 131 Abel Emily K. (1989), 'The ambiguities of social support: adult daughters caring for frail elderly parents', *Journal of Aging Studies*, 3, 211-30.

This article describes the types of support adult daughters caring for frail elderly parents receive from various sources and the barriers they face in requesting additional help. The data are provided by in-depth interviews. It was found that family and friends helped exacerbate stress as well as alleviating it.

DAUGHTERS; PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 132 Abel, Emily K. (1989), 'Family care of the frail elderly: framing an agenda for change', *Women's Studies Quarterly*, (1/2), 75-86.

This article begins with a description of some of the negative aspects of caring for a frail elderly person. It then goes on to consider gender, ethnic and class differences in the caregiving role and to state that there is a need for policy change in this area. It analyses some of the main proposals for change in the areas of financial compensation, support services and educational and counselling programs. Some policy recommendations are made such as restructuring of the world of work and reform of the nursing home industry. Finally, it is pointed out that particular consideration must be given to a considerable number of the aged without relatives to provide care.

COUNSELLING; EDUCATION; ETHNICITY; GENDER; PAYMENT; POLICY; SUPPORT GROUPS; UNITED STATES

- 133 Abel, Emily K. (1990), 'Family care of the frail elderly' in Emily K. Abel and Margaret K. Melon (Eds), *Circles of Care: Work and Identity in Women's Lives*, State University of New York Press, Albany, 65-91.

This chapter demonstrates that most long-term care occurs in the private household and that women predominate among informal caregivers to the elderly and also constitute the majority of care recipients. It focuses on two issues; firstly, it delineates the burden caregiving places on many family members, paying particular attention to the ways in which factors of gender, class and race shape the experience of caring for an elderly relative. Secondly, it discusses the problems entailed in three proposals for alleviating the costs of caregiving: financial compensation, supportive services and educational programs.

COMMUNITY SERVICES; EDUCATION; ETHNICITY; FAMILY; GENDER; PAYMENT; PSYCHOLOGICAL ASPECTS; SOCIOECONOMIC STATUS; UNITED STATES

- 134 Abel, Emily K. (1990), 'Informal care for the disabled elderly', *Research on Aging*, 12(2), 139-57.

'Most studies of informal care for the disabled elderly are based on structured interviews, which are analyzed statistically, and they focus on two issues that lend themselves to quantification - the tasks caregivers perform and the stress they experience. The focus of chores restricts researchers' understanding of the experience of caregivers. Task-oriented research may be particularly inappropriate for an activity dominated by women. Because stress has critical implications for public health, researchers have attempted to identify caregivers most at risk of stress and to evaluate interventions. Although these studies have provided useful information for practitioners, the preoccupation with stress compels researchers to miss essential aspects of the caregiving experience and restricts the range of policy

recommendations. Researchers should employ qualitative, as well as quantitative, methodologies and should incorporate the theoretical insights of a wide range of disciplines. Because scholars in the field of women's studies have directed considerable attention to personal relationships and caregiving issues, their writings may be especially useful for charting an agenda for research.'

GENDER; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 135 Abel, Emily K. (1991), *Who Cares for the Elderly? Public Policy and the Experiences of Adult Daughters*, Temple University Press, Philadelphia, (Women in the Political Economy), viii, 220pp.

This book examines how public policies affect the nature of caregiving at home. The amount of care that women deliver to elderly relatives is determined not only by demographic trends but by inadequacies in the long-term care system of the United States. These inadequacies impact more on low-income people and members of ethnic and racial minority groups. It traces the history of family caregiving in the United States since 1800 and criticises current research which is almost exclusively focused on the issue of stress. This latter preoccupation denies a full understanding of the experience of caregivers. The author presents findings from her in-depth study of 51 women caring for disabled elderly parents and asks how the accounts of these women can guide policy analysis and frame an agenda for change that responds to their needs.

DAUGHTERS; HISTORICAL ASPECTS; POLICY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 136 Abel, Emily K. and Margaret K. Melon (1990), 'Circles of care: an introductory essay', in Emily K. Abel and Margaret K. Melon, eds, *Circles of Care: Work and Identity in Women's Lives*, State University of New York Press, Albany, 4-34.

'Only by examining caregiving within specific contexts can we understand what it actually entails and the meaning it has in women's lives.' This chapter begins by defining caregiving, underlining the significance of this topic and reviews some major feminist perspectives on this issue. The characteristics of the specific contexts within which care is provided are delineated, demonstrating how each affects the experience of caregivers and the type of care they give. Finally it addresses the relationships among caregivers in different settings and notes the dilemmas experienced by caregivers who operate in more than one setting. 'Caregivers require flexibility, social support, a means of establishing limits, congruence between external expectations and the emotional work of caring, and the ability both to act on the basis of their own knowledge and to form attachments with the recipients of their

care.' This chapter has shown that each of the contexts of care examined provides these conditions imperfectly.

CONCEPTUAL ISSUES; GENDER; METHODOLOGY; RELATIONSHIPS;
UNITED STATES

- 137 Albert, Steven M. (1991), 'Cognition of caregiving tasks: multidimensional scaling of the caregiver task domain', *The Gerontologist*, 31(6), 726-34.

'This research investigates the distinctions caregivers use in thinking about home care tasks. A sample of 52 adult children caregivers sorted 25 cards with caregiving tasks printed on them into different piles based on the similarity of the tasks. Multidimensional scaling of the aggregate proximity matrix for the items showed three dimensions in the caregiving task domain: type of impairment (physical vs. cognitive-emotional), location of caregiving (within home vs. outside home), and response to parental incompetency (autonomy-fostering vs. guardianship). Respondents' statements support the dimensionality of the domain.'

DAUGHTERS; DEPENDENCY; METHODOLOGY; SONS; UNITED STATES

- 138 Albert, Steven M., Sandra J. Litvin, Morton H. Kleban and Elaine M. Brody (1991), 'Caregiving daughters' perceptions of their own and their mothers' personalities', *The Gerontologist*, 31(4), 476-82.

'This research explores differences between caregiving daughters' perceptions of their own and the mothers' personalities. A sample of caregiving daughters (N=150) rated themselves and their mothers on the same 17 personality attributes. Daughters generally rated their mothers more negatively than themselves. Within this pattern of generally negative evaluations, varying types of impairment function differently. Functional impairment is not related to assessments of mothers' personalities, whereas psychological and cognitive impairments are.'

DAUGHTERS; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED STATES

- 139 Allan, Graham (1988), 'Kinship, responsibility and care for elderly people', *Ageing and Society*, 8(3), 249-68.

'As is now widely recognised, children, but especially daughters, are often involved in providing their elderly infirm parent(s) with care and tending. This paper seeks to examine two aspects of this care provision. First, how it relates to the nature of kinship solidarity between parents and adult children during other phases of their lives. More specifically, it will be suggested that while children are usually thought to bear some responsibility for their parents' welfare, actually providing support can none the less entail a far more extensive commitment than is normally expected of

them. Yet the paradox is that such caring often seems to intensify the feelings of responsibility rather than generate a sense of moral worth amongst those most highly involved. The second part of the paper examines some of the factors responsible for this. It will argue that the responses of carers to their situation need to be understood in terms of the immediate social environment in which they find themselves. In particular, what needs to be recognised in the sense of individual, rather than shared or collective, responsibility which develops.'

DAUGHTERS; RELATIONSHIPS; SONS; UNITED KINGDOM

- 140 Allen, Isobel, Malcolm Wicks, Janet Finch and Diana Leat (1987), *Informal Care Tomorrow*, Occasional Paper, Policy Studies Institute, London, 44pp.

This paper reports on a seminar on the future of care in the community by family, friends, neighbours and volunteers. Malcolm Wicks looks at family and demographic changes and how these will affect informal care. Janet Finch focuses on the extent to which the tradition of caring has been women's work and how this might change in the future. Diana Leat looks at the changes affecting the availability of neighbourhood care and volunteers. In the opening section Isobel Allen examines some of the issues to come out of research and practice in recent years. One theme that emerges is that there is very little known about the quality of care. It asks how untapped resources of informal care can be released in the community and how much should professionals interweave with the informal sector. The concept of 'choice' is discussed. A lot of stress has been put on the right of the individual to choose but this usually means the dependent. What of the carer? Should people be offered incentives to care by being paid and what are the implications of that? There must be planning for future developments.

CONCEPTUAL ISSUES; DEMOGRAPHY; GENDER; PAYMENT; SUPPORT NETWORKS; UNITED KINGDOM

- 141 Allen, Katherine R. and Alexis J. Walker (1992), 'Attentive love: a feminist perspective on the caregiving of adult daughters', *Family Relations*, 41(3), 284-9.

'In this article, a new look at caregiving to the elderly is proposed by linking it conceptually to another form of intergenerational caregiving.' According to S. Ruddick in his book *Maternal Thinking: Towards a Politics of Peace*, Boston, Beacon, 1989, to understand caregiving one must start with the caregiver. 'Ruddick's theory of attentive love is applied to interview data from 29 adult daughters caring for their aging mothers. The aim of this project was to look for similarities and differences between the thinking and practice of caregiving to children and the related but distinct type of caring labor that adult daughters provide for their frail, elderly mothers. Support was found for the theory that adult daughters preserve their aging mothers' lives, foster their growth, and try to help their mothers

remain acceptable to society. Implications for family and gerontological practitioners from a feminist analysis of parental caregiving are discussed.'

CONCEPTUAL ISSUES; DAUGHTERS; GENDER; THEORY DEVELOPMENT;
UNITED STATES

- 142 American Association of Retired Persons and Travelers Companies Foundation (1988), *National Survey of Caregivers: Summary of Findings*, American Association of Retired Persons, Washington D.C., 41pp.

'Approximately four-out-of-five older Americans who suffer from physical and/or mental disabilities which impair their ability to function avoid institutionalization because of personal care and financial assistance received from family members or friends. Such "caregiving" assistance involves activities related to managing a household and activities related to direct personal care to the individual. Prior research has suggested that caregiving creates physical, economic and emotional stresses for the care providers. Caregiving can be the equivalent to taking on a second job for those who work outside the home. There is still a void in terms of national data on the magnitude of the phenomenon; the financial costs associated with providing care; the use of services especially developed for caregivers and the effects of caregiving on employment. To fill this void, a National Caregivers Survey was conducted among a random sample of U.S. telephone households. The National Caregivers Sample was sponsored by the AARP, with support from the Travelers Companies Foundation.' This is a summary of the findings of that Survey.

DEMOGRAPHIC ASPECTS; EMPLOYMENT; FINANCIAL ASPECTS;
METHODOLOGY; NATIONAL STUDIES; SERVICE USE; SOCIAL ASPECTS;
STATISTICS; UNITED STATES

- 143 Anderson, Robert (1988), 'The quality of life of stroke patients and their carers', in Robert Anderson and Michael Bury, eds, *Living with Chronic Illness: The Experience of Patients and Their Families*, Unwin Hyman, London, 14-42.

This chapter deals with the problems associated with caring for a stroke patient and the main causes of distress for carers. More specifically, it considers problems caused by changes in the patient, in the carers's relationship to the patient, and in the carer's social life. It discusses the link between these problems and the ways in which patients and carers feel that their enjoyment of and satisfaction with life change following a stroke.

PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SOCIAL ASPECTS;
STROKE; UNITED KINGDOM

- 144 Anthony-Bergstone, Cheri R., Steven H. Zarit and Margaret Gatz (1988), 'Symptoms of psychological distress among caregivers of dementia patients', *Psychology and Aging*, 3(3), 245-8.

'Nine subscales of the Brief Symptom Inventory (BSI) were examined for caregivers of dementia patients. Caregivers (N=184) were divided into groups on the basis of age (<59 and 60+) and gender. Their scores were compared with age-matched norms. All of the caregiving groups were significantly elevated on the Hostility cubical. Both younger and older women scored higher than the norm on the Anxiety cubical, and the older women were significantly elevated on three other subscales as well. The Anxiety and Hostility subscales of the BSI were most strongly correlated with the Burden Interview, a measure of the demands imposed by caregiving activities. This relation between burden and symptomatology highlights the stressful nature of caregiving.'

AGED CAREGIVERS; COMPARATIVE STUDIES; DEMENTIA; GENDER; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 145 Arber, Sara, G. Nigel Gilbert and Maria Evandrou (1988), 'Gender, household composition and receipt of domiciliary services by elderly disabled people', *Journal of Social Policy*, 17(2), 153-75.

'Using data from the 1980 General Household Survey, differences in the provision of statutory domiciliary services to disabled elderly people are explored. Domiciliary services vary in their degree of "substitutability", that is, in the extent to which the care may be performed either by state services or by other members of the elderly person's household. Domestic support services are substitutable depending on the relationship between the carer and the cared for; and medical services are not substitutable by informal carers. The paper shows that discrimination by statutory services against women carers is dependent primarily on the household composition of the elderly person rather than on gender *per se*. Taking into account the level of disability of the elderly person, younger "single" women carers receive no less support than "single" men carers, but carers who are married women under 65 obtain the least domestic and personal health care support. Carers who are elderly receive more support than carers under 65. Among disabled elderly people who live alone, men receive somewhat more domestic and personal health services than women.'

COMMUNITY SERVICES; GENDER; NATIONAL STUDIES; UNITED KINGDOM

- 146 Arber, Sara and G. Nigel Gilbert (1989), 'Men: the forgotten carers', *Sociology*, 23(1), 111-8.

'The extent to which men are the primary carers of infirm elderly people and the amount of support men carers receive from the statutory and voluntary services relative to women carers is examined using data from the 1980 General Household

Survey. It is shown that men make a larger contribution to caring than is often recognised.'

GENDER; LIVING ARRANGEMENTS; NATIONAL STUDIES; SERVICE USE;
UNITED KINGDOM

- 147 Arber, Sara and G. Nigel Gilbert (1989), 'Transitions in caring: gender, life course and the care of the elderly', in Bill Bytheway, Teresa Keil, Patricia Allatt and Alan Bryman, eds, *Becoming and Being Old: Sociological Approaches to Later Life*, Sage, London, 72-92.

'An emphasis on the impact of community care policies on women leads to the danger of neglecting men as carers.' This chapter examines 'the ways in which the biographies of the elderly person and the carers are intertwined, resulting in differences in the nature of the caring relationship,' showing 'that women predominate only in certain types of caring biographies. Using nationally representative data from the [British] 1980 General Household Survey (GHS)' the authors 'examine the gender of co-resident carers and explore the contradiction that, while men are assumed not to care, data from the GHS and other studies demonstrate that at least a third of carers are men.' It is suggested that men have been neglected as carers and in order to understand why, this chapter examines how gender influences the trajectory of the elderly-carers relationship, and how the reasons for caring differ between men and women. It also examines the conflicts between caring and other public and private roles of the carer.

GENDER; NATIONAL STUDIES; RELATIONSHIPS; UNITED KINGDOM

- 148 Arber, Sara and Jay Ginn (1990), 'The meaning of informal care: gender and the contribution of elderly people', *Ageing and Society*, 10(4), 429-54.

"Caring" and "carers" are words in frequent use in social policy, but their meaning is often vague and undefined, encompassing a wide range of activities and relationships. This paper discusses the meaning of caring and focuses particular attention on older carers. Secondary analysis of the 1985 Office of Population, Censuses and Surveys (OPCS) Informal Carers Survey data shows that of the estimated six million informal carers in Britain, the largest contribution is made by women in their early 60s, and that elderly men are more likely than younger men to be carers. The bulk of informal caring work, in terms of total time spent, is provided by co-resident carers, most of whom are a spouse or parent of the dependant. However, the largest number of those receiving help live in separate households, and these are mainly parents or parents-in-law of their carers. The emphasis on elderly people as "a social burden" neglects their contribution as providers of informal care. Over a third of informal care to people over 65 is provided by elderly people. Elderly men and women provide *equal* amounts of co-resident care, reflecting gender equality in the care of elderly spouses. But among younger people marked gender

differences are apparent in co-resident care, and in the provision of informal care to elderly people living in separate households.'

AGED CAREGIVERS; CONCEPTUAL ISSUES; DAUGHTERS; GENDER;
LIVING ARRANGEMENTS; NATIONAL STUDIES; SONS; SPOUSES; UNITED
KINGDOM

- 149 Archbold, Patricia G. (1983), 'Impact of parent-caring on women', *Family Relations*, 32(1), 39-45.

'The impact of parent-caring on the lives of 30 Caucasian women was studied using data from: 1) intensive interviews, 2) participant observations, and 3) the OARS Multidimensional Functional Assessment. Analysis of the qualitative data identified two caregiving modalities: 1) care provision and 2) care management. The social and behavioral precedents and consequences of entering the careprovider or manager role were identified. The costs of caregiving were much greater for providers than managers.'

DAUGHTERS; RELATIONSHIPS; UNITED STATES

- 150 Arling, Greg and William J. McAuley (1983), 'The feasibility of public payments for family caregiving', *The Gerontologist*, 23(3), 300-6.

'The use of direct payments to persons providing in-home care to impaired elderly is currently the object of increased interest. This paper draws upon data from two studies of impaired elderly to address the feasibility and potential impact of such policies. Findings suggest that family members are heavily involved in support to the impaired elderly and that institutionalization is most often the result of non-financial rather than financial factors. The study concludes with a discussion of the issues which must be resolved in designing policies incorporating public payments for family caregiving.'

EMPLOYMENT; FINANCIAL ASPECTS; PAYMENT; POLICY; UNITED
STATES

- 151 Arling, Greg and William J. McAuley (1984), 'The family, public policy, and long-term care, in William H. Quinn and George A. Hughston, eds, *Independent Aging: Family and Social Systems Perspectives*, Aspen Systems Corporation, Rockville, Md., 133-48.

'The purpose of this chapter is to describe the role of the family in community long-term care for the impaired elderly.' It debunks the myths that families no longer provide for their elders, that community agencies or other formal sources of care in the home replace family caregivers, and that families dump their elders into institutions. It also describes the types of community care provided by family

members and other sources, and examines the circumstances associated with the use of family care versus non-family assistance among the impaired elderly.

FAMILY; COMMUNITY SERVICES; POLICY; UNITED STATES

- 152 Aronson, Jane (1985), 'Family care of the elderly: underlying assumptions and their consequences', *Canadian Journal on Aging*, 4(3), 115-25.

'Through a review of the literature, this article explores the debate between the traditional perspective that conceives it as natural that families take care of their elderly members when frail or in need and an emerging critique of this view. The critique exposes the invisible divisions of caring work between men and women and between public and private arenas, and challenges the comfortable imagery of 'family care'. The implications of this analysis for the future are considered, both for constructive changes in social policies and for the reformulation of assumptions on which research and practice with the frail elderly and their families are based.'

FAMILY; GENDER; HISTORICAL ASPECTS; LITERATURE REVIEW; POLICY; RELATIONSHIPS; CANADA

- 153 Aronson, Jane (1986), 'Care of the frail elderly: whose crisis? Whose responsibility?' *Canadian Social Work Review*, 3, 45-71.

The division between 'visible' public and 'hidden' private provision of health and social care for the elderly is about 10 per cent public and 90 per cent private. This private or informal care is largely provided by families and within families predominantly by female family members. Most public discussion of the care of the frail aged focuses on publicly provided services and is cast in the language of crisis. This article examines the rhetoric with two questions in mind: '(1) We see the identification of a crisis in the provision of public services for the care of the elderly, but what do we know about the experience of old people and unpaid family caregivers...? How is this crisis privately borne? (2) How is the existing division of responsibility for care accomplished? What happens at the boundary between public and private provision, where responsibility is actually assigned and policy implemented?'

COMMUNITY SERVICES; GENDER; POLICY; RELATIONSHIPS; CANADA

- 154 Aronson, Jane (1990), 'Women's perspectives on informal care of the elderly: public ideology and personal experience of giving and receiving care', *Ageing and Society*, 10(1), 61-84.

'Drawing on a qualitative study of thirty-two women aged between 35 and 85, this paper links women's experiences of giving and receiving care in the informal sphere to their wider social and ideological context. While subjects subscribed to cultural

assumptions about families, responsibility, gender and old age, they experienced awkwardness in translating them into their own lives. Younger women and women looking back on their middle years experienced contradiction between the cultural expectation that they be responsive to others and their wishes for self-enhancement. Older women experienced contradiction between the cultural imperative to be unburdensome and independent and their wish for security. Feelings of guilt and shame were associated with not living up to these expectations. They rendered subjects' concerns, individual failings and stifled expression of their needs. To facilitate such expression and work towards social policies that enhance women over the life course, it will be necessary to envision alternative types of supportive services and to challenge the ideological barriers to their use that the subjects of this study had so acutely internalised.'

GENDER; IDEOLOGY; PSYCHOLOGICAL ASPECTS; QUALITATIVE
STUDY; SERVICE USE; SUPPORT NETWORKS; CANADA

- 155 Aronson, Miriam K., Gilbert Levin and Rochelle Lipkowitz (1984), 'A community-based family/patient group program for Alzheimer's disease', *The Gerontologist*, 24(4), 339-42.

'Alzheimer's disease may cause progressive impairment to the patient and of the family system. Coping with this disease and its consequences may require a new repertory of defense mechanisms for family members and confrontation of issues ranging from anger to agitation to adaptation. An Alzheimer's Family/Patient group program has been developed for community-based patients with moderate to severe dementia and their caregivers. Its components are discussed in relation to clinical observations.'

DEMENTIA; FAMILY; SUPPORT GROUPS; UNITED STATES

- 156 Askham, Janet (1991), 'The problem of generalizing about community care of dementia sufferers', *Journal of Aging Studies*, 5(2), 137-46.

'Although it is necessary to generalize about client groups in order to provide a service it is argued that it is also essential to be aware of the complexity and variability of needs and circumstances. With particular reference to dementia sufferers, this article explores the concepts of "community", "care", "carer" and "dementia sufferer" itself. Problems of stereotyping, labelling and failing to recognize people's own perceptions of their situation are addressed and examples presented from a study of the home support of dementia sufferers.'

COMMUNITY SERVICES; CONCEPTUAL ISSUES; DEMENTIA; UNITED
KINGDOM

- 157 Askham, Janet, Emily Grundy and Anthea Tinker (1992), *Caring: The Importance of Third Age Carers*, Carnegie United Kingdom Trust, Fife and Age Concern Institute of Gerontology, King's College, University of London, Carnegie Inquiry Into the Third Age, Research Paper No.6, xii, 88pp.

This study establishes the important part played by people of the third age (50-74 years) in the provision of informal care. In 1985, 46 per cent of all carers in Britain were third agers. Over half of the third agers providing care, and three quarters of those caring for someone they lived with, were caring for a partner or spouse. One in 20 provided more than 20 hours of care per week. 'Although caring brings some satisfaction, and is often undertaken willingly, this satisfaction is nearly always outweighed by serious problems. These include financial sacrifices due to both loss of earnings and other benefits, and to the direct costs of care, such as help with the living expenses of the person being cared for. These expenses rise with the level of disability. An important factor is the low level of dependants' incomes.' Carers can be differentiated in several ways. Gender: women are slightly more likely to be carers than men and more likely than men to provide substantial amounts of care. They appear to experience more stress and marital breakdown. Care setting: co-residential carers were more likely to have low incomes, to lose pay through time off, have lower paid employment and retire early because of caring responsibilities. Relationship to dependant person: the willingness to care is particularly strong among spouse carers but they may suffer a change in self image as well as mental and physical health problems. Debate on the extent to which caring should be a matter for public policy must take place and consider for each aspect of caring the point at which the state responsibility should start and end. It is proposed that: resources must be devoted to carers vis-a-vis other groups (including the dependant person); the level of independence of the person cared for should be maintained or restored if possible; the financial independence of carers should be preserved through opportunities for paid work; there could be training and information in preparation for caring. Carers need: respite care; support services linked to caring tasks or money to purchase them; compensation for loss of earnings/time; rewards, e.g. extra tax relief; acknowledgement and praise; protection from exploitation; and counselling/rehabilitation after they cease caring. Several options are put up under each of these proposals.

AGED CAREGIVERS; COMMUNITY SERVICES; COUNSELLING;
EDUCATION; FINANCIAL ASPECTS; INCOME SUPPORT; NATIONAL
STUDIES; PAYMENT; PSYCHOLOGICAL ASPECTS; RESPITE CARE;
POLICY; RELATIONSHIPS; SPOUSES; UNITED KINGDOM

- 158 Atkin, Karl (1992), 'Similarities and differences between informal carers', in Julia Twigg, ed., *Carers: Research and Practice*, HMSO, London, 30-58.

This chapter 'concentrates on the differences between carers, fleshing out the experience of caring in a range of circumstances' drawing heavily on qualitative research. It looks at six different caring relationships: spouse carers, parental carers,

filial carers, sibling carers, child carers, and non-kin carers, concentrating on three important areas of difference: the relationship between the carer and the person cared for; the disability of the cared-for person; and more general aspects of the carers' backgrounds such as age, gender, class, ethnicity and geographical differences.

AGED CAREGIVERS; DAUGHTERS; DISABLED; ETHNICITY; GENDER;
MIDDLE AGED CAREGIVERS; QUALITATIVE STUDY; RELATIONSHIPS;
SOCIOECONOMIC STATUS; SONS; SPOUSES; UNITED KINGDOM

- 159 Atkin, Karl and Janet Rollings (1992), 'Informal care in Asia and Afro/Caribbean communities: a literature review', *British Journal of Social Work*, 22(4), 405-18.

'The multi-racial nature of British society can no longer be ignored by those responsible for planning and implementing social care policy, particularly since community care is presently at a crossroads. Informal care provides a useful starting point from which to introduce the notion of race into social care debates. The paper, by reviewing a mix of empirical studies and policy debates emerging from the literature on informal care and black communities, examines the experience of informal care within black communities. By discussing topics such as the demography of care, the nature of informal care, and service provision to black carers, it gives coherence to a fragmented literature and illustrates gaps in present understanding.'

COMMUNITY SERVICES; DEMOGRAPHIC ASPECTS; ETHNICITY;
FINANCIAL ASPECTS; HEALTH; HOUSING; LITERATURE REVIEW;
POLICY; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 160 Baines, Carol T., Patricia M. Evans and Sheila M. Neysmith (1991), 'Caring: its impact on the lives of women', in Carol T. Baines, Patricia M. Evans and Sheila M. Neysmith, eds, *Women's Caring: Feminist Perspectives on Social Welfare*, McClelland and Stewart, Toronto, 11-35.

This chapter explores the concept of caring and examines the reasons why women are the primary caregivers with the intention of uncovering the complexities and contradictions of caring from the perspective of women. Addressing the burden of women's caring is complicated by the fact that it is also a labour of love. 'An analysis of women's role in caring needs to examine the ways in which the private and public worlds of women intersect. Women experience these boundaries as artificial.'

CONCEPTUAL ISSUES; GENDER; CANADA

- 161 Baines, Carol T., Patricia M. Evans and Sheila M. Neysmith, eds (1991), *Women's Caring: Feminist Perspectives on Social Welfare*, McClelland and Stewart, Toronto, 310pp.

This book focuses on Canadian experience to 'investigates the influence of an ethic of care on the development of social work, nursing, and teaching, and examines the connections between caring and poverty, wife abuse, and child neglect. The book also explores the way that caring shapes the experience of women at different points in the life cycle. Each chapter has been written by an expert on the topic, but all are linked by three major questions: What are the prevailing assumptions made about caring? What are the consequences of these assumptions? How can caring be reformulated to support rather than disadvantage women and to make our society - the state, the family, the economy - function more effectively and fairly?' The book demonstrates how the welfare state has served 'as a powerful reinforcer of women's caring' emphasising the importance of women providing care but limiting their ability to express their own needs for care. 'The first section of the book develops theoretical and historical perspectives on women's caring. The ordinary expectations of women's caring are explored throughout the life cycle in the second section', the third section looks at the issues of women's poverty, wife battering, and child neglect. 'The final chapter discusses several aspects of the current social construction of Canadian programs and policies, which must be changed if responsibility for providing care to vulnerable groups in our society is to be shared more equitably.'

GENDER; HISTORICAL ASPECTS; IDEOLOGY; POLICY; SOCIOECONOMIC STATUS; THEORY DEVELOPMENT; CANADA

- 162 Baldwin, Sally (1992), 'Cash and care in the provision of support for frail older people', in *Social Security 59 Years After Beveridge: An International Conference*, Volume 3, Legal and Administrative Issues, Gaps in the System, European Institute of Social Security, York, 23-32.

'The "gap in the system" which this paper addresses is care, and its particular focus on the respective roles of social security, as opposed to services, in the social protection of, particularly, older people with long-standing care needs...The paper is concerned not only with the security and quality of life of people with such needs, but with that of the relatives and friends who support them.' In this regard the paper examines benefits to carers, in particular the Invalid Care Allowance, and points out its shortcomings and lack of clarity of purpose. It is argued that 'very little progress has been made in the United Kingdom towards establishing basic rights and dignified forms of social support for people with long-standing care needs.'

COMMUNITY SERVICES; INCOME SUPPORT; POLICY; UNITED KINGDOM

- 163 Baldwin, Sally and Gillian Parker (1991), 'Support for informal carers - the role of social security', in Gillian Dalley, ed., *Disability and Social Policy*, Research Report No.731, Policy Studies Institute, London, 163-98.

There is widespread agreement about the paucity and ineffectiveness of services to support people with disabilities and their caregivers. 'This chapter looks at what research can tell us about the number of people involved and the intensity of their involvement.' It looks at the number of caregivers and the hours of care they provide, what they do and for whom. It examines household and personal incomes of caregivers, whether or not they are in paid employment and the relationship between caregiving and paid work. It describes income support arrangements and the effectiveness of the Invalid Care Allowance. Finally, it makes recommendations for change.

DISABLED; EMPLOYMENT; FINANCIAL ASPECTS; INCOME SUPPORT; POLICY; UNITED KINGDOM

- 164 Baldwin, Sally and Julia Twigg (1991), 'Women and community care: reflections on a debate', in Mavis Maclean and Dulcie Groves, eds, *Women's Issues in Social Policy*, Routledge, London, 117-35.

This chapter reviews the current state of the debate on community care and its exploitation of women's labour. In doing so it refers particularly to two authors, Janet Finch and Gillian Dalley. Both draw extensively on feminist analyses and their related but differing viewpoints are used as a springboard to discuss the current tension within community care policy, with particular regard to the role of women. There are suggestions for ways forward out of the impasse the debate seems to have reached. A strategy to improve the situation of carers while also weakening sexual divisions of caring would require three elements: policies to minimise the dependency of older people and people with disabilities; the creation of frameworks to enable women to exercise real choices; and support for people who opt to care. There are details of what such policies would involve. The long-term aim is to create 'a society in which caring for and about vulnerable people is seen as men's, as well as women's, work.'

DEPENDENCY; GENDER; POLICY; UNITED KINGDOM

- 165 Barer, Barbara M. and Colleen L. Johnson (1990), 'A critique of the caregiving literature', *The Gerontologist*, 30(1), 26-9.

'In this critical review of the recent caregiving literature...several methodological problems [are identified]. Specifically noted are the variable and often confusing definitions of the caregiver, the lack of specification of needs, overrepresentation of self-selected samples, and the absence of attention to the total support network. [It is concluded] that future researchers should focus on the total support process in later

life, rather than on a single caregiver, so that policy can best be designed to mesh the informal and formal support systems.'

CONCEPTUAL ISSUES; LITERATURE REVIEW; METHODOLOGY;
SUPPORT NETWORKS; UNITED STATES

- 166 Barnes, Carla L., Barbara A. Given and Charles W. Given (1992), 'Caregivers of elderly relatives: spouses and adult children', *Health & Social Work*, 17(4), 282-9.

'A problem in the provision of home health care for elderly people is the limited number of family members available for caregiving. Current trends in federal, state, and local policy formation suggest an increasing emphasis on the family as an appropriate caregiver. Therefore, it is necessary to examine how family relationships affect the caregivers' responses to their caregiver situation. Data are presented from 206 caregivers enrolled in a larger longitudinal study of family members caring for elderly dependent relatives. The sample is divided into four caregiver groups: (1) spouses who have children, (2) spouses who have no children, (3) adult children who have siblings, and (4) adult children who have no siblings. Measures selected for comparison were perception of burden, caregiver involvement, affective social support, mental health status, and use of community services. Differences were found among the four groups of caregivers. Implications for social work intervention are discussed.'

COMPARATIVE STUDIES; DAUGHTERS; FAMILY; PSYCHOLOGICAL
ASPECTS; RELATIONSHIPS; SERVICE USE; SONS; SPOUSES; SUPPORT
NETWORKS; UNITED STATES

- 167 Barnes, Robert F., Murray A. Raskind, Monte Scott and Colleen Murphy (1981), 'Problems of families caring for Alzheimer's patients: use of a support group', *Journal of the American Geriatrics Society*, 29(2), 80-5.

'An eight-week support group program was conducted for 15 members of the families of Alzheimer patients still living at home. It became clear that caring for an Alzheimer patient at home created tremendous practical, psychological and social problems for family members. Frequently discussed problems included lack of support and information from physicians, poor understanding of the disease, depression, a trapped feeling, anger and fear about the patient's behavioral problems, isolation, and the caretaker's loss of self-identity. Group participation was especially beneficial for spouses who functioned as primary care providers. It increased their understanding of the disease, made them feel more supported and less isolated, and helped them resolve some of the feelings created by the illness. It also helped spouses to become more patient. Such family support programs offer a way to

strengthen the emotional well-being and treatment skills of the care-providing family and are an important aid to treatment in Alzheimer's disease.'

DEMENTIA; EDUCATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
SOCIAL ASPECTS; SPOUSES; SUPPORT GROUPS; UNITED STATES

- 168 Barusch, Amanda S. (1988), 'Problems and coping strategies of elderly spouse caregivers', *The Gerontologist*, 28(5), 677-85.

'In-depth interviews were conducted with 89 spouse caregivers to identify problem situations which strain their abilities and to identify coping techniques which prove effective. The diversity of problems encountered by these elderly caregivers requires a varied repertoire of coping techniques. Findings revealed caregivers' general preference for managing situations on their own. Implications for the design of caregiver support programs are discussed.'

AGED CAREGIVERS; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 169 Barusch, Amanda S. and Wanda M. Spaid (1989), 'Gender differences in caregiving: why do wives report greater burden?' *The Gerontologist*, 29(5), 667-76.

'Women typically report greater burden associated with caregiving than do men...Data from interviews with 131 older spouse caregivers [were used] to explore potential explanations for this difference. A linear regression model explained 35% of the variance in caregiver burden. The patient's cognitive and behavioral difficulties emerged as the most important predictor of burden, followed by caregiver age, unpleasant social contacts, caregiver sex, and overall coping effectiveness. Findings suggest that age differences in male and female caregivers contribute to the observed differences in burden.'

AGED CAREGIVERS; GENDER; PSYCHOLOGICAL ASPECTS; SPOUSES;
UNITED STATES

- 170 Bass, David M. and Karen Bowman (1990), 'The transition from caregiving to bereavement: the relationship of care-related strain and adjustment to death', *The Gerontologist*, 30(1), 35-42.

'This study examines two competing hypotheses about the relationship between care-related strain and the difficulty adjusting to the impaired relatives death. One hypothesis, and the limited available empirical evidence, suggests that family members who perceive caregiving as stressful will experience some relief when their relative dies because care responsibilities end. An alternative hypothesis, derived from several conceptualizations, posits the opposite relationship, with greater care-

related strain predictive of greater strain during bereavement. Panel data from spouse and adult-child caregivers collected before and after the death support the second hypothesis. Respondents who appraise caregiving as more difficult and those who report more negative caregiving consequences for the family assess bereavement as more difficult and report greater bereavement strain for the family.'

BEREAVEMENT; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 171 Bass, David M., Karen Bowman and Linda S. Noelker (1991), 'The influence of caregiving and bereavement support on adjusting to an older relative's death', *The Gerontologist*, 31(1), 32-50.

'This study examines the influence of both caregiving social support to an impaired older relative and bereavement social support to a surviving caregiver on that caregiver's bereavement adjustment. Although past research has considered the link between bereavement support and adjustment to a loved one's death, the influence of support to the care recipient has not been investigated. Analyses of prospective panel data from 73 spouse and adult-child caregivers show caregiving support characteristics to be more important for bereavement adjustment than support provided to the surviving caregiver after their relative's death.'

BEREAVEMENT; SUPPORT GROUPS; UNITED STATES

- 172 Baum, Danielle and Dolores Gallagher (1985/86), 'Case studies of psychotherapy with depressed caregivers', *Clinical Gerontologist*, 4(2), 19-29.

This article begins with a brief review of the literature of the psychological effects experienced by caregivers. 'While the caregiver literature describes many of these problems and suggests interventions such as problem-solving and support groups, little is said about the efficacy of treating such affect-laden problems with psychotherapy. The distress experienced by caregivers from isolation, decreased sense of self, loss, denial, parent-child issues, and lack of personal satisfaction may lead to a receptiveness to psychotherapy and an opportunity for personal growth.' Discussion of two successful short-term cases provides an in-depth view of the process and outcome of therapy with selected patients who sought assistance from a psychotherapy centre for elders. The first case depicts a behavioural approach; the second is approached eclectically.'

CASE STUDIES; LITERATURE REVIEW; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 173 Baum, Martha and Mary Page (1991), 'Caregiving and multigenerational families', *The Gerontologist*, 31(6), 762-9.

'This paper examines the possibility that the extension of traditional family household boundaries foreshadows an expanded caregiving system as family lines grow longer. An original study of 25 four-generation families, mapping all linear and lateral members, offers findings that confirm evidence found in a literature review. One primary caregiver, either a spouse or daughter, generally shoulders responsibility for members in adversity. A caregiving system encompassing more than two generations in direct descent was not discernible. Problems in caring for the oldest old are noted.'

DAUGHTERS; FAMILY; METHODOLOGY; RELATIONSHIPS; SPOUSES;
UNITED STATES

- 174 Bentelspacher, C.E., S. Chitran and M.B.A. Rahman (1994), 'Coping and adaptation patterns among Chinese, Indian, and Malay families caring for a mentally ill relative', *Families in Society*, 75(5), 287-94.

'Families caring for chronically mentally ill relatives often experience considerable stress and hardship. To adapt, family members must learn new coping strategies and make sufficient use of formal and informal support systems in the community. The authors examined cultural variations in the coping and adaptation process among three main ethnic groups in Singapore (Chinese, Malay, and Indian). Interviews conducted with primary caregivers in 30 families showed cross-cultural differences in the adverse effects on the family system, the use of coping strategies, and the utilization of support networks. A culturally sensitive, indigenous model of community mental health services designed to overcome family resistance is presented.'

COMMUNITY SERVICES; COMPARATIVE STUDIES; ETHNICITY; FAMILY;
MENTAL ILLNESS; PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS;
SINGAPORE

- 175 Berman, Stephen, Nancy Delaney, Dolores Gallagher, Phyllis Atkins and Mark P. Graeber (1987), 'Respite care: a partnership between a Veterans Administration nursing home and families that care for frail elders at home', *The Gerontologist*, 27(5), 581-4.

'Described is the 10-bed respite program which provided 4 weeks of inpatient care over a 1 year period to frail older veterans who lived with an unpaid caregiver. Since its inception, the 850 families who received the program's services were taught health care delivery skills needed to maintain a disabled person at home and how to build community support systems. The program has prevented premature or

inappropriate placement by providing training and relief to sustain the in-home caregiver.'

CASE STUDIES; EDUCATION; RESPITE CARE; UNITED STATES

- 176 Berry, Greta L., Steven H. Zarit and Vince X Rabatin (1991), 'Caregiver activity on respite and nonrespite days: a comparison of two service approaches', *The Gerontologist*, 31(6), 830-5.

'Use of time was examined among female caregivers of dementia patients who used home care (n=20) and day care (n=20) respite services. Assessment of caregiver activity during respite and nonrespite days revealed significant program differences in the amount of caregiving time. Use of respite time was also examined. Significant predictors of willingness to continue care were identified. Ratings of program satisfaction were very high.'

DAY CARE; DEMENTIA; GENDER; RESPITE CARE; UNITED STATES

- 177 Biegel, David E. and Arthur Blum, eds (1990), *Aging and Caregiving: Theory, Research and Policy*, Sage, Newbury Park, Calif., Sage Focus Editions Vol.110, 294pp.

The first two chapters of this book provide 'a review and assessment of the current state of theory and research with an emphasis on gaps in the current literature. The following chapters present new theoretical approaches, research studies, and policy analyses...responsive to the current gaps in knowledge'. The goal is 'to provide new insight and to give direction for future developments.' The book is deliberately interdisciplinary in nature. Part 1 covers theory, conceptual framework and methodology; Part 2, research - cognitive and physical impairment; and Part 3, public policy perspectives.

CONCEPTUAL ISSUES; HEALTH; LITERATURE REVIEW; METHODOLOGY; POLICY; PSYCHOLOGICAL ASPECTS; THEORY DEVELOPMENT; UNITED STATES

- 178 Biegel, David E., Esther Sales and Richard Schulz (1991), *Family Caregiving in Chronic Illness: Alzheimer's Disease, Cancer, Heart Disease, Mental Illness, and Stroke*, Sage, Newbury Park, Calif., Family Caregiver Applications Series Vol.1, 332pp.

This book examines five specific diseases: cancer, heart disease, stroke, Alzheimer's disease, and chronic mental illness, and develops a conceptual framework identifying key variables which are used to examine family caregiving across these diverse population groups. The book begins with an examination of 'demographic, economic, social, and technological trends leading to the emergence of caregiving as

a major societal issue; provides an overview of the nature and extent of family caregiving; discusses the meaning and impact of chronic illness; and analyzes the status of caregiving research from an historical perspective'. For each of the diseases examined there is a discussion of the nature of the disease, psychosocial reactions of patients and their caregivers, a brief summary of existing services to patients and caregivers and a summary of existing research on caregiver stress and outcome. The variables identified in the conceptual framework are used to summarise both existing knowledge and gaps in the literature. Research knowledge for each of the five diseases is then synthesised to identify general similarities and differences in caregiving roles and relationships. Intervention models for the five population groups are examined, with separate discussions of support groups, educational interventions and the provision of direct services. The literature on the effects and impacts of intervention models is reviewed. The book offers a dual level of analysis. It uses empirical research findings pertaining to specific problem populations to tease out commonalities and differences in caregiving issues, and suggests new directions for research and practice.

CANCER; CARDIOVASCULAR DISEASE; CHRONIC ILLNESS;
COMMUNITY SERVICES; CONCEPTUAL ISSUES; DEMENTIA;
DEMOGRAPHIC ASPECTS; EDUCATION; HISTORICAL ASPECTS;
LITERATURE REVIEW; MENTAL ILLNESS; PSYCHOLOGICAL ASPECTS;
SOCIAL ASPECTS; STROKE; UNITED STATES

- 179 Biegel, David M., David M. Bass, Richard Schulz and Richard Morycz (1993), 'Predictors of in-home and out-of-home service use by family caregivers of Alzheimer's disease patients', *Journal of Aging and Health*, 5(4), 419-38.

'Few studies have examined whether the use of different types of services is predicted by different characteristics of elderly care recipients and primary kin caregivers. Most research aggregates services into a single category, thereby assuming that different services have the same predictors. This investigation differs from the aggregation approach by comparing four groups of elderly care recipients: in-home service users, out-of-home service users, users of both in- and out-of-home services, and those who do not use services. Data come from personal interviews with 171 family caregivers of mild to moderate dementia patients who reside in the community. Using the modified Andersen framework and multiple group discriminant analysis, results show that care recipients who do not use services and those using only in-home services have inadequate informal supports, more emotionally strained caregivers, and more functionally impaired care recipients compared with users of out-of-home or both in- and out-of-home services.'

COMPARATIVE STUDIES; DEMENTIA; METHODOLOGY; SERVICE USE;
UNITED STATES

- 180 Birchwood, Max and Raymond Cochrane (1990), 'Families coping with schizophrenia: coping styles, their origins and correlates', *Psychological Medicine*, 20, 857-65.

'An analysis of the coping styles adopted by relatives of schizophrenic patients has been identified by many reviewers as essential to an understanding of the complex interactions between patient and caregiver and the origins of relatives' expressed emotion (EE). This study reports a taxonomy of coping behaviour derived from interviews with relatives of schizophrenic patients. It was found that relatives adopted broad styles of coping across all areas of patients' behaviour change. Relationships were uncovered between the styles and (a) relatives perceived control, burden and stress, (b) patients' social functioning, severity of behavioural disturbance and progress of the illness. It is suggested that advising relatives of changes in their coping styles in the course of family intervention must be tempered with an understanding of their origins in patients' behaviour. Further research is recommended to identify the coping styles associated with the high EE/low EE research classification.'

MENTAL ILLNESS; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS;
UNITED KINGDOM

- 181 Bledin, K.D., B. MacCarthy, L. Kuipers and R.T. Woods (1990), 'Daughters of people with dementia: expressed emotion, strain and coping', *British Journal of Psychiatry*, 157, 221-7.

'Twenty-five women who were the primary carers for a parent with dementia were rated for expressed emotion (EE) and then divided into two groups: 11 with low-EE ratings and 14 with high-EE ratings. Although there were no differences between these groups in the levels of their parents' cognitive impairment, when such impairment was taken into account, high-EE subjects were found to report higher levels of strain and distress. More efficient coping strategies were reported by subjects who made fewer critical comments and more positive remarks. High-EE subjects more frequently had no living siblings, and were more likely to have had a respite break from caring. EE status was not associated with continuing care in the community at a nine-month follow-up.'

DAUGHTERS; DEMENTIA; PSYCHOLOGICAL ASPECTS; UNITED
KINGDOM

- 182 Blieszner, Rosemary and Peggy A. Shifflett (1989), 'Affection, communication, and commitment in adult-child caregiving for parents with Alzheimer's disease', in Jay A. Mancini, ed., *Aging Parents and Adult Children*, Lexington Books, Lexington, Mass., 231-43.

The chapter reports on a study that examined the feelings of adult children about caring for their parents under the difficult and intensive circumstances of

Alzheimer's disease. It explored 'the effects of this disease on aspects of the parent-child relationship such as affection, communication, and commitment, to better understand perceptions about the adult child role of those who meet this most demanding challenge.' It was found that 'interventions aimed at reinforcing and supporting caregiver's feelings of personal commitment to patients may be more acceptable to caregivers and more successful in alleviating their feelings of burden than those dealing with external constraints.'

DAUGHTERS; DEMENTIA; GENDER; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; SONS; UNITED STATES

- 183 Blieszner, Rosemary and Raeann R. Hamon (1992), 'Filial responsibility: attitudes, motivators, and behaviors', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 105-19.

This chapter reviews 'the literature on attitudes of filial obligation, motivations to carry out filial duties, and filial role enactment in the form of parental caregiving, with an emphasis on gender differences in these areas.' It concludes with 'an analysis of theoretical explanations for gender differences in filial attitudes and behaviors and suggestions for future research.'

DAUGHTERS; LITERATURE REVIEW; SONS; THEORY DEVELOPMENT;
UNITED STATES

- 184 Blust, Evangelina P. Novero and Rick J. Scheidt (1988), 'Perceptions of filial responsibility by elderly Filipino widows and their primary caregivers', *International Journal of Aging and Human Development*, 26(2), 91-106.

'This study assessed perceptions of filial responsibility among forty older Filipino mothers and their primary caregiver daughters from two urban and two rural barangays in the town of Los Banos (39 miles southeast of Manila). Using parallel standard structured interview measures, perceptions of filial expectations and filial behaviors were gathered across five categories of parental support: financial and material aid; personal care; service provision; respect; and warmth and affection. Intragenerational comparisons (analyses of variance) showed that widows' reports of actual amount of support received significantly exceeded their expectations for most forms of aid. In contrast, daughters' expectations for level of parental support exceeded their behaviors, but only for the more instrumental forms of aid. Intergenerational comparisons (t-test analyses) revealed that daughters held reliably higher filial expectations for almost all forms of support than did their mothers. Comparisons of reports of actual support showed intergenerational consensus on the

whole. Implications of these data for research and intervention in this area are discussed.'

COMPARATIVE STUDIES; DAUGHTERS; FINANCIAL ASPECTS;
RELATIONSHIPS; RURAL ASPECTS; PHILIPPINES

- 185 Bonjean, Marilyn J. (1988), 'Psychotherapy with families caring for a mentally impaired elderly member', in Catherine S. Chilman, Elam W. Nunnally and Fred M. Cox, eds, *Chronic Illness and Disability*, Sage Newbury Park, Calif., 141-55.

'The objectives of this chapter are to provide a profile of the challenges facing family caregivers of dementia patients and to outline a model for psychotherapy with these families.'

DEMENTIA; FAMILY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 186 Borsay, Anne (1990), 'Disability and attitudes to family care in Britain: towards a sociological perspective', *Disability, Handicap & Society*, 5(2), 107-22.

'Attitudes to family care are critical to the quality of community support offered to people with physical and mental handicaps. Yet despite their importance, they have attracted comparatively little social research. This paper examines the "hotchpotch" of material which is available through the eyes of psychology and sociology. The potential of the psychologist's four-part anatomy of attitudes is recognised: the perceptual, evaluative, affective and behavioural components. However, attention is drawn to the narrow, consensual framework within which these components are often placed, and an alternative sociological or structural model is developed for family care, where the attitudes of disabled people and their relatives are seen as products of the family's socio-economic role. The conclusion discusses some of the policy implications.'

DISABLED; LITERATURE REVIEW; METHODOLOGY; POLICY;
PSYCHOLOGICAL ASPECTS; SOCIOECONOMIC STATUS; THEORY
DEVELOPMENT; UNITED KINGDOM

- 187 Bowling, Ann (1982), 'I feel so responsible', *Community Care*, October, 13-15.

Samples from interviews with the carers of elderly widowed people in England show that their need for support is acute. There is discussion of the ways their lives are affected and suggestions for relief.

BEREAVEMENT; QUALITATIVE STUDY; POLICY; SOCIAL ASPECTS;
UNITED KINGDOM

- 188 Bowling, Ann (1984), 'Caring for elderly widowed: the burdens on their supporters', *British Journal of Social Work*, 14(5), 435-55.

'This paper examines how caring for elderly widowed people affects the lives of their "families". This study is part of a larger national study on widowhood in old age carried out by the Institute for Social Studies in Medical Care. The families tended to be the children of the widowed, particularly their daughters. Children of the widowed, again often daughters, were more likely than other families to suffer life restrictions before and after the death because of the care and support given to the deceased and the surviving spouse. In addition to their caring role families were often committed to full or part-time employment and most also had their own families to support. The care they provide for the elderly is not always without cost. The contribution towards community care given by such informal helpers deserves greater recognition and the social, psychological and financial costs thus incurred merit greater relief. As the help is needed by a minority only of such informal carers, adoption of a policy relieving them as far as possible of the costs they incur, would not involve intolerable financial outlays.'

BEREAVEMENT; DAUGHTERS; EMPLOYMENT; FINANCIAL ASPECTS;
NATIONAL STUDIES; PAYMENT; POLICY; PSYCHOLOGICAL ASPECTS;
UNITED KINGDOM

- 189 Boyd, Sandra L. and Judith Treas (1989), 'Family care of the frail elderly: a new look at "women in the middle"', *Women's Studies Quarterly*, (1/2), 66-74.

Despite the warnings of the grim lot of "women in the middle" from previous research, the situation may not be as grim as was described. The life cycle helps protect women against competing family responsibilities; only a small percentage of women simultaneously care for dependent parents and children. The addition of paid employment to caregiving responsibilities may have positive as well as negative consequences. However, some women do find caregiving overwhelming and do need special assistance. 'Although being a "woman in the middle" may not be a "normative" experience, demographic trends suggest it may become more common in the future.'

DEMOGRAPHIC ASPECTS; EMPLOYMENT; MIDDLE AGED CARERS;
UNITED STATES

- 190 Briggs, Anna (1983), *Who Cares? The Report of a Door-to-Door Survey into the Numbers and Needs of People Caring for Dependent Relatives*, Rochester, Kent, Association of Carers, 33pp.

This is the report of a door-to-door survey of carers in the North Tyneside Metropolitan Borough, funded by the Equal Opportunities Commission. Its purpose is twofold: an attempt to estimate the numbers of carers in the population; and compare the population of carers with the population in general. It tested two

hypotheses: that more women than men care for relatives, and that employment status was likely to be affected by caring. It also aimed to find out whether they would be helped by joining groups which could perhaps improve their lot. The report describes the methodology used, the results of the survey and draws conclusions.

EMPLOYMENT; GENDER; METHODOLOGY; SUPPORT GROUPS; UNITED KINGDOM

- 191 Briggs, Anna and Judith Oliver, eds (1985), *Caring: Experiences of Looking After Disabled Relatives*, Routledge and Kegan Paul, London, xviii, 121pp.

Carers of disabled relatives of all ages from a wide variety of backgrounds all over the United Kingdom talk about their personal experiences of caring. The first-hand testimony is linked by the editors who provide a wider context into which these accounts fit. The concluding chapter presents the options for care and the stresses and problems faced by carers.

DISABLED; NATIONAL STUDIES; PERSONAL NARRATIVES; POLICY; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; UNITED KINGDOM

- 192 Brody, E.M. (1981), 'The dependent elderly and women's changing roles', *Mount Sinai Journal of Medicine*, 48(6), 511-19.

'This review of the literature considers the negative impact on the mental and physical health of the family caregivers, who are almost always women. Such care can restrict the family's social leisure activities, disrupt household and work routines, cause conflict and reduce income. It is particularly stressful for middle aged women who are likely to be widowed and have lowered incomes (often having had to give up paid employment) to care for elderly relatives.'

GENDER; HEALTH; LITERATURE REVIEW; MIDDLE AGED; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; SOCIOECONOMIC STATUS; UNITED STATES

- 193 Brody, E.M. (1981), '"Women in the middle" and family help to older people', *The Gerontologist*, 21(5), 471-80.

'This [article] examines myths about care of the elderly; particularly the myth that the provision of services by the formal system undermines family responsibility and encourages the family to shirk and that families repay the devotion of elderly parents by abandoning them. It also examines the roles of "women in the middle" who, in addition to their roles as paid workers and roles as wives, mothers, grandmothers, have the added roles as caregiving daughters and daughters-in-law to dependent

older people. Brody argues that attitudes about gender-appropriate roles must change and that a "revised contract" for care of the elderly must be negotiated.'

DAUGHTERS; EMPLOYMENT; FAMILY; GENDER; MIDDLE AGED
CAREGIVERS; UNITED STATES

- 194 Brody, E.M. (1983), 'Women's changing roles and help to elderly parents: attitudes of three generations of women', *Journal of Gerontology*, 38(5), 597-607.

'Elderly women, middle-generation daughters, and young-adult grand-daughters (N=403) were compared with their responses to Likert-scaled items that evaluated their attitudes toward gender-appropriate roles and the care of elderly people (including filial responsibility and the acceptability of formal and informal supports). Although significant generational differences emerged in relation to subjects' attitudes toward the sharing by men and women of household tasks and the care of children and parents, majorities of all groups of subjects favored such sharing. The oldest generation was the most receptive and the youngest least receptive to formal services for the elderly. However, all three generations agreed that elderly individuals should be able to depend on their children for help.'

AGED CAREGIVERS; DAUGHTERS; FAMILY; GENDER; MIDDLE AGED
CAREGIVERS; SERVICE USE; UNITED STATES

- 195 Brody, Elaine M. (1985), 'Parent care as a normative family stress', The Donald P. Kent Memorial Lecture, *The Gerontologist*, 25(1), 19-29.

'It is argued that parent care has become a normative but stressful experience for individuals and families and that its nature, scope, and consequences are not yet fully understood. Some of the complex factors that interact to determine filial behavior are explored. A hypothesis is advanced that may explain in part the persistence of the myth that adult children nowadays do not take care of their elderly parents as was the case in the good old days. Some of the ways in which social policy responds to knowledge about filial behavior are noted.'

FAMILY; IDEOLOGY; POLICY; THEORY DEVELOPMENT; UNITED STATES

- 196 Brody, Elaine M. (1986), 'Filial care of the elderly and changing roles of women (and men)', *Journal of Geriatric Psychiatry*, 19, 175-201.

This paper summarises 'the developments that led to parent care becoming a common phenomenon and the research information on filial care of the elderly.' This phenomenon took place at the same time as women's work force participation was increasing. Selected information from studies conducted at the Philadelphia Geriatric Center which explored the intersection of these two trends are presented to highlight

the interaction of caregivers' inner processes with values, situational factors, and the service environment. Case studies illustrate that interaction. The paper concludes with some comments about the inner processes at work when parent care becomes necessary and about women's and men's changing roles in such situations.

CASE STUDIES; EMPLOYMENT; FAMILY; GENDER; RELATIONSHIPS;
UNITED STATES

- 197 Brody, Elaine M. (1990), *Women in the Middle: Their Parent-Care Years*, Springer, New York, xv, 288pp.

This book describes the feelings, experiences and problems of 'women in the middle' who care for elderly parents. The first part of the book presents data relevant to the widespread phenomenon of women in the middle. Part II looks closely at these women and includes 24 case studies. It describes the effects of caring for a parent upon their mental and physical well-being, lifestyles and family relationships. Part II describes the effects of parent care on women who are employed and on those who do not work outside the home. It also discusses issues around the decision to institutionalise a parent. It is concluded that 'professionals, educators, researchers and policy-makers must understand the problems so that a situation that has been unrecognized and unattended too long can be alleviated.'

CASE STUDIES; DAUGHTERS; EMPLOYMENT; GENDER; HEALTH;
INSTITUTIONALISATION; MIDDLE AGED CAREGIVERS;
PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SOCIAL ASPECTS; UNITED
STATES

- 198 Brody, Elaine M., Pauline T. Johnson, Mark C. Fulcomer and Abigail M. Lang (1983), 'Women's changing roles and help to elderly parents: attitudes of three generations of women', *Journal of Gerontology*, 38(5), 597-607.

Data from three generations of women on the effects of women's changing roles on attitudes towards responsibility for care of elderly adults are presented in this article. 'The oldest generation was most receptive (and the youngest the least receptive) to formal services for elderly persons, but all three generations agreed that old people should be able to depend on adult children for help. Values about family care of elderly adults have not eroded despite demographic and socioeconomic changes.'

DAUGHTERS; FAMILY; GENDER; RELATIONSHIPS; SERVICE USE;
SOCIAL ASPECTS; UNITED STATES

- 199 Brody, E.M., Pauline T. Johnson and Mark C. Fulcomer (1984), 'What should adult children do for elderly parents? Opinions and preferences of three generations of women', *Journal of Gerontology*, 39(6), 736-46.

'Three generations of women (N=403) were surveyed to discover their opinions about appropriate filial behaviour toward elderly parents and their personal preferences among various providers of services that might be needed in old age. Opinions were elicited by a vignette focused on what hypothetical adult children with differing situational characteristics should do to help meet the needs of their dependent widowed mother. Preferences were obtained from subjects' rankings of six potential providers (representing formal and informal support systems) for eight types of services. In the responses to the vignette, adjustment of family schedules and help with costs of professional health care were seen as appropriate for adult children, but adjustment of work schedules and sharing of households were not. For themselves, the women preferred adult children as providers of emotional support and financial management but not of income. The middle generation was least in favour of receiving financial support or instrumental help from children, preferring formal services for such assistance.'

DAUGHTERS; FAMILY; FINANCIAL ASPECTS; GENDER; RELATIONSHIPS; SERVICE USE; UNITED STATES

- 200 Brody, Elaine M. and Claire B. Schoonover (1986), 'Patterns of parent-care when adult daughters work and when they do not', *The Gerontologist*, 26(4), 372-81.

'Patterns of help to disabled elderly widows are described as they vary when caregiving adult daughters work and when they do not. Mothers of the 2 work-status groups received the same total number of hours of help from all sources combined. Employed and nonworking daughters provided equal amounts of help with shopping/transportation, household tasks, managing money/service arrangement, and emotional support. Workers provided less personal care and cooking than nonworkers, with the difference being offset by purchased help.'

COMPARATIVE STUDIES; DAUGHTERS; EMPLOYMENT; UNITED STATES

- 201 Brody, Elaine M., Morton H. Kleban, Pauline T. Johnson, Christine Hoffman and Claire B. Schoonover (1987), 'Work status and parent care: a comparison of four groups of women', *The Gerontologist*, 27(2), 210-08.

'Four groups of parent caring daughters were compared. Two groups were nonworkers: traditional homemakers and those who had quit jobs to help their mothers. Two groups were workers: the "conflicted", who had reduced their working hours or considered quitting and those who had not. The conflicted workers and women who had quit work had the most impaired mothers and more of them had experienced lifestyle disruptions and caregiving strain. Both groups of workers were

more career-oriented; both groups of nonworkers help more traditional views of women's roles.'

COMPARATIVE STUDIES; DAUGHTERS; EMPLOYMENT; UNITED STATES

- 202 Brody, E.M., M.H. Kleban, C. Hoffman and C.B. Schoonover (1988), 'Adult daughters and parent care: a comparison of one-, two- and three-generation households', *Home Health Care Services Quarterly*, 9(4), 19-45.

'This paper compares the effects of parent-care associated with three living arrangements of elderly widowed mothers who were being helped by married daughters: elderly mother living separately; two-generation households (mothers, daughters, sons-in-law); and three-generation households (grandchildren present). Daughters whose mothers lived separately fared the best; their mothers were the most cognitively and functionally capable and the daughters reported the fewest negative effects of caregiving. Daughters in two-generation households provided the most care; their mothers were the oldest and the most impaired. Since daughters in three-generation households reported more negative mental and emotional effects of care, the unique problems of caregiving in such households are discussed.'

COMPARATIVE STUDIES; DAUGHTERS; FAMILY; LIVING ARRANGEMENTS; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 203 Brody, Elaine M., Christine Hoffman, Morton H. Kleban and Claire B. Schoonover (1989), 'Caregiving daughters and their local siblings: perceptions, strains, and interaction', *The Gerontologist*, 29(4), 529-38.

This study compares daughters who are principal caregivers to disabled elderly mothers with their geographically proximate sisters and brothers as to the amount of help each group provides, the effects of care they experience, and the problems and benefits of the siblings' interactions about the caregiving situation.

COMPARATIVE STUDIES; DAUGHTERS; RELATIONSHIPS; SONS; UNITED STATES

- 204 Brody, Elaine M., Avalie R. Saperstein and M. Powell Lawton (1989), 'A multi-service respite program for caregivers of Alzheimer's patients', *Journal of Gerontological Social Work*, 14(1/2), 41-74.

'This paper describes the services and procedures of the Philadelphia Geriatric Center's multi-service respite service demonstration project for 305 caregivers of elderly Alzheimer's patients. Selected sections of data are reported that provide information needed by professionals for planning and delivering such services. Of all caregivers who were offered respite, 52% actually availed themselves of the services. Of those, two-thirds chose in-home services, with smaller proportions using

day care and institutional respite. Reasons for such choices and for the non-use of respite, the advantages and problems of different types of respite, and implications for development of respite programs are discussed.'

CASE STUDIES; DEMENTIA; RESPITE CARE; SERVICE USE; UNITED STATES

- 205 Brody, Elaine M., Norah P. Dempsey and Rachel A. Pruchno (1990), 'Mental health of sons and daughters of the institutionalized aged', *The Gerontologist*, 30(2), 212-9.

'Predictors of depression in a study of 331 adult children whose parents resided in nursing homes were respondent's poor health, time pressures, viewing their parent as demanding, and lack of involvement with IADL tasks. Emotional effects specific to parent's situation were predicted by poor health, negative perceptions of nursing home staff, upsetting visits, time pressures, and being female and young. Predictors of depression and emotional effects between sons and daughters are compared.'

COMPARATIVE STUDIES; DAUGHTERS; HEALTH; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; SONS; UNITED STATES

- 206 Brody, E.M., S.J. Litvin, C. Hoffman and M.H. Kleban (1992), 'Differential effects of daughters' marital status and their parent care experiences', *The Gerontologist*, 32(1), 58-67.

'This study compared the parent care experiences of five groups of daughters (N=492) (married, remarried, separated/divorced, widowed, and never married). Data include demographic characteristics and measures of depression, positive affect, personality strength, health, social support, relationship quality, caregiving burden, caregiving mastery, and caregiving satisfaction. Women with husbands had more socio-emotional and instrumental support, much higher incomes, less financial strain from caregiving, and less depression. They felt their own particular marital status made caregiving easier than did the three groups of not-married women.'

COMPARATIVE STUDIES; DAUGHTERS; DEMOGRAPHIC ASPECTS; FINANCIAL ASPECTS; HEALTH; METHODOLOGY; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SUPPORT NETWORKS; UNITED STATES

- 207 Brotchie, Jane and Dione Hills (1991), *Equal Shares in Caring*, Socialist Health Association, London, Towards Equality in Health Series, 86pp.

Many inequalities exist in people's experiences of community care and these demand action. Changing demographic patterns make this issue all the more urgent as the numbers of people requiring care is increasing rapidly while changes in family

life and working patterns mean there are less people available to provide it. 'Public policy and employment practices have barely begun to catch up with these trends. Community care and employment policies are currently working in absolute contradiction to each other.' Women are particularly disadvantaged. 'This report attempts a global view of the issues because the authors argue that community care must be addressed by a broad policy agenda. This means improving opportunities for employment, income maintenance, housing, transport, physical access - as well as personal and health services. Information has been gathered from a number of sources: personal accounts, research studies, government reports, statements from action groups on disability and caring, as well as the authors' own experiences in working in the field.' The report suggests some of the main lessons to be learned and makes recommendations for change.

COMMUNITY SERVICES; EMPLOYMENT; GENDER; HOUSING; INCOME SUPPORT; POLICY; TRANSPORT; UNITED KINGDOM

- 208 Brown, Hilary and Helen Smith (1993), 'Women caring for people: the mismatch between rhetoric and women's reality', *Policy and Politics*, 21(3), 185-93.

'This paper explores the implications, for women, of the new structures and systems which are being introduced in the "Working for patients" and "Caring for people" legislation. An exploration which focuses on women is urgent, given their predominance as both paid and unpaid workers in, and users of, community care services. The fundamental changes which are being introduced, ostensibly to empower the disadvantaged and give them more choice and influence, will fail if they do not directly address and draw links between the experiences of women on the giving and receiving end of service delivery.'

COMMUNITY SERVICES; GENDER; POLICY; SERVICE USE; UNITED KINGDOM

- 209 Brown, Lisa J., Jane F. Potter and Betty G. Foster (1990), 'Caregiver burden should be evaluated during geriatric assessment', *Journal of the American Geriatrics Society*, 38(4), 455-60.

'This study examines the relationship between caregiver burden and use of long-term care services following geriatric assessment. One hundred nine older subjects underwent comprehensive assessment, which included a questionnaire completed by the primary caregiver to assess the sense of burden in providing care. Logistic regression was used to identify independent predictors of service use at 12 months. Among measures of the older person's cognitive and physical abilities, only activities of daily living predicted increased use of services. When the measure of caregiver burden was added, it also entered as an independent predictor, which significantly improved the prediction of service use...In a separate analysis, caregiver

burden predicted both the use of home services and nursing-home placement. During longitudinal follow-up, the measure of burden decreased over 12 months for the sample, with the greatest reduction in burden occurring for caregivers whose relative was placed in a nursing home. The fact that caregiver burden was the most important factor in determining who would use formal services suggests that burden should be evaluated as part of geriatric assessment.'

INSTITUTIONALISATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
SERVICE USE; UNITED STATES

- 210 Browne, Colette and Roberta Onzuka-Anderson (1985), *Our Aging Parents: A Practical Guide to Eldercare*, University of Hawaii Press, Honolulu, 278pp.

This book 'provides practical suggestions for families faced with caring for a dependent elder at home.' It includes information on community services, institutionalisation, care of the aged at home, the role of the family, and techniques for financial management, setting limits and minimising stress.

COMMUNITY SERVICES; EDUCATION; FAMILY; FINANCIAL ASPECTS;
HEALTH; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; UNITED STATES

- 211 Brubaker, Ellie and Timothy H. Brubaker (1992), 'The context of retired women as caretakers', in Maximiliane Szinovacz, David J. Ekerdt, and Barbara H. Vinick, eds, *Families and Retirement*, Sage, Newbury Park, Calif., Sage Focus Editions Vol.137, 222-35.

Research on caregiving has tended to focus on descriptions of the caregivers and the stress associated with caregiving with little attention being paid to the process of caring for a dependent older person. 'What individual, familial, and social factors are important in understanding the development of stress in the caregiving situation? What are the individual, familial and social contexts in which caregiving occurs?...The primary objectives of this chapter are to discuss the caregiving situation during retirement from a contextual framework. This discussion is limited to retired women who are presently involved in caregiving.' It is suggested that the caregiver's retirement expectations will impact on the caregiving situation for the individual, the recipient of care and other family members and on the caregiver's resources. 'Further research should focus on the effects of caregiving on retirement plans, retirement timing, and retirement adaptation as well as on the impact of retirement has on the caregiver's resources, feelings of burden, and stress.'

AGED CAREGIVERS; GENDER; PSYCHOLOGICAL ASPECTS; SOCIAL
ASPECTS; UNITED STATES

- 212 Brubaker, Timothy H. (1990), 'A contextual approach to the development of stress associated with caregiving in later-life families', in Mary Ann Parris Stephens, et al., eds, *Stress and Coping in Later-Life Families*, Hemisphere, New York, 29-47.

This chapter focuses on later-life families and, in particular, the development of family stress that is due to caregiving. It discusses the unique aspects of later-life families and reviews research on family structure, caregiving, and stress. Finally, based on family stress literature, it presents a contextual approach to the development of family stress in caregiving families.

FAMILY; LITERATURE REVIEW; PSYCHOLOGICAL ASPECTS; THEORY DEVELOPMENT; UNITED STATES

- 213 Brubaker, Timothy H. and Ellie Brubaker (1989), 'Toward a theory of family caregiving: dependencies, responsibility, and use of services', in Jay A. Mancini, ed., *Aging Parents and Adult Children*, Lexington Books, Lexington, Mass., 245-57.

The family situations in which caregivers to the elderly are involved are heterogeneous. This has resulted in a variety of formal policies, programs and services for caregiving yet lack of use of these services often prevents them from carrying out their intended purpose. A theory of family caregiving, in relation to use of services, is needed. 'Within this chapter, a theory is developed about family caregiving and the use of services. The crucial concepts in understanding the use of services include: the types of dependencies experienced by recipients of family care; perceptions of responsibility for provision of services; and individual and family ethos. Family caregiving literature is reviewed, a model is presented and its use in working with caregiving families is illustrated through a case example.'

CASE STUDIES; DEPENDENCY; FAMILY; LITERATURE REVIEW; SERVICE USE; THEORY DEVELOPMENT; UNITED STATES

- 214 Bulcroft, Kris, June Van Leynseele and Edgar F. Borgatta (1989), 'Filial responsibility laws: issues and state statutes', *Research on Aging*, 11(3), 374-93.

'A review of the state statutes on filial responsibility was conducted in the summer of 1988 in order to determine the current governmental orientations toward family support of the elderly. At the present time, 30 states have standards regarding filial responsibility. Variations between state statutes exist with regard to definitions of need for support of an older family member, who was to be held accountable for support, penalties for nonsupport, and enforcement procedures. The constitutionality of current state statutes is discussed, and consideration is given concerning the

feasibility of such filial responsibility statutes based on the notion of the "traditional" family.'

FAMILY; LEGAL ASPECTS; NATIONAL STUDIES; POLICY; UNITED STATES

- 215 Burdz, Michael P., Warren O. Eaton and John B. Bond (1988), 'Effect of respite care on dementia and nondementia patients and their caregivers', *Psychology and Aging*, 3(1), 38-42.

'The impact of a respite care program on the cognitive and physical functioning of dementia and nondementia patients, and on the burden perceived by their caregivers, was assessed in a pretest-posttest design. A total of 55 caregivers were interviewed twice, 5 weeks apart. In the respite group, the caregiver's patient experienced a 2-week respite stay in a nursing home during the 5-week interval, whereas in the waiting-list comparison group, the patient experienced ongoing in-home care during the interval...[It was] hypothesized that the patient diagnosis (dementia vs nondementia) would interact with respite exposure, with nondementia patients showing more improvement from respite than dementia patients. Regardless of diagnosis, however, positive effects from respite exposure were found for caregiver reports of the patient's memory and behavior.'

COMPARATIVE STUDIES; DEMENTIA; RESPITE CARE; UNITED STATES

- 216 Burnley, Cynthia S. (1987), 'Caregiving: the impact on emotional support for single women', *Journal of Aging Studies*, 1(3), 253-64.

'Even though filial caregivers are typically daughters rather than sons, examinations of caregiving have not adequately considered the impact of gender and marital status differences on the support systems that mediate the strain of caring. Because of competing demands on time and energy, caregivers make many changes in their personal activities while maintaining work and immediate family responsibilities. The friendships that provides emotional support for singles are perceived as less important than familial relationships. Therefore, the assumption is made that the single adult daughter has less to give up as compared to her married siblings. The parallel emotional support systems of the married and single caregivers go unrecognized. This study of never-married women over age 30 reveals that these caregivers essentially foreclosed social relationships in order to provide care.'

DAUGHTERS; EMPLOYMENT; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SOCIAL ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 217 Bytheway, Bill (1989), 'Poverty, care and age: a case study', in Bill Bytheway, Teresa Keil, Patricia Allatt and Alan Bryman, eds, *Becoming and Being Old: Sociological Approaches to Later Life*, Sage, London, 93-103.

The main focus of a study of informal care in families of older redundant South Wales steelworkers was the informal care system. This chapter provides a case study from the study that illustrates how care is provided within and between households. It raises a number of issues about poverty, disability, gender and the production of family care. It also provides good evidence of the dramatic changes that have occurred over the last thirty years in the process of becoming old.

CASE STUDIES; FAMILY; GENDER; SOCIOECONOMIC STATUS; SUPPORT NETWORKS; UNITED KINGDOM

- 218 Cairl, Richard E. and Jordan I. Kosberg (1993), 'The interface of burden and level of task performance in caregivers of Alzheimer's disease patients: an examination of clinical profiles', *Journal of Gerontological Social Work*, 19(3/4), 133-51.

'This paper examines four distinct clinical profiles of caregivers of Alzheimer's Disease patients. The four groups were empirically derived relative to their respective levels of burden and task performance. Each of the four groups are uniquely distinguished by a set of caregiver background, caregiver status, and patient status comparative factors. The implications of the determined heterogeneity of the four groups are discussed with direct reference to future policy/program issues and research issues.'

COMMUNITY SERVICES; DEMENTIA; POLICY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 219 Callahan, Daniel (1988), 'Families as caregivers: the limits of morality', *Archives of Physical Medical Rehabilitation*, 69(5), 323-8.

'There is a developing trend to look to families to provide care and support to those in need of rehabilitation. A widespread assumption is that family care is superior care and, with modest degrees of support, families can provide that care. Yet we may question the ethical limits of the obligation of a family or family member to provide care when the demands are severe. Psychologic and moral problems that confront caregivers are examined. In some cases caregivers must sacrifice their present and future welfare. That the moral claim made upon them may seem a justifiable one in many respects does not mean that it will be endurable; that it is endurable does not mean that it is justifiable. The problem is exacerbated by lack of a supportive culture, one that rewards and honors those who take on heroic duties. Caregivers

may be socially isolated. If heroic demands are to be made on family members, a richer moral culture is required, not just the provision of improvised social services.'

FAMILY; IDEOLOGY; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS;
UNITED STATES

- 220 Campbell, Ruth and Elaine M. Brody (1985), 'Women's changing roles and help to the elderly: attitudes of women in the United States and Japan', *The Gerontologist*, 25(6), 584-92.

'A three-generation study of women's attitudes toward gender-appropriate roles and filial responsibility was conducted by the Philadelphia Geriatric Center and replicated by the Tokyo Metropolitan Institute of Gerontology. U.S. gender-role attitudes were more egalitarian than those of the Japanese. In both countries, all three generations agreed that care of the elderly is a family responsibility, but attitudes toward filial responsibility were more positive among the Americans than among the Japanese.'

FAMILY; GENDER; INTERNATIONAL COMPARISONS; JAPAN; UNITED STATES

- 221 Cantor, Marjorie H. (1983), 'Strain among caregivers: a study of experience in the United States', *The Gerontologist*, 23(6), 597-604.

This article attempts to shed light on the variety of informal caregivers of the frail elderly and how the caregiving experience affects their lives. The data are drawn from a study of a major homemaker service funded by the New York City Department for the Aging, which provides 12 hours of service over 12 weeks. Clients and their caregivers were interviewed shortly after the commencement of the service and again after termination of the service. The findings suggest the extent of stress and dislocation involved in the role of the primary caregiver for the frail elderly. The amount of stress is different for different groups of caregivers - the closer the bond, the more stressful the caregiving role. The issue is what combination of financial aid, counselling, in-home and respite services are needed by which group of caregivers.'

PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED STATES

- 222 Cantor, Marjorie H. (1985), 'Families: a basic source of long-term care for the elderly', *Aging*, (349), 8-13.

Given the growing number of older people, in particular the rapid expansion in the numbers of those eighty and over, the role of the family is crucial from both the individual and societal points of view. Although there has been a shift in the importance of familial and societal roles with regard to the elderly in such areas as

income maintenance, health and housing, the family has by no means been supplanted by formal organisations. The social supports needed by the elderly are examined and in the United States the family remains the primary caretaker of the elderly, although for those who are childless, other relatives, friends and neighbours compensate as primary social supports. Changes in the family structure and the trend to more working women show no indication of the abandonment of filial responsibility, so carers (mainly women) are coping through considerable personal sacrifice. Something must be done to ease the burden on carers. More attention needs to be given to secondary informal systems based on neighbours and friends. Proper interaction between informal and formal systems is also crucial, and in times of financial restraint the informal system must not be offered as the only viable one.

FAMILY; GENDER; RELATIONSHIPS; SUPPORT NETWORKS; UNITED STATES

- 223 Caserta, Michael S., Dale A. Lund, Scott D. Wright and David E. Redburn (1987), 'Caregivers to dementia patients: the utilization of community services', *The Gerontologist*, 27(2), 209-14.

'Among 597 family caregivers to noninstitutionalized dementia patients, respite-oriented services were perceived as the most needed and, also, utilized the most. Of the 43% who knew of available services more than one-half were utilizers of respite-oriented services. Those not ready to use services, who were more likely to be spouses caring for younger patients with less impairment, reported significantly less burden and more social support. Those caregivers who did not use services for other reasons, however, were generally similar to utilizers.'

DEMENTIA; RESPITE CARE; SERVICE USE; UNITED STATES

- 224 Caserta, Michael S., J. Richard Connelly, Dale A. Lund and James L. Poulton (1987), 'Older adult caregivers and developmentally disabled household members: service needs and fulfillment', *Gerontological Social Work with Families*, 10(1/2), 35-50.

'The purpose of this study was to evaluate the extent to which there is a need for formal support services among older caregivers with individuals in their homes who are developmentally disabled or intellectually handicapped (DD/IH). The factors which influenced the fulfillment of such service needs were also explored. Information was obtained from a sample of 198 caregivers ranging in age from 50-84, concerning services needed and received, perceived health, competence, difficulty in locating services, as well as a variety of sociodemographic data. The sample reported a significant need for a number of key services, including housekeeping, home repairs, personal counseling, legal services, and physician's services. Only the identified need of physician's services was adequately filled. Multiple regression analyses revealed that perceived health was the strongest

predictor of need fulfillment among those caregivers 60 years of age or older, while difficulty in locating services and perceived competence were influential in explaining need fulfillment of those caregivers between the ages of 50-59. Implications for public policy and future research are discussed.'

AGED CAREGIVERS; COMMUNITY SERVICES; DISABLED; HEALTH;
MIDDLE AGED CAREGIVERS; POLICY; SERVICE USE; SOCIOECONOMIC
STATUS; UNITED STATES

- 225 Cattanach, Lynn and Jacob Kraemer Tebes (1991), 'The nature of elder impairment and its impact on family caregivers' health and psychosocial functioning', *The Gerontologist*, 31(2), 246-55.

'This study assessed the nature of elder impairment and its impact on the healthy psychosocial functioning of family caregivers. All caregivers were daughters or daughters-in-law living with an elderly parent. Contrary to expectations and previous research, no differences were revealed among caregivers of cognitively impaired, functionally impaired, and nonimpaired elderly relatives in terms of self-reported health or psychosocial functioning. Thus, other aspects of the caregiving context, such as familial generation, general and living arrangement, may affect caregiver health and psychosocial functioning more than the nature of the elder's impairment.'

DAUGHTERS; DEMENTIA; HEALTH; METHODOLOGY; PSYCHOLOGICAL
ASPECTS; SOCIAL ASPECTS; UNITED STATES

- 226 Cavanaugh, John C., Nancy Jo Dunn, Doug Mowery, Cathy Feller, George Niederehe, Ernest Frugé and Darci Volpendesta (1989), 'Problem-solving strategies in dementia patient-caregiver dyads', *The Gerontologist*, 29(2), 156-8.

'Examined was the applicability of concepts of the zone of proximal development and scaffolding to the study of dementia. Caregiver-patient dyads were compared to normal elderly dyads in the instructional strategies they used to complete the Block Design subtest of the WAIS-R. Shown by the results was that the use of a detailed behavioral coding scheme was successful in documenting systematic differences between the two groups. Potential use in assessment and intervention is discussed.'

COMPARATIVE STUDIES; DEMENTIA; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 227 Challis, David and Bleddyn Davies (1991), 'Improving support to carers: a considered response to Parker's critical review', *Ageing and Society*, 11(1), 69-73.

This is a rejoinder to the critical review of Gillian Parker in *Ageing and Society*, 10(4), December:459-67 which questioned the role of case management in meeting the needs of carers. It replies to some of the criticisms of methodology and experimental design and her comments on the costs borne by informal carers and states 'that the results of several studies indicate that the form of case management model described in these service developments improved the well being of carers compared with traditional services', however, it cannot be a 'panacea' and 'can at best only ameliorate the difficult circumstances within which carers are placed'.

COMMUNITY SERVICES; METHODOLOGY; UNITED KINGDOM

- 228 Chappell, Neena L. (1991), 'Living arrangements and sources of caregiving', *Journal of Gerontology: Social Sciences*, 46(1), 1-8.

'This study examined both the prevalence of different types of caregivers (in terms of the relations to the individual), and whether living with someone is more important for caregiving than the relation of an elder to an individual. Caregiving is examined in terms of IADL and emotional support. Analyses are conducted using three separate random samples of those who are married and living with a spouse, those who live alone, and those who live with nonspousal others in Winnipeg, Manitoba, Canada. The results confirm previous research pointing out that married people tend to receive assistance from their spouse. Among nonmarrieds, children are named most frequently as the primary caregiver. After children, however, those who live alone tend to receive assistance from friends, and those who live with nonspousal others receive assistance from siblings. The data further document the importance of the structural characteristic of living with someone, rather than marital status, for assistance with IADL.'

LIVING ARRANGEMENTS; CANADA

- 229 Chappell, Neena L. (1992), *Social Support and Aging*, Butterworths, Toronto, Butterworths Perspectives on Individual and Population Aging, xiv, 104pp.

This book 'critically reviews and interprets the theory, research, and policies on informal support.' There is an emphasis on gender differences in the receipt and giving of support and care throughout the book. The relationship between social support and well being and the relationship between the formal and informal care systems are also emphasised.

COMMUNITY SERVICES; GENDER; METHODOLOGY; POLICY;
RELATIONSHIPS; SOCIAL ASPECTS; SUPPORT NETWORKS; THEORY
DEVELOPMENT; CANADA

- 230 Chelst, Tamy S., Charles A. Tait and Tanya M. Gallagher (1990), 'Linguistic strategies used by normally hearing caregivers in conversations with elderly hearing-impaired spouses', in David E. Biegel and Arthur Blum, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 204-18.

This chapter highlights a frustrating aspect of caregiving - a breakdown in communication between caregiver and care recipient. 'Utilizing a laboratory-based experimental design, the authors study the linguistic strategies used by normally hearing caregivers in conversations with simulated elderly hearing-impaired spouses. Using linguistic and communication theory previously used to explain speech development in young children, the research suggests commonalities in communication patterns which are effective with hearing-impaired elderly.'

DISABLED; METHODOLOGY; SPOUSES; UNITED STATES

- 231 Chenoweth, Barbara (1986), 'Dementia: the experience of family caregivers', *The Gerontologist*, 26(3), 267-72.

'Caregivers of family members with dementia of the Alzheimer's type were surveyed for their experiences with early symptoms, obtaining a diagnosis, home care, and institutionalization. At each stage in the process of providing care there are new and difficult stresses that can be ameliorated by appropriate professional assistance.'

DEMENTIA; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 232 Chiriboga, David A, Philip G. Weiler and Karen Nielsen (1990), 'The stress of caregivers', David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 121-38.

This chapter examines 'the multiple domains of stressors that potentially affect the lives of caregivers. The first sections deal with stress as a general topic and why it is applicable to the caregiving context. The later sections then turn to findings from a specific research project. The target population in this project consisted of adult children who provide care to a parent afflicted with Alzheimer's disease. The general argument to be presented is that a more comprehensive understanding of the stress of caregivers will be obtained when the researcher or practitioner considers not only those stressors specific to the role of caregiving but those that represent other areas of the caregiver's life.'

CONCEPTUAL ISSUES; DAUGHTERS; LITERATURE REVIEW; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; SONS; UNITED STATES

- 233 Choi, Haekyung (1993), 'Cultural and noncultural factors as determinants of caregiver burden for the impaired elderly in South Korea', *The Gerontologist*, 33(1), 8-15.

'This study investigated the determining variables of caregiver burden in caring for impaired older relatives in South Korea. Economic factors, daily caregiving hours, and caregiver's health status emerged as the most important determinants of caregiver burden in Korea. Though not a powerful predictor, caregivers' congruency with the traditional caregiver selection norms remained a statistically significant predictor of certain dimensions of caregiver burden.'

FAMILY; HEALTH; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS;
SOCIOECONOMIC STATUS; KOREA

- 234 Cicirelli, Victor G. (1981), *Helping Elderly Parents: The Role of Adult Children*, Auburn House, Boston, Mass., xvi, 199pp.

Adult children continue to be the primary caregivers to their elderly parents but in the light of present demographic, social and economic trends, it is important to clarify this role. This book examines adult children caregivers as both primary caregivers and as co-ordinators of other service providers. Data are drawn from a field survey of 164 adult children of elderly parents undertaken in the city of Lafayette, Indiana. The research plan is explained and a descriptive overview of the adult children given. Their views on the needs of their parents; their feelings towards them; and their service provision described. Conclusions are drawn and implications for the future discussed.

COMMUNITY SERVICES; DAUGHTERS; DEMOGRAPHIC ASPECTS;
METHODOLOGY; MIDDLE AGED CAREGIVERS; PSYCHOLOGICAL
ASPECTS; SOCIAL ASPECTS; SOCIOECONOMIC STATUS; SONS; UNITED
STATES

- 235 Cicirelli, Victor G. (1983), 'Adult children and their elderly parents', in Timothy H. Brubaker, ed., *Family Relationships in Later Life*, Sage, Beverly Hills, Calif., 31-46.

This chapter considers two major aspects of the parent-child relationship: the interpersonal relationships between them and the helping relationship. These aspects of the relationship are considered from the perspective of life-span attachment theory. It begins with a brief overview of attachment theory itself, and proceeds by examining the adult child's proximity to and contact with the elderly parent, the quality of the relationship with the parent and whether it depends on the amount of interaction between the two, and the helping relationship. Some of the problems in

helping an elderly parent are considered and also the effects of an adult child's marital disruption on the parent-child relationship are discussed.

DAUGHTERS; RELATIONSHIPS; SONS; THEORY DEVELOPMENT; UNITED STATES

- 236 Cicirelli, Victor G. (1983), 'Adult children's attachment and helping behavior to elderly parents: a path model', *Journal of Marriage and the Family*, 45(4), 815-25.

'Based on attachment theory, a path model was constructed in which adult children's feelings of attachment lead to their attachment behaviors and in turn to their present helping behaviors and commitment to provide future help. Also included in the model were filial obligation, dependency, interpersonal conflict, and negative feelings resulting from helping behaviors. Field study data were obtained from 148 adult children with living elderly mothers. Results indicated that present helping behaviors, attachment behaviors, and feelings of attachment had the strongest influence on commitment to provide future help. Filial obligation had an indirect influence mediated by attachment behaviors.'

DAUGHTERS; RELATIONSHIPS; SONS; UNITED STATES

- 237 Cicirelli, Victor G. (1983), 'A comparison of helping behavior to elderly parents of adult children with intact and disrupted marriages', *The Gerontologist*, 23(6), 619-25.

'The help of 141 children with disrupted marriages (divorced, widowed, remarried) was compared with that of 164 adult children with intact marriages. Little difference was found in the amount of help given by divorced, widowed and remarried subgroups. Those with disrupted marriages gave significantly ($p < .05$) less total help and less help with 7 of 16 specific services; they also perceived lower parental needs, felt less filial obligation, and felt more limited in helping, primarily due to job responsibilities. Better communication with parents, better planning, and more flexible job demands may lead to more effective help to parents.'

COMPARATIVE STUDIES; DAUGHTERS; RELATIONSHIPS; SONS; UNITED STATES

- 238 Cicirelli, Victor G. (1984), 'Marital disruption and adult children's perception of siblings' help to elderly parents', *Family Relations*, 33(4), 613-21.

'Marital disruption (divorce, widowhood, or remarriage) may limit adult children's help to elderly parents. If a child is unable to help, then other members of the family support system (siblings) will compensate by giving additional help. In a field study, 120 adult children from maritally disrupted situations and 145 adult children in intact

marriages were asked about their own siblings' help to parents. Adult children in maritally disrupted situations gave about the same amount of help as siblings, while those with intact marriages gave more help than siblings. The rise in the frequency of marital disruption makes well planned sibling shared helping more important.'

COMPARATIVE STUDIES; DAUGHTERS; RELATIONSHIPS; SONS; UNITED STATES

- 239 Cicirelli, Victor G. (1985), 'The role of siblings as family caregivers', in William Sauer and Raymond T. Coward, eds, *Social Support Networks and Care of the Elderly*, Springer, New York, 93-107.

This chapter explores the nature of the sibling relationship by examining three questions: Do most elderly people have living siblings? What is the proximity of the elderly to their siblings? What is the quantity and quality of contact among the elderly and their siblings? 'If factors leading to sibling help are understood, ways of promoting and maintaining sibling help can be devised. Sibling help may be limited in amount, but siblings do appear to fulfil important and valuable functions in old age.'

FAMILY; RELATIONSHIPS; UNITED STATES

- 240 Cicirelli, Victor G. (1986), 'A comparison of helping behavior to elderly parents of adult children with intact and disrupted marriages', in Lillian Troll, ed., *Family Issues in Current Gerontology*, Springer, New York, 123-44.

This chapter explores how divorce, widowhood, and remarriage affect adult children's behaviour toward helping elderly parents. It compares the amount of help provided to elderly parents by divorced, widowed and remarried adult children and compares this help with that provided by adult children with intact marriages. Adult children with disrupted marriages provided less help. It is recommended that there be better communication between adult children with disrupted marriages and elderly parents who are frail and dependent, so that both groups can better understand critical events in their lives and develop a better idea of what to expect of each other.

COMPARATIVE STUDIES; DAUGHTERS; RELATIONSHIPS; SONS; UNITED STATES

- 241 Cicirelli, Victor G. (1988), 'A measure of filial anxiety regarding anticipated care of elderly parents', *The Gerontologist*, 28(4), 478-82.

'Factor analysis of a 13-item instrument administered to a sample of adult children (n=71) generated two dimensions: FAA, anxiety over an anticipated caregiving role, and FAB, anxiety over the parent's anticipated decline. Both were internally

consistent. In a second sample (n=53), validity was evidenced because FAA was significantly related to measures of adult children's resources, whereas FAB was related to their attachment to the parent and perceptions of parental decline.'

DAUGHTERS; METHODOLOGY; PSYCHOLOGICAL ASPECTS; SONS;
UNITED STATES

- 242 Cicirelli, Victor G. (1992), 'Siblings as caregivers in middle and old age', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 84-101.

This chapter examines literatures 'with an emphasis on gender differences in specific areas of caregiving for each of two generations of siblings, the middle-aged and the elderly.' It begins with an examination of existing theories of gender role development in adulthood. It is concluded that 'present generations of adult child siblings and elderly siblings appear to be influenced by sex role stereotypes that override the demands of individual caregiving situations.'

AGED CAREGIVERS; GENDER; LITERATURE REVIEW; MIDDLE AGED
CAREGIVERS; THEORY DEVELOPMENT; UNITED STATES

- 243 Cicirelli, Victor G., Raymond T. Coward and Jeffrey W. Dwyer (1992), 'Siblings as caregivers for impaired elders', *Research on Aging*, 14(3), 331-50.

'Most older people regard their siblings as a caregiving resource, but only small percentages actually receive sibling help. The purpose of the present study was to determine what elder characteristics are associated with receiving sibling care, and what causes its initiation and cessation over time. Using longitudinal data from the 1982-1984 National Long Term Care Survey, 293 elders were identified who received sibling help in either 1982, 1984, or both, and 146 elders were sampled who received no sibling help at either time period. The elder characteristics examined were age, gender, race, education, income, marital status, number of living children, perceived health, and ADL and IADL impairments. In LOGIT analyses, those receiving sibling help at Time 1 were more likely to be younger, to be maritally disrupted or never married, to have fewer living children, and to reside in small cities. Those reporting the onset of help by Time 2 were more likely to be younger, never married, and living in rural areas, and those reporting cessation of help were more likely to be older, to have a decrease in IADL impairment, and to have changed their area of residence. The findings support the concept of a substitution hierarchy where sibling help is given when the elder has functional impairments and support from a spouse or adult children is unavailable.'

FAMILY; NATIONAL STUDIES; RELATIONSHIPS; UNITED STATES

- 244 Clark, Noreen M. and William Rakowski (1983), 'Family caregivers of older adults: improving helping skills', *The Gerontologist*, 23(6), 637-42.

'Caregiving tasks reported by family members are summarized based on empirical, review, and service program reports, and a categorization of these tasks is presented. Reports of education and support programs for family caregivers are also analyzed. Current evaluation data point only to benefits in short-term, affective domains of caregiving. Needed areas for demonstration and study to determine how programs can yield more long-term benefits include skills development, stages of caregiving, characteristics of persons likely to benefit, and empirically-based approaches to development and evaluation of education and support programs.'

EDUCATION; EVALUATION; UNITED STATES

- 245 Clifford, Dermot (1990), *The social costs and rewards of caring*, Avebury, Aldershot, Hants., viii, 259pp.

This is a comparative study of the carers of the frail elderly and carers of people with a mental handicap in the Diocese of Kerry, Ireland. The carers of the frail elderly are compared with those of the mentally handicapped; the findings of the Irish setting are compared with similar studies in Britain; female carers are compared with male; and the concept of community care is examined to see whether or not it is open to the charge of being in reality family care or care by women. After setting the Irish context there is a review of the literature on caring and a description of the methodology used in the study. Then findings are described and followed by conclusions and recommendations for social policy in Ireland.

COMPARATIVE STUDIES; CONCEPTUAL ISSUES; DISABLED; GENDER; INTERNATIONAL COMPARISONS; LITERATURE REVIEW; METHODOLOGY; POLICY; IRELAND; UNITED KINGDOM

- 246 Clipp, Elizabeth C. and Linda K. George (1990), 'Caregiver needs and patterns of social support', *Journal of Gerontology: Social Sciences*, 45(3), 102-11.

'Levels of caregiver need were used to predict four patterns of continuity and change in social support over a one-year interval among 376 adults caring for a family member with Alzheimer's disease. Canonical correlation analysis was used to identify predictors of each support pattern from selected caregiver characteristics and needs (i.e., demographics, financial resources, physical and mental health, social and recreational activities, and aspects of the caregiving situation). Three significant canonical variates emerged for each type of support, instrumental and perceived adequacy of support, correctly classifying more than half of the caregiver sample. Results suggest that caregiver need does not necessarily elicit support. Needs do, however, predict several patterns of social support, the most common of which is

characterized by stability (high or low support). Depending on type of support (instrumental or perceived adequacy), different configurations of predictors emerge.'

DEMENTIA; FINANCIAL ASPECTS; HEALTH; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; SUPPORT NETWORKS;
UNITED STATES

- 247 Clipp, Elizabeth C. and Linda K. George (1990), 'Psychotropic drug use among caregivers of patients with dementia', *Journal of the American Geriatrics Society*, 38(3), 227-35.

'The majority of research on "caregiver burden" focuses on mental health consequences. These stresses are associated with psychotropic drug use among some caregivers. The purposes of this paper are to identify the correlates of psychotropic drug use among caregivers of demented older adults and to determine whether or not certain types of psychotropics (ie, antianxiety, antidepressant and sedative/hypnotic agents) have common or unique correlates. The prevalence of psychotropic drug use among caregivers in the sample (n=510) is substantially higher than previously reported prevalence rates in the general population and among-community dwelling elderly. Using logistic regression techniques, caregiver characteristics (eg, gender, health, relationship to the patient) rather than severity of the patient's condition emerge as predictors of antianxiety, antidepressant, and sedative/hypnotic use. The caregiver's perception of how well he or she is supported in the caregiving role emerges as an important correlate of psychotropic drug use in general and especially of antidepressant consumption. Results suggest that caregivers are a high-risk group for the development of emotional symptoms such as nervousness, exhaustion, decreased appetite, and difficulty sleeping, symptoms that may or may not constitute a psychiatric disorder. Characteristics of the caregiver, especially aspects of the support system, should be important considerations in decisions to prescribe psychotropic drugs.'

DEMENTIA; PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 248 Clipp, Elizabeth C. and Linda K. George (1993), 'Dementia and cancer: a comparison of spouse caregivers', *The Gerontologist*, 33(4), 534-41.

'Can prominent themes that have emerged in dementia caregiving research be extrapolated to caregivers of persons with other chronic illnesses such as cancer? To answer this question, this study compared 272 spouse caregivers of dementia sufferers with 30 spouse caregivers of cancer victims on multiple indicators of well-being. Group contrast using MANOVA revealed that dementia caregivers were more adversely affected by their role than cancer caregivers. Illness duration and caregiver

age was a robust covariate. Specifically, younger spouse caregivers were significantly more compromised than older spouse caregivers.'

AGED CAREGIVERS; CANCER; COMPARATIVE STUDIES; DEMENTIA;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 249 Cloke, Christopher (1985), *Caring for Carers: A Directory of Initiatives*, 3rd Edition, Age Concern England, Information and Policy Department. Mitcham, Surrey, v, 85pp.

This directory describes over 100 schemes designed to support and help meet family carers of dependent, mainly elderly, people in Britain. The initiatives include carer support groups, day and night sitting services, attendant schemes, day care provision, short-term residential care, fostering schemes, intensive domiciliary care services, courses and training initiatives for carers, information and advocacy services, and multi-purpose projects. It gives the organisation, a description of the initiative, commencement date, staffing, funding agencies, charges, monitoring agency and reports or articles published.

COMMUNITY SERVICES; DAY CARE; EDUCATION; RESPITE CARE;
SUPPORT GROUPS; UNITED KINGDOM

- 250 Coleman, Peter G. (1989), 'The impact of developing psychogeriatric services in the care of the mentally infirm elderly', in Rosalie S. Wolf and Shimon Bergman, eds, *Stress, Conflict and Abuse of the Elderly*, JDC-Brookdale Monograph Series, JDC-Brookdale Institute of Gerontology and Adult Human Development, Jerusalem, 159-70.

This chapter 'describes some observations on support to carers of mentally infirm elderly from professional psychogeriatric services, derived from a study carried out in the County of Hampshire in the south of England. The study, which took place in 1980-82, contrasted the situation of the Southampton area, which already had a relatively well-developed psychogeriatric service based in a hospital...with the much poorer service offered in the neighbouring health district of Winchester and Central Hampshire.' Information gathered confirmed the fact that the more active psychogeriatric service was better prepared to take over responsibility for cases, and provided better follow-up and general support. Particularly valuable to the caregivers was the counselling role and the day care and respite services.

COMPARATIVE STUDIES; COUNSELLING; DAY CARE; MENTAL ILLNESS;
RESPITE CARE; UNITED KINGDOM

- 251 Colerick, Elizabeth J. and Linda K. George (1986), 'Predictors of institutionalization among caregivers of patients with Alzheimer's disease', *Journal of the American Geriatrics Society*, 34(7), 493-8.

'The treatment aim of medical care for home-based patients with Alzheimer's disease is to maximise the functioning level of the patient without jeopardizing quality of life for the caregiver. Most demented elderly live in the community with their families who, until coping becomes ineffective, usually prefer to keep their relatives out of institutions for as long as possible. In the present study, the question of why some families continue to shoulder the burden of care, often beyond healthful limits, while others relinquish care to professionals is examined longitudinally in a sample of 209 caregivers. Using logistic regression techniques, caregiver characteristics and caregiver well-being, rather than patient characteristics, emerge as important predictors of placement decisions. Results suggest that practitioners, in evaluating the family's need for institutionalization, must move beyond duration of illness and current cognitive functioning to aspects of the caregiver support system.'

DEMENTIA; INSTITUTIONALISATION; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 252 Collins, Clare, Manfred Stommel, Sharon King and C.W. Given (1991), 'Assessment of the attitude of family caregivers towards community services', *The Gerontologist*, 31(6), 756-61.

It has been a consistent research finding over the past decade that family caregivers of individuals with dementia experience considerable stress yet make little use of community services. 'Previous research has not taken into account the influence of attitudinal variables on the use of community services by dementia caregivers. The Community Service Attitude Inventory (CSAI) was developed to provide a measurement tool to further understanding of community service use by family caregivers. Testing of the CSAI revealed five distinct components of family attitudes toward use of community services.'

COMMUNITY SERVICES; DEMENTIA; METHODOLOGY; SERVICE USE;
UNITED STATES

- 253 Collins, Clare, Manfred Stommel, Charles W. Given and Sharon King (1991), 'Knowledge and use of community services among family caregivers of Alzheimer's disease patients', *Archives of Psychiatric Nursing*, 5(2), 84-90.

'The number of people with dementia residing within the community is steadily increasing. Community services can alleviate the burdens experienced by families, but are used infrequently by families of dementia patients. Caregivers (N=93) of dementia patients were surveyed regarding their knowledge and use of community services. The most frequently used services were family support groups and home health aides. Overall, service use was low despite high levels of perceived

availability of services. Older and less educated caregivers had higher levels of uncertainty about service availability. Implications for practice and research are presented.'

COMMUNITY SERVICES; DEMENTIA; METHODOLOGY; SERVICE USE;
UNITED STATES

- 254 Couper, Donna P. and Nancy W. Sheehan (1987), 'Family dynamics for caregivers: an educational model', *Family Relations*, 36(2), 181-6.

'Previous research on the primary caregivers of elderly relatives emphasizes the importance of viewing their situation from a family perspective. Educational programs which focus on the potential stress and support within the family are needed for caregivers. However, current caregiver programs focus on the dyadic relationship with minimal attention to other family issues. This paper reviews the literature on primary caregivers and describes an educational model on family dynamics for adult children caregivers.'

EDUCATION; FAMILY; LITERATURE REVIEW; RELATIONSHIPS; UNITED
STATES

- 255 Coward, Raymond T. and Jeffrey W. Dwyer (1990), 'The association of gender, sibling network composition, and patterns of parent care by adult children', *Research on Aging*, 12(2), 158-81.

'Based on matched data from the 1982 National Long-Term Care Survey and the National Survey of Informal Caregivers, this article explores the degree to which separating adult children (N=3,742) by the composition of their sibling network (i.e., only children, single-gender networks, and mixed-gender networks) provides insight into the association between gender and patterns of parent care. Caregiving participation was calculated as a proportion of the availability of all children of a specific gender. The data reveal that, within all sibling network categories, daughters were more likely than sons to be providing care to an impaired parent; however, the repercussions of being a caregiver were not similarly uniform. Specifically, sons and daughters from only-child and single-gender networks reported a similar number of hours per day spent in parent-care and experienced comparable levels of stress and burden. In contrast, daughters from mixed-gender networks reported significantly higher levels of stress and burden and more hours per day spent caregiving than sons. These findings demonstrate that differentiating children by sibling network type does offer some clarity to our understanding of the complex association between gender and patterns of parent-care.'

DAUGHTERS; GENDER; NATIONAL STUDIES; PSYCHOLOGICAL
ASPECTS; SONS; UNITED STATES

- 256 Coward, Raymond T., Claydell Horne and Jeffry W. Dwyer (1992), 'Demographic perspectives on gender and family caregiving', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 18-33.

This chapter begins with a review of 'gender differences in recent demographic transformations that have occurred in the age structure of the population of the United States and the potential implications of those changes for the long-term family care of elders.' It then explores 'the composition of the helping networks described by frail elders as a function of the gender of the elder', using as a data source a large, nationally representative sample of impaired elders.

DEMOGRAPHIC ASPECTS; FAMILY; GENDER; NATIONAL STUDIES;
SUPPORT NETWORKS; UNITED STATES

- 257 Coyle, Jean M. (1991), *Families and Aging: A Selected, Annotated Bibliography*, Greenwood Press, New York, Bibliographies and Indexes in Gerontology No.14, xxv, 208pp.

'This book provides an extensive, selected bibliography on the topic of families and the aging process. The focus is on the diverse types of family relationships which exist for older Americans...Both pragmatic and theoretical publications are included.' It includes a section on family caregiving.

BIBLIOGRAPHIES; FAMILY; RELATIONSHIPS; UNITED STATES

- 258 Coyne, Andrew C. (1991), 'Information and referral service usage among caregivers for dementia patients', *The Gerontologist*, 31(3), 384-8.

'Questionnaires were mailed to 257 callers of a toll-free telephone "helpline" specializing in Alzheimer's disease and related dementing illnesses; 125(48.6%) were completed and returned. On the average, 3.94 requests for information were made per call. The most common requests concerned services delivered to the home, general information about dementia, information about adult day care, and support group information. Results indicated that a telephone-based information and referral helpline is useful in disseminating knowledge about resources to caregivers of older community-residing adults with cognitive impairment.'

DAY CARE; DEMENTIA; EDUCATION; METHODOLOGY; SUPPORT
GROUPS; UNITED STATES

- 259 Croft, Suzy (1986), 'Women, caring and the recasting of need: a feminist reappraisal', *Critical Social Policy*, (16), 23-39.

This article wishes to suggest 'that "care" is an unhelpful and destructive organising concept for women, and indeed men, in understanding and responding to need' and that we ought to reconsider how we frame both the issues involved and our demands around them. Policy makers must ensure that 'their proposals advance rather than conflict with equal rights and opportunities for women. There are two major and related policy developments concerning women and caring, both of which need to be considered in the light of this criterion.' The first is the increased burden placed on women as unpaid carers by central government policy. The second, the emergence of the idea and policy of 'caring for' or 'supporting the carers'. Strategies for both the long and short term are outlined.

CONCEPTUAL ISSUES; GENDER; IDEOLOGY; POLICY; UNITED KINGDOM

- 260 Crossman, Linda, Cecilia London and Clemmie Barry (1981), 'Older women caring for disabled spouses: a model for supportive services', *The Gerontologist*, 21(5), 464-70.

'With an emphasis on long term care of the elderly shifting from institutional to community-based services, the critical role of the caregivers in the support network is gaining more recognition. This paper identifies a particularly high-risk group of caregivers - older women caring for disabled spouses - and examines the issues and special problems they face. A multi-service project designed to provide support and respite is described. Implications for policy and practice are discussed and recommendations for further study made.'

AGED CAREGIVERS; CASE STUDIES; POLICY; RESPITE CARE; SPOUSES; SUPPORT GROUPS; UNITED STATES

- 261 Csillag, Dina (1989), 'Training families in care provision: a demonstration program', in Rosalie S. Wolf and Shimon Bergman, eds, *Stress, Conflict and Abuse of the Elderly*, JDC-Brookdale Monograph Series, JDC-Brookdale Institute of Gerontology and Adult Human Development, Jerusalem, 171-7.

This chapter describes a demonstration program in caregiving for families caring for elderly members in Israel. The purpose of the course was to provide knowledge and supportive guidance, to teach practical techniques of caregiving, and to develop the ability of families to share common concerns with other families as well as professionals so that they would be able to cope more effectively with their situation. A curriculum was designed and tested with one group of caregivers and then used with a second group who were video-taped. The process of developing the course as a multidisciplinary and interorganisational effort is outlined.

EDUCATION; METHODOLOGY; SUPPORT NETWORKS; ISRAEL

- 262 Curtis, S., D. Bucquet and A. Colvez (1992), 'Sources of instrumental support for dependent elderly people in three parts of France', *Ageing and Society*, 12(3), 329-54.

'The paper focuses on the provision of instrumental support provided to dependent elderly people in France, presenting information collected in social surveys conducted in the three regions of the country. This information is considered in the light of the results of studies from other countries on instrumental social support to the dependent elderly which are reviewed. The data analysed includes measures of the potential social network of the respondent based on household composition, marital status, number of living children and frequency of visits by family, friends and neighbours. Measures of instrumental support received were based on reported need for help for specific tasks, and the main source of help provided. The results reported here suggest that not all members of the dependent elderly person's social network were equally involved in providing instrumental help and supports a hierarchical model of the informal care structure with family members as the predominant source of help. The results also demonstrate the comparatively small role played by the formal caring services compared with the informal sector. The context of care for dependent elderly people in France is discussed and the implications of these results for social policy are considered.'

COMMUNITY SERVICES; FAMILY; INTERNATIONAL COMPARISONS;
NATIONAL STUDIES; POLICY; SUPPORT NETWORKS; FRANCE

- 263 Dalley, Gillian (1983), 'Ideologies of care: a feminist contribution to the debate', *Critical Social Policy*, (8), 72-81.

'This paper examines the ideological grounds underlying the dominant call for care of the chronically ill and disabled to be located "in the community". It looks at some of the competing concepts which are, nevertheless, rejected. The paper suggests that the ideologies of certain professions and the policies of certain agencies have chosen to incorporate some of the concepts current during the past two decades and to reject others; and that this has had demonstrable consequences for the development of policies relating to the provision of long-term care in the present period. Principally, it looks at a concept which has got lost - the concept of communality.'

CONCEPTUAL ISSUES; GENDER; IDEOLOGY; POLICY; UNITED KINGDOM

- 264 Dalley, Gillian (1988), *Ideologies of Caring: Rethinking Community and Collectivism*, Macmillan, Basingstoke, Hants., xiv, 165pp.

Community care policies appear to be premised on principles to which feminists are opposed, i.e. 'upon the primacy of the family and the home-bound status of women within it. They are the exact contradictions of the collectivist solutions to the problems of caring which feminists would propose.' The book examines why this familist ideology is so powerful. It begins by looking at the development of

community care policies and what these mean for women on the one hand, and men on the other, then relates these to an analysis of familism. Familism is also linked to the wider ideology of possessive individualism. The alternative of collectivism is analysed, taking ethnographic and historical examples and discussing the moral concept of 'responsibility' especially as it relates to the provision of support and care for the dependent. A later chapter is concerned with models of collective living, asking upon what criteria such forms should be based.

FAMILY; GENDER; HISTORICAL ASPECTS; IDEOLOGY; THEORY
DEVELOPMENT; UNITED KINGDOM

- 265 Daniels, Marcia and Michael Irwin (1990), 'Caregiver stress and well-being', in Enid Light and Barry D. Lebowitz, eds, *Alzheimer's Disease Treatment and Family Stress: Directions for Research*, Hemisphere, New York, 292-309.

This chapter reviews what is known about caregiver burden by looking at earlier and current studies and addresses the implications of the reviewed findings. It also comments on possible directions for future research.

DEMENTIA; HEALTH; LITERATURE REVIEW; PSYCHOLOGICAL
ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 266 Davies, Helen, J. Michael Priddy and Jared R. Tinklenberg (1986), 'Support groups for male caregivers of Alzheimer's patients', *Clinical Gerontologist*, 5(3/4), 385-95.

Recent research has investigated sex differences in the perception of and reaction to caregiving. This article describes a pilot intervention for male caregivers. As an adjunct to a large research center on Alzheimer's disease at the VA Medical Center in Palo Alto, CA., short-term support groups for male spouses of Alzheimer's patients were offered. This article describes these groups, their recruitment, format and groups cohesion; highlights common issues such as caregiver pride, the decision for institutionalisation and needs for validation, information, networks and physical care; and makes recommendations based on their experiences.

CASE STUDIES; DEMENTIA; GENDER; INSTITUTIONALISATION;
SPOUSES; SUPPORT GROUPS; UNITED STATES

- 267 Day, Alice T. (1985), *Who Cares? Demographic Trends Challenge Family Care for the Elderly*, Population Trends and Public Policy No.9, Population Reference Bureau, Washington, D.C., 16pp.

The author examines the relationship between the elderly and their caregivers and the social changes that are reshaping family roles and altering the nature of ageing in the United States. Trends in life expectancy, women's labour force participation and

delayed childbearing will put serious pressures on families' ability to provide care for older people in the coming years.

DEMOGRAPHIC ASPECTS; FAMILY; GENDER; SOCIAL ASPECTS; UNITED STATES

- 268 DeFilippo Lutzer, Victoria and Timothy H. Brubaker (1988), 'Differential respite needs of aging parents of individuals with mental retardation', *Mental Retardation*, 26(1), 13-

'Parents of individuals with mental retardation differ in their expressed need for types of respite care depending on their age. In this study we surveyed parents of adults with mental retardation. More parents under age 56 than over age 56 reported a need for respite services that would increase their involvement with intra- and extrafamilial social systems. More parents over age 56 reported need for out-of-home respite care. Implications of these results for training practitioners in gerontological issues were discussed.'

AGED CAREGIVERS; COMPARATIVE STUDIES; DISABLED; RESPITE CARE; UNITED STATES

- 269 Deimling, Gary T. and David M. Bass (1986), 'Symptoms of mental impairment among elderly adults and their effects on family caregivers', *Journal of Gerontology*, 41(6), 778-84.

'Research that has examined the relationship between caregiving stress and elders' symptoms of mental impairment has focused primarily on cognitive incapacity. This research expands the symptoms of mental impairment to include caregivers' reports of problems in elders' social functioning and the presence of disruptive behavior, in addition to the traditional measure of cognitive incapacity. Results of a study of 614 families living with and caring for an impaired elder show cognitive incapacity to have a less important direct effect on caregiving stress than disruptive behavior and impaired social functioning. Cognitive incapacity does have an important indirect effect through its influence on disruptive behavior and social functioning.'

DEMENTIA; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; UNITED STATES

- 270 DeLongis, Anita and Tess O'Brien (1990), 'An interpersonal framework for stress and coping: an application to the families of Alzheimer's patients', in Mary Ann Parris Stephens, et al., eds, *Stress and Coping in Later-Life Families*, Hemisphere, New York, 221-239.

This chapter considers the social context which determines the occurrence and effects of stressful events faced by later-life families. It describes the interpersonal

and cognitive processes that generate coping with and adaptation to stressful circumstances, drawing upon cognitive models of stress and coping 'with the goal of extending the model's predictive ability by elucidating interpersonal dimensions of the stress process.' It reviews the literature and highlights 'the critical role that interpersonal factors play in stress and coping in aging families, drawing on the context of caregiving for a family member with Alzheimer's disease to illustrate.' The authors posit the notion of relationship-focused coping, emphasising empathic coping as one mode of relationship-focused coping that could enhance the well-being of later-life families facing the task of caring for a chronically ill family member.

DEMENTIA; LITERATURE REVIEW; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; SOCIAL ASPECTS; THEORY DEVELOPMENT; UNITED
STATES

- 271 Dhooper, Surjit Singh (1992), 'Caregivers of Alzheimer's disease patients: a review of the literature', *Journal of Gerontological Social Work*, 18(1/2), 19-37.

'Based on an extensive review of the literature, this paper describes the major changes in the patient's behavior at the various stages of Alzheimer's disease and looks at the problems generally involved in caring from different perspectives. It also discusses factors that may explain the uniqueness of each caregiving situation and highlights the approaches to helping the caregiving families effectively.'

COMMUNITY SERVICES; DEMENTIA; LITERATURE REVIEW; POLICY;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 272 Dilworth-Anderson, Peggye (1987), 'Effectiveness of family support group involvement in adult day care', *Family Relations*, 36(1), 78-81.

Group meetings were held at two adult day care centres in the Chicago area with adult children caring for older relatives. The discussions focused on problems common to caregivers, information on ageing, and resources to help the caregivers. Caregivers benefited more from the sessions when the administrator and staff were involved and where there was high and consistent attendance.

CASE STUDIES; DAY CARE; EDUCATION; SUPPORT GROUPS; UNITED
STATES

- 273 Doherty, Emily Summers and Paul W. Power (1990), 'Identifying the needs of coronary patient wife-caregivers: implications for social workers', *Health and Social Work*, 14(4), 291-9.

'Ninety-three women married to men who had experienced major medical crises resulting from coronary heart disease responded to a mail questionnaire designed to elicit the needs directly or indirectly created for them by their husbands' disease. The three areas of need - education, prevention, and support services - selected for evaluation had not been submitted previously for assessment with this population. Responses to the questionnaire indicated strong needs in all three areas. The results of the survey have implications for intervention with families by professionals in the areas of assessment, programming, and the professional's relationship to individual members of this population.'

CARDIOVASCULAR DISEASE; COMMUNITY SERVICES; EDUCATION;
RELATIONSHIPS; SPOUSES; UNITED STATES

- 274 Dooghe, Gilbert (1992), 'Informal caregivers of elderly people: an European review', *Ageing and Society*, 12(3), 369-80.

This article reviews the literature on informal caregiving in Europe. It begins with the role of the informal caregiver and goes on to give a profile of informal caregivers who are predominantly middle-aged and female. Most care is given by one person, the 'central attendant', generally a spouse and if there is no spouse, children. The role of neighbours, friends and volunteers is limited. The willingness to provide care and the availability of family care is surveyed and it is found that the family continues to play an essential role but that there is a concern with the future supply of informal care by families, not through unwillingness but through demographic factors, labour force participation of women and family changes. Informal care is often stressful. The factors causing stress are reviewed. 'In order to continue family caregiving, a range of supportive fiscal, medical and social services must be provided...The potential contribution of the informal caregiver increases if they are sustained by formal services and professional organisations. This, in turn, can lead to the formal sector being overstretched and it has been found that few workers are attracted to the caregiving professions. European policy orientations are found to be insufficiently aware of the economic value of informal care. What is needed is more collaboration between the formal and informal sectors; tailor-made rather than standardised care; and more planning and management to provide sufficient services to give potential carers a choice.'

COMMUNITY SERVICES; FAMILY; GENDER; LITERATURE REVIEW;
MIDDLE AGED CAREGIVERS; POLICY; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; EUROPE

- 275 Doty, Pamela (1986), 'Family care of the elderly: the role of public policy', *Milbank Quarterly*, 64(1), 34-75.

A number of public policy issues are currently under discussion in the US Congress and elsewhere seeking to promote the family home care of disabled elderly people. These include tax incentives for family caregivers; public funding of respite care and other support services; cash grants to low-income families who are carers; changes to social security and food stamp rules so that they are not decreased if an elderly person moves in with the family; and, permitting family members to work as paid helpers under public programs. This article reviews existing research on family care-giving to address several questions. 'First, how much evidence is there that American families are becoming less able to provide home care to their elderly disabled relatives? Second, what, if any, impact would government support or incentives be likely to have on family care-giving? Would institutionalization of the elderly decrease? Would the "quality of life" of the disabled elderly receiving home care and that of their family care-givers improve? Third, is it likely to make any difference what form the government assistance takes - that is, whether support or incentives are given via tax credits or cash grants or vendor payments and which services are supported or subsidized through the various means?'

COMMUNITY SERVICES; FAMILY; FINANCIAL ASPECTS; INCOME SUPPORT; INSTITUTIONALISATION; PAYMENT; POLICY; UNITED STATES

- 276 Draper, Patricia and Jennie Keith (1992), 'Cultural contexts of care: family caregiving for elderly in America and Africa', *Journal of Aging Studies*, 6(2), 113-34.

'Societies differ in the way in which family members provide care to elderly. In this article a comparison is made between the caretaking of elderly in two communities, one in a suburb of Philadelphia, USA, another in rural Botswana, Africa. The differences in the manner and frequency of family caretaking of elderly are examined from the point of view of social and economic differences in the two communities as well as from the point of view of cultural values about the nature of relations between members of different generations.'

FAMILY; INTERNATIONAL COMPARISON; RELATIONSHIPS; RURAL ASPECTS; SOCIAL ASPECTS; AFRICA; UNITED STATES

- 277 Dressler, Paula L. and Ann Clark (1990), 'A critical look at family care', *Journal of Marriage and the Family*, 52(3), 769-82.

'This analysis represents an exploratory effort to rethink the phenomenon of family care. Qualitative data from self-report diaries and descriptive family care scenarios highlight behavioral, cognitive, and emotional components of family care and generate researchable questions surrounding interplay of gender and the expression

of care. The data analysis indicates that while family members hold idealized notions of family care, their behaviors and feelings are often at odds with their ideologies. Furthermore, certain expressions of family care appear to be linked to issues of women's family status and power. The study emphasized the need to conceptualize care multidimensionally in order to avoid the reification of gender and to explore family issues beyond the household.'

CONCEPTUAL ISSUES; FAMILY; GENDER; IDEOLOGY; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; UNITED STATES

- 278 Dura, Jason R. and Janice K. Kiecolt-Glaser (1990), 'Sample bias in caregiving research', *Journal of Gerontology: Psychological Sciences*, 45(5), P200-204.

'Data on subject selection biases in research with older adults are limited.' This article reports on 'two sample bias studies that assessed primary caregivers for dementia patients. The first study compared 46 caregivers, who required home interviews, with 63 caregivers willing to travel to the university hospital for assessment; all subjects had been offered free taxi service. Caregivers interviewed at home were helping more hours per day and were more depressed than those assessed at the university; in addition, the patients of caregivers assessed at home were more impaired and had greater personality changes. The second study compared available information from respite care users who chose to participate in [the] caregiving research project with those who chose not to participate. Nonparticipants provided care for more impaired patients. No demographic differences were found between groups in either study, and there were no differences in the chronicity of caregiving. The implications of these data for aging research are discussed.'

COMPARATIVE STUDIES; DEMENTIA; METHODOLOGY; PSYCHOLOGICAL ASPECTS; RESPITE CARE; UNITED STATES

- 279 Dura, Jason R., Elizabeth Haywood-Niler and Janice Kiecolt-Glaser (1990), 'Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: a preliminary comparison', *The Gerontologist*, 30(3), 332-6.

'Dementia occurs as a primary component of Senile Dementia of the Alzheimer's type (SDAT) and as a secondary component of Parkinson's Disease (PD) in a subset of PD patients...Caregiver distress subsequent to the unique features of these dementing illnesses [were compared]. Self- and other-related depression was compared in spousal caregivers for 23 SDAT patients, 23 PD with dementia patients, and 23 control subjects. The two caregiving groups were similar in the length of time they had been providing assistance and in caregiver distress, and both caregiver groups were more depressed than comparison subjects.'

COMPARATIVE STUDIES; DEMENTIA; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 280 Dwyer, Jeffrey W. and Michael K. Miller (1990), 'Differences in characteristics of the caregiving network by area of residence: implications for primary caregiver stress and burden', *Family Relations*, 39(1), 27-37.

'The objectives of this research are to (a) compare characteristics of impaired elderly care receivers, primary caregivers, informal networks, and formal networks likely to impact primary caregiver stress and burden by area of residence and (b) fit a conceptual model explaining caregiver stress and burden in rural, small city, and urban samples. The data are from a matched sample of 1388 noninstitutionalized functionally limited elderly people and their primary caregivers drawn from the 1982 National Long-Term Care Survey and the National Survey of Informal Caregivers. Results show that there are significant residential differences in characteristics of the caregiving network in general, but minimal variation in primary caregiver stress and burden. Furthermore, there are some structural differences in the ability of the conceptual model to explain stress and burden by area of residence. These findings suggest that residential differences in the complex factors associated with primary caregiver stress and burden should be considered when formulating public policy, designing intervention strategies, and conducting future research.'

COMPARATIVE STUDIES; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; RURAL ASPECTS; SUPPORT NETWORKS; THEORY DEVELOPMENT; UNITED STATES

- 281 Dwyer, Jeffrey W. and Karen Seccombe (1991), 'Elder care as family labor: the influence of gender and family position', *Journal of Family Issues*, 12(2), 229-47.

'This research indicates that gender differences in the performance of specific caregiving tasks and the amount of time spent providing care by family caregivers of frail elders should be considered in the context of family position-related norms and expectations. Using a nationally representative sample of noninstitutionalized impaired elderly people in the United States (N=813), the results show that husbands (when compared to wives) and daughters (when compared to sons) report spending more time and performing a greater number of caregiving tasks. The authors suggest that family position may confound interpretations regarding the association between gender and family caregiving.'

DAUGHTERS; FAMILY; GENDER; METHODOLOGY; NATIONAL STUDIES; SONS; SPOUSES; UNITED STATES

- 282 Dwyer, Jeffrey W. and Raymond T. Coward (1991), 'A multivariate comparison of the involvement of adult sons versus daughters in the care of impaired parents', *Journal of Gerontology: Social Sciences*, 46(5), S259-69.

'The purpose of this research was to explore whether gender differences in parent care (i.e., the greater participation of daughters) persisted after controlling for

additional caregiver and care-receiver characteristics known to affect the provision of care. Assistance with activities of daily living (ADLs) was examined separately from assistance with instrumental activities of daily living (IADLs). A multivariate analytical framework was employed to account for the effects of a wide range of variables. Moreover, data on all of the living children (N=13,172) of a sample of impaired elders (N=4,371) were used, not just data on those children who were known to be providing help. Net of other caregiver and care-receiver characteristics, daughters were 3.22 times more likely than sons to provide ADL assistance and 2.56 times more likely to provide IADL assistance. Although these results are not substantively different from previous research, the methodological approach taken provides a better empirical base for estimating the effect of gender on the probability of being involved in parent care.'

DAUGHTERS; METHODOLOGY; SONS; UNITED STATES

- 283 Dwyer, Jeffrey W., John C. Henretta, Raymond T. Coward and Amy J. Barton (1992), 'Changes in the helping behaviors of adult children as caregivers', *Research on Aging*, 14(3), 351-75.

'This research uses data from the longitudinal file of the 1982-1984 National Long-Term Care Survey to (a) describe changes in the caregiving responsibilities of adult children over time and (b) estimate the effect of adult child, impaired elder, and sibling participation characteristics on changes in the participation of adult children as providers of ADL and IADL assistance. The results show that 5.2% of adult children who did not provide ADL help and 12.6% of those who did not provide IADL help at Time 1 were helping with these tasks at Time 2. Conversely, 50.7% of adult children who provided ADL assistance and 29.9% of those who provided IADL assistance at Time 1 had stopped providing such care by Time 2. Logit models used to predict changes in the helping behaviors of adult children indicate that there are both differences and similarities in the factors that affect the likelihood of becoming a caregiver and of discontinuing assistance over time.'

DAUGHTERS; NATIONAL STUDIES; SONS; UNITED STATES

- 284 Dwyer, Jeffrey W. and Raymond T. Coward (1992), 'Gender and family care of the elderly: research gaps and opportunities', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 151-62.

This chapter is organised around six areas of family caregiving research that 'have particularly significant implications for understanding the role of gender in the social context of caregiving' with the purpose of establishing an agenda for future research. 'These areas are divided into two sections: one that addresses *how* we should build a knowledge base for the study of gender and family care of the elderly, and a second that focuses on *what* aspects of family caregiving hold the greatest potential for

furthering our knowledge.' A gender-sensitive family caregiving research agenda should emphasise 'the application of theory to research, the replication of research findings, and the use of longitudinal studies. It could be further improved by making cultural comparisons, by disentangling the effects of gender from other covariates, and by understanding whole families rather than only caregiving dyads.

FAMILY; GENDER; METHODOLOGY; UNITED STATES

- 285 Dwyer, Jeffrey W. and Raymond T. Coward, eds (1992), *Gender, Families, and Elder Care*, Sage Focus Editions No.138, Sage, Newbury Park, Calif., xv, 262pp.

This book identifies 'the fundamental demographic, conceptual, social, and economic factors that influence the association between gender and family care of the elderly;' provides literature reviews and examines 'the gender/family/aging nexus from the perspective of theory, research, policy, and practice' and considers implications for future policy and practice.

CONCEPTUAL ISSUES; DEMOGRAPHIC ASPECTS; FAMILY; GENDER; LITERATURE REVIEW; POLICY; THEORY DEVELOPMENT; UNITED STATES

- 286 Dwyer, Jeffrey W. and Coward, Raymond T. (1992), 'Gender, family, and long-term care of the elderly', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 3-17.

This chapter focuses on 'the sociohistorical role of the family in caring for frail elders, defining important concepts in family caregiving research, and exploring future trends that may affect the gendered nature of family care for the elderly..' A better understanding of the association between gender and family caregiving is essential if we are to develop an effective system of long-term care services that are sensitive to the needs of the elderly and their caregivers, both women and men.

CONCEPTUAL ISSUES; FAMILY; GENDER; HISTORICAL ASPECTS; POLICY; UNITED STATES

- 287 Eagles, J.M., J.A.G. Beattie, G.W. Blackwood, D.B. Restall and G.W. Ashcroft (1987), 'The mental health of elderly couples. I. The effects of a cognitively impaired spouse', *British Journal of Psychiatry*, 150, 299-303.

'In a general practice population, 274 elderly married couples completed the Mental Status Questionnaire (MSQ), the 60-item General Health Questionnaire (GHQ) and the Leeds General Scales for the Self-assessment of Depression and Anxiety. The only relationship detected between cognitive impairment on the MSQ and psychiatric morbidity in the partner was a fairly weak negative correlation between

the wives' MSQ and the Leeds Depression score of their husbands. These findings differ from those of previous studies, which have found high rates of psychiatric morbidity in the relatives of demented patients, and the possible reasons for these differences are discussed. Most importantly, other studies have involved the relatives of patients referred to psychiatric services, and these families may be quite different from those in which the demented relative is not referred to a psychiatrist.'

DEMENTIA; METHODOLOGY; PSYCHOLOGICAL ASPECTS; SPOUSES;
UNITED KINGDOM

- 288 Eagles, J.M., L.G. Walker, G.W. Blackwood, J.A.G. Beattie and D.B. Restall (1987), 'The mental health of elderly couples. II. Concordance for psychiatric morbidity in spouses', *British Journal of Psychiatry*, 150, 303-8.

'A community sample of elderly married couples completed the 60-item General Health Questionnaire and the Leeds General Scales for Self-assessment of Depression and Anxiety. Significant concordance was demonstrated between the spouses' scores on these scales. Concordance was higher for depression than for anxiety. There was little to support previous findings that wives are more likely than husbands to be concordant with an ill spouse. The spouse concordance rates for psychiatric morbidity were similar to those found in studies of younger married couples.'

MENTAL ILLNESS; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
SPOUSES; UNITED KINGDOM

- 289 Eagles, J.M., A. Craig, F. Rawlinson, D.B. Restall, J.A.G. Beattie and J.A.O. Besson (1987), 'The psychological well-being of supporters of the demented elderly', *British Journal of Psychiatry*, 150, 293-8.

'Interviews were conducted with the co-resident supporters of 79 elderly subjects. Forty of these elderly subjects had been diagnosed as being demented (20 mildly, 12 moderately and 8 severely) following psychiatric assessment. The supporters were screened for psychological well-being with the 60-item General Health Questionnaire (GHQ) and the Relatives' Stress Scale (RSS). Supporters of demented relatives showed significantly raised levels of stress on the RSS, but no increase in psychiatric morbidity on the GHQ, when compared with the supporters of non-demented relatives. The implications of these findings are discussed.'

DEMENTIA; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED
KINGDOM

- 290 Edelman, Perry and Susan Hughes (1990), 'The impact of community care on provision of informal care to homebound elderly persons', *Journal of Gerontology: Social Sciences*, 45(2), S74-84.

'This study examined the impact of community care on informal care provided by family and friends to homebound elderly persons. Secondary analyses were conducted on data collected from clients at baseline, 9 months (N=225), and 48 months (N=76) after acceptance to community care and home-delivered meals programs. Analyses revealed a significant increase in the amount of formal service provided to both groups of clients at 9 months and to community care clients at 48 months. The increase was attributed to the large proportion of "new" or "supplementary" services provided by agencies. No significant decrease in the amount of service provided by informal caregivers was found. In addition, regression analyses demonstrated only a weak impact of formal service on informal care. Analysis of patterns of service provision for each client demonstrated that formal care supplemented rather than substituted for informal care significantly more often in both the 9- and 48-month samples. [It was concluded] that formal care in general supplemented the efforts of informal caregivers, and that informal caregiving remained stable over time.'

FAMILY; METHODOLOGY; SERVICE USE; UNITED STATES

- 291 Engelhardt, Jean, Timothy Brubaker and Victoria Lutzer (1988), 'Older caregivers of adults with mental retardation: service utilization', *Mental Retardation*, 26(4), 191-5.

This article examines the relationship between service utilisation and the characteristics of older parents and other caregivers, their dependents with mental retardation, and their ability to provide care. 'Caregivers' assessment of current ability to provide care was significantly related to amount of service use, but caregiver and dependent characteristics were not.'

AGED CAREGIVERS; DISABLED; SERVICE USE; UNITED STATES

- 292 Enright, Robert B. (1991), 'Time spent caregiving and help received by spouses and adult children of brain-impaired adults', *The Gerontologist*, 31(3), 375-83.

'Caregivers for brain-impaired adults differ in living arrangements, amount of time spent giving care, and assistance received from family and friends and from paid help depending on their kin relationship and employment status. Spousal caregivers devote large amounts of time to caregiving, and husbands spend no less time than wives. Most caregivers receive little assistance from other family members and friends, but husbands receive more than others. Employed spouses receive more paid

help than those without jobs, but employment does not affect the amount of paid help received by adult daughters.'

DAUGHTERS; DISABLED; EMPLOYMENT; LIVING ARRANGEMENTS;
SONS; SPOUSES; UNITED STATES

- 293 Evandrou, Maria (1990), *Challenging the Invisibility of Carers: Mapping Informal Care Nationally*, Discussion Paper No.49, Welfare State Programme, Suntory-Toyota International Centre for Economics and Related Disciplines, London School of Economics, 39pp. Also published in Frank Laczko and Christina M. Victor, eds, *Social Policy and Elderly People: The Role of Community Care*, Avebury, Aldershot, Hants., 1-29.

'Recent government survey data has shown that there are six million adults in Britain faced with caring responsibilities for frail elderly people, and other incapacitated adults and children. Yet we know very little about them. This paper explores the demographic and socio-economic characteristics of informal carers. It examines "who they are", at what stage of the life-cycle they are, and the nature and extent of the care they provide. The health status, employment and financial resources of informal carers is also analysed. Analysis of the 1985 General Household Survey has shown the diverse nature of caring roles adopted and the wide economic differentials among carers. Of these six million carers, 3.7m shoulder the responsibilities on their own and 1.4m spend at least 20 hours per week providing care and support. Individuals aged 45-59 are most likely to have caring responsibilities, although one quarter of the people aged 60 or over also provide such care. This paper shows that informal care is not a female monopoly, with 2.5m male carers in Britain, although the nature and level of care varies. Female carers (2.1m) are more likely to be sole carers than male carers (1.2m). Sole carers are more likely to be providing a greater number of hours of care, over a longer time period with fewer opportunities of respite...The findings also show that sole carers have a higher probability of low income ...with female sole carers being particularly disadvantaged. Furthermore, carers with dependents within the household have a greater likelihood of experiencing poverty than those caring for someone outside the home.'

AGED CAREGIVERS; DEMOGRAPHIC ASPECTS; EMPLOYMENT;
FINANCIAL ASPECTS; GENDER; HEALTH; LIVING ARRANGEMENTS;
MIDDLE AGED CAREGIVERS; NATIONAL STUDIES; SOCIOECONOMIC
STATUS; UNITED KINGDOM

- 294 Evandrou, Maria, Sara Arber, Angela Dale and G. Nigel Gilbert (1986), 'Who cares for the elderly? Family care provision and receipt of statutory services', in Chris Phillipson, Miriam Bernard and Patricia Strang, eds, *Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives*, Croom Helm, in association with the British Society of Gerontology, London, 150-66.

'This paper examines, through the use of nationally representative data, the roles of formal and informal care networks in the provision of care for elderly people living at home.' Daughters and daughters-in-law are the largest group of carers for the elderly and this care is largely unshared and done with minimal service use. This paper examines the meaning of community care in terms of who provides that care for a range of specific tasks which the elderly are unable to do unaided. It examines how the balance of care between family members, other community members such as neighbours and friends, and statutory services varies according to whether the elderly person lives alone or in different types of household. The research is based on a secondary analysis of the 1980 General Household Survey in Great Britain.

COMMUNITY SERVICES; DAUGHTERS; FAMILY; LIVING
ARRANGEMENTS; NATIONAL STUDIES; RELATIONSHIPS; SUPPORT
NETWORKS; UNITED KINGDOM

- 295 Evandrou, Maria and David Winter (1992), 'Informal carers and the labour market in Britain', in *Social Security 50 Years after Beveridge: An International Conference*, University of York, September 1992, Volume 3, Legal and Administrative Issues, Gaps in the System, European Institute of Social Security, York, 45-72. Also published as Discussion Paper No.89, Welfare State Programme, Suntory-Toyota International Centre for Economics and Related Disciplines, London School of Economics, 1993, 66pp.

'This paper examines the labour market experience of individuals who provide consistent care for sick, handicapped or elderly people in Britain. It explores the economic impact of having caring responsibilities by comparing the labour force participation, earnings and wage rates of carers versus non-carers. The paper provides an empirical analysis using data from the 1985 General Household Survey employing both descriptive and regression techniques. The findings indicate that overall carers are less likely to be employed than their non-carer counterparts, and if they are employed, they are more likely to be in part-time jobs. However, at the individual level there are considerable differences between different types of carer in the way they change their behaviour in the labour market in response to their caring obligations. After taking into account receipt of social security benefits, carers tend to have lower disposable incomes than non-carers. The adequacy of current welfare

benefits for carers is discussed and the major issues for future policy reform are drawn out.'

COMPARATIVE STUDIES; EMPLOYMENT; INCOME SUPPORT; NATIONAL STUDIES; POLICY; SOCIOECONOMIC STATUS; UNITED KINGDOM

- 296 Evers, Adalbert and Kai Leichsenring (1994), 'Paying for informal care: an issue of growing importance', *Ageing International*, 21(1), 29-40.

'Payment made to informal caregivers has a long history in the form of various family and child care allowances. A more restricted definition of such payments captures only that extra care that relates to dependent people and is beyond the daily care duties of raising children or helping each other in families and communities. Allowances for this extra care may take the form of compensation for foster care, for disability care, or the care of frail elderly people. This article, based on [the authors'] and others' research in this area, concentrates on payments made for extra-care activities for both older people and persons of any age suffering from disabilities because of the strong links between benefits for these two vulnerable groups. Three main types of payments for care can be distinguished: (a) direct payments, usually called *care allowances*, to caring individuals who include friends, relatives, volunteers, or others; (b) indirect payments, usually called *attendance allowances*, that are paid to the person in need of care who may use them to pay informal carers; [and] (c) *new cash-based schemes for guaranteeing care* presently being debated or implemented in some countries.' This article aims to show how different regulations show different streams of thinking about welfare. The countries examined are Austria, Belgium, Finland, Sweden, and the Netherlands.

INTERNATIONAL COMPARISONS; PAYMENT; AUSTRIA; BELGIUM; FINLAND; NETHERLANDS; SWEDEN

- 297 Fadden, G., P. Bebbington and L. Kuipers (1987), 'The burden of care: the impact of functional psychiatric illness on the patient's family', *British Journal of Psychiatry*, 150, 285-92.

'This paper reviews the literature on the effect of severe mental illness on other members of the patient's family. The burdens of caring for a patient at home are considerable. They often affect the caring relative's social and leisure activities, and financial problems arise frequently. Relatives have difficulties in understanding and coming to terms with illness-related behaviour. "Negative" symptoms are often a particular problem. Despite their burden, relatives do not complain much, although they receive little support, advice or information from the professionals engaged in treating the patient; much is now known about the difficulties relatives face, but we

still need to know how they can best be helped. Failure to do this will have bad effects on both relatives and patients.'

COMMUNITY SERVICES; FAMILY; FINANCIAL ASPECTS; GENDER;
LITERATURE REVIEW; MENTAL ILLNESS; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; SOCIAL ASPECTS; UNITED KINGDOM

- 298 Famighetti, Robert A. (1986), 'Understanding the family coping with Alzheimer's disease: an application of theory to intervention', *Clinical Gerontologist*, 5(3/4), 363-84.

This paper attempts 'to understand the "multiple-crisis syndrome" of Alzheimer's disease and how it affects family coping.' It is the result of two years of qualitative interviews with families participating in Alzheimer's disease family self-help support groups in New Jersey. It attempts to utilise the theoretical frameworks of the Double ABC-X crisis model and family developmental theory to understanding chronic illness and a family's coping ability over time. The paper discusses the consequences of Alzheimer's disease for the family life-cycle, and offers suggestions for clinicians about intervention strategies for use with families.'

DEMENTIA; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES;
THEORY DEVELOPMENT; UNITED STATES

- 299 Family Policy Studies Centre (1984), *The Forgotten Army: Family Care and Elderly People*, Briefing Paper, Family Policy Studies Centre, London, 24pp.

This paper presents the demographic profile of the elderly population in Britain and analyses it for past, present and future trends into the next century. The reality of community care is that it is largely family care, and this in practice tends to be female care. The wider costs associated with the caring role are presented, and the caring role is considered alongside other roles. Economic costs are discussed, and a hypothetical 'value' for informal care calculated. The support carers receive from the personal social services are described, and it is argued that a realistic policy of community care must include the development of a statutory service infrastructure. Families often receive very little support. In conclusion, a ten point community care policy agenda is presented.

COMMUNITY SERVICES; DEMOGRAPHIC ASPECTS; FAMILY; FINANCIAL ASPECTS; GENDER; NATIONAL STUDIES; POLICY; UNITED KINGDOM

- 300 Family Policy Studies Centre (1986), *Caring Costs: The Social Security Implications*, Briefing Paper, Family Policy Studies Centre, London, 14pp.

'It is estimated that there are in Britain today at least 1.3 million people acting as principal carers to adults and children with disabilities necessitating support with

daily living. The Social Security Bill, however, makes no specific provisions for carers. Indeed, some will find themselves worse off. Informal care of this kind is not without costs. Quite apart from the emotional and physical costs are substantial financial ones. This briefing considers the evidence on lost earnings, foregone employment and additional expenditure. In order to consider the social security implications, we provide an estimate of the "value" of informal care. This is between 5.1 billion and 7.3 billion pounds per annum. We also show that if just ten percent of those who cared for at home had instead to be looked after in residential institutions of different kinds, the public cost would be over 1 billion pounds each year.'

EMPLOYMENT; FINANCIAL ASPECTS; INCOME SUPPORT; NATIONAL STUDIES; UNITED KINGDOM

- 301 Farran, Carol J., Eleanora Keane-Hagerty, Sandra Salloway, Sylvia Kupferer and Carolyn S. Wilken (1991), 'Finding meaning: an alternative paradigm for Alzheimer's disease family caregivers', *The Gerontologist*, 31(4), 483-9.

'Theoretical formulations of stress and coping, family systems, crisis intervention, and loss and grief have inadequately explained how persons might grow and find meaning through their caregiving experiences. An existential theoretical framework guided the data interpretation in a qualitative study of 94 dementia family caregivers. Results suggest that an existential framework provides an alternative paradigm for understanding the caregiving experience.'

DEMENTIA; METHODOLOGY; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; THEORY DEVELOPMENT; UNITED STATES

- 302 Farries, John (1985), 'Giving the carers a much needed break', *Health and Social Service Journal*, August 8, 986-7.

This article describes a family support unit set-up in Middlesbrough, UK, by the South Tees Health Authority, Cleveland Social Services Department and the Alzheimer's Disease Society to give special support to people who care for mentally infirm relatives. It provides day care, residential care or both for up to forty families at any one time. Relative support groups where carers can share their experiences are also being developed.

CASE STUDIES; DAY CARE; DEMENTIA; RESPITE CARE; SUPPORT GROUPS; UNITED KINGDOM

- 303 Field, David, Pauline Dand, Sam Ahmedzai and Bronwen Biswas (1993), 'Lay carers of patients admitted to a hospice: how caring restricts their lives', *Health & Social Care in the Community*, 1(3), 161-8.

'The aim of this paper is to examine how caring for a terminally ill person in the domestic home restricts the lives of their lay carers. Fifty-nine lay carers of hospice patients were interviewed in the hospice approximately a week after the patient's admission using a structured and primarily closed choice schedule. Respondents were mainly the spouse or other close kin of terminally ill patients admitted to the hospice. Respondents reported that in the month prior to their admission, patients were highly symptomatic and required a great deal of help with activities of daily living. Forty per cent of patients required help. Three-quarters of the lay carers reported receiving help from one to three other lay carers in looking after the patient. Two thirds of the carers said that either the patient or they themselves, or both, would have benefited from more help. Over one third of carers reported that in the month prior to the patient's hospice admission their own activities had been severely restricted, especially in the areas of visiting friends and relatives and going out to social activities. Activities least affected were looking after other members of the household and going out to paid work.'

EMPLOYMENT; SOCIAL ASPECTS; UNITED KINGDOM

- 304 Finch, Janet (1984), 'Community care: developing non-sexists alternatives', *Critical Social Policy*, (9), 6-18.

'This article seeks to further the debate prompted by feminist analyses of community care, by considering whether any form of community care for dependent adults can be non-sexist. It focuses on how alternative social policies acceptable to feminists and socialists could be developed, and argues that, in the process, considerations about the relational aspects of caring should occupy a prominent place.'

GENDER; IDEOLOGY; POLICY; UNITED KINGDOM

- 305 Finch, Janet (1985), 'A response to Robert Harris: end points and starting points', *Critical Social Policy*, (12), 123-6.

This is a reply to Robert Harris' criticism of her article 'Community care: developing non-sexists alternatives' in *Critical Social Policy*, (9), Spring, 1984:6-18.

GENDER; IDEOLOGY; POLICY; UNITED KINGDOM

- 306 Finch, Janet (1989), *Family Obligations and Social Change*, Family Life Series, Polity Press, Cambridge, viii, 269pp.

This book 'explores family relations in a historical perspective, considering whether families support each other less now than in the past. Empirical evidence on contemporary families is used to assess the kinds of support, and how far the support is based on a sense of duty and obligation within families. The discussion highlights the gaps in research on these topics and points out the important questions which need to be answered for the 1990s.'

FAMILY; FINANCIAL ASPECTS; HISTORICAL ASPECTS; RELATIONSHIPS; SOCIAL ASPECTS; THEORY DEVELOPMENT; UNITED KINGDOM

- 307 Finch, Janet (1990), 'The politics of community care in Britain', in Clare Ungerson, ed., *Gender and Caring: Work and Welfare in Britain and Scandinavia*, Harvester Wheatsheaf, Hemel Hempstead, Herts., 34-58.

Since the mid-1960s in Britain, policies have promoted community care rather than residential care for the aged and people with disabilities. Over the same period there has been an increased acknowledgement politically of the rights of women, stimulated in part by second-wave feminism. This chapter aims to link these two developments with the following questions in mind: 'How have these two sets of political changes connected with each other in relation to the role of women as providers of unpaid care for their relatives? As the politics of welfare have changed, have they in any way taken into account the issue of women's rights and women's roles? If so, in what ways and with what consequences?' One approach to developing a set of feminist demands about caring for elderly people would be to question whether the concept of 'community care' is appropriate at all, e.g. 'community care need not mean family care', or the replacement of care 'in' the community by care 'by' the community.

CONCEPTUAL ISSUES; GENDER; IDEOLOGY; POLICY; UNITED KINGDOM

- 308 Finch, Janet and Dulcie Groves (1980), 'Community care and the family: a case for equal opportunities?' *Journal of Social Policy*, 9(4), 486-511.

'Despite the existence of sex discrimination legislation certain social policies appear to militate against equal opportunities between the sexes. Community care policies are a case in point, especially with current interest shifting towards "care by the community", and the presumed existence of "informal caring networks", with a view to their effective mobilization at a time of cutbacks in both public expenditure and in domiciliary social service provision for groups such as the handicapped and elderly. To the extent that community care policies rely on women's unpaid domestic labour and may necessitate their withdrawal from the labour market, such policies could be counter-productive to the promotion of "equal opportunities". The challenge is to

devise community care policies which do not disadvantage women and which give men "equal opportunities" to take on caring roles usually assigned to women.'

GENDER; POLICY; UNITED KINGDOM

- 309 Finch, Janet and Dulcie Groves (1982), 'By women for women: caring for the frail elderly', *Women's Studies International Forum*, 5(5), 427-38.

'The care of the frail elderly should be a subject of especial and growing importance to the women's movement. Two-thirds of the 75+ age group in England and Wales are women, who, when subject to the disabilities of advancing age, are usually assisted or cared for by other women. Current government policies emphasize care at home and assume the availability of unpaid female labour. Care in residential institutions depends largely upon the low paid labour of women. How can the dilemmas posed by different policy options be resolved? Can modes of care be devised which do not rely on exploiting women's labour and which offer choice to elderly women?'

GENDER; POLICY; UNITED KINGDOM

- 310 Finch, Janet and Dulcie Groves, eds (1983), *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, ix, 182pp.

This book focuses on women who provide unpaid care outside of residential institutions, often in their own homes, for children and adults who are handicapped or chronically sick, and for frail elderly people. It is particularly interested in those female carers who have given up paid work in order to provide care or who have never worked full-time because of their caring role. The various contributions to this book 'explore different facets of women's experience of caring, the dilemmas which caring poses for women, the tensions between paid work and unpaid caring (which can be hard work) and the social policy issues raised'. For individual contributions see also Hilary Graham, Clare Ungerson, Sally Baldwin and Caroline Glendinning, Judith Oliver, Fay Wright, Alan Walker, Lesley Rimmer and Dulcie Groves and Janet Finch.

EMPLOYMENT; GENDER; POLICY; UNITED KINGDOM

- 311 Finch, Janet and Jennifer Mason (1990), 'Filial obligations and kin support for elderly people', *Ageing and Society*, 10(2), 151-75.

'This article explores the nature of obligation and responsibility within kin groups, focusing particularly upon how far these underscore the assistance which may be offered by children to their elderly parents. Both quantitative and qualitative data, drawn from a study of family obligations in the north-west of England, are discussed. The authors argue that relationships between parents and children are

founded on a sense of obligation up to a point, but assent for this is not universal and such obligations are seen as having definite limits. To understand how obligations operate in practice, it is necessary to focus upon the way in which support for elderly parents is a matter for negotiation in families, and to examine the principles which are incorporated into such negotiations.'

DAUGHTERS; FAMILY; NATIONAL STUDIES; QUALITATIVE STUDIES;
RELATIONSHIPS; SONS; UNITED KINGDOM

- 312 Finch, Janet and Jennifer Mason (1990), 'Gender, employment and responsibilities to kin', *Work, Employment & Society*, 4(3), 349-67.

'This article is concerned with conflicts of interest between people's commitment to employment and their responsibilities to kin, especially for the care of elderly relatives. Questions are raised about what is generally seen as the appropriate balance of priorities, and how such priorities and conflicts are actually handled and resolved in kin groups, by women in particular. The paper draws on both quantitative and qualitative data from a study of family obligations. The authors argue that choices between either maintaining or giving up employment to care for kin rarely arise in such stark form for a variety of reasons. When they do, however, compromise strategies tend to be sought which protect existing employment whilst at the same time enabling people to take some responsibility for their kin. Women's jobs, as well as men's, can be protected in these circumstances and this is widely approved of at the normative level. It is likely that in the future, if more women are encouraged into the labour market, and if they develop consistent employment patterns, many more may need to generate compromise strategies.'

EMPLOYMENT; FAMILY; GENDER; QUALITATIVE STUDIES; UNITED
KINGDOM

- 313 Finley, Nancy J. (1989), 'Theories of family labor as applied to differences in caregiving for elderly parents', *Journal of Marriage and the Family*, 51(1), 79-86.

'This study explores explanations for gender differences in caregiving to elderly parents. Similar to housekeeping and child care, caregiving to elderly parents is a type of family division of labor. Consequently, four popular hypotheses of family labor are applied - the time-available hypothesis, the socialization/ideology hypothesis, the external resources hypothesis, and the specialization of tasks hypothesis. Data obtained from a survey of adult respondents who currently have a mother over the age of 70 reveal that these theories of gender differences in divisions of family labor do not adequately explain caregiving for the elderly. The structural nature of the lack of contributions of males to family caregiving is addressed.'

FAMILY; GENDER; THEORY DEVELOPMENT; UNITED STATES

- 314 Finley, Nancy J., M. Diane Roberts and Benjamin F. Banahan (1988), 'Motivators and inhibitors of attitudes of filial obligation toward aging parents', *The Gerontologist*, 28(1), 73-8.

'Data from interviews of adult children with elderly parents were used to investigate motivators and inhibitors of attitudes to filial obligation. Revealed was that obligation is not simply a product of affection but that the degree of obligation is also explained by such structural and demographic factors as distance and role conflict. It was discovered that associations of predictor variables with filial obligation vary by parent type (mother, father, mother-in-law, or father-in-law) and by gender of the adult child.'

DAUGHTERS; FAMILY; GENDER; PSYCHOLOGICAL ASPECTS; SONS;
UNITED STATES

- 315 Fischer, Lucy Rose (1985), 'Elderly parents and the caregiving role: an asymmetrical transition', in Warren A. Peterson and Jill Quadagno, eds, *Social Bonds in Later Life: Aging and Interdependence*, Sage, Beverly Hills, Calif., 105-14.

This study examines the impact of a parent's health crisis on four dimensions of relationships with adult children: (1) role perspectives, i.e. how the partners view each other and interpret the nature of their relationship; (2) emotional attachment; (3) interdependency; and (4) power - who exercises decision-making control and under what circumstances. The research asks: what is the nature of this transition from the role positions of the elderly parent and the caregiving daughter or son?

DAUGHTERS; HEALTH; RELATIONSHIPS; SONS; UNITED STATES

- 316 Fischer, Lucy Rose and Nancy N. Eustis (1988), 'DRGs and family care for the elderly: a case study', *The Gerontologist*, 28(3), 383-9.

'A longitudinal case study of a suburban hospital in Minnesota, before and after the implementation of DRGs [Diagnostic Related Grouping], entailed in-depth interviews in 1982 and 1986 with family caregivers (15 and later 16) and patients (11 and 9), as well as hospital staff (16 and 36). In 1986, families and patients were much more likely to express concern about problems in hospital admissions, discharge, and quality of care. The elderly patients were also more likely to return home and receive home-care services. Along with other trends in health care, DRGs have increased the importance of the managerial family. Families increasingly serve as mediators, supervisors, and planners for both in-hospital and post-hospital care.'

CASE STUDIES; FAMILY; RELATIONSHIPS; UNITED STATES

- 317 Fisher, Berenice and Joan Tronto (1990), 'Toward a feminist theory of caring', in Emily K. Abel and Margaret K. Melon, eds, *Circles of Care: Work and Identity in Women's Lives*, State University of New York Press, Albany, 35-62.

'This chapter seeks to reconceptualize caring in a broad fashion, one that is comprehensive (including both the public and private), integrated (not based on the separation of spheres), and feminist (speaking to the ways in which caring often entails and perpetuates the oppression of women).' The aim is 'to provide a theoretical orientation that does not merely reproduce but helps to change how we think about caring.' The chapter consists of four sections: (a) a general argument about the nature of caring; (b) an analysis of the caring process that pinpoints its major phases and components; (c) a discussion of the primary modes of caring in society; and (d) an exploration of three prevalent feminist ideals of caring, based on motherhood, friendship and sisterhood.

GENDER; IDEOLOGY; THEORY DEVELOPMENT; UNITED STATES

- 318 Fitting, Melinda, Peter Rabins, M. Jane Lucas and James Eastham (1986), 'Caregivers for dementia patients: a comparison of husbands and wives', *The Gerontologist*, 26(3), 248-52.

'Using a structured interview, spouse caregivers of dementia patients were compared for measures of burden, family environment, social networks, psychological adjustment, demographic data, and feelings about the dementing illness. Female caregivers were more distressed than men, and younger caregivers were lonelier and more resentful of their role than older caregivers.'

DEMENTIA; GENDER; METHODOLOGY; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 319 Fortinsky, Richard H. and Tania Jo Hathaway (1990), 'Information and service needs among active and former family caregivers of persons with Alzheimer's disease', *The Gerontologist*, 30(5), 604-9.

'This study interprets results of a needs assessment completed by active and former caregivers of relatives with Alzheimer's disease (AD). Self-administered questionnaires yielded data about information and service needs at the time of diagnosis and at the time of the survey. Implications point to the need for high-quality educational material throughout the caregiving career, improved training for health professionals about AD, and an important role for former caregivers as resources to disseminate knowledge about AD to still-active caregivers and others in their own communities.'

COMMUNITY SERVICES; DEMENTIA; EDUCATION; METHODOLOGY; UNITED STATES

- 320 Fraser, J.C. (1992), *Community Care Plans: Consultation with Users and Carers. Report on Local Authority Consultation with Users and Carers in the Preparation of Community Care Plans*, Social Services Inspectorate, Northern Region, Department of Health, Gateshead, 1v.(various pagings)

This report describes the first round of consultation with users and carers in the preparation of community care plans in four local authorities in the Northern Region of Britain: Cleveland, Durham, North Tyneside and Gateshead. It identifies existing arrangements for consultation; the processes of consultation and response of users and carers. All authorities had been developing consultation initiatives and had obtained some success in publicising the process. In general it was found to be a positive experience and resources were committed to the process. However, the impact of widespread coverage on public attitudes was unmeasured and there was found to be potential for a more targeted approach to current users of services and their carers.

COMMUNITY SERVICES; EVALUATION; POLICY; SERVICE USE; UNITED KINGDOM

- 321 Freed, Anne O. (1990), 'How Japanese families cope with fragile elderly', *Journal of Gerontological Social Work*, 15(1/2), 39-56.

'Coping with caring for ill, fragile elderly is taxing the families in Japan, where longevity statistics predict early in the twenty-first century it will have the highest percentage of aged in the world. Interviews with 20 families revealed that although the culture mandates families care for their elderly, many are having considerable ambivalence and conflict, and caretakers suffer in the process unless they have assumed the defense of a martyr stance. Most do not seek nursing homes but are turning to government for supportive services. The trend in Japan, in spite of tradition, is for adult children to delay taking parents into their homes until they are unable to care for themselves.'

COMMUNITY SERVICES; FAMILY; GENDER; LIVING ARRANGEMENTS; SOCIAL ASPECTS; JAPAN

- 322 Friss, Lynn (1990), 'A model state-level approach to family survival for caregivers of brain-impaired adults', *The Gerontologist*, 30(1), 121-5.

This article describes a statewide program to support family caregivers of brain-impaired adults and identifies the major needs and problems of these family caregivers and delineates service interventions to meet those needs. It reports demographic data on the major characteristics of over 3,000 family caregivers and their cognitively impaired patients.

COMMUNITY SERVICES; DISABLED; METHODOLOGY; POLICY; UNITED STATES

- 323 Gallagher, Dolores (1987), 'Caregivers of chronically ill elders', in George Maddox, ed., *The Encyclopedia of Aging*, Springer, New York, 89-91.

This provides an overview of caring for the caregivers of chronically ill elders, intervention efforts to decrease caregiver burden, educational and supportive programs, respite programs, and psychotherapeutic interventions.

CHRONIC ILLNESS; EDUCATION; PSYCHOLOGICAL ASPECTS; RESPITE CARE; SUPPORT GROUPS; UNITED STATES

- 324 Gallagher, Dolores, Steven Lovett and Antonette Zeiss (1989), 'Interventions with caregivers of frail elderly persons', in Marcia G. Ory and Kathleen Bond, eds, *Aging and Health Care: Social Science and Policy Perspectives*, Contemporary Issues in Health, Medicine and Social Policy, Routledge, London, 167-90.

'This chapter reviews existing literature on four types of caregiver intervention programs [respite programs, peer-led support groups, professionally led educational support programs, and counselling and psychotherapy]. An in-depth discussion of the theoretical rationale for one particular type of intervention, psychoeducational programs, is presented. The Palo Alto Caregiver assistance project, which exemplifies this last approach, is described in detail and preliminary data are reported. Currently unanswered questions are raised and suggestions for future research are recommended.'

CASE STUDIES; COUNSELLING; DEMENTIA; EDUCATION; LITERATURE REVIEW; METHODOLOGY; RESPITE CARE; SUPPORT GROUPS; UNITED STATES

- 325 Gallagher, Dolores, Jonathan Rose, Patricia Rivera, Steven Lovett and Larry W. Thompson (1989), 'Prevalence of depression in family caregivers', *The Gerontologist*, 29(4), 449-56.

'Family caregivers who sought help to increase their coping skills (N=158) and caregivers who volunteered for a longitudinal study of Alzheimer's disease (N=58) were screened for depression. Among help-seekers, 46% had depression according to Research Diagnostic Criteria (RDC), but among non-help-seekers, only 18% met this criterion. In general, women were more depressed than men, but no major differences in the extent of depression were found in those who cared for more impaired persons.'

FAMILY; DEMENTIA; GENDER; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 326 Gallagher, Dolores, Amy Wrabetz, Steven Lovett, Susan Del Maestro and Jonathan Rose (1990), 'Depression and other negative affects in family caregivers', in Enid Light and Barry D. Lebowitz, *Alzheimer's Disease Treatment and Family Stress: Directions for Research*, Hemisphere, New York, 218-44.

This chapter reviews what is known about negative emotions, including depression, anger, and anxiety, experienced by family caregivers. It also presents data from the authors' ongoing longitudinal research regarding this issue. Finally, it raises some unanswered questions and makes suggestions for future research.

DEMENTIA; LITERATURE REVIEW; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 327 Gallagher, Sally K. (1994), *Older People Giving Care: Helping Family and Community*, Auburn House, Westport, Conn., xiv, 182pp.

This book provides an analysis of 'the amount, range and types of care older men and women provide to kith and kin. The purpose, however, is not only to chronicle the distribution and desire to help, but to analyze the ways in which age, gender and marriage affect the help given by the elderly. The analysis is arranged around gender and marriage.' The study is based on in-depth personal interviews with a stratified sample of 324 women and men aged 25 to 94.

AGED CAREGIVERS; ETHNICITY; GENDER; METHODOLOGY; RELATIONSHIPS; SPOUSES; UNITED STATES

- 328 George, Linda K. and Lisa P. Gwyther (1986), 'Caregiver well-being: a multidimensional examination of family caregivers of demented adults', *The Gerontologist*, 26(3), 253-9.

'The well-being of family caregivers of older memory-impaired adults was examined in four dimensions: physical health, mental health, financial resources, and social participation. Results indicated that, relative to random community samples, caregivers are most likely to experience problems with mental health and social participation. In addition, characteristics of the caregiving situation were more closely associated with caregiver well-being than were illness characteristics of the patients.'

FINANCIAL ASPECTS; HEALTH; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; UNITED STATES

- 329 Getzel, George S. (1982), 'Group work with kin and friends caring for the elderly', *Social Work with Groups*, 5(2), 91-102.

'The significant roles of kin and friends in caring for the frail elderly necessitates an extension of group services to this population. The rationale for caregiver groups is developed through an examination of gerontological research. A group program and a practice framework for services to kin and friends are presented. Practice issues in running groups entail profound stresses on families and friends and the worker's ability to face thematic and interactional problems of considerable intensity. Guidelines for intervention are specified to handle phase specific situations in these groups.'

COUNSELLING; SUPPORT GROUPS; UNITED STATES

- 330 Gibeau, Janice L. and Jeane W. Anastas (1989), 'Breadwinners and caregivers: interviews with working women', *Journal of Gerontological Social Work*, 14(1/2), 19-40.

'Until recently, studies of family caregivers for the elderly have not considered the work lives of caregivers. Based on interviews with 77 women who were working full-time while caring for an elderly family member, this study examined the strains experienced and supports needed to balance work and family responsibilities. One in 5 of the women interviewed had considered quitting work because of caregiving. The functioning of the elderly family member, the amount of caregiving work performed, and selected job factors affected absenteeism and the likelihood that a women might consider quitting her job. Implications for the development of employee benefits to assist family caregivers are discussed.'

EMPLOYMENT; UNITED STATES

- 331 Gibson, Mary Jo (1982), 'An international update on family care for the ill and elderly', *Ageing International*, 9(1), 11-14.

This article outlines research findings on the burden which caregiving can place on the responsible family member and gives examples of several programs which have been developed to alleviate some of the stress. An innovative social action partnership forged to increase support for family caregivers in New York is described.

CASE STUDIES; INTERNATIONAL COMPARISONS; PSYCHOLOGICAL ASPECTS

- 332 Gibson, Mary Jo (1984), 'Family support of the elderly mentally ill: an international overview', *Australian Journal on Ageing*, 3(3), 19-14.

This article provides an overview of family support patterns around the world in developing and developed nations and then focuses more specifically on the role of the family in supporting mentally ill older people. Research indicates that the caretakers of physically and mentally impaired older people suffer a number of stresses and are themselves in need of supportive services. Some of these services are outlined. Finally, a few of the difficult policy issues that nations face in trying to find ways to encourage family support are described.

COMMUNITY SERVICES; FAMILY; INTERNATIONAL COMPARISONS;
MENTAL ILLNESS; POLICY; PSYCHOLOGICAL ASPECTS

- 333 Gibson, Mary Jo and Charlotte Nusberg (1986), 'Caregiving in developed nations: Part I', *Ageing International*, 13(1), 17-19.

This article reports on recent findings about caregiving in developed nations. It examines the nature of 'burden' of care, and concludes that a range of services must be developed to meet the heterogeneous needs of carers and their frail elderly.

COMMUNITY SERVICES; INTERNATIONAL COMPARISONS; POLICY;
PSYCHOLOGICAL ASPECTS

- 334 Gibson, Mary Jo and Charlotte Nusberg (1986), 'Caregiving in developed nations: Part II', *Ageing International*, 13(2), 13-19.

This article provides an update on some of the policy options being examined by industrialised nations as well as research findings that bear on the central policy question of which needs of the dependent elderly can be met by informal carers and which by the formal service sector.

INTERNATIONAL COMPARISONS; POLICY

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

'The aim of this paper is to present findings concerning a variety of factors expected to influence, either directly or indirectly as mediators, the psychological well-being of persons caring for a dementing relative in the community. The sample included both co-resident and non-resident supporters and the data were collected via a semi-structured interview. Only sex of dependent, sex of supporter, satisfaction with help from relatives, blood/role relationship, duration of care, frequency of visits from a home help and community nurse were significantly correlated with supporters'

morale and mental health. The directions of these correlations were, however, not always as expected, e.g. the longer the duration of care-giving the higher the supporters' morale and the better the supporters' mental health. It was interesting to find that the level of impairment and help from family and friends were not significantly associated with morale and mental health of supporters.'

DEMENTIA; GENDER; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
UNITED KINGDOM

- 336 Gilhooly, Mary L.M. (1986), 'Senile dementia: factors associated with caregivers' preference for institutional care', *British Journal of Medical Psychology*, 59(2), 165-71.

'This paper presents findings concerning variables expected to influence the motivation of persons caring for a dementing relative in the community to continue giving care and support. The variables examined in relation to "preference for institutional care" were those previously examined in relation to supporters' psychological well-being (Gilhooly, 1984). The results indicate that factors within the relationship between supporter and the dependent dementing relative are important determinants of motivation to continue giving support. Other variables significantly associated with advocacy of institutional care included the age of the supporter, supporter's contacts with friends, satisfaction with help from relatives, another dependent relative, and whether or not the supporter was employed. Help from the services and supporters' well-being were not significantly correlated with ratings of preference for institutional care.'

DEMENTIA; INSTITUTIONALISATION; METHODOLOGY; UNITED
KINGDOM

- 337 Gilleard, C.J. (1984), *Living with Dementia: Community Care of the Elderly Mentally Infirm*, Croom Helm, London, 136pp.

'This book is concerned with the social pressures arising from and current societal responses to the problem of dementia sufferers living in non-institutional settings...the experience of dementia is one which cannot be separated from the deterioration in personal relationships.' This book covers the interior and exterior processes of dementia and sets them within the context of the community. After describing the disease itself, it goes on to discuss community services for the mentally infirm; the problems faced by caregivers and the consequences of caring. The final chapter looks to the future and proposes a model of care.

COMMUNITY SERVICES; DEMENTIA; PSYCHOLOGICAL ASPECTS;
SOCIAL ASPECTS; THEORY DEVELOPMENT; UNITED KINGDOM

- 338 Gilleard, C.J. (1985), 'The impact of psychogeriatric day care on the patients supporting relatives', *Health Bulletin*, 43(4), 199-205.

This article reports on a 1981 research project which examined psychogeriatric day care in the Lothians, Scotland, and which was funded by the Scottish Home and Health Department. The study lasted two years and addressed itself to three main questions: (1) Are the family supporters of patients referred for day care under significant strain? (2) What seems to influence the level of strain experienced? (3) How much does the day hospital reduce any strain and help the carers? It was found that carers of mentally infirm relatives suffered severe strain, burden and emotional disturbance and that stress was reduced in cases where the aged relative attended day care. The best candidates for day care were found to be those with some degree of self care impairment, but continent, with a supporter receiving family help rather than community services, who feels in rather poor health, and who foresees few if any disadvantages in their relative attending day care.

DAY CARE; MENTAL ILLNESS; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 339 Gilleard, C.J. (1985), 'Predicting the outcome of psychogeriatric day care', *The Gerontologist*, 25(3), 280-5.

'The present study examined the contribution of the problems faced by caregivers, the strain they experienced, their relationship with their dependent, and their attitudes towards day care in determining the outcome placements of psychogeriatric day hospital patients, using discriminant function analysis. Features contributing to the continued attendance of the demented elderly at the day hospital are examined to ascertain their implications for such services.'

DAY CARE; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED KINGDOM

- 340 Gilleard, C.J., W.D. Boyd and G. Watt (1982), 'Problems in caring for the elderly mentally infirm at home', *Archives of Gerontology and Geriatrics*, 1, 151-8.

'The supporters of psychogeriatric patients attending 5-day hospitals were asked to complete questionnaires concerning the particular problems they experienced in caring for their patients at home. The information provided by the supporter was then related to measures of mood, self-reported strain, and outcome 12 [months] from the patients first attendance. The results pointed to the importance of problems reflecting attentional and emotional demand from such patients, in determining the level of strain, and the supporters' capacity to continue to care for the patient in the community.'

MENTAL ILLNESS; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 341 Gilleard, C.J., E. Gilleard, K. Gledhill and J.E. Whittick (1984), 'Caring for the elderly mentally infirm at home: a survey of the supporters', *Journal of Epidemiology and Community Health*, 38(4), 319-25.

'A sample of 129 supporters caring for an elderly mentally infirm relative consecutively referred to psychogeriatric daycare services was interviewed. Information was obtained on the problems encountered by their dependant, the extent of their involvement, the amount of formal and informal support received, the subjective strain and burden reported, and their expectations of their ability to continue in the caring role. An attempt has been made to use this information to describe the extent of strain and some of the determinants of strain involved in caring. The results suggest that the sex of the dependant and the age of the supporter together with a number of problems faced all influence the reported level of strain. The amount of existing community support, whether formal or informal, does not seem to mitigate significantly the strain placed on the principal carers.'

DAY CARE; MENTAL ILLNESS; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 342 Gilleard, C.J., H. Belford, E. Gilleard, J.E. Whittick, and K. Gledhill (1984), 'Emotional distress amongst the supporters of the elderly mentally infirm', *British Journal of Psychiatry*, 145, August, 172-7.

'Three samples of supporters of elderly infirm dependents who were either attending or about to attend day hospitals were given the 30-item General Health Questionnaire (GHQ) to complete. Prevalence levels of disturbance varied from 57% to 73%; female supporters (the majority) reported higher levels of distress. High scores were related to a diagnosable psychiatric condition, and were significantly associated with a combination of poor self-health ratings in the supporters, more frequent behaviour problems in the dependents, and a more negative view of the premorbid relationship between supporter and dependent. Reported amount of contact time and levels of formal and informal outside support were not related to GHQ scores.'

DAY CARE; GENDER; HEALTH; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 343 Glasser, Michael, Susan Rubin and Mary Dickover (1990), 'The caregiver role: review of family caregiver-physician relations and dementing disorders', in Sidney M. Stahl, ed., *The Legacy of Longevity: Health and Health Care in Later Life*, Sage, Newbury Park, Calif., 321-37.

'This chapter reviews and examines the relationship between physicians and both their patients and the caregivers to those patients.' It focuses on Alzheimer's disease and other dementing disorders. It explores this relationship through the concept of the social triad. Past studies are summarised and discussed as is a study conducted

by the authors. Finally, there is an assessment of the current and future state of this relationship from a clinical as well as a theoretical standpoint.

DEMENTIA; RELATIONSHIPS; THEORY DEVELOPMENT; UNITED STATES

- 344 Glazer, Nona Y. (1990), 'The home as workshop: women as amateur nurses and medical care providers', *Gender & Society*, 4(4), 479-99.

'The high-tech health service work done by amateur family caregivers in U.S. homes challenges the conventional division of the social world into public and private. Under new federal reimbursement systems, the diagnosis-related groups (DRGs), patients are being discharged sicker than before from hospitals and nursing homes, or after treatments in outpatient clinics. Health care facilities depend on a work transfer, shifting their earlier responsibilities for the sick to the family. There, women family members do for free the work once done by paid health service workers in health care facilities, caring for family members who need their nursing and housekeeping services. Women's unpaid work knits together "public" and "private", demonstrating how capitalism reorganizes the labor process to make use of free service labor.'

GENDER; IDEOLOGY; POLICY; RELATIONSHIPS; UNITED STATES

- 345 Glendinning, Caroline (1988), 'Dependency and interdependency: the incomes of informal carers and the impact of social security', in Sally Baldwin, Gillian Parker and Robert Walker, eds, *Social Security and Community Care*, Avebury, Aldershot, Hants., 131-9.

The Social Policy Research Unit at the University of York explored the coherence and adequacy of social security supports for carers by examining the incomes of a sample of working age, informal carers who were looking after a severely disabled or dependent relative (usually a parent/parent-in-law) living in the same household. This chapter summarises the findings of that research. It goes on to suggest that the shortcomings identified could be remedied by firstly, the introduction of a non-means-tested, tax-free allowance for all carers, regardless of age, marital or employment status to compensate for the social, psychological and financial costs of caring and secondly, to compensate for the earnings lost by part-time employed carers as well as replacing earnings lost by carers with no paid employment at all. Both benefits should be paid for a short specified period after caring ceases.

DEPENDENCY; EMPLOYMENT; FINANCIAL ASPECTS; INCOME SUPPORT; UNITED KINGDOM

- 346 Glendinning, Caroline (1989), *The Financial Needs and Circumstances of Informal Carers: Final Report*, Social Policy Research Unit, University of York, iii, 200pp.

'The aim of this study was to undertake a detailed and comprehensive investigation of the financial impact on a sample of carers of providing help and support to a severely disabled or infirm elderly relative. Four main areas of investigation were identified': employment outside the home and its relationship to the provision of care; impact on income and living standards; transfers of resources and their impact on carers' material circumstances; and receipt of statutory, private and voluntary services.

COMMUNITY SERVICES; EMPLOYMENT; FINANCIAL ASPECTS; INCOME SUPPORT; UNITED KINGDOM

- 347 Glendinning, Caroline (1990), 'Dependency and interdependency: the incomes of informal carers and the impact of social security', *Journal of Social Policy*, 19(4), 469-97.

'Consideration of the income and social security needs of informal carers has remained conspicuously absent from discussions about "community care". Similarly, carers have been more or less invisible in the development of social security policies. This paper reports on a study of the financial circumstances of a sample of working age carers, who were living with and providing substantial amounts of help and support to a disabled person in the same household. The study highlights first, the substantial work-related costs incurred by carers with full time employment; and second the financial dependency of carers without full time earnings, on their spouse, sibling or on the person being cared for. The implications of these findings are discussed in the light of recent developments in social security policies.'

DEPENDENCY; EMPLOYMENT; FINANCIAL ASPECTS; INCOME SUPPORT; POLICY; UNITED KINGDOM

- 348 Glendinning, Caroline (1992), *The Costs of Informal Care: Looking Inside the Household*, HMSO, London, for the Social Policy Research Unit, University of York, vi, 119pp.

'Research into the financial consequences of informal care-giving is, by and large, still at a fairly rudimentary stage. The reasons for this lie partly in the overwhelming concern of policy-makers, politicians and administrators alike about the *public* expenditure consequences of various policy options.' It has become increasingly clear, however, that very considerable private costs are also involved and that these are borne in an unequal manner between women and men. Should the state take a more active role in attempting to equalise the costs of caring in the form of increased taxation and public expenditure on services and social security provision? Overlooking the privately-borne costs of community care may increase the physical,

emotional and social costs of informal care-giving which may have substantial public policy implications in the long-term. In looking at these issues this monograph describes the financial circumstances of a small group of carers in order to put together a comprehensive picture of the financial consequences of giving care.

FINANCIAL ASPECTS; GENDER; INCOME SUPPORT; POLICY; UNITED KINGDOM

- 349 Glendinning, Caroline (1993), 'Paying for informal care: lessons from Finland', *Journal of European Social Policy*, 3(4), 239-53.

'Growing numbers of elderly people, combined with falling birthrates, have generated increasing interest within most western European and Scandinavian countries in measures which might increase the supply of care-giving labour while at the same time reducing the unit costs of that labour. To what extent, and how, might expensive formal service provision be replaced by less costly and more plentiful help from informal sources; and what is the role of the welfare state in protecting and regulating the different interests of those who give and those who receive care on an informal basis? This paper describes the pressures for change in the UK, especially the shortcomings in the current social security approach to paying informal care-givers; the demands of disabled people for greater control over personal assistance services; and the implementation of the "community care" reforms. It then describes and evaluates the Finnish system of Home Care Allowances, in which local municipalities pay friends and relatives who are providing very substantial amounts of care to a frail elderly person. Focusing particularly on the issues of adequacy, autonomy and independence (both for those giving and those receiving care), and territorial equity, the paper discusses the potential advantages and disadvantages of possible moves towards a Home Care Allowance approach in the UK.'

DEPENDENCY; EMPLOYMENT; FINANCIAL ASPECTS; GENDER; INCOME SUPPORT; POLICY; RELATIONSHIPS; FINLAND; UNITED KINGDOM

- 350 Glendinning, Caroline and Eithne McLaughlin (1993), *Paying for Care: Lessons from Europe*, Research Paper 5, Social Security Advisory Committee, HMSO, London, viii, 161pp.

In commissioning this research, the Social Security Advisory Committee specified three main areas of interest: the current arrangements for social security provision for informal carers in at least six European countries; the way in which these arrangements overlap and interact with service provision for informal carers; and the relationship between both social security and service provision and the labour market behaviour of carers. The first chapter introduces the informal care issues in Europe such as demographic aspects; public expenditure; quality of life issues; and disability. It also outlines the information sought and methodology used in the research. The next chapters look at the situation in Great Britain, the Republic of

Ireland, Italy, France, Germany, Finland and Sweden. The final chapter is a summary of the findings and conclusions.

COMMUNITY SERVICES; DEMOGRAPHIC ASPECTS; DISABLED;
FINANCIAL ASPECTS; INCOME SUPPORT; INTERNATIONAL
COMPARISONS; METHODOLOGY; POLICY; RELATIONSHIPS; EUROPE;
FINLAND; FRANCE; GERMANY; IRELAND; ITALY; SWEDEN; UNITED
KINGDOM

- 351 Glosser, Guila and Debra Wexler (1985), 'Participants' evaluation of educational/support groups for families of patients with Alzheimer's disease and other dementias', *The Gerontologist*, 25, 232-6.

'Fifty-four participants of seven 8-week educational/support groups for relatives of patients with Alzheimer's Disease and other dementias evaluated the "helpfulness" of various aspects of their group experience. Evaluations were generally very positive. The supportive aspects of the group and the information provided about medical and behavioral management of the patient were most highly rated. Resolution of intrafamilial conflict and information pertaining to specific legal/financial/social problems were evaluated as somewhat less helpful.'

DEMENTIA; EDUCATION; EVALUATION; SUPPORT GROUPS; UNITED STATES

- 352 Gonyea, Judith G. (1991), 'Alzheimer's disease support group participation and caregiver well-being', *Clinical Gerontologist*, 10(2), 17-34.

'The primary objective of this study was to explore the relationship between support group participation and families' sense of psychological well-being. Comparison of 301 Alzheimer's disease families attending support groups and 75 control Alzheimer's disease families was undertaken. While correlational analysis did reveal group participation was associated with both lower levels of objective and subjective burden and a more positive sense of morale; regression analysis revealed the most salient predictors of care-giver well-being were the family and Alzheimer's disease victim characteristics.'

COMPARATIVE STUDIES; DEMENTIA; PSYCHOLOGICAL ASPECTS;
SUPPORT GROUPS; UNITED STATES

- 353 Gonyea, Judith G. and Nina M. Silverstein (1991), 'The role of Alzheimer's disease support groups in families' utilization of community services', *Journal of Gerontological Social Work*, 16(3/4), 43-55.

'The relationship between support group participation and families' knowledge and utilization of community services was explored through the comparison of 301

Alzheimer's disease families attending ADRDA support groups and 75 control Alzheimer's disease families. The data revealed that while support group membership was not associated with families' knowledge of community resources, it was correlated with families' use of formal services. Practice implications and future research directions are addressed.'

COMMUNITY SERVICES; COMPARATIVE STUDIES; DEMENTIA; SERVICE USE; SUPPORT GROUPS; UNITED STATES

- 354 Goodman, Catherine Chase (1991), 'Perceived social support for caregiving: measuring the benefit of self-help/support group participation', *Journal of Gerontological Social Work*, 16(3/4), 163-75.

'Literature affirming the importance of social supports and the popularity of a self-help ideology have resulted in professional initiation of support groups. Support groups have become an important source of help particularly for caregivers of Alzheimer's victims. However, existing measures of social support assess the benefit of family and friend relationships and not the unique contribution of relationships developed in support groups. This study represents a preliminary report on a 9-item scale (Perceived Social Support for Caregiving) developed to include aspects of self-help support as well as information exchange and emotional support. In addition, a 3-item scale (Social Conflict) was developed to measure negative aspects of supportive relationships. The two scales were developed through factor analysis on a sample of 206 caregivers. Both have good internal consistency and can easily be adapted for use with other populations participating in self-help and support groups.'

DEMENTIA; METHODOLOGY; SUPPORT GROUPS; UNITED STATES

- 355 Goodman, Catherine Chase and Jan Pynoos (1988), 'Telephone networks connect caregiving families of Alzheimer's victims', *The Gerontologist*, 28(5), 602-05.

'The telephone network, a new concept in social support, brought family caregivers of Alzheimer's victims together over the telephone in a rotating pattern of twosomes. Five caregiving spouses and five adult children were matched and connected to each other over a 3-month period. The program included 25 audiotaped mini-lectures accessed over the telephone that guided the networks and provided information about Alzheimer's disease. Topics ranged from day-to-day care, to legal, financial and medical issues. The tapes are summarized in workbooks that include instructions for those who wish to start a telephone program.'

CASE STUDIES; DEMENTIA; EDUCATION; SUPPORT GROUPS; UNITED STATES

- 356 Goodman, Sharon (1991), 'Patterns of participation in support groups for dementia caregivers', *Clinical Gerontologist*, 10(4), 23-34.

'Anecdotal evidence suggests that inconsistent participation in support groups for dementia caregivers negatively affects both the continuing attenders and the brief attenders; however, prior research has not directly evaluated patterns of support group participation. Sixty-nine caregivers of relatives with dementia participated in the present study. Forty-three subjects were current members of a support group, while the remaining 26 were former members who attended fewer than six sessions. Continuing attenders were more likely to be primary care providers, to be more similar to other group members, and to report greater burden and less family support than the brief attenders.'

DEMENTIA; SUPPORT GROUPS; UNITED STATES

- 357 Gorey, Kevin M., Robert W. Rice and Gary C. Brice (1992), 'The prevalence of elder care responsibilities among the work force population', *Research on Aging*, 14(3), 399-418.

'This review synthesizes the findings of 17 independent studies dealing with the prevalence of elder care responsibilities among the work force population. Across-study, summative findings were: (a) approximately one fifth ($M=21.1\%$) to one quarter ($Md=23.1\%$) of employees provide care for an elderly dependent; primary study findings varied by a factor of nearly 25, ranging from a high estimate of 46.0% to a low of 1.9%; (b) the average response rate was fairly low ($M=45.0\%$ and $Md=41.1\%$), indicating that the studies captured only slightly more than one third, but less than half of all eligible in-sample assignments; (c) the correlation of prevalence and response rates was found to be $r=-.69$, $p<.01$; (d) the partial correlation of prevalence with response rate, adjusted for the breadth of the elder care operational definition, remained significant, $r=-.50$, $p<.05$; and (e) these two methodological characteristics together accounted for half ($R^2=.505$) of the variability in reported prevalence, response rate accounting for nearly all (95.4%) of this explained criterion variation. Bias due to nonresponse thus represents a potent threat to the validity of the mean prevalence estimate found in this body of research (21.1%). The implementation of statistical controls for nonresponse and definitional inconsistencies resulted in an estimated prevalence of 7.4% to 11.8%; however, this review outcome is tentative at best and must be tested with future, better controlled primary studies.'

EMPLOYMENT; METHODOLOGY; UNITED STATES

- 358 Graham, Hilary (1983), 'Caring: a labour of love', in Janet Finch and Dulcie Groves, eds, *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, 13-30.

This chapter examines the concept of caring and distinguishes between what caring means and what it entails. It has particular consequences for the identity and activity of women. 'The first section defines the everyday experience of caring as a labour of love. The next two sections examine the way in which social scientists have represented the love and the labour of caring, the second section drawing from the psychological literature and the third section outlining some of the insights provided by recent research within policy. The final section, summarising the contributions and limitations of these two approaches, lays out some ground rules for the construction of an alternative analysis of caring.' It must be recognised 'that caring defines both the identity and the activity of women in Western society.'

CONCEPTUAL ISSUES; GENDER; IDEOLOGY; POLICY; THEORY
DEVELOPMENT; UNITED KINGDOM

- 359 Graham, Hilary (1985), 'Providers, negotiators, and mediators: women as the hidden carers', in Ellen Lewin and Virginia Olesen, eds, *Women, Health, and Healing: Towards a New Perspective*, Tavistock, New York, 25-52.

'This chapter describes the informal, unpaid work which women do to protect and promote the health of others. It examines the domestic activities which sustain, literally and symbolically, what we know as the British way of life...The nature of this health work is explored in three sections. The first considers the way in which it has been represented within the two disciplines most deeply committed to the study of health and welfare, namely medical sociology and social policy. The second examines the experiences of informal caring, focusing on women's role as health providers. The third sets this experience in a wider political context, looking at the recent developments in health policy which shift the burden of caring from the public to the private domain.'

GENDER; POLICY; UNITED KINGDOM

- 360 Grant, Gordon (1986), 'Older carers, interdependence and the care of mentally handicapped adults', *Ageing and Society*, 6(3), 333-51.

'Elderly people are often seen as the recipients of informal care. In the study reported here, there are clear indications that carers of mentally handicapped people are predominantly female and often beyond retirement age. For some the task is burdensome, but for many it provides a reciprocity both of care and of companionship. Older carers are observed to receive more professional aid than younger carers. But as demographic trends make this caring relationship more

common it will be necessary for formal support systems to become more integrated and comprehensive.'

AGED CAREGIVERS; DISABLED; UNITED KINGDOM

- 361 Grant, Gordon (1989), 'Letting go: decision-making among family carers of people with a mental handicap', *Australia and New Zealand Journal of Developmental Disabilities*, 15(3/4), 189-200.

'Data were presented from a study of informal carers of people with a mental handicap in North Wales to illustrate the variety of attitudes adopted by carers towards long-term care strategies and to trace influences on decision-making. Stepwise discriminant function analysis was used to differentiate between carers with alternative long-term care strategies. Results suggested the importance of social support, socio-economic class and subjective well-being as predictors. Implications for further research and policy were considered.'

DISABLED; METHODOLOGY; PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS; SOCIOECONOMIC STATUS; UNITED KINGDOM

- 362 Grant, Gordon and Mike Nolan (1993), 'Informal carers: sources and concomitants of satisfaction', *Health & Social Care in the Community*, 1(3), 147-59.

'Empirical and conceptual explorations of informal care have concentrated on the difficulties and problems of carers to the virtual exclusion of the gratifications and rewards that can be experienced. Whilst not seeking to minimize the undoubted problems which carers face, this paper attempts to redress the balance by providing evidence that caring can be a source of personal satisfaction for many individuals and that such satisfaction can co-exist with high levels of stress. It begins by highlighting some common conceptual elements from the available literature on the satisfactions of informal carers. Qualitative data from an investigation by the authors are used to illustrate the range of rewards and satisfactions experienced by informal carers. Analysis of the presence of rewards and satisfactions suggest that factors in the social context of care rather than the personal or dependency characteristics of the cared-for are important concomitants. Theoretical, methodological, policy and practice implications are considered in turn.'

CONCEPTUAL ISSUES; METHODOLOGY; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; SOCIAL ASPECTS; UNITED KINGDOM

- 363 Great Britain - Equal Opportunities Commission (1980), *The Experience of Caring for Elderly and Handicapped Dependents*, Equal Opportunities Commission, Manchester, iv, 31pp.

This report is the result of a postal survey of carers carried out in West Yorkshire, which was followed up by in-depth interviews of some of the respondents. 'The aim of this report is to show something of what it is like to be a carer, and to demonstrate how these women's lives are affected by their caring role. To some degree the report draws upon statistical evidence thrown up by the survey but more importantly it sets down the viewpoints of the carers themselves - what they said about their lives, their problems and their needs.'

GENDER; PERSONAL NARRATIVES; QUALITATIVE STUDIES; UNITED KINGDOM

- 364 Great Britain - Equal Opportunities Commission (1982), *Caring for the Elderly and Handicapped: Community Care Policies and Women's Lives*, Equal Opportunities Commission, Manchester, viii, 46pp.

Community care, in reality, means care by women on an unpaid and often unaided basis. The Commission is concerned with the serious consequences of this for the promotion of equal opportunities between the sexes. It is important that action is taken in relation to social services, health, housing and social security provision to enable women and men with dependents to choose the extent to which they provide care and the form of that care. There must be flexible, humane and non-discriminatory domiciliary and residential resources available as a basis for community care.

COMMUNITY SERVICES; GENDER; POLICY; UNITED KINGDOM

- 365 Great Britain - Equal Opportunities Commission (1982), *Who Cares for the Carers? Opportunities for Those Caring for the Elderly and Handicapped*, Equal Opportunities Commission, Manchester, iii, 31pp.

This document is concerned with the implications for women of current community care policies and considers ways in which they can be freed from the sole responsibility of caring for dependents other than children. A properly resourced community care policy could ensure appropriate financial and supportive arrangements and the Commission feels these measures should be given priority over other demands upon public expenditure. The term 'care in the community' is defined. The costs of caring are discussed under the subheadings Housing and transport and Financial. There is a section on the support a carer can expect. Finally, recommendations for an equal opportunities community care policy are made.

FINANCIAL ASPECTS; GENDER; HOUSING; POLICY; TRANSPORT; UNITED KINGDOM

- 366 Green, Hazel (1988), *Informal Carers: A Study Carried Out on Behalf of the Department of Health and Social Security as Part of the 1985 General Household Survey*, HMSO, London, iii, 41pp.

A series of questions was included in the 1985 General Household Survey (Great Britain) to identify people looking after a sick, handicapped or elderly person. Information was collected on the prevalence of informal care; who is caring for whom; the nature of care; and who supports the carers.

NATIONAL STUDIES; STATISTICS; UNITED KINGDOM

- 367 Greenberg, Jan R., Todd Monson and Jack Gesino (1993), 'Development of University of Wisconsin Family Assessment Caregiver Scale (UW-FACS): a new measure to assess families caring for a frail elderly member', *Journal of Gerontological Social Work*, 19(3/4), 49-68.

'The purpose of this research was to construct a reliable and valid instrument to assess the functioning of families as caregiving systems. Five dimensions of family functioning relevant to caregiving were identified: *validation, family of origin, problem solving, roles, and boundaries*. A 21-item scale was constructed to measure these 5 dimensions. The scale was administered to 83 family caregivers. As predicted, the scale correlated significantly with clinical ratings of the family's overall functioning, the degree of family stress and the caregiver's mental health.'

FAMILY; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 368 Greenberg, Jan Steven, James R. Greenley, David McKee, Roger Brown and Claire Griffin-Francell (1993), 'Mothers caring for an adult child with schizophrenia: the effects of subjective burden on maternal health', *Family Relations*, 42(2), 205-11.

'One of the major gaps in studies of families of persons with schizophrenia is an understanding of the long-term effects that the burdens associated with coping with mental illness have on parental health. In this study, data were gathered from a sample of 81 mothers of adult children with schizophrenia. The results revealed that subjective burden associated with stigma and worries are related to lower levels of physical well-being. Practice implications of the findings are discussed.'

HEALTH; MENTAL ILLNESS; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 369 Greene, Vernon L. and Deborah J. Monahan (1987), 'The effect of a professionally guided caregiver support and education group on institutionalization of care receivers', *The Gerontologist*, 27(6), 716-21.

'Family caregivers participating in support and education groups had lower institutionalization rates among their care receivers than did caregivers who enrolled but did not participate (3.8% as compared to 8.6%, respectively). When baseline differences were controlled, the implied treatment effect was to reduce the enrollment group institutionalization rate from 17.2% to 5.2%. These differences were statistically significant at the .1 and .05 levels, respectively. Savings from deferred nursing home utilization more than offset program costs.'

EDUCATION; INSTITUTIONALISATION; SUPPORT GROUPS; UNITED STATES

- 370 Greene, Vernon L. and Deborah J. Monahan (1989), 'The effect of a support and education program on stress and burden among family caregivers to frail elderly persons', *The Gerontologist*, 29(4), 472-7.

'An eight-week professionally guided caregiver support group program was found to produce statistically significant reductions in anxiety, depression, and sense of burden among family caregivers to frail elderly persons living in the community. Effects were weaker four months after the intervention ended than immediately after, but reductions in anxiety and depression were still evident.'

EDUCATION; FAMILY; PSYCHOLOGICAL ASPECTS; SUPPORT GROUPS; UNITED STATES

- 371 Groves, Dulcie and Janet Finch (1983), 'Natural selection: perspectives on entitlement to the invalid care allowance', in Janet Finch and Dulcie Groves, *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, 148-66.

In Britain, the only state benefit which recognises the financial relationship between paid work and unpaid caring is the Invalid Care Allowance. It provides the only mechanism whereby state policies acknowledge the economic costs of giving up work in order to provide care. However, rights of entitlement vary between men and women and between different categories of women on grounds of marital status. The rules of access are such that gender divisions are reinforced 'with the result that state policies have the effect of *shaping* social life and social relations, and not merely reflecting them'.

GENDER; INCOME SUPPORT; POLICY; UNITED KINGDOM

- 372 Guberman, Nancy (1988), 'The family, women and caring: who cares for the carers?' *Resources for Feminist Research*, 17(2), 37-40.

In the past few years government policies have been aimed at deinstitutionalisation and community care, which in reality means family care and this in turn means mainly care by women. This poses a dilemma for many women. This article addresses three issues: why do women care? at what cost to themselves do women care? and what, if any, are the alternatives to women's caring?

GENDER; PSYCHOLOGICAL ASPECTS; CANADA

- 373 Gubrium, Jaber F. (1988), 'Family responsibility and caregiving in the qualitative analysis of the Alzheimer's disease experience', *Journal of Marriage and the Family*, 50(1), 197-207.

'Following the trend of research on the caregiving side of the Alzheimer's disease experience, field data are presented in illustration of the interpretive dynamics of family responsibility. Four features are addressed: social comparison, issue contingency, family history, and kinship priority. It is argued that qualitative analysis offers empirical lessons about family responsibility and caregiver functioning that remain untaught by other methods.'

DEMENTIA; FAMILY; METHODOLOGY; QUALITATIVE STUDIES; RELATIONSHIPS; UNITED STATES

- 374 Gubrium, Jaber F. and Robert J. Lynott (1987), 'Measurement and the interpretation of burden in the Alzheimer's disease experience', *Journal of Aging Studies*, 1(3), 265-85.

'Three components of the Alzheimer's disease care equation are considered: impairment, felt burden, and the institutionalization decision. Measurement and the results of existing studies are compared with field data on the descriptive organization of the caregiving experience. It is suggested that measurement is an inappropriate language for depicting the experience, empirically distorting what is otherwise a practical process of definition and interpretive transformation, shaped in, and constrained by, caregivers' continuing attention to the meaning of their burden.'

DEMENTIA; INSTITUTIONALISATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 375 Gwyther, Lisa P. (1992), 'Research on gender and family caregiving: implications for clinical practice', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 202-18.

This chapter highlights 'the use of gender research findings on elder care in three areas of clinical practice: the assessment of the individual and social context and the effects of gender on subjective perceptions of caregiver burden, gender-sensitive targeting of clinical support strategies, and professional interventions to overcome gender-specific barriers to the use of appropriate, timely informal and formal support.' Five areas of gender-sensitive research that would benefit practitioners are identified: studies of the efficacy and cost-effectiveness of various services specifically targeted to men or women as caregivers; research targeted to underserved or hard-to-reach male or female caregivers; the role of gatekeepers; research on gender friendly adaptations or modifications to services or reimbursement systems; and the evaluation of new gender-sensitive designs in the context of demonstrations.

COMMUNITY SERVICES; EVALUATION; GENDER; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 376 Gwyther, Lisa P. and Linda K. George (1986), 'Symposium: caregivers for dementia patients: complex determinants of well-being and burden', *The Gerontologist*, 26(3), 245-7.

In summarising the papers at a symposium on caregivers for dementia patients, the authors point to the heterogeneity of caregivers which has significance for both caregiver function and the likelihood of institutionalisation. A second theme is the relative unimportance of the symptoms and behaviours of the patients for understanding caregiver functioning. This has important implications for programs to alleviate caregiver burden. Some limitations of the research methodology used are pointed out. For the three papers themselves see: Fitting, Rabins and Lucas (1986), George and Gwyther (1986) and Zarit, Todd and Zarit (1986).

DEMENTIA; INSTITUTIONALISATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 377 Haavio-Mannila, Elina (1983), 'Caregiving in the welfare state', *Acta Sociologica*, 26(1), 61-82.

'Changes in the care given by the family, social networks and the state to children, the elderly and the sick have been examined empirically on the basis of 744 personal interviews conducted among urban population aged between 25-64 years in Finland in 1981. Sources of help in solving conjugal crisis, problems with teenage children and financial problems were investigated according to age and sex of respondents. Also type of confidants in personal troubles was questioned. Caregiving to children

during day-time, care of the elderly and the sick have increasingly been taken over by the state (shown by comparison with the situation in the respondent's own childhood and the present). It is still mainly women who perform the caregiving functions in society, nowadays often as paid work instead of as unpaid work. Women give and receive outside help more than men, who tend to keep problems inside the family. For example, women have more confidants than men, who feel they can talk out troubles only with their wives.'

GENDER; QUALITATIVE STUDIES; SUPPORT NETWORKS; FINLAND

- 378 Haffenden, Sharon (1991), *Getting It Right for Carers: Setting up Services for Carers: A Guide for Practitioners*, Social Services Inspectorate, Department of Health, London, 81pp.

'This book is for practitioners and managers in statutory and voluntary organisations who are planning to make practical support for carers a high priority. The book aims to provide them with information about the possible range of support, and highlights services of particular value to carers. It will also give a guide to comparative costs. In addition, the book will outline key points affecting the organisation and delivery of services to carers that need to be given special attention.' For a companion volume to this publication see (Hills, 1991).

COMMUNITY SERVICES; FINANCIAL ASPECTS; UNITED KINGDOM

- 379 Haley, William E. (1989), 'Group intervention for dementia family caregivers: a longitudinal perspective', *The Gerontologist*, 29(4), 478-80.

'Reported here are longitudinal follow-up data from caregivers who participated in an experimental study of group intervention for dementia caregivers. Methodologies and clinical issues evident from this long-term follow-up include differential attrition from treatment issues in selection of participants, and need for measures appropriate to long-term outcomes.'

DEMENTIA; METHODOLOGY; SUPPORT GROUPS; UNITED STATES

- 380 Haley, William E., S. Lane Brown and Ellen G. Levine (1987), 'Experimental evaluation of the effectiveness of group intervention for dementia caregivers', *The Gerontologist*, 27(3), 376-82.

'Family caregivers of elderly community-dwelling dementia patients who were randomly assigned to 1 of 2 types of support groups completed pregroup, postgroup, and followup assessments. A waiting list condition was also used. Results indicated that although caregivers rated the groups as quite helpful, group participation did not lead to improvements on objective measures of depression, life satisfaction, social

support, or coping variables. Discussed are methodological issues in assessing the efficacy of caregiver groups, as well as clinical implications.'

DEMENTIA; EVALUATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS; SUPPORT GROUPS; UNITED STATES

- 381 Haley, William E., S. Lane Brown and Ellen G. Levine (1987), 'Family caregiver appraisals of patient behavioral disturbance in senile dementia', *Clinical Gerontologist*, 6(4), 25-34.

'In the present study, 44 primary family caregivers of elderly patients with dementia were interviewed concerning the prevalence of 31 specific behavioral problems in the home setting, the subjective stressfulness of each problem, and caregivers' perceived self-efficacy in managing each problem. Results indicate that, although self-care deficits and disorientation are extremely common, they are of less concern to caregivers than a number of prevalent and highly stressful behavioral problems such as agitation, hallucinations, and dangerous or embarrassing behaviors. These specific behavioral problems deserve greater attention in the management of dementia patients who live in community settings.'

DEMENTIA; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 382 Haley, William E., Ellen G. Levine, S. Lane Brown and Alfred A. Bartolucci (1987), 'Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers', *Psychology and Aging*, 2(4), 323-30.

'A stress and coping model was used to study predictors of individual differences in caregiver adaptation. A total of 54 family caregivers of elderly dementia patients completed interviews and questionnaires assessing the severity of patient impairment and caregiving stressors; caregiver appraisals, coping responses, and social support and activity; and caregiver outcomes, including depression, life satisfaction, and self-rated health. Correlational and regression analyses supported the utility of the stress and coping model. Appraisal, coping responses, and social support activity were significant predictors of caregiver outcome, even when severity of caregiving stressors was statistically controlled. The importance of a multidimensional approach to assessing caregiver outcomes was supported by regression analyses indicating that each caregiver outcome was predicted by different patterns of stressors, appraisal, coping and social support and activity. Results are discussed in terms of a stress and coping model of caregiving, and clinical implications for work with caregiving families.'

DEMENTIA; EVALUATION; PSYCHOLOGICAL ASPECTS; THEORY DEVELOPMENT; UNITED STATES

- 383 Haley, William E., Jeffrey M. Clair and Karen Saulsberry (1992), 'Family caregiver satisfaction with medical care of their demented relatives', *The Gerontologist*, 32(2), 219-26.

'Eighty-eight family caregivers were interviewed concerning their experience with medical care of their demented relatives. Although the majority of caregivers expressed overall satisfaction, they showed higher levels of dissatisfaction than are commonly found in studies of satisfaction with medical care. Greatest dissatisfaction was expressed in regard to receiving insufficient information about dementia; fewest concerns were expressed about inappropriate physician control. Families reported frequently receiving vague diagnoses and insufficient referrals for support services.'

COMMUNITY SERVICES; DEMENTIA; EDUCATION; METHODOLOGY; RELATIONSHIPS; UNITED STATES

- 384 Halpert, Burton P. and Tessa S. Sharp (1989), 'A model to nationally replicate a locally successful rural family caregiver program: the Volunteer Information Provider Program', *The Gerontologist*, 29(4), 561-3.

This article discusses the transplanting of a local caregiver program beyond state lines. It identifies the strategy, the steps taken, and key elements of piloting and dissemination of the Volunteer Information Provider Program.

CASE STUDIES; EDUCATION; METHODOLOGY; UNITED STATES

- 385 Hammell, Karen R. Whalley (1992), 'The caring wife: the experience of caring for a severely disabled husband in the community', *Disability, Handicap & Society*, 7(4), 349-62.

'Modern medicine has dramatically increased the chances of survival following major trauma such as a severe head injury or high level injury to the spinal cord. Greater numbers of seriously disabled people are thus returning to live in the community. This article examines the situation of the wife who assumes a caring role following the onset of severe disability in her husband. The study examines community care for people with traumatic disabilities and the social expectations of women's role in the provision of that care. Reference is made to the British situation although similar experiences are shared by women in other developed countries. As health care and social service professionals seek to serve the needs of their physically disabled client it is recommended that they view also the needs of their other client - the carer.'

DISABLED; GENDER; POLICY; SPOUSES; UNITED KINGDOM

- 386 Hanks, Roma S. and Barbara H. Settles (1990), 'Theoretical questions and ethical issues in a family caregiving relationship', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 98-118.

Using a case study approach, this chapter 'weds social science theory with ethical theory and a feminist ideology within a historical analysis of the nature of the relationship between caregiver and receiver leading up to the current caregiving situation...Ethical considerations related to the quality of life, rather than only survival, will play an increasing role in caregiving decisions as medical technologies make it possible to prolong life. Issues such as the degree of family responsibility for caregiving carry with them powerful ethical considerations which must be recognized in the caregiving process and in policy development.'

CASE STUDIES; FAMILY; GENDER; IDEOLOGY; POLICY; THEORETICAL DEVELOPMENT; UNITED STATES

- 387 Harper, David J., Paul R. Manasse, Owen James and J. Tim Newton (1993), 'Intervening to reduce distress in caregivers of impaired elderly people: a preliminary evaluation', *International Journal of Geriatric Psychiatry*, 8(2), 139-45.

'Data from a sample of 82 impaired elderly people and their carers were gathered before (T1) they started to receive support from a home-based care aide service. Several variables were significantly correlated with, but only two were predictive of reported carer distress at T1. Data gathered from a subsample of 45 carers after receiving support for 3 months (T2) showed that reported distress decreased significantly between T1 and T2. The only variable which significantly correlated with, and was predictive of carer distress at T2 was distress at T1. A ladder plot showed greater variability in changes in distress with 11 subjects actually reporting increased distress at T2. There was no relationship between initial distress scores and change in distress over time. The implications of these findings are discussed.'

COMMUNITY SERVICES; EVALUATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 388 Harper, Sarah and Dale A. Lund (1990), 'Wives, husbands, and daughters caring for institutionalized dementia patients: towards a model of caregiver burden', *International Journal of Aging and Human Development*, 30(4), 241-62.

'The primary purposes of this article are to clarify some of the inconsistencies in the previous research studies done on factors associated with caregiver burden; to identify specific sets of variables that best explain the differential burden levels among caregivers; and to provide a substantial foundation for developing a model of caregiver burden useful for both research and clinical interventions. The caregiver's

gender, relationships to the patient, and the residential location of the patient (same house, community, or institution) are major considerations in our analyses. This study is also unique, because it uses a relatively large national sample of caregivers, which is necessary to accomplish the study's objectives. Mailed questionnaires were completed by 409 caregivers identified by fifty local support groups in sixteen different states in the United States. Generally, the primary correlates of burden were factors related to the levels and types of impairment in patient functioning, caregiver life satisfaction, and social support. Each category of caregiver circumstances had a unique set of three to five correlates with the total amount of variance explained in burden ranging from 25 percent (husbands living with the patients) to 68 percent (husbands with spouses in nursing homes). Implications for future research and interventions are discussed.'

DAUGHTERS; DEMENTIA; GENDER; INSTITUTIONALISATION; LIVING
ARRANGEMENTS; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; SPOUSES; SUPPORT NETWORKS; THEORY
DEVELOPMENT; UNITED STATES

- 389 Harris, P.B. (1993), 'The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's disease victims', *The Gerontologist*, 33(4), 551-6.

'The focus of the qualitative study of husbands caring for their wives with Alzheimer's disease was to gain insight into the complex world of the male caregiver and to identify commonalities as well as with in-group differences. Specifically, the aim was to obtain an in-depth understanding of what it is like for a man to take on the role of primary caregiver: his motivations, stresses, coping strategies, support networks, use of services, losses, accomplishments/satisfactions, and needs. A generated typology of male caregivers included four types: (1) those men who were workers, who modeled their new caregiver roles after their work roles, so that caregiving became for them a work identity; (2) those men who cared for their wives out of a labour of love because they had deep feelings for their wives; (3) those men who developed a sense of responsibility and duty for caring for their wives; and (4) those men who felt they were at the crossroads, not knowing what to do with their new caregiver roles.'

DEMENTIA; GENDER; PSYCHOLOGICAL ASPECTS; QUALITATIVE
STUDIES; SERVICE USE; SPOUSES; SUPPORT NETWORKS; UNITED
STATES

- 390 Harris, Robert (1985), 'End points and starting points: some critical remarks on Janet Finch's "Community care: developing non-sexist alternatives"', *Critical Social Policy*, (12), 115-22.

This article offers some critical comments on Janet Finch's article in *Critical Social Policy* (9), Spring 1984:6-18. The author claims that Finch's recommendations are 'not only based on a biased analysis of "care" and "community" they also contradict her pragmatic criterion of achievability within society as it exists...They take no account of mass unemployment or recent changes in the gender composition of the labour market which...hold enormous implications for family life and, hence, for community care.'

EMPLOYMENT; GENDER; IDEOLOGY; POLICY; UNITED KINGDOM

- 391 Hartford, Margaret E. and Rebecca Parsons (1982), 'Uses of groups with relatives of dependent older adults', *Social Work with Groups*, 5(2), 77-89.

'This paper reviews and analyses work with several small groups of relatives of older adults who have increased dependency problems due to physical frailty, diagnosed brain diseases, disorganisation, memory loss, reduced mobility, depression and other physical and mental changes. Content includes: 1) Usefulness of group approaches with peers led by professionals (social workers, social gerontologists, psychologists) for stresses experienced by care giving relatives; 2) group objectives including support giving, understanding the older relatives' problems and behaviors, anticipatory planning for inevitable changes, coping, improved interpersonal functioning, and gaining insight to feelings of both the older person and the care giving relative; 3) group processes deliberately used by workers in the creation, convening, maintenance and termination of these groups; 4) repetitive themes of concern expressed by the care givers and their dependent relatives.'

SUPPORT GROUPS; UNITED STATES

- 392 Hasselkus, Betty Risteen (1988), 'Meaning in family caregiving: perspectives on caregiver/professional relationships', *The Gerontologist*, 28(5), 686-91.

'A series of four ethnographic interviews with 15 family caregivers revealed organizing themes of meaning: Senses of Self, of Managing, of Future, of Fear or Risk, and of Change in Role and Responsibility. Relationships among the caregivers, the care-receivers, other family members, and professionals were characterized by a theme of tension from discordant views of the caregiving situation. Effective partnership between formal and informal caregivers depend on understanding family perspectives.'

FAMILY; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; QUALITATIVE STUDIES; UNITED STATES

- 393 Hasselkus, Betty Risteen (1992), 'Physician and family caregiver in the medical setting: negotiation of care?', *Journal of Aging Studies*, 6(1), 67-80.

'Forty clinic visits with physician, older patient, and family caregiver were audio-taped and analyzed for topical themes and exchanges of meaning. The extent to which the caregivers contributed to traditional physician domains of care during the visits (diagnosis, interpretation of symptoms, treatment recommendations) was unexpected. This presentation of self as a practitioner by the caregiver differed from the physician's view of the caregiver as a patient-substitute. In addition to Health Care, the problem situations most often discussed were Eating, Moving Around and Risk. In general, the participants in the clinic visit - physician, caregiver and patient - brought very little of the social context of the illness and care into the medical visit.'

RELATIONSHIPS; SOCIAL ASPECTS; UNITED STATES

- 394 Heller, Tamar and Alan Factor (1988), 'Permanency planning among black and white family caregivers of older adults with mental retardation', *Mental Retardation*, 26(4), 203-8.

'Differences among older black/white families (25 black, 75 white) regarding permanency planning for a member with mental retardation was examined. Family characteristics, functioning of the individual with mental retardation, and support resources were compared. These differences were examined in relation to the family's planning efforts. Results showed that black families were less likely to (a) desire residential placements outside the family home and (b) make financial arrangements for their relative with mental retardation for after their own lifetime. Both economic and sociocultural factors explained these planning differences.'

AGED CAREGIVERS; DEPENDENCY; DISABLED; ETHNICITY; FAMILY; METHODOLOGY; SOCIOECONOMIC STATUS; UNITED STATES

- 395 Hendrickson, Michael C. (1988), 'State tax incentives for persons giving informal care to the elderly', *Home Health Care Financing Review*, Annual Supplement, 123-8.

'Programs for informal caregivers of frail elderly can be adopted by States to address some of the problems associated with an expanding and costly long-term care system. In this article, highlights are given from a 3-year study of Idaho and Arizona tax incentive programs. Characteristics of informal caregivers and elderly participants are described, and elderly participants are compared with nonparticipants and with the general elderly population. Tax incentives were positively related to the level of service and financial support provided by informal caregivers. Data were inadequate to determine whether the induced informal help substituted for public expenditures.'

FINANCIAL ASPECTS; INCOME SUPPORT; UNITED STATES

- 396 Henton, June, Rodney Cate and Beth Emery (1984), 'The dependent elderly: targets for abuse', in William H. Quinn and George A. Hughston, eds, *Independent Aging: Family and Social Systems Perspectives*, Aspen Systems Corporation, Rockville, Md, 149-62.

This chapter addresses the frequency and definition of abuse and lack of protective mechanisms for the elderly. The authors recommend intervention and support provisions to aid the practitioners or persons providing support to the abused elderly.

ELDER ABUSE; UNITED STATES

- 397 Hicks, Cherrill (1988), *Who Cares: Looking After People at Home*, Virago Press, London, 271pp.

'Through the voices of individual women and men we learn of the physical drudgery, financial stress, isolation and loss of freedom which caring for a dependent relative often entails. The book concentrates on the emotional conflicts which carers experience.' The book is based on over eighty interviews with carers from all over Britain and includes chapters on institutional and community care and examines the Thatcher government's record on supporting carers. What carers and their dependents need is a radical new deal which would offer them an alternative to an ever-worsening situation.

COMMUNITY SERVICES; DAUGHTERS; ETHNICITY; INCOME SUPPORT; INSTITUTIONALISATION; MIDDLE AGED CARERS; PERSONAL NARRATIVES; POLICY; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; SONS; SPOUSES; UNITED KINGDOM

- 398 Hills, Dione (1991), *Carer Support in the Community: Evaluation of the Department of Health Initiative: 'Demonstration Districts for Informal Carers, 1986-1989*, Social Services Inspectorate, Department of Health, London, v, 104pp.

'This publication provides a summary of the findings from a programme funded by the Department of Health, called "Demonstration Districts for Informal Carers". In each of three local authority areas [East Sussex, Sandwell and Stockport], voluntary consortia were established to distribute grants to voluntary organisations that undertook to set up or run services for carers.' The guidelines were: 'i. to enhance developments and promote new initiatives in the voluntary sector in supporting informal carers in specific local authority areas, in order to demonstrate the value of these, ii. to provide reports for use in other areas to promote support for informal carers, and engage with other developments on a wider front, and iii. to monitor and

identify outcomes and indicators for the future in terms of support for carers.' For a companion volume to this publication see (Haffenden, 1991).

COMMUNITY SERVICES; EVALUATION; FINANCIAL ASPECTS; UNITED KINGDOM

- 399 Hinrichsen, Gregory A., Nancy A. Hernandez and Simcha Pollack (1992), 'Difficulties and rewards in family care of the depressed older adult', *The Gerontologist*, 32(4), 486-92.

'Spouse and adult child caregivers of older adults with a major depressive disorder (N=150) were asked what was most difficult and most rewarding about providing assistance to their relatives. Content analysis of their responses revealed seven areas of difficulty and three areas of reward. Difficulties and rewards were selectively associated with the caregiver's identity, patient clinical characteristics, and caregiver emotional adjustment. Caregiver perceived family difficulties and emotional difficulties were associated with the course of patient psychiatric illness over 1 year.'

FAMILY; MENTAL ILLNESS; METHODOLOGY; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; UNITED STATES

- 400 Hodder, J. (1985), 'Supporting the informal carers', in J.A. Yoder, J.M.L. Jonker and R.A.B. Leaper, eds, *Support Networks in a Caring Community: Research and Policy, Fact and Fiction*, Martinus Nijhoff, Dordrecht, 155-61.

'Support for informal carers was the subject of a project undertaken by the Social Work Service Development Group of the Department of Health and Social Security in the United Kingdom in 1983. The project was both a professional and a political initiative, and its origin, aims, method and outcome are outlined briefly in this paper.' It examines the needs of carers, the response of service providing agencies, prevention and early detection of problems, the social work task, domiciliary services and day care, respite care and ways in which carers help each other. As a result of this research, models of practice are being resourced, support given to information projects in the voluntary sector and the establishment of more self-help groups.

COMMUNITY SERVICES; DAY CARE; RESPITE CARE; SUPPORT GROUPS; SUPPORT NETWORKS; UNITED KINGDOM

- 401 Hokenstad, Merl C. and Lennarth Johansson (1990), 'Caregiving for the elderly in Sweden: program challenges and policy initiatives', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 254-69.

In Sweden the accepted policy position is that publicly provided care is a citizen's right and should be available to any family or individual who needs it. The mix of informal and formal care is the choice of the family. The question is how much formal care is necessary so that no family is forced to substitute informal for formal care. However, many families prefer informal care so the debate is how formal care can be used to reinforce and complement informal care. Some policy initiatives include the provision of more economic assistance and better-focused service support for caregiving families. This chapter provides a detailed discussion about research findings and policy initiatives relating to care of the elderly in Sweden.

FAMILY; POLICY; RELATIONSHIPS; SWEDEN

- 402 Homer, Ann C. and C. Gilleard (1990), 'Abuse of elderly people by their carers', *British Medical Journal*, 301, 15 December, 1359-62.

The object of this study was to assess the prevalence of elder abuse by their caregivers and the characteristics of the abused and the abuser. Information was collected over a period of 6 months from patients referred for respite care and risk factors identified in the abused group and compared with those in a non-abused control group. Caregivers were interviewed at home and patients examined in hospital. The most significant risk factor was alcohol consumption by the caregiver. Another factor was a poor pre-morbid relationship and previous abuse over many years. Abuse was often reciprocated and was associated with social dysfunction in many patients. Service delivery, respite care, and level of mental and physical disability were not significantly associated with abuse. It is concluded that care in the community may not be the best solution for these people.

ELDER ABUSE; METHODOLOGY; RELATIONSHIPS; UNITED KINGDOM

- 403 Hooker, Karen, Deborah Monahan, Kim Shifren and Cheryl Hutchinson (1992), 'Mental and physical health of spouse caregivers: the role of personality', *Psychology and Aging*, 7(3), 367-75.

'Although personal resources of caregivers, such as coping skills and social support, have been shown to be important in understanding caregiver stress and health outcomes, personality traits have not previously been considered. The purpose of this study was to examine the association between the personality traits of neuroticism and dispositional optimism and mental and physical health outcomes. It was predicted that personality would have direct effects, and indirect effects through perceived stress, on health outcomes. Participants were spouse caregivers of patients diagnosed with Alzheimer's disease. Results showed that neuroticism and optimism

were significantly related to mental and physical health. Furthermore, neuroticism had significant direct effects on all of the health outcomes, and substantial indirect effects, through perceived stress, on mental health outcomes. Optimism showed stronger indirect than direct effects on all health outcomes. These findings demonstrate the importance of including personality of the caregiver in theoretical and empirical models of the caregiving process.'

DEMENTIA; HEALTH; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 404 Hooyman, Nancy R. (1986), *Taking Care: Supporting Older People and Their Families*, Free Press, New York, 322pp.

This book discusses families' needs for information, social support, respite, and financial assistance in providing care to dependent older relatives. It includes the reasons for caring for ageing parents, spouses as caregivers, sharing care among family members, support networks, care for the caregivers, coping with physical and mental changes, depression in homebound older people, money, community services, home care, alternative living arrangements, and the transition to nursing homes.

COMMUNITY SERVICES; EDUCATION; FAMILY; FINANCIAL ASPECTS; HEALTH; INSTITUTIONALISATION; LIVING ARRANGEMENTS; PSYCHOLOGICAL ASPECTS; RESPITE CARE; SPOUSES; SUPPORT NETWORKS; UNITED STATES

- 405 Hooyman, Nancy R. (1990), 'Women as caregivers of the elderly: implications for social welfare policy and practice', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 221-41.

'This chapter examines how the "new conservatism" of the past decade, by its emphasis on privatization, fiscal restraints, cost-effectiveness, and efficiency, combined with the ideology of community care, has overlooked equity issues and intensified burdens faced by family caregivers, particularly women. Two underlying trends that have served to make female caregivers hidden victims of out social and health care policies are discussed: (a) historically, an ideology of separate spheres between men's and women's work has perpetuated the expectation that women's major role is to provide uncompensated care to dependents; and (b) the welfare of family caregivers has not been a goal of public policy. Current policy changes to support family caregivers of the elderly are also examined...A major theme is that health and social service professionals must carefully examine their policy objectives and strategies to avoid inadvertently perpetuating such inequities and increasing

caregiver stress.' Caregiving of the elderly must become a shared public and private, male and female, responsibility.

FAMILY; GENDER; HISTORICAL ASPECTS; IDEOLOGY; POLICY; UNITED STATES

- 406 Hooyman, Nancy R. (1992), 'Social policy and gender inequities in caregiving', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 181-201.

'This chapter focuses on structural gender inequities in elder care, how these inequities interact with and are perpetuated by inadequate community care policies, and how the outcome thereby perpetuates dependence on the unpaid labor of female family members for elder care. This analysis begins with an examination of some of the assumptions and values underlying current policies that serve to perpetuate gender inequities in elder care. After a discussion of how the values of privatization and the ideology of separate spheres result in structural economic inequality for women, the negative impacts to current health and social service policies upon female caregivers' economic status, especially in old age, are examined. A feminist perspective is then used to critique selected policy and program initiatives as well as to suggest future directions for policy development for family caregivers.'

GENDER; IDEOLOGY; SOCIOECONOMIC STATUS; POLICY; UNITED STATES

- 407 Hooyman, Nancy, Judith Gonyea and Rhonda Montgomery (1985), 'The impact of in-home services termination on family caregivers', *The Gerontologist*, 25(2), 141-5. Also published in Lillian Troll, ed. (1986), *Family Issues in Current Gerontology*, Springer, New York, 214-25.

'This article examines the impact of a state policy change - the loss of in-home chore services - on families providing care for older relatives. The presence or absence of chore services was not associated with caregiving behavior, perceptions of burden, or stress among relatives of both terminated and continuing clients. A significant relationship was found, however, between the perception of burden and the performance of personal care tasks, which suggests that chore services do not coordinate with families regarding the most burdensome caregiving tasks.'

COMMUNITY SERVICES; FAMILY; POLICY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 408 Hooyman, Nancy R. and Wendy Lustbader (1986), *Taking Care: Supporting Older People and Their Families*, Free Press, New York, xvi, 322pp.

This book begins by looking at the importance of family caregivers, trends affecting caregiving, the stress associated with it and social policy issues. It goes on to ask 'why care?' and looks at the various types of caregivers and their situations. It discusses spouses as caregivers and the sharing of care among other family members. It then examines some of the problems associated with caregiving, ways of coping, and services available outside the home. Finally, there is advice on how to handle the transition to a nursing home.

COMMUNITY SERVICES; FAMILY; INSTITUTIONALISATION; POLICY;
PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 409 Horowitz, Amy (1985), 'Family caregiving to the frail elderly', *Annual Review of Gerontology and Geriatrics*, 5, 194-246.

This chapter provides a literature review of the current state-of-the-art of family caregivers to the frail aged. The first section provides an historical overview of the development of knowledge in the field. The second section focuses on caregiving to the frail aged and reviews descriptive data concerning the characteristics of caregivers, caregiving behaviour, and caregiving impacts. 'The third section is concerned with the context and variability of family caregiving. Attention is given to the structural and dynamic forces which have been identified as influencing the course and consequences of the caregiving relationship. Conceptual and methodological issues are also discussed within this section. A discussion of special issues, such as the effects on the older person and process of caregiving over time, follows in the next section. The chapter concludes with a discussion of the critical policy, service, and research issues which face us today.'

CONCEPTUAL ISSUES; DEMOGRAPHIC ASPECTS; EMPLOYMENT;
FAMILY; FINANCIAL ASPECTS; HEALTH; HISTORICAL ASPECTS;
LITERATURE REVIEW; LIVING ARRANGEMENTS; METHODOLOGY;
POLICY; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SOCIOECONOMIC
STATUS; UNITED STATES

- 410 Horowitz, Amy (1985), 'Sons and daughters as caregivers to older parents: differences in role performance and consequences', *The Gerontologist*, 25(6), 612-7.

'This paper examines gender differences within a sample of 131 adult children identified as the primary caregiver to an older frail parent. Findings indicate that sons tend to be caregivers only in the absence of an available female sibling; are more likely to rely on the support of their own spouses; provide less overall

assistance to their parents, especially "hands-on" services; and tend to have less stressful caregiving experiences independent of their involvement.'

COMPARATIVE STUDIES; DAUGHTERS; METHODOLOGY; SONS; UNITED STATES

- 411 Horowitz, Amy (1992), 'Methodological issues in the study of gender within family caregiving relationships', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 132-50.

'The purpose of this chapter is to review the range of methodological issues that arise in the study of gender differences in family caregiving and to explore the extent to which these problems may cloud our understanding of gender influences and/or limit our ability to examine key questions relative to gender differences in the care of the elderly.' The methodological concerns include: 'issues relevant to sample recruitment, small sample sizes, the traditional focus on primary caregivers to the exclusion of the larger family caregiving network, reporting and measurement biases, and the predominance of both cross-sectional and quantitative research designs. Relevant to each of these areas is the sophistication (or lack thereof) of the analytic techniques used.' It is argued that 'many of these general issues are interdependent, with the most serious problems and analytic constraints stemming from the variety of sample deficiencies.'

FAMILY; GENDER; METHODOLOGY; UNITED STATES

- 412 Horowitz, Amy, Barbara M. Silverstone and Joann P. Reinhardt (1991), 'A conceptual and empirical exploration of personal autonomy issues within family caregiving relationships', *The Gerontologist*, 31(1), 23-31.

This study 'explored personal autonomy issues within family caregiving relationships and found little evidence of significant autonomy conflicts. Findings did suggest, however, that family members were more sensitive to autonomy issues than were their frail older relatives and that both groups defined the disability itself as the major impediment to autonomy in later life. Findings support the usefulness of an expanded definition of autonomy, emphasizing the importance of goal-directed behavior, which may be inhibited by intrinsic conditions as well as external forces.'

CONCEPTUAL ISSUES; DEPENDENCY; FAMILY; METHODOLOGY; RELATIONSHIPS; UNITED STATES

- 413 Horton, Christine and Richard Berthoud (1990), *The Attendance Allowance and the Costs of Caring*, Policy Studies Institute, London, Occasional Paper No.49, 84pp.

Attendance allowance is paid by the British Department of Social Security to disabled people who require regular assistance with their personal care. This study examines the financial circumstances and care arrangements of 29 'ordinary' claimants of the attendance allowance plus 9 members of a special scheme, the Bexley Community Care Scheme, which uses the allowance to organise rotas of paid carers to look after confused elderly people at home. 'The research was designed to find out what role, if any, the attendance allowance played in bringing together the package of care suited to each individual, and about the actual or potential role of paid carers in support of, or as substitute for, kin carers.'

CASE STUDIES; DISABLED; FINANCIAL ASPECTS; INCOME SUPPORT; PAYMENT; UNITED KINGDOM

- 414 Hoskins, I. (1993), 'Combining work and care for the elderly: an overview of the issues', *International Labour Review*, 132(3), 347-69.

This article provides 'an overview of the issues affecting workers with eldercare responsibilities and highlights associated policy initiatives in the public and private sectors. Until more reliable data and information are available about the circumstances of both caregivers and recipients, it will be difficult to assess which policy approaches work most efficiently and effectively in different settings. What is already clear is that national strategies to help relieve the burden of eldercare on workers will be composed of many different approaches, ranging from statutory family leave policies and social security provision to voluntary, community and employer-sponsored measures. The critical issue is which policies mix works best and at least cost to society.'

EMPLOYMENT; GENDER; INTERNATIONAL COMPARISON; POLICY

- 415 Howell, Mary (1984), 'Caretakers' views on responsibilities for the care of the demented elderly', *Journal of the American Geriatrics Society*, 32(9), 657-60.

This article provides a perspective on the day-to-day care of demented elderly persons.

DEMENTIA; PERSONAL NARRATIVES; UNITED STATES

- 416 Hoyert, Donna L. and Marsha Mailick Seltzer (1992), 'Factors related to the well-being and life activities of family caregivers', *Family Relations*, 41(1), 74-81.

'This article examines the heterogeneity of the caregiving experience for female family caregivers, using a national probability sample. Caregiving was found to have negative associations for caregivers in a number of domains, with women who cared for their husbands reporting the most negative outcomes. Both a longer duration of caregiving and coresidence put the caregiver at risk for more negative outcomes. The implications of these findings for future research and service delivery are examined.'

DAUGHTERS; LIVING ARRANGEMENTS; NATIONAL STUDIES;
PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 417 Hudson, Bob (1984), 'Who cares for the carers?', *Health and Social Service Journal*, (4904), July 5, 790-1.

It has been found that the majority of carers of the elderly in Britain are family members and women, and that the demands for community care will increase over the next quarter of a century. Present government policies rest upon the assumption that families can and must do more than in the past and implicit in this is: a model of the family as a nuclear family with a women at home supported by her husband, which only applies to about 15 per cent of families. Also, changes in family life make it less likely that families will be able to take on more responsibility for care. Increasing demands on carers are not met with increasing support for them by government.

FAMILY; GENDER; POLICY; UNITED KINGDOM

- 418 Hughes, Susan and M. Jean Keller (1992), 'Leisure education: a coping strategy for family caregivers', *Journal of Gerontological Social Work*, 19(1), 115-28.

'This article presents the concept of using leisure time as a potential coping resource for family caregivers of impaired older persons, that could be facilitated through a leisure education program within a caregiver support group. Included is a review of literature relevant to stresses of caregiving, barriers to caregivers' leisure involvement, and rationale for a leisure education program within a family caregiver support group. It is suggested that leisure education programs be based on the Peterson and Gunn leisure education model which consists of four components: leisure awareness, leisure activity skills, leisure resources, and social skills. Each component is considered in relation to caregivers' situations. Reasons for caregivers' resistance to intervention and outreach techniques are also discussed.'

EDUCATION; LITERATURE REVIEW; SOCIAL ASPECTS; SUPPORT
GROUPS; UNITED STATES

- 419 Hunt, Audrey (1988), 'The effects of caring for the elderly and infirm on women's employment', in Audrey Hunt, ed., *Women and Paid Work: Issues of Equality*, St Martin's Press, New York, 150-72.

'This chapter examines one aspect of the problems faced by women with caring responsibilities, namely the effect of such responsibilities on the employment of women.' It seeks to supplement the qualitative information provided by some previous research with detailed statistical evidence of the recent past, present and future. This information is derived from data from two large-scale surveys done in 1965 and 1980. In comparing the two surveys it was found that the percentage of carers increased overall; the percentage of part-time employment among carers increased; carers were more likely than others to work part-time; in both surveys the percentage of non-employed carers who expected to return to employment was lower than the percentage of non-employed women in general; carers in 1980 exhibited more stress; and predicted changes in the age composition of the general population are likely to lead to an increase in the percentage of women responsible for looking after elderly people.

DEMOGRAPHIC ASPECTS; EMPLOYMENT; FINANCIAL ASPECTS;
GENDER; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; UNITED
KINGDOM

- 420 Ingersoll-Dayton, Berit, Nancy Chapman and Margaret Neal (1990), 'A program for caregivers in the workplace', *The Gerontologist*, 30(1), 126-30.

'In four demonstration sites, an educational seminar series was offered to employed caregivers, followed by a choice of service options (i.e. care planning, a support group, a buddy system). An increase in absenteeism and knowledge of aging services was associated with attendance at the seminar series. Among the service options, only care planning and support groups were utilized by employees. A decrease in negative affect was associated with each of the options.

EDUCATION; EMPLOYMENT; SUPPORT GROUPS; UNITED STATES

- 421 'Invalid care allowance and married women: latest developments', *Welfare Rights Bulletin*, (82), 1-3 and (84), 12-13.

In 1986 the campaign by the Steering Group and the test case taken to the European Court by the Child Poverty Action Group in the United Kingdom forced the government to extend Invalid Care Allowance to married and cohabiting women retrospectively to December 1984. For tens of thousands of women this success resulted in substantial backpayments and entitlement to a new weekly benefit. For others, a combination of delay by the Department of Health and Social Security and

the application of obscure rules has produced only hardship and frustration. This two part article looks at the issues in detail.

GENDER; INCOME SUPPORT; POLICY; UNITED KINGDOM

422 Isaacs, Bernard (1980), 'Burden of care', *New Age*, Winter, 23-5.

The task of looking after dependent and ill old people can place a terrible strain on the supporting family. This article argues that domiciliary care is not simply a cheap, easy alternative to institutional provision and identifies the disabilities which cause dependency in the elderly, examines the burden they impose on the carers and argues for a whole range of new services to help those people providing care.

COMMUNITY SERVICES; DEPENDENCY; FAMILY; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

423 Jarrett, William H. (1985), 'Caregiving within kinship systems: is affection really necessary?', *The Gerontologist*, 25(1), 5-10.

'Contemporary thinking on family supports and intergenerational relations is seen as idealistic. Research suggests that filial affection for aged dependents is not always sufficient to enable caregivers to cope with the strains of caregiving. A relabeling strategy (cognitive therapy) is suggested to help caregivers redefine their situations so that caregiving is done from motives of kinship obligations which, historically, have formed the basis for family aid.'

FAMILY; RELATIONSHIPS; THEORY DEVELOPMENT; UNITED STATES

424 Jarvik, Lissy and Gary Small (1988), *Parentcare: A Commonsense Guide for Adult Children*, Crown Publishers, New York, 309pp.

This book offers pragmatic responses for the major problems associated with caring for ageing parents. Topics include dealing with the anger and stress of caregiving, managing financial resources and facing dying and death. There are appendices with information on useful resources.

BEREAVEMENT; COUNSELLING; EDUCATION; FINANCIAL ASPECTS; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 425 Jerrom, Bill, Ihsan Mian and Nimal G. Rukanyake (1993), 'Stress on relative caregivers of dementia sufferers, and predictors of the breakdown of community care', *International Journal of Geriatric Psychiatry*, 8(4), 331-7.

'The stress upon the principal relative caregivers of a series of dementia sufferers attending an assessment day hospital was studied. The main variables influencing stress levels were the caregiver's own health self-rating and a measure of behaviour and mood disturbance in the patient. Predictors of the breakdown of community care over a 1-year follow-up period were studied. At 12 months caregiver's "caseness" on the GHQ was a highly significant predictor. Clinical work with dementia sufferers in the community should include an assessment of the health and psychological status of the caregiver. Future research should focus upon evaluating specifically targeted interventions aimed at reducing stress in caregivers.'

DEMENTIA; HEALTH; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
UNITED KINGDOM

- 426 Johansson, Lennarth (1991), 'Informal care of dependent elderly at home - some Swedish experiences', *Ageing and Society*, 11(1), 41-58.

'This study as an attempt to explore the dynamics in a group of family caregivers in a small rural setting in Sweden. Thirty-nine caregivers giving extensive help to elderly family members, who were all on the verge of institutionalisation, were interviewed. The results showed that the motives of caring were usually based on feelings of reciprocity and that the perceived burden of care was related to the proximity of the carer to the person cared for. Despite the existence of a rather well-developed system of formal care, these resources were poorly co-ordinated with the informal provision of care.'

COMMUNITY SERVICES; FAMILY; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; RURAL ASPECTS; SWEDEN

- 427 Johnson, Colleen Leahy and Donald J. Catalano (1983), 'A longitudinal study of family supports to impaired elderly', *The Gerontologist*, 23(6), 612-8.

'The family supports of 115 individuals 65 years and older were studied after discharge from the hospital and again an average of 8 months later. From the group as a whole at Time 2, the mean functional level had stabilized. Probably as a result, the family supports declined, although more patients reported problems with morale and loneliness. An analysis was also made of those patients who were dependent during the 8-month period. In comparison with those who had achieved independent functioning, it was found that strain was high and more families used formal supports. Adaptive mechanisms to the burdens of care are also described.'

DEPENDENCY; FAMILY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 428 Jones, Dee A. (1986), *A Survey of Carers of Elderly Dependents Living in the Community*, Research Team for the Care of the Elderly, University of Wales College of Medicine, Cardiff, 88pp.

This survey sought to explore the network of formal and informal care available to frail elderly people, to define those factors contributing to the maintenance or breakdown of the caring relationship, examine the extent to which statutory services could alleviate the burden of care and make recommendations concerning future activities and policies of health and social services. The study used a variety of measures to determine such factors as physical disability, stress and distress, health, psychological morbidity and psychosocial aspects. The results of the study show that families are caring for their dependents at great costs to themselves and yet only a minority were receiving the support of personal health and social services. Community nursing and home helps were the most commonly used services. General practitioners were the key to services and yet they rarely reported on housing, environment or social needs or the needs of carers. It was felt that health visitors were the most appropriate professionals to assess the needs and train carers for their caring role. Respite care was an overwhelming need which none of those interviewed received in a planned way. It is concluded that services must be more flexible and allocated not only according to physical disability but by mental impairment and degree of carer stress also. Most carers were ignorant of attendance allowance which must be made more widely known. Future policies must be family, not individual, oriented.

COMMUNITY SERVICES; FAMILY; HEALTH; INCOME SUPPORT;
NATIONAL STUDIES; POLICY; PSYCHOLOGICAL ASPECTS; RESPITE
CARE; SERVICE USE; UNITED KINGDOM

- 429 Jones, Dee A., Christina R. Victor and Norman J. Vetter (1983), 'Carers of the elderly in the community', *Journal of the Royal College of General Practitioners*, 33, 707-10.

'A random sample of 657 over 70-year-olds from a large urban general practice in South Wales were interviewed to assess their physical, mental and social well-being. Questions were asked about the carers of these elderly people: which subjects had carers, the relationships of the carers to the subjects and the tasks that the carers performed. Spouses and daughters were by far the commonest carers and indeed the family bore the major part of the burden of caring for the elderly. Apart from home helps, statutory and voluntary services played minor roles in supporting the elderly in the community.'

COMMUNITY SERVICES; DAUGHTERS; FAMILY; METHODOLOGY;
NATIONAL STUDIES; RELATIONSHIPS; SERVICE USE; SPOUSES; UNITED
KINGDOM

- 430 Jones, Dee and Norman J. Vetter (1984), 'A survey of those who care for the elderly at home: their problems and their needs', *Social Science and Medicine*, 19(5), 511-4.

'One thousand and sixty-six over 70s [in Wales] were interviewed in their own homes, 256 of the subjects had main carers who were non-statutory. These informal carers of the dependent elderly were then interviewed to examine the nature of the care that they provided, the assistance both formal and informal that they received and the consequences such caring had on their quality of life. The evidence from this study supports the view that the family is the main source of assistance to dependent elderly; usually the women in the family. Very little assistance, either formal or informal, was received by the carers. Consequently there was a great deal of distress and psychological morbidity among the carers.'

COMMUNITY SERVICES; FAMILY; GENDER; NATIONAL STUDIES;
PSYCHOLOGICAL ASPECTS; SERVICE USE; UNITED KINGDOM

- 431 Jones, Dee A. and Norman J. Vetter (1985), 'Formal and informal support received by carers of elderly dependents', *British Medical Journal*, 291, September 7, 643-5.

'This study describes the activity of informal carers who look after elderly dependents and particularly investigates the role of the formal services in supporting these carers in maintaining dependent, elderly people in the community. The results lend no support to the view that families neglect their elderly relatives or that community services displace the role of informal carers, but rather suggest that carers support elderly dependents at great cost to themselves and with inadequate support from community services.'

COMMUNITY SERVICES; NATIONAL STUDIES; PSYCHOLOGICAL
ASPECTS; SERVICE USE; UNITED KINGDOM

- 432 Jones, Dee A. and Ann V. Salvage (1992), 'Attitudes to caring among a group of informal carers of elderly dependents', *Archives of Gerontology and Geriatrics*, 14, 155-65.

'Two hundred and fifty-six carers of elderly people aged 70 and over were questioned on their attitudes towards their caring role and their preferences for their own future care. Despite the fact that most were providing assistance at high personal cost, most carers were highly committed to their caring role. However, those who felt that their caring role caused them high levels of stress were more likely to say that they would accept institutional care for their dependents, and less likely to have positive expectations of family care for themselves. It is suggested that, in planning services, the needs of carers (especially those under high levels of stress) should be

taken into account as much as those of the elderly people for whom they provide care.'

INSTITUTIONALISATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; UNITED KINGDOM

- 433 Joshi, Heather (1987), 'The cost of caring', in Caroline Glendinning and Jane Millar, eds, *Women and Poverty in Britain*, Wheatsheaf Books, Brighton, 112-33.

'This chapter examines the earnings that women forgo as a result of their role as carer of first and last resort. The notion of foregone earnings is an example of what is known as an "opportunity cost". This concept compares a course of action with the best possible alternative that it pre-empts; opportunity costs are the value of what has to be given up to achieve a particular goal. Although some carers sacrifice a lot more than their potential money earnings, the cash they forgo is a crucial component of the opportunity cost of their unpaid work and of women's mutually reinforcing disadvantages in the labour market.' It examines how caring affects first, women's labour market participation and their hours of paid work; and secondly, their pay both in the short term and the long term.

EMPLOYMENT; FINANCIAL ASPECTS; GENDER; UNITED KINGDOM

- 434 Kahan, Jason, Bryan Kemp, Fred R. Staples and Kenneth Brummel-Smith (1985), 'Decreasing the burden in families caring for a relative with a dementing illness: a controlled study', *Journal of the American Geriatrics Society*, 33(10), 664-70.

'The purpose of this study was to investigate the efficacy of a specifically designed group support program for relatives of patients with Alzheimer's disease and related disorders. The group program included educational/supportive activities and used basic principles of the cognitive-behavioral approach. Twenty-two subjects participated in an eight-session program. Eighteen control subjects received no treatment. Measures of family burden, levels of depression, and knowledge of dementia were obtained. Experimental subjects showed a significant decrease in total family burden, whereas control subjects actually showed a significant increase, experimental subjects also showed reduction in their levels of depression. Experimental subjects showed a significantly greater improvement than did control subjects on knowledge of dementia. The acquisition of new knowledge was an important ingredient in reducing perception of burden and levels of depression, but other facets of the intervention also accounted for the improvement. Results indicated that a relatively short but intensive support experience can have a positive

effect in reducing some of the burden and depression associated with the care of a demented relative.'

DEMENTIA; EDUCATION; EVALUATION; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; SUPPORT GROUPS; UNITED STATES

- 435 Kahana, Eve and Rosalie Young (1990), 'Clarifying the caregiving paradigm: challenges for the future', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 76-97.

'In order to develop a useful conceptual framework for considering different elements and dimensions of caregiving and to develop a useful way of comparing existing research findings, a brief overview of implicit models of caregiving [are] given' using the dyadic relationship as an example. It demonstrates the need to expand current paradigms to include the interaction between care-giver and care-recipient. 'Variables which could give direction to interactive studies are identified as well as the need to develop paradigms which go beyond the dyad.'

CONCEPTUAL ISSUES; METHODOLOGY; THEORY DEVELOPMENT;
UNITED STATES

- 436 Kashner, Michael T, Jay Magaziner and Sheri Pruitt (1990), 'Family size and caregiving of aged patients with hip fractures', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 184-203.

This chapter 'examines the association of household size and family size with informal caregiving, use of formal caregivers, and use of institutional placement for aged patients with hip fractures at three points in time: prefracture, two months postfracture, and six months postfracture. Findings suggest that characteristics of the entire family, not only the designated caregiver, are important determinants of the amount of time devoted to caregiving, as are an optimal family size of two to four members and the duration of the period of dysfunction related to the hip fracture. In addition to the overall informal caregiving time, the study examines the amount of time devoted to eight categories of informal caregiving and provides a data base which could be used to compare caregiver time for the physically and cognitively impaired elderly.' The study points to the importance of considering the whole family and not just the central caregiver.

FAMILY; INSTITUTIONALISATION; RELATIONSHIPS; SERVICE USE;
UNITED STATES

- 437 Kaufman, Alan V., James P. Adams and Vincent A. Campbell (1991), 'Permanency planning of older parents who care for adult children with mental retardation', *Mental Retardation*, 29(5), 293-300.

'In a study of 57 older parent caregivers of adult children with mental retardation, more than half had not planned for their child's future care. Income, race, child's gender and level of adaptive behavior, and degree of parental interaction with relatives and friends were significantly related to future care-planning activity.'

AGED CAREGIVERS; DEPENDENCY; DISABLED; METHODOLOGY; RELATIONSHIPS; SUPPORT NETWORKS; UNITED STATES

- 438 Keigher, Sharon M. and Robyn I. Stone (1994), 'Family care in America: evolution and evaluation', *Ageing International*, 21(1), 41-8.

This article describes 'the fragmented and limited array of support programs for family caregivers currently provided by the federal, state and local governments and by private corporate employers in America. These range from services and direct payments to tax allowances, dependent-care tax credits, and unpaid leaves. [It highlights the] inadequacies, including the proscriptions and means testing, which still characterize many of the state eligibility criteria. Finally [it] argues for a more explicit federal policy to provide financial remuneration - directly or indirectly - to family caregivers.'

COMMUNITY SERVICES; EMPLOYMENT; EVALUATION; FINANCIAL ASPECTS; PAYMENT; POLICY; UNITED STATES

- 439 Kiecolt-Glaser, Janice K. and Ronald Glaser (1990), 'Caregiving, mental health, and immune function', in Enid Light and Barry D. Lebowitz, eds, *Alzheimer's Disease Treatment and Family Stress: Directions for Research*, Hemisphere, New York, 245-66.

This chapter briefly describes evidence suggesting that family caregivers of Alzheimer's disease victims are at high risk of depression. Studies that have linked both acute and chronic distress or dysphoria with alterations in immune function are discussed, including data from a cross-sectional study of caregivers. Finally, a conceptual framework that provides a structure for understanding these data is presented, emphasising possible pathways through which psychological resources such as supportive interpersonal relationships might have an impact on health.

DEMENTIA; HEALTH; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SUPPORT NETWORKS; THEORY DEVELOPMENT; UNITED STATES

- 440 Kermis, Marguerite D., Neal S. Bellos and Charles R. Schmidtke (1987), 'Our parents' keepers: an analysis of values and dilemmas in home care of the frail elderly', *Journal of Applied Gerontology*, 5(2), 126-38.

'The rapid increase in numbers of older people, combined with a decrease in financial support for human and health services, has led to values and policy dilemmas in home care of the frail elderly. A consideration of four sets of American values - democratic utilitarianism, individual rights and self-fulfillment, equality, and efficiency in work and production - is made as they apply to policies and programs relating to home care. It is important for those involved in gerontological education, research, and practice to rethink home care policies in order to examine the value-laden assumptions upon which these policies are based. Such examination may lead to a remediation of the dilemmas currently encountered by clients and caregivers in the home care situation.'

CONCEPTUAL ISSUES; IDEOLOGY; POLICY; UNITED STATES

- 441 King, Deborah A., David D. Bonacci and Lyman C. Wynne (1990), 'Families of cognitively impaired elders: helping adult children confront the filial crisis', *Clinical Gerontologist*, 10(1), 3-15.

'When psychiatric or cognitive decline disrupts the elder's ability to make independent decisions, grown children may be called upon to make decisions for their parents for the first time. Successful case management and treatment will depend upon the clinicians recognition of the distinctive issues posed by this unique stage of family development. The normative stresses and conflicts of this transition period are discussed, along with several dimensions of family functioning observed to influence its course. A case example is used to illustrate the clinician's role in facilitating change, as well as the patterns of denial and resistance often encountered.'

CASE STUDIES; DAUGHTERS; DEPENDENCY; FAMILY; PSYCHOLOGICAL ASPECTS; SONS; UNITED STATES

- 442 Kingson, Eric R. and Regina O'Grady-LeShane (1993), 'The effects of caregiving on women's social security benefits', *The Gerontologist*, 33(2), 230-9.

Using data from the Social Security Administration's 1982 New Beneficiary Survey [the authors] tested a life-course model that suggests that early- and late-life caregiving reduce monthly Social Security benefits of newly retired women workers. Leaving work to care for others exerted a stronger depressing effect on the Social Security benefits of women with low- and moderate- as opposed to high-earnings histories.

GENDER; INCOME SUPPORT; NATIONAL STUDIES; UNITED STATES

- 443 Kinney, Jennifer M. and Mary Ann Parris Stephens (1989), 'Caregiver Hassles Scale: assessing the daily hassles of caring for a family member with dementia', *The Gerontologist*, 29(3), 328-32.

'Examined was a scale designed to assess the daily hassles of caring for a family member with Alzheimer's Disease (AD). Primary caregivers to AD patients (N=60) completed the Caregiving Hassles Scale on two occasions and reported on their well-being. The 42-item scale provides a reliable and psychometrically sound instrument for assessing hassles associated with assistance in basic ADL, assistance in instrumental ADL, care-recipients' cognitive status, care-recipients' behavior, and caregivers' social network.'

DEMENTIA; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 444 Kivett, Vira R. (1988), 'Older rural fathers and sons: patterns of association and helping', *Family Relations*, 37(1), 62-7.

'This study examined the extent to which adult sons were incorporated into the support network of older rural men through a convergent symbolic-interaction/exchange theory perspective. Respondents were 56 rural men, 65 years or older, selected through an area cluster sampling strategy. The findings showed adult sons play a relatively minor role in the support network of older fathers as seen through helping. Neither were they frequent recipients of help. Sons played a moderately active role through their participation in family ceremonies and emergencies (association). The extent to which older fathers received or gave help could not be predicted. Association between fathers and sons, however, could be explained through proximity. Suggestions are provided for practitioners concerned with the support network of older adults living in geographical areas experiencing a rural to urban change.'

METHODOLOGY; RURAL ASPECTS; SONS; THEORY DEVELOPMENT; UNITED STATES

- 445 Kivett, Vira R. and Maxine P. Atkinson (1984), 'Filial expectations, association, and helping as a function of number of children among older rural-transitional parents', *Journal of Gerontology*, 39(4), 499-503.

'Older adults with an only child (n=57) were compared with parents with two or three children (n=139) and parents with four or more children (n=83) with regard to filial expectations and frequency of parent-child association and assistance. The results showed no differences between groups with regard to filial expectations. Parents of only children, however, were less likely to receive assistance and to have seen a child in the last day or two. Only a minimal amount of variance could be explained in parent-child association and helping except for parents of only children. Factors influencing association and helping patterns were observed to vary according

to number of children. Whereas income, geographical proximity, and health of older parents were central to the assistance received by parents of only children, sex-linked factors, health of parents, and geographical proximity were found to contribute to the amount of help received by parents with more than one child. The research suggests the importance of controlling for number of children in future studies of intergenerational relationships and raises important questions regarding the adequacy of limited family networks as certain subgroups of the current "young-old" cohort move further into the dependencies of old age.'

COMPARATIVE STUDIES; DAUGHTERS; GENDER; HEALTH;
METHODOLOGY; RELATIONSHIPS; SONS; UNITED STATES

- 446 Kleban, Morton H., Elaine M. Brody, Claire B. Schoonover and Christine Hoffman (1989), 'Family help to the elderly: perceptions of sons-in-law regarding parent care', *Journal of Marriage and the Family*, 51(2), 303-12.

'This article examines the consequences of parent care reported by the husbands (N=150) of women who were principal caregivers of their elderly disabled mothers and compares the men's perceptions of the caregiving situation with those of their wives. Many of the husbands reported the personal effects of parent care often cited by principal caregivers. Those sharing households with their mothers-in-law were more likely to report consequences such as interference in social lives, family vacation plans, time with wives and children, and relationships with other relatives. Overall, husbands and wives disagreed on the extent to which relationships in the nuclear family were affected by caregiving but agreed about the occurrence of more objectively apparent lifestyle disruptions.'

DAUGHTERS; LIVING ARRANGEMENTS; RELATIONSHIPS; SOCIAL
ASPECTS; UNITED STATES

- 447 Knight, Bob G., Steven M. Lutzky and Felice Macofsky-Urban (1993), 'A meta-analytic review of interventions for caregiver distress: recommendations for future research', *The Gerontologist*, 33(2), 240-8.

'This review summarizes articles from 1980 to 1990 on psychosocial interventions and respite care for caregivers. The review was limited to controlled studies that attempted to change emotional distress in caregivers. Cumulatively, they suggest that individual psychosocial interventions and respite programs are moderately effective; psychosocial interventions with groups are less so.'

LITERATURE REVIEW; PSYCHOLOGICAL ASPECTS; RESPITE CARE;
SUPPORT GROUPS; UNITED STATES

- 448 Knipscheer, C.P.M. (1985), 'Problems and possibilities in informal care for the impaired elderly', in J.A. Yoder, J.M.L. Jonker and R.A.B. Leaper, eds, *Support Networks in a Caring Community: Research and Policy, Fact and Fiction*, Martinus Nijhoff, Dordrecht, 171-81.

In discussing the possibilities of promoting informal care for impaired elderly people it is necessary to understand the problems associated with it. With this in mind, this paper presents an overview of the recent literature on informal care and comments upon the most straining problems for those caring for an impaired elderly person with a view to finding ways of easing that strain. It develops some possibilities for promoting informal care of the impaired elderly both within the family and by others. It is necessary for there to be intensive interaction between the formal and informal sectors. Co-ordination between the two might perhaps be best realised within a professional frame and ought to be provided as near to each other as possible. Formal care provisions have to create ample opportunities for temporary relief of informal caretakers. It warns against unrealistic expectations.

COMMUNITY SERVICES; LITERATURE REVIEW; POLICY;
PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; RESPITE CARE;
NETHERLANDS

- 449 Koch, Tom (1993), *A Place in Time: Care Givers for Their Elderly*, Praeger, Westport, Conn., 236pp.

Through personal narratives, this book presents and explores the experiences of both family caregivers and the frail elderly people in their care with the purpose of providing support and education for caregivers and also to 'provide a platform from which social and social scientific assumptions concerning caring for others, and especially those who are both fragile and aged, can be examined in the light of individual experience.'

CASE STUDIES; PERSONAL NARRATIVES; UNITED STATES

- 450 Koin, Diana (1990), 'The effects of caregiver stress on physical health status', in Enid Light and Barry D. Lebowitz, eds, *Alzheimer's Disease Treatment and Family Stress: Directions for Research*, Hemisphere, New York, 310-20.

Although the psychosocial aspects of caregiving have received a growing amount of attention, the physical health status of caregivers has been only minimally studied. Some of the methodological difficulties involved in this type of research are examined. One area of health affected by stress is cardiovascular disease. 'Any attempt to investigate the relationship between caregiving and physical health status will need to carefully appraise the objective indicators to be used in the study.'

CARDIOVASCULAR DISEASE; DEMENTIA; HEALTH; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 451 Kosberg, Jordan I. and Richard E. Cairl (1986), 'The cost of care index: a case management tool for screening informal care providers', *The Gerontologist*, 26(3), 273-8.

'The Cost of Care Index (CCI) has been developed as a case management tool to assist professionals in family assessments and to identify actual or perceived problem areas of families in the care of elderly relatives. The 20-item CCI has been determined to be reliable and focuses upon five dimensions, related to family care of the elderly. The CCI has been used for family screening, intervention, and peer group interaction.'

FAMILY; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 452 Krauss, Marty Wyngaarden and Marji Erickson (1988), 'Informal support networks among aging persons with mental retardation: a pilot study', *Mental Retardation*, 26(4), 197-201.

This article reports on data collected on the informal support networks of 49 aging persons with mental retardation. Findings indicated that persons living with family had significantly smaller support networks (composed primarily of family members), and those mentally retarded aging persons living in community residences or institutions had informal support networks composed equally of family, friends, and professionals.

DISABLED; INSTITUTIONALISATION; SUPPORT NETWORKS; UNITED STATES

- 453 Krulik, Tamar and Miriam J. Hirschfeld (1985), 'The continuation of home care to severely impaired children and aged in Israel: family attitudes', *Home Health Care Services Quarterly*, 5(3/4), 283-313.

'There are a growing number of children and aged with severe chronic health problems in the community. Mothers become the prime caregivers to these children and aging spouses or middle-aged offspring the caregivers to the aged. The services offered to these families are determined by economic and social conditions, as well as changing fashions, rather than knowledge of the patients' and caregivers' needs. The purpose of this study was to assess the impact of home care upon families caring for children versus those caring for aged and these families' attitudes towards continuation of home care versus institutionalization. The families included in the study were drawn randomly from the case load of community nurses in central Israel. In-depth interviews were conducted with 92 families of severely impaired children and 181 families of severely impaired adults and aged in their homes. While the majority of both populations carry a heavy burden of caregiving over the years, they also receive gratification from their ability to care for their patients at home. There is little difference between those caring for children and those caring for adults in their attitudes towards continuation of home care. Mental rather than physical

impairment, a deteriorating illness trajectory, depression, aggression and tension of the caregiver, the absence of sufficient social support and home care services correspond with negative feelings toward continued home care. The perceived impact of caregiving responsibilities upon caregivers' lives, the ability to tolerate and manage symptoms and above all the quality of the patient-caregiver relationship influenced the caregivers' attitudes towards institutionalization in both populations. Family attitude towards continued home care and institutionalization of children and adults are compared and the needs for services discussed.'

COMMUNITY SERVICES; COMPARATIVE STUDIES; FAMILY;
INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS;
ISRAEL

- 454 Laczko, Frank and Sallie Noden (1992), 'Eldercare and the labour market: combining care and work', in Frank Laczko and Christina R. Victor, eds, *Social Policy and Elderly People: The Role of Community Care*, Avebury, Aldershot, Hants., 30-48.

'The purpose of this chapter is to show, by reviewing the current literature, that informal carers face considerable difficulties when trying to combine caring and employment, and that the present social security and employment policies provide little support for carers who wish to be employed. The chapter also shows that employers are largely unaware of the need for eldercare, despite the fact that the lack of it has costs for enterprises as well as carers. Employers must be made aware of the needs of carers in employment and so be encouraged to provide more flexible employment practices.

EMPLOYMENT; LITERATURE REVIEW; POLICY; UNITED KINGDOM

- 455 Laczko, Frank and Sally Noden (1993), 'Combining paid work with eldercare: the implications for social policy', *Health & Social Care in the Community*, 1(2), 81-9.

'Government policy relies upon the continued provision of unpaid care from informal carers to groups such as elderly people. The majority of carers of elderly people are in employment and the number of people who combine care and work is likely to rise as the proportion of women and older workers in the labour force increases. However, recent public policy statements make little mention of the impact of informal care on employment and the difficulties associated with combining care and work. Likewise this issue has been ignored in the policy debate about the promotion of equal opportunities in employment, and in discussion of social policies for older workers, who among workers below pension age are the main providers of care for elderly people. This paper reviews the evidence concerning the relationship between employment and care of the elderly. It suggests an agenda of policy issues that need to be addressed, taking account of the fact that

carers of elderly people are not a homogeneous group. A range of policy measures are discussed which would enable more carers to remain in employment, and allow other carers to return to the labour market, and hence reduce some of the financial and other costs associated with loss of employment.'

EMPLOYMENT; FINANCIAL ASPECTS; POLICY; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; UNITED KINGDOM

- 456 Land, Hilary (1991), 'Time to care', in Mavis Maclean and Dulcie Groves, eds, *Women's Issues in Social Policy*, Routledge, London, 7-19.

Where there were some gains in recognition and reward of caring work done by women, whether in the social welfare industry or in caring work in the home, in the 1970s, in the 1980s these have been eroded. Caring work in the home won some recognition in the state benefit system in the 1970s but in the 1980s these benefits have been reduced in value and it has been made more difficult to qualify to receive them. The lack of recognition of women's caring work is not just because recognition would prove to be very costly in terms of money. Women's time is an invisible factor when it comes to household and national accounting. Resistance is also due to the very nature and meaning of caring and servicing work. Caring needs to be valued more highly and this means recognising that women's time is not just divided between paid work and leisure. 'Too many women are not free to choose *not* to care without damaging either those whom they care about or their own self-esteem. Worse, those who do, face tasks and experiences little valued, supported or even acknowledged in material terms, and their reward is all too often poverty which may extend years after the caring has ceased. This will continue unless we develop analyses and policies which take into account the complexity of the relationship between the family, the market and the State and challenge the assumption that caring is an attribute and activity which naturally belongs to women.'

GENDER; INCOME SUPPORT; POLICY; SOCIOECONOMIC STATUS; UNITED KINGDOM

- 457 Lang, Abigail M. and Elaine M. Brody (1983), 'Characteristics of middle-aged daughters and help to their elderly mothers', *Journal of Marriage and the Family*, 45(1), 193-202.

'This paper examines the relationships between selected characteristics of a sample of middle-aged daughters (N=161) and the nature and amount of help they provided to their elderly mothers. Univariate analysis of variance and regression analyses indicated that the daughters' characteristics - their ages, marital status, work/non-work status, and living arrangements (whether daughters and mothers share households or live separately) - were related significantly to the amount of help they provided. Shared households and older ages of the daughter were associated with more caregiving, while both being married and being employed "pulled" slightly

from the amount of help given. The findings illuminate the situations of "women in the middle" - that is, middle-aged women involved in parent care - and suggests social policy directions and further research needs.'

DAUGHTERS; EMPLOYMENT; METHODOLOGY; LIVING
ARRANGEMENTS; MIDDLE AGED CAREGIVERS; POLICY; UNITED
STATES

- 458 Lawton, M. Powell, Elaine M. Brody and Avalie R. Saperstein (1991), *Respite for Caregivers of Alzheimer Patients: Research and Practice*, Springer, New York, xi, 164pp.

'This book describes and reports the findings from a respite service project conducted by the Philadelphia Geriatric Center (PGC) that was designed specifically for families caring for victims of Alzheimer's disease and related disorders. Moreover, implications for planning and delivering respite programs are detailed, based on the project's operating experiences as well as on its research findings.' It focuses on the needs of carers, their use of services and their caregiving behaviour.

CASE STUDIES; DEMENTIA; RESPITE CARE; SERVICE USE; UNITED
STATES

- 459 Lawton, M. Powell, Miriam Moss, Morton H. Kleban, Allen Glicksman and Michael Rovine (1991), 'A two-factor model of caregiving appraisal and psychological well-being', *Journal of Gerontology: Psychological Sciences*, 46(4), P181-9.

'Groups of spouse (N=285) and adult children (N=244) caregivers of elderly parents suffering from Alzheimer's disease were interviewed regarding their caregiving behaviors, evaluations of caregiving, and general psychological well-being. A model of caregiving dynamics where the objective stressor, caregiver resources, and subjective appraisal of caregiving (operationalized as caregiving satisfaction and burden) were studied as they affected both positive affect and depression was tested. For spouses, caregiving satisfaction was not related to aspects of the stressor, but was a significant determinant of positive affect. Among adult children, high levels of caregiving behavior resulted in both greater caregiving satisfaction and burden. Burden, in turn, was related to depression in both groups but, among adult child caregivers, positive affect was not affected by caregiving satisfaction. Limited support was found for the hypothesis that the positive and negative aspects of caregiving contributed to analogous aspects of generalized psychological well-being but not to the opposite-valence outcomes.'

PSYCHOLOGICAL ASPECTS; THEORY DEVELOPMENT; UNITED STATES

- 460 Lazarus, Lawrence W., Bridget Stafford, Kathleen Cooper, Bertram Cohler and Maurice Dysken (1981), 'A pilot study of an Alzheimer patients' relatives discussion group', *The Gerontologist*, 21(4), 353-8.

'The impact of a time-limited discussion group for relatives of patients with Alzheimer's disease, co-led by psychiatrists, was studied. Participants became more knowledgeable about the illness and more accepting of their ambivalence toward their afflicted relative. They learned new ways of coping, while struggling to achieve mastery as they began the painful process of disengagement. Follow-up studies are indicated comparing educationally-oriented with problem-oriented discussion groups.'

DEMENTIA; EDUCATION; METHODOLOGY; SUPPORT GROUPS; UNITED STATES

- 461 Leat, Diana (1992), 'Innovations and special schemes' in Julia Twigg, ed., *Carers: Research and Practice*, HMSO, London, 94-125.

'This chapter is concerned with innovations and with special schemes for the support of carers.' One of the difficulties is trying to decide what constitutes 'innovation'. Innovation does not necessarily entail anything very new. It is not good *per se* but must be judged in terms of relevance, accessibility, reliability and acceptability from the viewpoint of the carer. Voluntary organisations are not, as is often assumed, the only or indeed the most significant source of innovations. Examples of innovations are given under five headings: neighbourhood care, community care and sitting schemes; flexible care attendance; flexible respite; information, advice and support; and consultation and involvement in planning. Five common themes in setting up such schemes are discussed in the second part of the chapter. These are: needs, goals and strategies; resources; recruiting and retaining paid staff and volunteers; identifying, stimulating and maintaining demand from carers; and management issues.

COMMUNITY SERVICES; EDUCATION; EVALUATION; SUPPORT GROUPS; RESPITE CARE; UNITED KINGDOM

- 462 Leat, Diana and Pat Gay (1987), *Paying for Care: A Study of Policy and Practice in Paid Care Schemes*, Research Report No.661, Policy Studies Institute, London, 81pp.

'This report is concerned with the growing practice within social service departments of paying "ordinary people" to provide various forms of care for a wide range of client groups.' This is referred to as 'paying for care' and the practice can be seen as a reflection of a number of strands of current thinking about the provision of social care. 'It does not examine in detail any particular type of provision or scheme, rather it attempts to identify and discuss some of the broader issues', focusing on 'the principles and problems underlying the practice of payment for care. The report is

based on a small exploratory study and is intended to raise questions and suggest hypotheses rather than present firm conclusions or answers.' It discusses scope and extent, accountability and protection, presents data on the perceived costs and benefits, and raises the issue of exploitation.'

COMMUNITY SERVICES; PAYMENT; UNITED KINGDOM

- 463 Lechner, Viola M. (1991), 'Predicting future commitment to care for frail parents among employed caregivers', *Journal of Gerontological Social Work*, 18(1/2), 69-84.

'A study of 133 full time employees with parent care responsibilities investigated various factors that could reduce this group's future caregiving commitment to aging parents. Study factors included: caregiver attributes, level of caregiving involvement, job stress, tensions between the caregiver and the dependent parent, caregiver's level of physical and mental strain, and limited support from family and friends. The relationship between the caregiver and the parent was the best predictor of sustained commitment to caregiving. One aspect of the employees' work experience made a small, but important contribution to respondents' future care plans. Those employees who frequently adjusted their work schedule and routine to accommodate parent care demands were less likely to sustain their caregiving commitment. Reasons for these findings are explored and implications for social policy and clinical practice are discussed.'

EMPLOYMENT; FINANCIAL ASPECTS; HEALTH; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED STATES

- 464 Lee, Gary R. (1992), 'Gender differences in family caregiving': a fact in search of a theory', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 120-31.

This chapter considers possible explanations for the preponderance of females as family caregivers to the elderly. The focus is on the greater role played by daughters than sons in the care of ageing parents. It is argued that differences in the provision of parental care by sons and daughters are a special case of gender differences in broader domains of family behaviour, i.e. the domestic division of labour, nurturance in family role behaviour, and kinship relations. Theoretical propositions are advanced that summarise what is known about the adult-child caregiving relationship and place care of the elderly in this broader context. Possible directions for future theory development are also discussed.

DAUGHTERS; FAMILY; GENDER; RELATIONSHIPS; SONS; THEORY DEVELOPMENT; UNITED STATES

- 465 Leeson, George and Eva Tufte (1994), 'Concerns for carers: family support in Denmark', *Ageing International*, 21(1)6, 49-53.

The findings of this study found that relatives have difficulties in coping, especially in regards to the practical and long-term aspects of their role as carers. However, municipalities and the Ministry of Social Affairs in Denmark have not yet addressed the needs of these people nor have they coordinated any kind of practical assistance and information for family caregivers. Many good pilot projects aimed at coordinating public and private sector services do not become firmly established, mainly for financial reasons. There is a need to plan and more information is also needed on service and program deficiencies, together with better identification of relatives' need for help.

POLICY; DENMARK

- 466 Leff, J., R. Berkowitz, N. Shavit, A. Strachan, I. Glass and C. Vaughn (1990), 'A trial of family therapy versus relatives' group for schizophrenia: two-year follow-up', *British Journal of Psychiatry*, 157, 571-7.

'The results are reported of a two-year follow-up of a trial of family sessions in the home (including patients) (12 families) versus a relatives' support group (excluding patients) (11 families). Subjects were patients with schizophrenia living in high face-to-face contact with high-EE [expressed emotion] relatives. Patients were maintained on neuroleptic drugs for two years where possible. Relatives' critical comments and hostility were significantly lowered by nine months, but no significant changes occurred subsequently. Relatives' overinvolvement reduced steadily throughout the trial, and reduction in relations' EE, either alone or in combination with reduced face-to-face contact, appeared to be associated with a lower relapse rate. The relapse rates for patients in the family-therapy and relatives'-group streams were 33% and 36% at two years. When these data were combined with the results of a previous trial, it was found that patients in families assigned to any form of social intervention had a two-year relapse rate of 40%, significantly lower than the 75% relapse rate for patients whose families were offered no help.' It is recommended 'that relatives' groups are established in conjunction with some family sessions in the home for patients at high risk of relapse.'

MENTAL ILLNESS; SUPPORT GROUPS; UNITED KINGDOM

- 467 Lerner, Melvin J., Darryl G. Somers, David Reid, David Chiriboga and Mary Tierney (1991), 'Adult children as caregivers: egocentric biases in judgments of sibling contributions', *The Gerontologist*, 31(6), 746-55.

'This study examined filial caregivers' views of their own and their siblings' costs and contributions to the care of their parents. The respondents viewed their siblings' responses to the parents' needs as remarkably similar to their own, in spite of there being no actual similarity. Despite these perceived similarities, however, respondents

perceived their siblings as contributing less than themselves, gaining less satisfaction, feeling freer to alter their caregiving, and being resistant to increasing their relative contributions. In order of importance, the extent of contact between the siblings, their feelings of closeness, the extent of parents' needs, their gender, the extent of resources spent, and personal regard for their siblings were significant predictors of these egocentrically biased perceptions. As expected, these egocentrically biased perceptions were important predictors of personal regard for their siblings.'

DAUGHTERS; FAMILY; GENDER; METHODOLOGY; RELATIONSHIPS;
SONS; UNITED STATES

- 468 Levin, Enid (1989), 'Elderly people with dementia and their carers: problems, strains and community support systems', David Wallace Memorial Address in Australian Association of Gerontology, *Proceedings of the 24th Annual Conference, Hobart 1989*, Parkville, Vic., 4-10.

'An understanding of the experience of families is basic to planning for the needs of people with dementia and their supporters. A study by the National Institute for Social Work, London] of problems and stresses experienced by the supporters and of the effectiveness of services in relieving them is described. Psychological assessment of 150 persons was combined with interviews with their main supporting relatives; both procedures were repeated a year later. The findings, which provide evidence for giving priority to services for the supporters, are described with reference to the elderly persons, the supporters and the services. The helping relatives proved to be central to the success of community care. Strain in supporters was found to be associated with a number of precise problems and was also related to whether the elderly persons were at home or in residential care at the time of follow-up. The impact of services varied according to the particular service and to the psychological health of the supporters. Ten key requirements for services, including residential care, are mentioned. Improvements might be achieved through changes in resources and attention to training, planning and coordination.'

COMMUNITY SERVICES; COUNSELLING; DEMENTIA; EDUCATION;
INCOME SUPPORT; INSTITUTIONALISATION; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; RESPITE CARE; SERVICE USE; UNITED
KINGDOM

- 469 Levin, Enid, Jo Moriarty and Peter Gorbach (1994), *Better for the Break*, HMSO, London, v, 200pp.

'This book is based on a study of respite services for the carers of confused elderly people. The research was commissioned by the Department of Health and carried out by the national Institute for Social Work Research Unit [in Britain]...The main aims of the study were: First, to establish and compare the characteristics and problems of

groups of confused elderly people and their carers using different types and mixes of respite services. Second, to elicit the carers', elderly people's and practitioners' views of these services so that guidelines for practice can be based upon them. And third, to examine the effectiveness of different types and mixes of respite services in terms of their acceptability, their impact on the carers' psychological health, their impact on the elderly people, and their effects on the admission of the elderly people to permanent residential care.' Respite care services are central to successful community care and it is vital that they are flexible and tailored to meet individual needs and preferences.

COMMUNITY SERVICES; DAY CARE; DEMENTIA;
INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; RESPITE CARE;
UNITED KINGDOM

- 470 Levin, E., I. Sinclair and P. Gorbach (1984), *The Supporters of Confused Elderly Persons at Home: Extracts from the Main Report*, National Institute of Social Work, Research Unit, London, 31pp.

'The incidence of dementia in elderly people is high, and eighty per cent of these are cared for at home. The study of supporters excluded paid helpers, and non-relatives, and aimed to find out what were their problems and implications for service delivery. Study areas in two London boroughs and a county district were selected, each with a community psychiatric service. Chapters 2-7 of the report, cover detailed analysis of the data [to be disseminated after discussions with the DHSS]. The conclusions confirm the need to support the carers who suffer considerable strain. The relevant support services are highly valued by the carers, but there should be more back-up, especially information, practical help and regular breaks. Problems and variation in resources training for health and welfare workers, and co-ordination between the statutory services.'

COMMUNITY SERVICES; DEMENTIA; EDUCATION; PSYCHOLOGICAL
ASPECTS; RESPITE CARE; UNITED KINGDOM

- 471 Levin, Enid, Ian Sinclair and Peter Gorbach (1989), *Families, Services and Confusion in Old Age*, Avebury, Aldershot, Hants., x, 328pp.

'This book is based on an intensive study of the principal supporting relatives of 150 elderly persons identified as confused by health and social service workers in three areas. The study was commissioned by the central government Department of Health and Social Security (DHSS) and carried out by the Research Unit at the National Institute for Social Work (NISW) between 1979 and 1983.' The aims were to identify the specific problems faced by supporting relatives and to explore the effectiveness of services in alleviating them. In the section on services, separate chapters examine the gatekeepers to the services; the main domiciliary services; the services which provide supporter with breaks; and other services, private and

voluntary help and the gaps in provision. The concluding chapter brings together the evidence from this study which makes the case for providing services to relatives and outlines the kinds of help they require.

COMMUNITY SERVICES; DEMENTIA; EVALUATION; FAMILY; POLICY;
UNITED KINGDOM

- 472 Levine, Norman B., Dolly P. Dastoor and Carole E. Gendron (1983), 'Coping with dementia: a pilot study', *Journal of the American Geriatrics Society*, 31(1), 12-18.

'Ten supporters of demented elderly dependents were studied in order to examine their coping behavior in the context of caring for their relatives at home. Coping skills were described with respect to problems, solutions, and cognitive aspects of motivation and stress tolerance. The observations made suggest the hypothesis that tolerance of debility in a demented relative is related not only to the number and type of problems in the dependent but also to the availability and quality of coping skills in the supporter. This hypothesis was explored through the elaboration of a skills training program (Supporter Endurance Training), which was designed and employed to improve and expand the coping skills of a supporter. Supporter Endurance Training may prove to be a useful approach to the maintenance of the demented elderly person at home as a possible alternative to institutionalization.'

DEMENTIA; EDUCATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
SUPPORT GROUPS; UNITED STATES

- 473 Lewis, Jane and Barbara Meredith (1988), 'Daughters caring for mothers: the experience of caring and its implications for professional helpers', *Ageing and Society*, 8(1), 1-21.

'Recent research on ways of "supporting the supporters" of elderly people at home has taken a "snapshot" approach to assessing carers' needs and has focussed primarily on the perceptions of service providers. Such an approach tends to neglect the complexity of caring relationships (particularly that between carer and person cared for), which must be understood if carers are to be offered appropriate help. The present paper reports the construction of "caring biographies", using in-depth interviews with 41 daughters who had cared for their mothers on a co-resident basis and who had ceased to do so within the last ten years. The biographies were used to examine the nature of the caring process in terms of the carer's motivation to care, changes in the mother/daughter relationship and in the carer's extra-caring life. The research reveals both the power exerted by the injunction to care and the mixed legacy of satisfaction overlaid with bitterness that was experienced by a majority of respondents, largely as a result of inadequate and/or inappropriate support. We suggest ways in which professional workers may recast the way in which they

approach the needs of carers based on a deeper understanding of the temporal and relational dimensions of caring.'

DAUGHTERS; STUDIES; PERSONAL NARRATIVES; PSYCHOLOGICAL ASPECTS; QUALITATIVE RELATIONSHIPS; UNITED KINGDOM

- 474 Lewis, Jane and Barbara Meredith (1988), *Daughters Who Care: Daughters Caring for Mothers at Home*, Routledge, London, vi, 194pp.

This study focuses on 41 daughters who had cared for their mothers on a co-residential basis and had ceased to do so when the mother died or entered an institution. It examines the costs and benefits of caring for the carer, including uncoded outcomes such as loss of social life or poor self-image. The major task was to develop a method of obtaining, and a vocabulary for describing, what are called 'caring biographies', and in particular, work out the elements that were crucial to the caring experience. This central relationship was also set in the context of secondary relationships with kin and others at the workplace and in the community to determine the mixes of experiences and supports over the life course giving rise to particular responses to caring, and more positive or more negative outcomes. The injunction to care is very powerful and most carers experienced both satisfaction with the caring role and a deal of self-sacrifice and resentment with lack of suitable support. Attention is drawn to the importance of understanding the complexity of the caring experience, particularly so that formal services may offer appropriate support.

DAUGHTERS; PERSONAL NARRATIVES; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; RELATIONSHIPS; UNITED KINGDOM

- 475 Lewis, Jane and Barbara Meredith (1989), 'Contested territory in informal care', in Margot Jefferys, ed., *Growing Old in the Twentieth Century*, Routledge, London, 186-200.

Recent calls for exploring different ways of constructing care packages using informal, voluntary and formal supporters call for caution. Drawing on information from their study of London-based daughters caring for a frail or disabled mother at home, the authors 'show how the caring relationship typically develops as the mother becomes more handicapped and the daughter herself ages. They emphasize the ambivalence of the emotional bonds between mothers and daughters.' They consider 'the issues raised by attempts to mix formal and informal care in the setting of the home' and also other less immediately obvious aspects of conflict that are part of the informal caring process and which bear upon any assessment paid workers may make of the situation. They examine the conflicts which may develop between the carer and the person cared for and the limits to the parts played by kin, neighbours and friends in caring. Finally, they discuss 'the way in which paid

workers come into the picture, and how the nature of other caring relationships bears upon their contribution.'

COMMUNITY SERVICES; DAUGHTERS; RELATIONSHIPS; SUPPORT NETWORKS; UNITED KINGDOM

- 476 Lichtenberg, Peter A. and Jeffrey T. Barth (1989), 'The dynamic process of caregiving in elderly spouses: a look at longitudinal case reports', *Clinical Gerontologist*, 9(1), 31-44.

'Family caregiving to the elderly has become a source of major concern only in the last decade. Due to the abundance of cross-sectional research, caregiving has been portrayed as a static process. This study was a longitudinal investigation of mental health problems among elderly spouse caregivers. The results revealed an important relationship between mental health problems and the changing caregiving situation. The greatest prevalence of mental health problems was among the group of individuals who had only recently placed their spouse in a nursing home. The second greatest number of problems were found in those caregiving in their home. Four case vignettes served to illustrate common changes in caregiver's mental health.'

AGED CAREGIVERS; CASE STUDIES; HEALTH; INSTITUTIONALISATION; SPOUSES; UNITED STATES

- 477 Lidoff, Lorraine and Linda Beaver (1983), *Caregiver Support Groups: Guidelines for Practice Based on Federally Funded Demonstrations*, National Council on Aging, Washington, DC, 22pp.

This report is based on two demonstration projects, both funded by the United States Administration on Aging. The aim is to disseminate an effective approach to addressing caregivers' needs. It suggests ways of establishing and maintaining caregiver support groups using the successful elements of the two demonstration projects (a) The Natural Supports Program, and (b) As Parents Grow Older. There is also an additional list of references and resources at the end of the report.

SUPPORT GROUPS; UNITED STATES

- 478 Light, Enid and Barry D. Lebowitz, eds (1990), *Alzheimer's Disease Treatment and Family Stress: Directions for Research*, Hemisphere, New York, xiv, 486pp.

'The overall goal of this volume is to stimulate research on the development of effective treatment, management, and service delivery models for patients with Alzheimer's disease and related disorders and to increase our understanding of and ability to reduce the negative health/mental health consequences experienced by many family caregivers of dementia patients. This volume is divided into four

sections that address research on Alzheimer's disease and the family, caregiver stress, the management of Alzheimer's disease patients, and services.' It highlights the need for a multidisciplinary approach.

DEMENTIA; HEALTH; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 479 Linsk, Nathan L., Sharon M. Keigher and Suzanne E. Osterbusch (1988), 'States' policies regarding paid family caregiving', *The Gerontologist*, 28(2), 204-12.

'To investigate the uses of paid family caregivers, a nationwide survey of jurisdictional programs was conducted. In all, 50 jurisdictions, including 46 states, the District of Columbia and 3 territories responded to a questionnaire mailed to 3 agencies in each jurisdiction. A total of 89 questionnaires were returned by 165 possible respondents. Of the 50 jurisdictions 70% permitted some form of family caregiver payment. Most jurisdictions had provisions to limit the size and possible abuses of their program. The findings suggested that an opportunity exists for advocates of family caregiving to incorporate families into formal service programs.'

NATIONAL STUDIES; PAYMENT; UNITED STATES

- 480 Linsk, Nathan L., Sharon M. Keigher, Lori Simon-Rusinowitz and Suzanne E. England (1992), *Wages for Caring: Compensating Family Care of the Elderly*, Praeger, New York, x, 281pp.

'This book examines the issues and prospects of compensated family care from four key perspectives, reflecting the perceptions of four key stakeholders who have an investment in this issue.' These are: the policy perspective, what are the implications of compensating family care upon the larger policy arena? The service delivery perspective: what are the consequences for the delivery of health and social services? The family caregiver perspective: what are the implications upon families including those who provide the care informally? The consumer perspective: what are the implications for those receiving services? Part 1 looks at the United States and other countries. Part 2 examines and compares policies in Michigan and Illinois. Part 3 assesses the impacts and implications of wages for caring.

COMMUNITY SERVICES; COMPARATIVE STUDIES; INTERNATIONAL COMPARISONS; PAYMENT; POLICY; UNITED STATES

- 481 Litvin, Sandra J. (1992), 'Status transitions and future outlook as determinants of conflict: the caregiver's and care receiver's perspective', *The Gerontologist*, 32(1), 68-76.

'This study examined the effects of status transitions and future outlook on conflict from the perspective of both caregiver and receiver. As predicted, future outlook had

a powerful association with dyadic conflict. Other strong predictors of conflict for care receivers were current state of happiness and changes in the relationship over a 3-year period. For caregivers, conflict was associated with care receivers' lack of social participation with family and friends, and changes in dyadic relationship.

METHODOLOGY; RELATIONSHIPS; SOCIAL ASPECTS; UNITED STATES

- 482 Mace, Nancy L. and Peter V. Rabins (1981), *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life*, Johns Hopkins University Press, Baltimore, xvii, 253pp.

This book is a comprehensive guide to the home care of those in the early and middle stages of progressive dementing illness. It combines practical advice with specific examples and covers all of the medical, legal, financial and emotional aspects of caring for an impaired relative.

DEMENTIA; EDUCATION; FINANCIAL ASPECTS; LEGAL ASPECTS; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 483 Magnus, Margaret (1988), 'Eldercare: corporate awareness but little action', *Personnel Journal*, 67, 19, 23.

The personal costs of family problems are corporate costs. Personnel Journal polled personnel executives in corporations about eldercare. The results of the poll are described. Although there is increasing awareness of the problems for some employees of caring for an elderly relative, most companies do not have any plans.

EMPLOYMENT; UNITED STATES

- 484 Mancini, Jay A. and Rosemary Blieszner (1989), 'Aging parents and adult children: research themes in intergenerational relations', *Journal of Marriage and the Family*, 51(2), 275-90.

'Dominant themes representing the relationships of older parents and their adult children are discussed. These pertain to roles and responsibilities, parent-child interaction (contact patterns, exchange, assistance, and support), individual well-being, relationship quality, and caregiving by adult children. These are discussed within the context of societal age structure changes. Speculation on the future of research on aged parents and adult children focuses on the application of theory, the need for studies on conflict, the role that qualitative inquiry could play, alternative

approaches to family companionship, and investigation on socialization in adulthood.'

DAUGHTERS; QUALITATIVE STUDIES; RELATIONSHIPS; SONS; UNITED STATES

- 485 Marsden, Dennis and Sheila Abrams (1987), "'Liberators', 'companions', 'intruders' and 'cuckoos in the nest': a sociology of caring relationships over the life cycle", in Patricia Allatt, Teresa Keil, Alan Bryman and Bill Bytheway, *Women and the Life Cycle*, Macmillan, Basingstoke, Hants., 192-207.

This chapter describes a study of 38 married daughters caring for their elderly mothers who live with them. The authors have devised a typology of caring relationships involving different degrees and balances of tending and emotional support, and explored whether current relationships can be explained in terms of socialisation, altruism or reciprocity over the life cycle. They ask whether the physical, financial or psychological burdens of caring for disabled persons can cause the breakdown caring of relationships. It was found that in many of the cases studied, the situations were forced upon carers and dependents for lack of an adequate alternative. 'On grounds of social justice, even the carers in more harmonious situations should receive much greater official support. Society's neglect to provide adequate supportive and alternative services is reinforcing and perpetuating the "structured dependency" of the elderly and the subordination of women.'

DAUGHTERS; DEPENDENCY; FINANCIAL ASPECTS; GENDER; POLICY; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED KINGDOM

- 486 Martinus, Pia (1988), 'Quantifying the effects of respite care', *Geriatric Medicine*, 18(10), 73-9.

The subjects for this research project on the effects of respite care were drawn from the Portsmouth and Southampton health districts, UK. A questionnaire was administered at three stages of the respite program: one to two weeks prior to admission, in the middle of the respite break, and one to two weeks after return home. In hospital patients experienced decrease in level of pain, improved sleep, and increase in physical mobility but respite care had no effect on the less 'physical' aspects of patients' lives, namely social isolation, energy levels and emotional state. Carers had increased energy levels while their relative was in hospital but other aspects such as social isolation were not significantly affected. This improvement was not maintained when the patient returned home. There was an extremely high unsolicited comment rate expressing feelings of anger and dissatisfaction with the

service provided. It may be concluded that geriatric respite care is not functioning efficiently in its role of carer support.

HEALTH; METHODOLOGY; RESPITE CARE; SOCIAL ASPECTS; UNITED KINGDOM

- 487 Masciocchi, Carla, Adria Thomas and Tamerra Moeller (1984), 'Support for the impaired elderly: a challenge for family care-givers', in William H. Quinn and George A. Hughston, eds, *Independent Aging: Family and Social Systems Perspectives*, Aspen Systems Corporation, Rockville, Md., 115-32.

This chapter discusses the potential consequences to families as they adapt to their roles as providers of care to elderly relatives. The provision of support by families to their elderly impaired relatives is illustrated through studies conducted at the University of Pennsylvania. In addition, existing services to meet the needs of caregivers are discussed.

COMMUNITY SERVICES; FAMILY; UNITED STATES

- 488 Matthews, Sarah H. (1987), 'Provision of care to old parents', *Research on Aging*, 9(1), 45-60.

'Unlike research on parent care in which a primary caregiver is the focus, this research begins with the assumption that filial responsibility is shared in older families that comprise more than one child. Results of the analysis indicate that structural variables are significant. More important, they support the argument that conceptualizing filial responsibility as shared is important for future research.'

DAUGHTERS; SONS; UNITED STATES

- 489 Matthews, Sarah H. and Tena Tarler Rosner (1988), 'Shared filial responsibility: the family as the primary caregiver', *Journal of Marriage and the Family*, 50(1), 185-95.

'How adult siblings organize to meet the needs of their old parents is explored in this research. Fifty pairs of sisters who had at least one parent aged 75 or older responded in face-to-face interviews to questions about their parents' situation and the way they and their siblings divided filial responsibilities. Data were analyzed qualitatively. Once parents were perceived to have needs, sibling groups mobilized to meet them. Five styles of participation are identified, as well as three factors - family structure, family history, and extrafamilial ties - that affected which styles were included and who was likely to use a particular style in a sibling group mobilized to meet filial obligations.'

DAUGHTERS, FAMILY; QUALITATIVE STUDIES; UNITED STATES

- 490 Matthews, Sarah H., Janet E. Werkner and Paula J. Delaney (1989), 'Relative contributions of help by employed and nonemployed sisters to their elderly parents', *Journal of Gerontology: Social Sciences*, 44(1), S36-44.

'The relationship between daughters' employment status and involvement in the provision of services to old parents was examined using information collected from 50 pairs of sisters whose employment status differed. The Wilcoxon matched-pairs, signed-ranks test was used to assess whether employment status affected perceptions of parents' needs, relative contributions to parents, and relative contributions when parents' health status was poorer. Nonemployed sisters contributed relatively more tangible services than their employed sisters when parents' health status was poorer. Qualitative analysis of the interviews indicated that although nonemployed sisters usually took disproportionate responsibility for medical appointments and day-time emergencies and care, employed sisters were expected to contribute in other ways. That the significance of individual attributes of family members makes sense only within the family context is stressed.'

COMPARATIVE STUDIES; DAUGHTERS; EMPLOYMENT; FAMILY;
QUALITATIVE STUDIES; RELATIONSHIPS; UNITED STATES

- 491 McGrath, Morag and Gordon Grant (1993), 'The life cycle and support networks of families with a person with a learning disability', *Disability, Handicap & Society*, 8(1), 25-41.

'This paper presents data from semi-structured interviews with 190 families enabling comparisons across the life cycle of problems faced by carers of children and adults with learning difficulties, the informal support received and support from the statutory services. The size of the kin support network described was invariably related to the number of marked behaviour problems. Age, social class and degree of handicap were all found to be associated with different expectations about services and services received. Frequency of professional visits appeared to relate more to dependency levels and age than to numbers of behavioural problems. One implication of these trends was a marked service deficit for carers of adults with either high levels of dependency or challenging behaviour. Two groups of carers were particularly vulnerable - carers of adolescents and carers of individuals aged 40 years or over. The implications for professional practice are discussed.'

COMMUNITY SERVICES; DEPENDENCY; DISABLED; FAMILY;
SOCIOECONOMIC STATUS; SUPPORT NETWORKS; UNITED KINGDOM

- 492 McLaughlin, Eithne (1991), *Social Security and Community Care: The Case of the Invalid Care Allowance*, Research Report No.4, Department of Social Security, HMSO, London, xii, 67pp.

This report describes a study done of the role of social security in providing for unpaid carers through the Invalid Care Allowance (ICA). The study examined the

targeting and effectiveness of ICA in 1989 through a survey of claimants and secondary analyses of existing data. It begins by outlining the origins, development and operation of ICA. Carers' perception of ICA are described. ICA is seen as a valuable addition to the resources of individuals and households otherwise depleted by the provision of high levels of informal care, however, the personal and household incomes of carers, whether receiving ICA or not, remain substantially lower than average, and this is especially so in household affected by overlapping benefit regulations, and among unsuccessful claimants of ICA. Ways of improving the targeting and effectiveness of ICA are: increasing the level of ICA, permitting higher levels of earnings from part-time work in combination with ICA, by disregarding some or all of ICA for the purpose of assessing entitlement to income support, and by improving the administration, and extending the take-up of ICA.

INCOME SUPPORT; NATIONAL STUDIES; SOCIOECONOMIC STATUS;
UNITED KINGDOM

- 493 McLaughlin, Eithne and Jane Ritchie (1994), 'Legacies of caring: the experiences and circumstances of ex-carers', *Health & Social Care in the Community*, 2(4), 241-53.

'This paper documents the socio-economic and psychological legacies of care-giving among 157 ex-carers who were included in a larger national study of the effectiveness and targeting of social security help to carers, which was carried out in 1989. Therefore, the sample included only those whose care-giving responsibilities had been relatively substantial, that is, over 35 hours a week. Survey data covering the employment status and income levels of these ex-carers are presented, as is in-depth interview material on the psychological and social circumstances of a small group of ex-carers. The article concludes that there are long-term negative financial effects of caring, which the social security system appears to ignore. In addition, the psychological, social and physical health consequences of caring may leave some carers poorly equipped for life after care, a situation which might call for the development of support services in the immediate post-care period. Further investigation of the material and non-material circumstances of ex-carers, preferably on a longitudinal basis, should be a priority in health and social care research. Without such research, our knowledge of the costs of caring being borne by individuals, and our assessment of the appropriate contributions that should be made by statutory welfare agencies, remains incomplete. Finally, given the prevalence of informal care-giving, our lack of knowledge of the legacies of care-giving limits our understanding of the causes of income and health inequalities between people approaching pension age and older.'

EMPLOYMENT; FINANCIAL ASPECTS; HEALTH; INCOME SUPPORT;
PSYCHOLOGICAL ASPECTS; SOCIOECONOMIC STATUS; UNITED
KINGDOM

- 494 McMahon, Betty and Barbara Ames (1983), 'Educational programming for midlife adults with parent-caring responsibilities', *Educational Gerontology*, 9(5/6), 377-87.

This article describes the use of adult education programming to address the needs of 50 midlife caregivers. Findings indicated that younger respondents had more requests for information, with information related to the ageing process being of greatest concern.

CASE STUDIES; EDUCATION; MIDDLE AGED CAREGIVERS; UNITED STATES

- 495 Melville, Joy (1983), 'What on earth shall we do with mother', *New Society*, 7 July, 7-9.

If cared for in their own home or in their children's home, the needs of the elderly parent can take over the lives of the children. On the other hand, if the elderly relative is admitted to a nursing home the children feel extremely guilty. This article looks at the problems which are felt particularly by women when placed in this difficult situation and highlights the lack of external support given to families placed in this dilemma.

GENDER; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 496 Miller, Baila (1990), 'Gender differences in spouse caregiver strain: socialization and role explanations', *Journal of Marriage and the Family*, 52(2), 311-21.

'Few consistent differences by gender in responses of spouses to the stress and strains of caregiving have yet been identified. The theoretical perspectives of gender socialization vulnerability and social role exposure offer two alternative hypotheses for gender differences in caregiver strain. This study examines the hypotheses by using a multivariate model in which caregiver strains are a function of caregiver stressors and support resources. The data are from a subsample of 554 spouse caregivers from the 1982 National Long Term Care Survey of Caregivers of the Frail Elderly. The effect of gender is small. Husbands and wives show (a) few differences in caregiver stressors and social support, (b) no difference in time strain and emotional strain, and (c) a small but statistically significant difference in health strain. Wives' greater experience of health strains appears to be determined by a combination of situational factors and traditional gender-role socialization.'

GENDER; HEALTH; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; SPOUSES; THEORY DEVELOPMENT; UNITED STATES

- 497 Miller, Baila (1990), 'Gender differences in spouse management of the caregiver role', in Emily K. Abel and Margaret K. Nelson, eds, *Circles of Care: Work and Identity in Women's Lives*, State University of New York Press, Albany, 92-104.

In the first part of this chapter which analyses spousal caregiving the author draws on data from the United States Health Care Financing Administration's 1982 Long-Term Care Study. It demonstrated that, contrary to findings in prior studies, husbands and wives caring for spouses with some form of dementia do not experience differences in perceived stress. In the second part of the chapter there is an analysis of in-depth interviews with spousal caregivers. These reveal more subtle differences between men and women. In general, whereas husbands are able to distance themselves emotionally from their caregiving responsibilities, wives are more attentive to their husbands' needs.

GENDER; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; SPOUSES;
UNITED STATES

- 498 Miller, Baila and Andrew Montgomery (1990), 'Family caregivers and limitations in social activities', *Research on Aging*, 12(1), 72-93.

'Constriction of social and personal activities is one of the most frequently noted consequences of caring for a frail elder. This study analyzed the correlates of perceived limitations in social activities using data from a national sample of the frail elderly and their caregivers. Two research issues were addressed: 1) What differences in demographic, family, and caregiving attributes are associated with variation in perceived restricted social activities? and, 2) How does the process influencing restriction of social activities vary by family relationship of the caregiver? Higher levels of elder dependency and task demands were characteristic of those who reported social limitations, and daughters and wives were more likely to report such limitations than sons and husbands. Subjective assessment of time and task demands, however, were more important influences than objective caregiving activities for all family caregivers.'

DAUGHTERS; FAMILY; GENDER; NATIONAL STUDIES; RELATIONSHIPS;
SOCIAL ASPECTS; SONS; SPOUSES; UNITED STATES

- 499 Miller, Baila, Stephanie McFall and Andrew Montgomery (1991), 'The impact of elder health, caregiver involvement, and global stress on two dimensions of caregiver burden', *Journal of Gerontology: Social Sciences*, 46(1), S9-19.

'This study examined the simultaneous effects of an elder's health, caregiver involvement, and stress on caregiver burden, addressing the questions: (a) What are the direct and indirect effects of level of elder's impairment, caregiver involvement, and stress on personal and interpersonal burden? (b) How do these relationships differ between spouse and adult-child caregivers? Data were from the 1982 National

Long Term Care Survey. Results using linear structural relations analysis showed the effect of a frail elder's health and functioning on personal and interpersonal burden is mediated by task involvement and perceived global stress. Contrary to expectation, there were few differences in the direct effect of each dimension of health, functional limitations, cognitive status, and global health rating on each dimension of burden. Although the results suggested mean differences between spouse and adult child caregivers on key variables, there were no differences by family relationship in the system of relationships that comprise the process linking health and burden.'

DAUGHTERS; GENDER; HEALTH; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SONS; SPOUSES; UNITED STATES

- 500 Miller, Baila and Stephanie McFall (1991), 'Stability and change in the informal task support network of frail older persons', *The Gerontologist*, 31(6), 735-45.

'This study examines predictors of stability and change in composition, size and intensity of help of the informal task support networks of frail elders and their primary caregivers. The sources of data are the 1982 and 1984 National Long Term Care Surveys and the companion 1982 Informal Caregivers Survey. There was slightly more stability than change in the size and composition of family task support networks.' Little evidence was found 'that shifts in network composition were in the direction of including more distant kin. Changes in network size and intensity of help occurred in response to changes in health and functional status of the frail older person, but not in response to the level of burden of the primary caregiver.'

FAMILY; HEALTH; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SUPPORT NETWORKS; UNITED STATES

- 501 Miller, Baila and Stephanie McFall (1992), 'Caregiver burden and the continuum of care', *Research on Aging*, 14(3), 376-98.

'This article integrates the results of a series of prospective studies that used data from the 1982-1984 National Long Term Care Survey to (a) provide a comprehensive view of the effects of caregiver burden over a two-year period, (b) suggest ways in which caregiver burden intersects with the continuum of care, and (c) explore the implications for long-term care research and policy. Each dimension of caregiver burden had different consequences for each long-term care outcome. Neither personal nor interpersonal burden had an independent effect on changes in the informal task support network. Personal burden, but not interpersonal burden, influenced changes in the use of formal services. Interpersonal burden, but not personal burden, influenced nursing home admissions.'

INSTITUTIONALISATION; NATIONAL STUDIES; POLICY; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED STATES

- 502 Miller, Baila and Lynda Cafasso (1992), 'Gender differences in caregiving: fact or artifact', *The Gerontologist*, 32(4), 498-507.

'This study applies meta-analysis techniques to the results of 14 descriptive studies of gender differences in caregiving to determine the size and significance of gender differences in caregiving stressors (level of elder impairment and level and type of task involvement) and in caregiver burden. There were essentially no significant differences in functional impairment of the frail care recipient, total caregiver involvement in care, or in money management tasks. Female caregivers were more likely to carry out personal care and household tasks and more likely to report greater burden. Given the relatively small size of the effects found, we conclude that future research should focus on the part that gender-role explanations play in assigning meaning to caregiving behaviors.'

GENDER; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 503 Miller, Dorothy A. (1981), 'The "sandwich" generation: adult children of the aging', *Social Work*, 26, September, 419-23.

Adult children caring for aged parents are 'sandwiched' between these parents and their own children and are often subjected to a great deal of stress. This group is in great need of support and services that is only beginning to be met by the helping professions. This article presents demographic data illustrating the role of adult children as the major resource and support group of the aged and secondly, describes the limited services available.

COMMUNITY SERVICES; DEMOGRAPHIC ASPECTS; MIDDLE AGED CAREGIVERS; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 504 Miller, Dulcy, Natividad Gulle, and Fern McCue (1986), 'The realities of respite for families, clients, and sponsors', *The Gerontologist*, 26(5), 467-70.

This article reports on evaluation of two respite programs for families caring for aged relatives - an institutional program for elderly persons needing constant nursing attention and a residential plan for housekeeping and companion services. Based on a year's experience, 'benefits of respite services to the client, family, and community appear to be undisputable'.

EVALUATION; RESPITE CARE; UNITED STATES

- 505 Miller, Dulcy and Lorraine Goldman (1989), 'Perceptions of caregivers about special respite services for the elderly', *The Gerontologist*, 29(3), 408-10.

A study of 48 family members who had arranged respite care for ill elderly relatives is reported on in this article. 'Caregiver families used their respite for vacations,

personal business, freedom from caregiving, and surgery. Eighteen (78%) wished to participate in respite again because they thought it the best possible arrangement to maintain their mental health during caregiving.'

RESPITE CARE; SERVICE USE; UNITED STATES

- 506 Milne, Derek, Irene Pitt and Neil Sabin (1993), 'Evaluation of a carer support scheme for elderly people: the importance of "coping"', *British Journal of Social Work*, 23(2), 157-68.

'One year's consecutive referrals to an Age Concern carer support scheme entered an evaluation of the carers' stress, coping and strain. Unlike a comparison group who did not use the scheme, these carers of elderly dependants had significantly poorer personal coping strategies, which were bolstered by the scheme. Stress and strain were high for both groups of carers, indicating that the critical variable in the continued role as carers was coping. Implications for the formal services are discussed.'

COMMUNITY SERVICES; COMPARATIVE STUDIES; EVALUATION; PSYCHOLOGICAL ASPECTS; SUPPORT GROUPS, UNITED KINGDOM

- 507 Monahan, D.J., V.L. Greene and P.D. Coleman (1992), 'Caregiver support groups: factors affecting use of services', *Social Work*, 37(3), 254-60.

'Use of time-limited psychoeducational support groups by family caregivers to help frail elderly people in the community reflects a mixture of predisposing, enabling, and need factors. Using multivariate regression methods that control for dependent-variable censoring, the authors found that attendance in support groups by primary caregivers is greater for those who are older, who have a secondary informal caregiver involved in providing care, or who have significant health problems. Attendance is also greater for those caring for Alzheimer's victims and for those experiencing higher levels of burden in their caregiving role. In English-language groups, Mexican-American caregivers show markedly lower attendance than Anglo-American caregivers, but in Spanish-speaking groups attendance by Mexican-American caregivers is essentially the same as that of Anglo-Americans in English-language groups. Data for this study are from a federally funded support group demonstration project conducted in a southwestern metropolitan area.'

ETHNICITY; SUPPORT GROUPS; UNITED STATES

- 508 Montgomery, Rhonda J.V. (1992), 'Gender differences in patterns of child-parent caregiving relationships', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 65-83.

This chapter provides a context within which patterns and consequences of caregiving by adult children of elderly parents can be considered. The focus is on the stress and burden associated with providing care, reciprocity between care provider and care recipient, the level of impairment of the care receiver, the interaction between family members and the formal service sector, and the affection and life satisfaction of the caregiver and care recipient. It examines the predominance of daughters over sons as caregivers giving some reasons for this.

DAUGHTERS; GENDER; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SONS; UNITED STATES

- 509 Montgomery R.J.V., J.G. Gonyea and N.R. Hooyman (1985), 'Caregiving and the experience of subjective and objective burden', *Family Relations*, 34(1), 19-26.

'The investigators of this project examined the relationships between caregiving experience and subjective and objective burden. Interviews were conducted with 80 people caring for, or assisting, an elderly relative. The findings indicate that different factors are related to subjective burden than are related to objective burden. The age and income of the caregiver were found to be the best predictors of subjective burden. Caregiving tasks that confine the caregiver either temporally or geographically were found to be the best predictors of objective burden. It was concluded that the level of objective burden could best be reduced through the introduction of personal aid services, supportive equipment that enables greater self-care, and respite services.'

COMMUNITY SERVICES; PSYCHOLOGICAL ASPECTS; RESPITE CARE; SOCIAL ASPECTS; SOCIOECONOMIC STATUS; UNITED STATES

- 510 Montgomery, Rhonda J.V., Donald E. Stull and Edgar F. Borgatta (1985), 'Measurement and the analysis of burden', *Research on Aging*, 7(1), 137-52.

'Past research on the concept of burden has failed to place it in the larger context of social interaction and small group analysis. This failure to integrate the concept into a more general area of knowledge prevents researchers from viewing as a product of dyadic interaction that is best studied over time. This article moves the concept and measurement of burden into a more general system of variables, showing that the issues of burden relating to the elderly and the mentally impaired are special cases. A

model that accommodates the crucial element of time is presented for the conceptualization of burden and the analysis of antecedents and consequences.'

CONCEPTUAL ISSUES; THEORY DEVELOPMENT; UNITED STATES

- 511 Montgomery, Rhonda J.V., Laurie Russell Hatch, Thomas Pullum, Donald E. Stull and Edgar F. Borgatta (1987), 'Dependency, family extension, and long-term care policy', in Edgar F. Borgatta and Rhonda J.V. Montgomery, eds, *Critical Issues in Aging Policy: Linking Research and Values*, Sage, Newbury Park, Calif., 162-77,

'This chapter identifies the research process that is necessary to generate systematic data on the levels and patterns of family caregiving that now exist, and the levels and patterns that are likely in the future. Because the level of public resources necessary for long-term care of the elderly is related to the extent of family resources devoted to their care...the availability of such systematic data will enable policymakers to plan for the future needs of the elderly.'

DEPENDENCY; FAMILY; POLICY; UNITED STATES

- 512 Montgomery, Rhonda J.V. and Laurie Russell Hatch (1987), 'The feasibility of volunteers and families forming a partnership for caregiving', in Timothy H. Brubaker, ed., *Aging, Health, and Family: Long Term Care*, Sage, Newbury Park, Calif., 143-61.

'This chapter reports findings from a research and demonstration project in which volunteers were employed to provide respite for families caring for elderly relatives. Volunteer respite was one of four services offered to families participating in the Family Support Project. The purpose of the project was to identify costs, benefits, and feasibility of three model programs for supporting families. An experimental design was used to determine which model, if any, could sufficiently enhance the families' resources to enable them to extend their caregiving efforts.' This chapter focuses on respite care, describes the service, analyses difficulties encountered in implementation and assesses the impact on caregivers. It was concluded that volunteer respite services cannot meet the wide range of needs that exist among families caring for the elderly.

EVALUATION; RESPITE CARE; UNITED STATES

- 513 Montgomery, Rhonda J.V. and Edgar F. Borgatta (1989), 'The effects of alternative support strategies on family caregiving', *The Gerontologist*, 29(4), 457-64.

'Family units (N=541) of impaired elderly persons and caregivers were randomly assigned to a control group of one of five treatment groups eligible for a variety of

respite or educational services. After 12 months of service eligibility, caregivers of elderly persons remaining in the community reported lower levels of subjective burden. Services appeared to delay nursing home placement among families with adult child caregivers, but encouraged placement by spouse caregivers.'

EDUCATION; EVALUATION; RESPITE CARE; SUPPORT GROUPS; UNITED STATES

- 514 Montgomery, Rhonda J.V. and Yoshinoro Kamo (1989), 'Parent care by sons and daughters', in Jay A. Mancini, ed., *Aging Parents and Adult Children*, Lexington Books, Lexington, Mass., 213-30.

Recent research points to the fact that when sons assume the role of primary caregiver they not only do so in a different manner, but they experience the role differently than do daughters. 'This chapter reports findings from a recent study of caregivers that further delineates differences and similarities between sons and daughters in the ways in which they engage in caregiving and the way they experience their role. Additionally, the chapter explores plausible reasons for the differences and makes suggestions for future research.' The data do not indicate that fewer sons than daughters provide care, although it is found that sons perform fewer hours of service and tend to engage in less intensive tasks for shorter periods of time. Differences are explained here as tied to sex role socialisation. Despite this, sons report equal levels of subjective burden with daughters.

COMPARATIVE STUDIES; DAUGHTERS; SONS; UNITED STATES

- 515 Montgomery, Rhonda J.V., Karl Kosloski and Edgar Borgatta (1990), 'Service use and the caregiving experience: does Alzheimer's disease make a difference?' in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 139-59.

This chapter describes a study of three groups of caregivers and receivers over time: those presumed to be suffering from Alzheimer's disease, those with cognitive impairment but for whom Alzheimer's disease was not the suspected cause, and those with no cognitive impairment. 'Controlling for differences in background characteristics, the results produced few meaningful differences among the three groups in the caregiving experience or in the use of formal services. The authors raise important questions about policies and programmes which assume uniqueness among diagnostic categories of the elderly.'

COMPARATIVE STUDIES; DEMENTIA; POLICY; SERVICE USE; UNITED STATES

- 516 Montgomery, Rhonda J.V. and Mary McGlinn Datwyler (1990), 'Women & men in the caregiving role', *Generations*, 14, 34-8.

This article reviews the literature on the caregiving role. Little value has been placed on the caregiving role by society and this has been incorporated into public policies and practices. The caregiving role, however, is not a uniform one. Different typologies of care are described. The predominant theme in the literature has been the extensive degree to which the family has provided care and assistance to the elderly. A second major theme has been gender differences in caregiving and the implications of these differences. The 'bulk of research suggests that substantial differences exist in the ways sons and daughters engage in and are affected by the caregiving role. Reasons for gender differences are examined.

DAUGHTERS; FAMILY; GENDER; LITERATURE REVIEW; POLICY; SONS;
UNITED STATES

- 517 Morgan, Ann and Mildred Zimmerman (1990), 'Easing the transition to nursing homes: identifying the needs of spousal caregivers at the time of institutionalization', *Clinical Gerontologist*, 9(3/4), 1-17.

This article looks at the transition to nursing home and its impact on the caregiving spouse using a combination of qualitative and quantitative approaches to assess the family needs. 'Families caring for relatives with dementing illnesses experience physical and emotional stress throughout the period of extended care; one of the critical periods is the time when placement in an institution is imminent. This study was designed to identify the factors which made the transition from in-home care to institutional care less stressful for spousal caregivers. A qualitative study of spousal caregivers was done in an attempt to understand the needs of the caregiver at this crucial time. The data suggest five distinct categories which offer support to the caregivers and thus ease the transition.'

DEMENTIA; INSTITUTIONALISATION; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; SPOUSES; UNITED
STATES

- 518 Morgan, David L. (1990), 'Combining the strengths of social networks, social support, and personal relationships', in Steve Duck, ed., *Personal Relationships and Social Support*, Sage, London, 190-215.

This chapter argues for recognising the distinctiveness of three fields within social relationships: social networks, social support and personal relationships. It describes what is unique to each perspective and how they overlap. After developing this argument it presents an illustration using research on caregivers to family members with Alzheimer's disease. Focusing on the changes that accompany major life events

reveals the conceptual connections among social networks, social support and personal relationships.

CONCEPTUAL ISSUES; DEMENTIA; RELATIONSHIPS; SUPPORT NETWORKS; THEORY DEVELOPMENT; UNITED STATES

- 519 Morginstin, Brenda (1989), 'Evaluation of a support group', in Rosalie S. Wolf and Shimon Bergman, eds, *Stress, Conflict and Abuse of the Elderly*, JDC-Brookdale Monograph Series, JDC-Brookdale Institute of Gerontology and Adult Human Development, Jerusalem, 179-90.

'This paper examines issues related to patterns and characteristics of caregiving, and the impact of family support services which might be provided to alleviate the burden of care. The findings presented here are based on empirical data gathered in a project designed to organise a caregiver support group in the community of Kiryat Ono [Israel]. The burden of care as perceived by participants [is] discussed in the hope of gaining an idea as to who would be suitable candidates for support services, and a better understanding of caregivers' expectations of, and benefits from, participation in groups.' It was found that the burden of care was likely to be less related to objective factors such as the ADL status of the elderly person than to the personal characteristics of the caregiver, particularly the caregiver's self concept as a caregiver. It is concluded, therefore, that in planning services, greater attention ought to be paid to the emotional rather than the physical aspects of caring.

EVALUATION; PSYCHOLOGICAL ASPECTS; SUPPORT GROUPS; ISRAEL

- 520 Moritz, Deborah J., Stanislav V. Kasl and Lisa F. Berkman (1989), 'The health impact of living with a cognitively impaired elderly spouse: depressive symptoms and social functioning', *Journal of Gerontology: Social Sciences*, 44(1), S17-27.

'The purpose of this study was to identify the social and psychological consequences of living with a cognitively impaired spouse among community-dwelling elderly individuals. The study sample consisted of 318 spouse pairs drawn from a representative sample of noninstitutionalized elderly individuals. [The] principal findings were that: (a) Cognitive impairment in wives is significantly ($p < .05$) associated with depressive symptomatology in husbands, whereas cognitive impairment in husbands is only weakly ($p > .20$) associated with depressive symptomatology in wives; (b) Decreased participation in social/leisure activities is selectively related to spouses' level of cognitive functioning among both men and women; (c) The relationship between wives' cognitive impairment and husbands' depressive symptoms is influenced by perceived availability of financial support from friends and relatives, but not by ADL limitations in wives, lack of emotional or

instrumental support from wives, household responsibilities among husbands, or lack of participation in social/leisure activities in husbands.'

DEMENTIA; HEALTH; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS;
SPOUSES; UNITED STATES

- 521 Morris, Robin G., Lorna W. Morris and Peter G. Britton (1988), 'Factors affecting the emotional wellbeing of the caregivers of dementia sufferers', *British Journal of Psychiatry*, 153, 147-56.

'Recent research on the factors that mediate the emotional wellbeing of the caregivers of dementia sufferers is reviewed. The roles of such factors as the caregiver's attributional style and coping strategies, the caregiver's relationship with the dementia sufferer, and levels of formal and informal support are discussed with reference to identifying those caregivers who are particularly vulnerable to emotional disorder or strain.'

DEMENTIA; LITERATURE REVIEW; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; UNITED KINGDOM

- 522 Morrissey, Elizabeth, Joseph Becker and Mark P. Rubert (1990), 'Coping resources and depression in the caregiving spouse of Alzheimer patients', *British Journal of Medical Psychology*, 63(2), 161-71.

'This study deals with the self-rated impact of caring for a spouse with Alzheimer's disease at home. Impacts on the caregiver's marriage, work, recreation and mood were investigated as a function of the patient's disability level and of the coping resources which caregivers reported were available to and/or used by them. The patient's disability level had a more negative impact on the caregiver's marriage and recreation than did the coping resource variables whereas the reverse was true for work. The caregiver's work was the only life area in which the availability and mobilization of coping resources influenced the caregiver's level of depression. To clarify these results, additional regression analyses were conducted separately for homemakers and employed subjects. While mobilized coping resources (social activity level and homemaking activity level) were correlated with depression among homemakers, none of the indicators of mobilized coping resources was correlated with depression among workers. These findings suggest that the role in which stress occurs is an important factor in understanding stress and the coping process.'

DEMENTIA; EMPLOYMENT; PSYCHOLOGICAL ASPECTS; SOCIAL
ASPECTS; SPOUSES; UNITED STATES

- 523 Morycz, Richard K. (1985), 'Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: possible predictors and model development', *Research on Aging*, 7(3), 329-61.

'This research explores whether the strain experienced by caregivers of relatives with Alzheimer's disease will be strongly related to the desire of families to institutionalize their older members. The desire of a caregiver to institutionalize a patient with Alzheimer's disease was found to be greater when the caregiver experiences increased strain or burden, when a patient is widowed, when there is more physical labor involved in caregiving tasks, and when the patient lives alone. Intensity of family strain (or felt stress) can best be predicted by the availability to the caregiver of social support: less support implied more strain. However, for male caregiving groups and for all black caregivers, strain does not play a significant role in predicting the desire to institutionalize.'

DEMENTIA; ETHNICITY; GENDER; INSTITUTIONALISATION;
PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 524 Motenko, Aluma Kopito (1989), 'The frustrations, gratifications, and well-being of dementia caregivers', *The Gerontologist*, 29(2), 166-72.

'Face-to-face interviews with 50 older women caring at home for a husband with dementia revealed that gratification was associated with greater well-being and frustration with more distress. Wives who perceived continuity in marital closeness since the illness had greater gratification than those who perceived change. Frustrations, in disrupting life plans, are apparently greatest at the onset of symptoms and as routines are developed, diminish despite the need to provide more care. Still, the meanings of caregiving are more important to caregiver well-being than the amount of care provided.'

AGED CAREGIVERS; DEMENTIA; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; SPOUSES; UNITED STATES

- 525 Mui, Ada C. (1992), 'Caregiver strain among black and white daughter caregivers: a role theory perspective', *The Gerontologist*, 32(2), 203-12.

'The emotional strain associated with caregiving as experienced by both black (n=117) and white (n=464) daughter caregivers was examined from a role theory perspective. Black daughters reported less role strain overall. Conflict between caregiving duties and the caregivers' personal and social life was a predictor for both groups. For black women the unique predictors were: poor perceived health, unavailability of respite support, and lower caregiving role demand. For white

women poor quality of parent-daughter relationship and work conflict were the unique predictors.'

DAUGHTERS; EMPLOYMENT; ETHNICITY; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; SUPPORT NETWORKS; THEORY DEVELOPMENT;
UNITED STATES

- 526 Mullan, Joseph T. (1992), 'The bereaved caregiver: a prospective study of changes in well-being', *The Gerontologist*, 32(5), 673-83.

'This study analyzes short-term bereavement adaptation among caregivers to spouses or parents with a progressive dementia, assessing the changes in depression, mastery, overload, and guilt to examine the impact of bereavement on caregivers, and the characteristics of caregiver experience that affect bereavement adaptation. The bereavement group, as compared with active caregivers, dropped substantially in overload and increased in mastery and guilt. Depression showed a curvilinear trend, declining from the time of death and then rising to preloss levels by the end of the year. Caregiver stressors, baseline adaptation, relationship difficulties, and psychological preparation were all related to changes in well-being.'

BEREAVEMENT; COMPARATIVE STUDIES; DEMENTIA; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 527 Mutschler, Phyllis H. (1993), 'Bearing the costs of our eldercare policies: work constraints among employed caregivers', *Journal of Aging & Social Policy*, 5(4), 23-49.

'For many caregivers, rendering aid to frail parents, grandparents, siblings, and spouses comes at a high price: compromised physical and mental health, disturbed relationships with spouse and children, truncated opportunities for social life, and, for caregivers who are employed, declining job performance. Using the 1982 National Long Term Care Survey's "Survey of Informal Caregivers", this study investigates how the sociodemographic characteristics of caregivers, care requirements, the availability of backup caregivers, and conditions of employment affect the likelihood that caregivers will suffer work constraints. Estimations of both the probability of work constraints and hours of work reveal that proxies for work conditions figure prominently, as do care requirements. In the model of constrained work, ill health, financial burdens, and primary responsibility for care are significant determinants; the estimation of hours of work revealed that low income and competing care demands wielded major influence. Women and white caregivers are employed fewer hours, while spouses are more likely than other informal caregivers to face constrained work. Occupation, as an indicator of work conditions, is shown

to be an important addition to the factors considered in investigations of circumstances that affect caregivers experiencing work constraints.'

EMPLOYMENT; ETHNICITY; FINANCIAL ASPECTS; GENDER; HEALTH;
NATIONAL STUDIES; SPOUSES; UNITED STATES

- 528 Myers, Jane E. (1989), *Adult Children and Aging Parents*, American Counseling Association, Alexandria, Va., xv, 2216pp.

This is a book on counselling older people and their adult children. The book is divided into five parts. It begins with a general overview of ageing. This is followed by some of the issues of ageing, including suicide, depression, drug and alcohol abuse and organic brain disorders, with implications for counselling and strategies for assessment. The third chapter addresses the needs of caregivers as well as the needs of the older person. Chapter four deals with family stress situations and possible responses; and finally, there is a chapter on general information useful to counsellors working with older people and their carers.

COUNSELLING; FAMILY; RELATIONSHIPS; UNITED STATES

- 529 Neal, Margaret B., Nancy J. Chapman, Berit Ingersoll-Dayton, Arthur C. Emlen and Linda Boise (1990), 'Absenteeism and stress among employed caregivers of the elderly, disabled adults, and children', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 160-83.

This chapter examines the impact of different kinds of caregiving responsibilities on employed caregivers comparing four groups: caregivers of the elderly, disabled adults, children, and employees with no caregiving responsibilities. It addresses three questions: how do employees with no dependent care responsibilities differ from those with caregiving responsibilities with respect to levels of absenteeism and various kinds of stress; how do employees with different types of caregiving responsibilities compare; and how do various socioeconomic and job-related characteristics differentially affect employees levels of absenteeism and stress? Differences were found between caregivers and noncaregivers and between the different types of caregivers, with caregivers of children experiencing the greatest amount of work interruption. Implications are drawn for the potential adjustments which are necessary in the workplace to support caregivers of different types.

COMPARATIVE STUDIES; DISABLED; EMPLOYMENT; PSYCHOLOGICAL
ASPECTS; SOCIOECONOMIC STATUS; UNITED STATES

- 530 Neary, Mary Anne (1993), 'Community services in the 1990s: are they meeting the needs of caregivers?' *Journal of Community Health Nursing*, 10(2), 105-11.

'The community-based, long-term care system not only sustains the older person in the community but also helps to maintain him or her at the highest level of functioning possible. A broad spectrum of services exists, including personal care, transportation, home-delivered meals, adult day care, and respite care. One hundred sixty-eight primary caregivers were interviewed regarding awareness of, inquiry into, utilization of, and satisfaction with community services during the caregiving period. The majority of caregivers were aware of and utilized 7 of the 15 services listed, including personal care services, home-delivered meals, rehabilitation services, housekeeping services, nursing services, and information referral services. Nurses remain the key individuals in providing linkages among elderly and their families and community-based services. One of the key roles that nurses can play is to inform caregivers about available community services, to help caregivers recognize the need for these services, and to recognize their need for support during this process. Finally, the community nurse can also provide support to the caregiver when institutionalization of the older family member becomes a reality.'

COMMUNITY SERVICES; SERVICE USE; UNITED STATES

- 531 Nissel, Muriel (1982), 'Measuring the cost: family care of the handicapped elderly', *New Age*, Spring, 29-31. Also published in *Policy Studies*, 3(1), 45-53.

'There is a general assumption that the shortfall in health and personal social services expenditure should be made up by family and community care. What this means is family care, and support for the family. To try to find out whether indirect non-market costs to the family could be evaluated a survey was undertaken with a sample of married couples caring for a disabled elderly relative. A questionnaire, interviews and time diary were completed, and data collected on the families and the extent of disability. There were a variety of different circumstances in relation to family composition, employment patterns and caring activities. Financial costs are only partially quantifiable, and there are indirect costs both economic and social. In addition there are the unquantifiable qualitative costs for families.'

EMPLOYMENT; FAMILY, FINANCIAL ASPECTS; METHODOLOGY; MIDDLE AGED CAREGIVERS; SOCIAL ASPECTS; UNITED KINGDOM

- 532 Nissel, Muriel (1984), 'The family costs of looking after handicapped elderly relatives', *Ageing and Society*, 4(2), 185-204.

'This article is principally concerned with the measurement and evaluation of the cost of the time which families devote to the care of handicapped elderly relatives living with them. One way of measuring the contribution is by means of time diaries which document the amount of time given to caring activities throughout the 24 hours of the day. How this was done in a small pilot study, carried out in

Oxfordshire, England, is described. It is preceded by a brief general discussion of some of the factors which determine time use and by a description of the empirical findings from a few of the existing surveys. Some broad estimates of the indirect financial costs involved are offered, including an estimate using a different approach based on the loss of opportunity suffered by women who are prevented from undertaking paid work.'

EMPLOYMENT; FAMILY; FINANCIAL ASPECTS; GENDER;
METHODOLOGY; MIDDLE AGED CAREGIVERS; UNITED KINGDOM

- 533 Nissel, Muriel and Lucy Bonnerjea (1982), *Family Care of the Handicapped Elderly: Who Pays?*, Research Report No.602, Policy Studies Institute, London, 67pp.

This exploratory study aimed to examine the extent to which the caring functions of the family operate as a constraint on women's participation in the community on an equal footing with men. It consisted of interviews with married couples in two main categories - those with an elderly, resident, handicapped relative and those with a youngest child aged three and under eleven. The project involved a small sample of between 20 and 30 families in each category, and included women in full or part-time work as well as those without paid jobs. They studied the time use and help with care in the households, the family experience, the carers' experience, quantitative costs and policy implications from the study.

EMPLOYMENT; FAMILY; GENDER; MIDDLE AGED CAREGIVERS;
POLICY; UNITED KINGDOM

- 534 Noelker, Linda S. and Robert W. Wallace (1985), 'The organization of family care for impaired elderly', *Journal of Family Issues*, 6(1), 23-44.

'Although families currently provide the bulk of care for aged relatives, demographic changes affecting family structure and documentation of the negative effects of caregiving have resulted in reservations about its continued prevalence. The purpose of this research was to examine the assumptions underlying these reservations as well as the notion that caregiving is facilitated by a large and active support network. In contrast to previous research, this study used interview data from 597 families in which the impaired elder resided with and was cared for by household kin. Findings indicated that caregiving occurred in diverse household configurations involving a substantial proportion of male caregivers, employed caregivers, and multi-generational contexts. Despite the diversity, most caregivers indicated a permanent commitment to the role. Although each day they provided on average three hours of personal care alone, wide variation was found in the incidence

and severity of stress effects. Informal and formal supports, though present, seemed to supply relatively little hands-on care.'

DEMOGRAPHIC ASPECTS; FAMILY; PSYCHOLOGICAL ASPECTS;
SUPPORT NETWORKS; UNITED STATES

- 535 Noelker, Linda S. and Aloen L. Townsend (1987), 'Perceived caregiving effectiveness: the impact of parental impairment, community resources, and caregiver characteristics', in Timothy H. Brubaker, ed., *Aging, Health, and Family: Long-Term Care*, Sage, Newbury Park, Calif., 58-79.

The research presented in this chapter draws from a model proposing that 'a delicate balance exists between the impaired elderly's needs and demands, the family's resources, and the community's resources and supports. If a shift occurs in any of these three key elements, readjustments must be made in the other two so that a balance is restored to the system.' Although this model makes family resources the fulcrum of the system, the authors believe that the resources of the individual family caregiver must be differentiated from those of the family unit and recent research lends support to this. This chapter examines 'the differential effects of parental impairment, community supports, and the caregiving child's characteristics on caregiving effectiveness.'

DAUGHTERS; FAMILY; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
SERVICE USE; SONS; SUPPORT NETWORKS; UNITED STATES

- 536 Noelker, Linda S. and David M. Bass (1989), 'Home care for elderly people: linkages between formal and informal caregivers', *Journal of Gerontology: Social Sciences*, 44(2), S63-70.

'Prior research has generally focused on characteristics of elderly persons that predict contact with community services or the volume of services used. In contrast, this study investigates how personal care and home health services are used in relation to assistance from primary kin caregivers. A typology was developed based on task sharing or segregation between kin caregivers and service providers, and four types of informal-formal linkages around these tasks were identified: kin independence, formal service specialization, dual specialization, and supplementation. Findings regarding the predictors of the types showed that caregiver and care recipient need variables were most significant in differentiating among them, although caregiver gender also had some discriminatory power.'

COMMUNITY SERVICES; METHODOLOGY; RELATIONSHIPS; SERVICE
USE; UNITED STATES

- 537 Nolan, Mike and Gordon Grant (1992), 'Respite care: factors influencing consumer perceptions of quality and acceptability', in Frank Laczko and Christina R. Victor, eds, *Social Policy and Elderly People: The Role of Community Care*, Avebury, Aldershot, Hants., 49-73.

This paper explores factors which influence consumer perceptions of the quality and acceptability of respite care and addresses the implications of these perceptions for the delivery of services. 'In challenging the assumptions which underpin the provision of respite care it is argued that there exists currently a paucity of appropriate outcomes for user groups resulting in evaluations which can be superficial and fail to highlight important contextual variables. Using the relevant literature as an analytic tool the potentialities of respite care are explored and developed within a pluralistic evaluation of a hospital rota bed scheme. Whilst the empirical evidence supporting the conclusions relate to a specific form of respite provision, the results are considered to have wider applicability and relevance.'

EVALUATION; LITERATURE REVIEW; RESPITE CARE; UNITED KINGDOM

- 538 Norris, Jane, ed. (1988), *Daughters of the Elderly: Building Partnerships in Caregiving*, Indiana University Press, Bloomington, x, 223pp.

This book begins with the voices of three generations of one family: an adult daughter, her elderly mother who lives with her and whom she cares for, and her daughter. All speak of their positive and negative experiences of the caring relationship. This is responded to by advocates for family supports in relation to intergenerational issues as well as stress and adjustments. Others discuss their experiences as caregivers and give practical advice; others discuss decision-making and issues which arise when independent living for an elder is no longer possible. The problems of caring for a person with dementia are also discussed. There is a section on men as caregivers and a section on dealing with loss and grief.

BEREAVEMENT; DAUGHTERS; DEMENTIA; GENDER; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; RELATIONSHIPS; UNITED STATES

- 539 Novak, Mark and Carol Guest (1989), 'Application of a multidimensional caregiver burden inventory', *The Gerontologist*, 29(6), 798-803.

'Multidimensional measures of caregiver burden give a sensitive reading of caregivers' feelings and a sophisticated picture of caregivers' responses to the demands of care. This paper reports on the development of a 24-item, five-subscale Caregiver Burden Inventory (CBI) and demonstrates its use as a diagnostic tool for professional caregivers. It concludes with a discussion of several ways that professional caregivers can use this multidimensional measure of caregiver burden.'

METHODOLOGY; PSYCHOLOGICAL ASPECTS; CANADA

- 540 Novak, Mark and Carol Guest (1989), 'Caregiver response to Alzheimer's disease', *International Journal of Aging and Human Development*, 28(1), 67-9.

This article presents questionnaire data from 30 caregivers of Alzheimer's disease patients in Manitoba. There was found no significant correlation between length of time a caregiver has given care to a particular patient and the caregiver's subjective feelings of burden. There was found a significant, moderate correlation between length of time a caregiver has given care to a particular patient and the patient's functional ability. The authors conclude that 'caregivers' subjective feelings and needs best predict their feelings of burden.' They offer suggestions on how to improve support for caregivers in the light of these findings.

DEMENTIA; PSYCHOLOGICAL ASPECTS; CANADA

- 541 O'Connor, D.W., P.A. Pollitt, M. Roth, C.P.B. Brook and B.B. Reiss (1990), 'Problems reported by relatives in a community study of dementia', *British Journal of Psychiatry*, 156, 835-41.

'The supporters of 120 demented elderly people completed rating scales of the frequency and severity of the problems they faced, the amount of strain they experienced and their psychological well-being. Problems and strain increased with the degree of dementia. Problems relating to physical dependency, forgetfulness and inertia were relatively common, while disturbed behaviours were relatively uncommon. Physical dependency and disturbed behaviour were less well tolerated than forgetfulness and inertia, but all problem categories were positively associated with measures of strain. Wives reported more problems and strain than husbands, and co-resident children were under greater strain than children who lived independently.'

DEMENTIA; DEPENDENCY; GENDER; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 542 Oldridge, M.L. and I.C.T. Hughes (1992), 'Psychological well-being in families with a member suffering from schizophrenia: an investigation into long-standing problems', *British Journal of Psychiatry*, 161, 249-51.

'Levels of stress in carers of long-term schizophrenia sufferers attending a depot clinic were assessed. Nine out of 25 carers (36%) were identified as possible or definite cases on either the GHQ [General Health Questionnaire] or the HAD [Hospital Anxiety and Depression Scale]. However, a substantial proportion of carers managed to cope with the difficulties without suffering psychologically.'

MENTAL ILLNESS; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
UNITED KINGDOM

- 543 Oliver, Judith (1983), 'The caring wife', in Janet Finch and Dulcie Groves, eds, *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, 72-88.

Drawing on her contacts as founder of the Association of Carers in the UK, the author gives a picture of the lives and experiences of married women caring for a disabled husband as reported by the women themselves. Evidence of their feelings about their lives and how they respond to circumstances was collected in two ways; interviews, and the correspondence received before and after the establishment of the Association of Carers. Some of the problems encountered are illustrated, such as no preparation on discharge from hospital, lack of state support services, sexual problems and lack of communication and social life. The most common requests made by these women were for 24 hour access to community nursing, care attendant schemes, respite care, day centre care and an extension of Invalid Care Allowance. These women felt they are being taken for granted and that their services are used as cheap labour and as a substitute for good housing, adaptations and rehabilitation. They need recognition and help.

COMMUNITY SERVICES; DISABLED; INCOME SUPPORT; PERSONAL NARRATIVES; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; SPOUSES; UNITED KINGDOM

- 544 Oliver, Rose (1985), 'Alleviating the distress of caregivers of Alzheimer's disease patients: a rational-emotive therapy model', *Clinical Gerontologist*, 3(4), 17-34.

'Caring for a person with senile dementia of the Alzheimer type places an enormous emotional burden upon the caregiver. Common responses of caregivers include denial, anger, guilt, self-pity and depression. These negative emotions exacerbate the difficulties of caring for the patient, as well as constrict the caregiver's ability to develop appropriate coping skills for his/her own life. Rational-emotive therapy (RET) specifies the maladaptive cognitions which elicit and sustain maladaptive emotions and behaviors, and provides a model for cognitive, affective and behavioral change. Excerpts from therapy sessions are presented to illustrate the process.'

DEMENTIA; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 545 Ory, Marcia G. (1985), 'The burden of care: a familial perspective', *Generations*, 10, Fall, 14-18.

This paper discusses several issues related to informal caregiver burden, including the demographics and health profile of the aged population; availability of potential caregivers; major characteristics of ongoing caregiver behaviours; intended and unintended consequences of caregiving behaviours; and promising new avenues of research, e.g. longitudinal studies are needed to map the dynamic process of caregiving behaviours over time. It is suggested that research must go beyond mere

descriptions of caregiver burdens to examine the major social and behavioural factors that affect the amount of burden experienced by different people in different settings. Characteristics of the caregiver, the care-receiver and the caregiving context need to be further delineated and it is critical that future studies take a family perspective.

DEMOGRAPHIC ASPECTS; FAMILY; GENDER; HEALTH;
PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 546 Ory, Marcia G., T. Franklin Williams, Marian Emr, Barry Lebowitz, Peter Rabins, Jeffrey Salloway, Teresa Sluss-Radbaugh, Eliza Wolff and Steven Zarit (1985), 'Families, informal supports, and Alzheimer's disease: current research and future agendas', *Research on Aging*, 7(4), 623-44.

'With the aging of most Western populations, there is growing research attention to the social and behavioral aspects of age-related chronic diseases and disabilities. Research is just beginning to focus on how families and other social supports are affected by Alzheimer's Disease and related disorders. This article reviews the current state of knowledge in this area and suggests a future research agenda.'

CONCEPTUAL ISSUES; DEMENTIA; LITERATURE REVIEW; POLICY;
PSYCHOLOGICAL ASPECTS; RELATIONSHIPS

- 547 Osterbusch, Suzanne E., Sharon M. Keigher, Baila Miller and Nathan L. Linsk (1987), 'Community care policies and gender justice', *International Journal of Health Services*, 17(2), 217-32.

'The current approach in the United States to the provision of community care to the elderly interacts with the feminized structure of family care-giving to foster inequities for women, who provide the bulk of informal, unpaid care. The central concern of present policies with limiting eligibility and rationing benefits results in policies that reduce the choices of these carers, many of whom are already substantially disadvantaged by their economic position in society. What is necessary for gender justice is development of policies that address the needs and rights of carers and elders by providing necessary supports to families, including, when appropriate, adequate compensation to carers. [The authors] argue for an approach that takes into account the relationship of the adequacy of government support and the capacity of individuals to freely choose the caregiving role.'

COMMUNITY SERVICES; GENDER; INCOME SUPPORT; POLICY;
SOCIOECONOMIC STATUS; UNITED STATES

- 548 Paringer, Lynn (1983), *The Forgotten Costs of Informal Long-Term Care*, Working Paper 1466-28, Urban Institute, Washington, D.C., 41pp.

This paper estimates the amount and value of informal care services provided to functionally disabled elderly persons in the United States. It looks at the characteristics of the dependent population and the sources from which they receive long-term care services. It also discusses the characteristics of the caregivers and the role of the household in caring for disabled family members. Data are presented on the amount of time required to care for individuals with different impairments and estimates are made for the economic cost of informal long-term care services. The findings are summarised and policy implications discussed.

DEPENDENCY; FAMILY; FINANCIAL ASPECTS; NATIONAL STUDIES; POLICY; UNITED STATES

- 549 Parker, Gillian (1989), *The Same Difference? The Experience of Men and Women Caring for a Spouse with a Disability or Chronic Illness*, Social Policy Research Unit, University of York, York, 27pp.

There has been less research on carers of non-elderly adults than carers of the elderly and yet the literature suggests that the burden borne by them is likely to be as great. Earlier work has also underestimated the role of male carers. To redress the balance the Social Policy Research Unit at the University of York carried out a study of those caring for a disabled or chronically ill spouse. This study used qualitative methods to explore the experiences of 21 couples where one of the partners had acquired a disability or chronic illness since marriage. This paper explores three areas: the carer's paid work, their experience of and attitudes towards service receipt, and their accounts of the experience and meaning of care.

CHRONIC ILLNESS; DISABLED; EMPLOYMENT; GENDER; METHODOLOGY; QUALITATIVE STUDIES; SERVICE USE; SPOUSES; UNITED KINGDOM

- 550 Parker, Gillian (1989), 'Unending work and care', *Work, Employment & Society*, 3(4), 541-53.

This is a review article on several publications on informal care and carers. It concentrates on three specific areas: the extent to which informal caring is constructed as 'work', either by those who do it or those who comment on it; the interrelationships between paid work and caring; and the role of men as carers.

EMPLOYMENT; GENDER; LITERATURE REVIEW; UNITED KINGDOM

- 551 Parker, Gillian (1990), *With Due Care and Attention: A Review of Research on Informal Care*, 2nd ed. Occasional Paper No.2, Family Policy Studies Centre, London, 142pp.

'The aim of this review is to set out what is currently known about the implications and consequences of this emphasis of "care by the community", focusing on the non-statutory care provided for heavily dependent people either in their own homes or in the homes of their carers...[it] concentrates on those caring for elderly people, for children with disabilities, and for adults of working age who have disabilities or chronic serious illnesses. Non-elderly adults with mental illnesses are excluded'. It begins with demographic and employment trends and their implications for the size of the dependent population and the potential caring capacity of the community and then asks who are the carers, what are their costs and what are the extent and level of those costs? The current patterns of service provision for carers are reviewed and some recent innovative developments in the support of carers outlined. It is concluded that available services are unlikely to have little overall effect for informal carers because few receive them and for those that do they are generally crisis-oriented rather than long-term and the criteria by which they are allocated are often irrational and discriminatory. Another reason is the fragmentation of services. It is difficult to say what the most effective and cost-effective forms of support might be because 'we still do not know enough about the respective needs of carers and cared-for people and how these might sensibly be balanced.'

CHRONIC ILLNESS; COMMUNITY SERVICES; DAY CARE; DEMOGRAPHIC ASPECTS; DISABLED; EMPLOYMENT; FINANCIAL ASPECTS; HEALTH; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; RESPITE CARE; SERVICE USE; SUPPORT GROUPS; UNITED KINGDOM

- 552 Parker, Gillian (1990), 'Whose care? Whose costs? Whose benefit? A critical review of research on case management and informal care', *Ageing and Society*, 10(4), 459-67.

This review article examines the following books: David Challis and Bleddyn P. Davies, *Case Management in Community Care*, Gower, Aldershot, Hants., 1986; David Challis, et al., *Supporting Frail Elderly People at Home*, Personal Social Services Research Unit, University of Kent, Canterbury, 1989; and Bleddyn P. Davies and David Challis, *Matching Resources to Needs in Community Care*, Gower, Aldershot, Hants., 1986, to challenge two explicit claims made for case management in relation to carers. 'The first is that case management improves "outcomes" for carers, and the second that case management does not impose additional financial costs on informal carers.' It does so by looking at the methodology and interpretations of the evaluations of Kent, Gateshead and Darlington in these books. 'Case management is not the panacea for both client and carer that it has claimed to be. As well as the methodological and interpretative issues...there are substantial philosophical, or "personal political" issues which the

model fails adequately to address...Gains in the quality of life of people with special needs may be made at the expense of those who care for them, or vice versa.'

EVALUATION; FINANCIAL ASPECTS; LITERATURE REVIEW;
METHODOLOGY; UNITED KINGDOM

- 553 Parker, Gillian (1992), 'Counting care: numbers and types of informal care', in Julia Twigg, ed., *Carers: Research and Practice*, HMSO, London, 6-29.

This chapter 'draws heavily on quantitative national survey data to explore the numbers and patterns of informal carers.' It 'addresses the kinds of questions that planners need to consider in preparing a systematic response to the issue of informal care.' It asks: are there really six million carers? Who are the carers and who are the carers most likely to need service support? It finds that although carers experience a higher level of stress than the community at large, there are few clear indicators to the specific factors causing stress. A more useful approach may be to think about factors which help carers to 'cope' such as respite, satisfaction with help from others in their informal network and services. Existing patterns of service receipt seem to disparate against those caring for relatives who live with them, yet these are the groups in most need.

COMMUNITY SERVICES; LIVING ARRANGEMENTS; NATIONAL STUDIES;
POLICY; PSYCHOLOGICAL ASPECTS; RESPITE CARE; SERVICE USE;
SUPPORT NETWORKS; UNITED KINGDOM

- 554 Parker, Gillian (1993), *With This Body: Caring and Disability in Marriage*, Open University Press, Buckingham, x, 145pp.

'This book breaks new ground by examining the views both of younger people who become disabled after marriage and of their partners who become involved in helping and supporting them. It explores the giving and receiving of personal care in marriage, and the roles of informal networks, services and income in supporting these couples and their children. It shows how, in the absence of help and support from elsewhere, couples are left in an extremely precarious position - practically, financially, emotionally, and socially. Disabled people argue the need for resources and services that would allow them to be independent of "informal" help. This book shows that age, class, gender and existing power relations in the marriage affect the experience of both disability and caring and the extent to which "independence" from informal help is seen by either partner as a legitimate or desirable goal.'

COMMUNITY SERVICES; DEPENDENCY; DISABLED; FINANCIAL
ASPECTS; GENDER; INCOME SUPPORT; RELATIONSHIPS; SOCIAL
ASPECTS; SOCIOECONOMIC STATUS; SPOUSES; SUPPORT NETWORKS;
UNITED KINGDOM

- 555 Parker, Gillian and Dot Lawton (1994), *Different Types of Care, Different Types of Carers: Evidence from the General Household Survey*, HMSO, London for the Social Policy Research Unit, University of York, 121pp.

This book analyses the data on carers from the 1985 General Household Survey in Britain. It develops a framework for understanding the picture of caring activity by looking at the kinds of tasks people do for others. The analysis shows a clear distinction between those people heavily involved in caring for someone and those providing help on a more informal basis. The study also reveals a wide range of factors influencing the lives of carers such as the effects of caring on financial resources and work patterns. The book includes sections on the characteristics of carers and examines variations in the delivery of services. It concludes with a comment on the likely future trends in caring activities, with greater numbers of people being involved in caring for someone and an increasing distinction between formal and informal help.

COMMUNITY SERVICES; EMPLOYMENT; FINANCIAL ASPECTS;
NATIONAL STUDIES; UNITED KINGDOM

- 556 Parks, Susan Hiller and Marc Pilisuk (1991), 'Caregiver burden: gender and psychological costs of caregiving', *American Journal of Orthopsychiatry*, 61(4), 501-09.

'Rapid demographic change has made family caregiving a pressing social issue in the 1990s. An estimated 80 percent of all caregiving for elderly people in the United States is performed by the family - usually the women - even when secondary assistance is available. A study examined the psychological costs of providing care for a parent with Alzheimer's disease, as well as the consequences of depression, anxiety, guilt, and resentment in relation to the caregiver's coping style, social support, and sense of control. The use of fantasy by women as a coping mechanism was associated with greater anxiety and depression, adequate social support was somewhat more helpful for men, and a sense of control was more helpful for women. Implications of the study's findings are (1) that the psychological aspects of the caregiver burden can be reliably documented and (2) that this documentation supports findings from other case studies of high psychological costs, inadequate support for effective coping, and deficiencies in respite care. Finally, suggestions are made for adequate assistance in addressing the resources needed by caregivers, the effectiveness of different coping styles, and the cultural expectations that place so much of this difficult task on women.'

DEMENTIA; GENDER; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 557 Paveza, Gregory J., Donna Cohen, Carl Eisdorfer, Sally Freels, Todd Semla, J. Wesson Ashford, Philip Gorelick, Robert Hirschman, Daniel Luchins and Paul Levy (1992), 'Severe family violence and Alzheimer's disease: prevalence and risk factors', *The Gerontologist*, 32(4), 493-7.

'This study describes the prevalence of violence and the putative risk factors for violence in 184 Alzheimer patients and their primary caregivers living in the community. Analysis of the severe violence subscale of the Conflict Tactics Scale indicated that 15.8% of patients had been violent in the year since the diagnosis. A total of 5.4% of caregivers reported being violent toward the patient. The overall prevalence of violence was 17.4%. The variables most associated with violence were caregiver depression and living arrangement.'

DEMENTIA; ELDER ABUSE; LIVING ARRANGEMENTS; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 558 Pearlin, Leonard I., Joseph T. Mullan, Shirley J. Semple and Marilyn M. Skaff (1990), 'Caregiving and the stress process: an overview of concepts and their measures', *The Gerontologist*, 30(5), 583-94.

'This paper views caregiver stress as a consequence of a process comprising a number of interrelated conditions, including the socioeconomic characteristics and resources of caregivers and primary and secondary stressors to which they are exposed. Primary stressors are hardships and problems anchored directly in caregiving. Secondary stressors fall into two categories: the strains experienced in roles and activities outside of caregiving, and intrapsychic strains, involving the diminishment of self-concepts. Coping and social support can potentially intervene at multiple points along the stress process.'

CONCEPTUAL ISSUES; METHODOLOGY; PSYCHOLOGICAL ASPECTS; SOCIOECONOMIC STATUS; SUPPORT NETWORKS

- 559 Pearlin, Leonard I., Heather Turner and Shirley Semple (1990), 'Coping and the mediation of caregiver stress', in Enid Light and Barry D. Lebowitz, eds, *Alzheimer's Disease Treatment and Family Stress: Directions for Research*, Hemisphere, New York, 198-217.

Information for this chapter came from a pilot study conducted to research how people cope with caring for a person with Alzheimer's disease. It describes the stressors people encounter as caregivers as well as the coping strategies they employ. It also addresses the apparent limitations of coping and the conditions under which caregivers' coping seems to be most effective. It begins with a clarification of some of the conceptual issues which guide the thinking behind this study.

CONCEPTUAL ISSUES; DEMENTIA; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 560 Pearson, Jane, Sumer Verma and Colette Nellett (1988), 'Elderly psychiatric patient status and caregiver perceptions as predictors of caregiver burden', *The Gerontologist*, 28(1), 79-83.

'Aspects of patient status and caregiver perceptions considered important contributors to caregiver burden were examined in a sample of 46 pairs of elderly psychiatric patients and their caregivers. The patient had been referred to a geriatric assessment unit. Significant predictors of caregiver burden included disruptive patient behavior, caregiver distress, and patients' functional limitations. The results, and those from previous studies, suggested that predictors of caregiver burden vary with the elderly patients' diagnoses.'

MENTAL ILLNESS; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
SOCIAL ASPECTS; UNITED STATES

- 561 Pearson, M. and E. Deitrick (1989), 'Support for family caregivers: a volunteer program for in-home respite care', *Caring*, 8(12), 18-201.

This article describes Respite Care Corps, a community-based, in-home, volunteer respite care program, and discusses issues involved in developing and implementing such a program. The volunteer program is one component of a nurse-managed range of services identified as important by caregivers.

CASE STUDIES; METHODOLOGY; RESPITE CARE; UNITED STATES

- 562 Perring, Christina, Julia Twigg and Karl Atkin (1990), *Families Caring for People Diagnosed as Mentally Ill: The Literature Re-Examined*, HMSO, London in conjunction with Social Policy Research Unit, University of York, v, 62pp.

This discussion paper has a twofold aim: 'to review such literature as is relevant to an understanding of the informal care of people diagnosed as mentally ill; and to begin to explore possible relationships between findings from the psychological and psychiatric literature on the one hand, and those from the work on informal care on the other.' Literature that has investigated the impact of mental illness on families is small compared with that on informal care or on community mental health in general. Some of the barriers to understanding posed by this literature are that it focuses on families rather than individuals; the situation is seen as one of 'burden' rather than informal care; and there has been a focus on the well-being of the patient, and on people with schizophrenia. Methods of inquiry have neglected the meaning of the situation to those concerned. The review examines the impact on the family, including what has become known as 'family burden' and why the impact of caring may be more difficult for some people than others. There is a review of families and service provision. The final chapter makes comparisons with other carers and highlights some areas for further research. The paper concludes that it is 'entirely

appropriate to apply the concept of informal care to the situation of people diagnosed as mentally ill' and that this will 'enrich our understanding of informal care.'

COMMUNITY SERVICES; COMPARATIVE STUDIES; FAMILY;
LITERATURE REVIEW; MENTAL ILLNESS; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 563 Phillips, Judith (1994), 'The employment consequences of caring for older people', *Health & Social Care in the Community*, 2(3), 143-52.

'This paper describes and discusses an exploratory study which highlights the difficulties faced by employees attempting to balance work and caring for an older adult. Methodological issues arising from the study are explored and issues for further research considered. A significant proportion of the elderly population is cared for by those in full-time employment. This situation will become yet more significant given the current demographic changes and the pressures that carers are increasingly experiencing to remain in employment. A "care audit" profiling of the workforce of a large company was undertaken to explore the issues and the effects of caregiving on employment. Over three-quarters of the 123 employees who responded reported that they either are, have been, or will be, providing care for an adult in the next few years. Many reported or anticipated disruption at work as a result of caring.'

EMPLOYMENT; UNITED KINGDOM

- 564 Pilisuk, Marc and Susan Hiller Parks (1988), 'Caregiving: where families need help', *Social Work*, 33, 436-40.

'Demographic and medical changes are turning numerous individuals into caregivers. The concept of caregiver burden is examined relative to the resources available for supporting family members who care for an ill or disabled member. An examination of the magnitude of the problem shows that there must be a national policy on caregiving and a shift in national priorities if the need is to be met.'

DEMOGRAPHIC ASPECTS; INSTITUTIONALISATION; LITERATURE
REVIEW; POLICY; PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS;
UNITED STATES

- 565 Pillemer, Karl, Margaret MacAdam and Rosalie S. Wolf (1989), 'Services to families with dependent elders', *Journal of Aging & Social Policy*, 1(3/4), 67-88.

'This article analyzes the role of states in providing services and financial incentives for family caregivers to impaired older people. Results from a recent Massachusetts study of family relations of the elderly are reported, focusing on the role of relatives

in providing care. Next, critical needs of family caregivers are discussed, and major service initiatives to respond to these needs are reviewed. The Massachusetts home care system is used as an example of how services that support family care can be delivered in a comprehensive fashion. Two financial incentive programs (tax incentives and direct payment of caregivers) are then presented. The article concludes with a call for experimental demonstration projects to expand knowledge in this area.'

COMMUNITY SERVICES; INCOME SUPPORT; POLICY; UNITED STATES

566 Pitkeathley, Jill (1989), *It's My Duty, Isn't It? The Plight of Carers in Our Society*, Souvenir Press, London, 180pp.

This book has been written to draw attention to the plight of carers, three out of four of whom are women, in Britain today. It is intended to help carers and to point to the reality which lies behind the phrase 'care in the community'. It examines the historical precedents that have created the present situation (now exacerbated by recent financial cutbacks), explains how to apply for the benefits and services which are available in theory but not readily offered or granted in practice, and shows how professional attitudes contribute to the maintenance of the status quo. Above all, it records the feelings and experiences of the carers themselves - their sense of duty, their isolation and despair. Carers must receive recognition and compensation for their devoted work. The author sets out a model for good practice, but also emphasises essential changes which must be made immediately, before the strain becomes too great. 'Present trends suggest that women will not always be so willing to shoulder the burden society now inflicts upon them.'

COMMUNITY SERVICES; DISABLED; EDUCATION; GENDER;
HISTORICAL ASPECTS; INCOME SUPPORT; MENTAL ILLNESS;
PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; RELATIONSHIPS;
RESPIRE CARE; UNITED KINGDOM

567 Pitkeathley, Jill (1991), 'The carers' viewpoint', in Gillian Dalley, ed., *Disability and Social Policy*, Research Report No.731, Policy Studies Institute, London, 203-9.

The view of carers and the Carers National Association of whom the author is the Director, is that they believe the needs of both the carer and the person cared for need to be taken into consideration together. There is general agreement as to the needs of carers - the five most commonly mentioned are: recognition, information, practical help, money, and time off. The author also points out the importance of taking into consideration the variety of relationships which exist within a caregiving situation and the many different reasons for caring. Finally, the importance of the

need for carers' organisations and other representative groups to work together is stressed.

COMMUNITY SERVICES; EDUCATION; INCOME SUPPORT; RESPITE CARE; UNITED KINGDOM

- 568 Platt, Stephen (1985), 'Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales', *Psychological Medicine*, 15, 383-93.

'The gradual shift towards non-institutional treatment for severe and chronic psychiatric illnesses has been accompanied by a recognition of potentially harmful effects ("burden") upon the patient's caregivers. This paper aims to provide a framework for the development of further research into the burden of "community care" by offering a clear definition of the burden concept, an exposition of the criteria for evaluating rating scales to measure the concept, a review of major rating scales of burden, and some suggestions for improvements in methodology which are urgently required.'

CONCEPTUAL ISSUES; EVALUATION; MENTAL ILLNESS; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 569 Popay, Jennie and Chris Rossiter (1982), 'Who cares about the carers?', *The Health Services*, September 3, 17.

Home care for the elderly and handicapped saves millions every year. The many costs of informal care, both direct and indirect are met, largely, by female carers. Personal emotional costs which are difficult to quantify are no less real. There is need of financial help for the carers, more flexible employment policies and a wide range of relief services.

EMPLOYMENT; FINANCIAL ASPECTS; GENDER; POLICY; RESPITE CARE; UNITED KINGDOM

- 570 Poulshock, S. Walter and Gary T. Deimling (1984), 'Families caring for elders in residence: issues in the measurement of burden', *Journal of Gerontology*, 39(2), 230-9. Also published in Lillian Troll, ed. (1986), *Family Issues in Current Gerontology*, Springer, New York, 226-45.

'This paper examines the concept of caregiving burden and urges a multidimensional perspective in which burden is viewed as a mediating force between the elders' impairments and the impact that caregiving has on the lives of caregivers and their families. The analysis underscores the need to apply the concept of burden to subjective interpretations by caregivers of the elders' different kinds of impairments including impairment of activities of daily living, cognitive incapacity, disruptive

behavior, and lack of sociability. The analysis also demonstrates that a variety of less subjective effects of caregiving are important and measurable. These issues are elaborated and illustrated using data and findings from the Benjamin Rose Institute's survey of 614 families in which impaired elders resided with and were provided care by family members.'

CONCEPTUAL ISSUES; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
UNITED STATES

- 571 Pratt, Clara C., Vicki Schmall, Scott Wright and Marilyn Cleland (1985), 'Burden and coping strategies of caregivers to Alzheimer's patients', *Family Relations*, 34(1), 27-33.

'The investigators of this project examined several coping strategies used by caregivers of Alzheimer's disease patients and the relationship of those strategies to the caregivers' subjective sense of burden. Two hundred and forty subjects were surveyed. Differences in burden scores were not significantly affected by caregivers' age, sex, income, education, or patient residence (i.e. community dwelling, institutions). However, burden scores were significantly related to caregivers' health status. Also burden scores were not significantly related to presence of confidant or support group membership. Three internal coping strategies (confidence in problem-solving, reframing the problem, and passivity) and two external coping strategies (spiritual support and extended family) were found to be significantly related to caregiver burden scores. Implications for future research and intervention programs are discussed.'

DEMENTIA; HEALTH; PSYCHOLOGICAL ASPECTS; SOCIOECONOMIC
STATUS; SUPPORT GROUPS; SUPPORT NETWORKS; UNITED STATES

- 572 Pratt, Clara, Scott Wright and Vicki Schmall (1987), 'Burden, coping and health status: a comparison of family caregivers to community dwelling and institutionalized Alzheimer's patients', *Gerontological Social Work with Families*, 10(1/2), 99-112.

'This study investigates caregiver health, burden and coping strategies of family caregivers to institutionalized and community dwelling Alzheimer's disease patients. Patient residence was significantly related to caregiver health status, sources of burden and the efficacy of various strategies for reducing burden. Implications for intervention with family caregivers are discussed.'

COMPARATIVE STUDIES; DEMENTIA; HEALTH;
INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 573 Pratt, Clara, Vicki Schmall and Scott Wright (1987), 'Ethical concerns of family caregivers to dementia patients', *The Gerontologist*, 27(5), 632-8.

'The ethical concerns in statements of 116 family caregivers to dementia patients were identified. Concerns included family obligations for caregiving; conflicts with responsibilities to family, career or personal well-being; financing health care; standards of care; and patient roles in planning care. These concerns are related to societal allocation of resources for health care, the principle of autonomy, and several other ethical issues.'

DEMENTIA; FAMILY; FINANCIAL ASPECTS; POLICY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 574 Pratt, Clara C., Tim Nay, Linda Ladd and Bobby Heagerty (1989), 'A model legal-financial education workshop for families caring for neurologically impaired elders', *The Gerontologist*, 29(2), 258-62.

This article describes a program through which families become familiar with issues, legal terminology, and resources for planning to provide and finance care to neurologically impaired elderly. In a survey of 68 participating families, over 90% had taken one or more planning actions following the workshop, including developing a specific plan for providing and financing services and developing a power-of-attorney for decision making.

DEMENTIA; EDUCATION; FINANCIAL ASPECTS; LEGAL ASPECTS; UNITED STATES

- 575 Pratt, Clara C., Alexis J. Walker and Barbara L. Wood (1992), 'Bereavement among former caregivers to elderly mothers', *Family Relations*, 41(3), 278-83.

'Understanding the process of bereavement among former caregivers to the elderly will enable practitioners to offer support more effectively. This study examines bereavement among 38 daughters who were caregivers to their elderly mothers. Comparing bereavement feelings at 2 months to feelings 6 months following the mother's death, daughters reported decreases in grief resolution behaviors and feelings of emotional shock, anger, and helplessness. Comparison to elderly widows indicated similarities in reported rates of most bereavement feelings at 2 and 6 months. Depression rates measured by the CES-D were not elevated for bereaved daughters. Implications for practice are discussed.'

BEREAVEMENT; DAUGHTERS; UNITED STATES

- 576 Pruchno, Rachel A. (1990), 'The effects of help patterns on the mental health of spouse caregivers', *Research on Aging*, 12(1), 57-71.

'Investigated were the patterns of task assistance and social support received by 315 people who were the primary caregivers to spouses suffering from Alzheimer's Disease. Despite the fact that spouse caregivers themselves are old and frail, they continue to provide the bulk of care required by their impaired partner. When help is forthcoming from any source, it is minimal. Contrary to the hypothesis that back-up sources of support or confidants should buffer the primary caregiver from negative mental health effects, there was no relationship between existence of either task support or social support and mental health.'

AGED CAREGIVERS; DEMENTIA; PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS; SPOUSES; UNITED STATES

- 577 Pruchno, R.A. and S.L. Potashnik (1989), 'Caregiving spouses: physical and mental health in perspective', *Journal of the American Geriatrics Society*, 37(8), 697-705.

'The self-reported physical and mental health of 315 persons caring for a spouse who has been diagnosed with Alzheimer's disease or a related disorder was compared with general population norms for existing data bases controlling for age and gender. Results suggest that across all indicators of mental health, spouse caregivers are more depressed, express higher levels of negative affect, are more likely to use psychotropic drugs, and have more symptoms of psychological distress than the general population. In terms of physical health, caregivers report higher than expected rates of diabetes, arthritis, ulcers, and anemia, yet they use medical services at rates which are similar or lower than those reported by the general population. Since no simultaneous control group was studied, these results suggest, but do not prove, the presence of differences between caregivers and non-caregivers.'

DEMENTIA; HEALTH; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 578 Pruchno, Rachel A. and Nancy L. Resch (1989), 'Husbands and wives as caregivers: antecedents of depression and burden', *The Gerontologist*, 29(2), 159-65.

'Contrasting predictors of depression among 101 men and 214 women providing care to spouses suffering from Alzheimer's Disease indicated that the sole predictor for husbands was ill health, whereas for wives less emotional investment was also predictive. While there were no significant predictors for burden among husbands, for wives, burden was associated with poorer health, less emotional investment, greater spouse impairment, and provision of more assistance with tasks.'

COMPARATIVE STUDIES; DEMENTIA; GENDER; HEALTH; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 579 Pruchno, Rachel A., Morton H. Kleban, J. Eileen Michaels and Norah P. Dempsey (1990), 'Journal of Gerontology: Psychological Sciences, 45(5), P192-9.

'This study modeled the causal relationship between physical health and depression among a sample of 315 people providing home care for a spouse who had been diagnosed as having Alzheimer's disease. In addition to significant stability paths and correlations among variables at any one point in time, significant lagged paths were found in which depression (1) predicted physical health (2), depression (2) predicted physical health (3), and depression (1) predicted burden (2). Contrasting the overall model for husband and wife caregivers over a 6-month period indicated that the model was significantly for wives but not for husbands.'

DEMENTIA; GENDER; HEALTH; PSYCHOLOGICAL ASPECTS; SPOUSES;
THEORETICAL DEVELOPMENT; UNITED STATES

- 580 Pruchno, Rachel A., J. Eileen Michaels and Sheryl L. Potashnik (1990), 'Predictors of institutionalization among Alzheimer disease victims with caregiving spouses', *Journal of Gerontology: Social Sciences*, 45(6), S259-66.

'A theoretical model predicting "desire to institutionalize" and actual institutionalization was developed and tested on a sample of 220 persons caring for a demented spouse. Significant predictors of "desire to institutionalize" include age and education of caregiver, spouses forgetful behaviors, ADL tasks done by the caregiver, medications taken by the caregiver, services used, and quality of relationship with spouse. Predictors of actual institutionalization are desire to institutionalize, length of time spent as a caregiver, religion, uplifts, and forgetful behaviors of the impaired spouse.'

AGED CAREGIVERS; DEMENTIA; HEALTH; INSTITUTIONALISATION;
PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SERVICE USE; SPOUSES;
THEORY DEVELOPMENT; UNITED STATES

- 581 Purdy, Julie K. and David Arguello (1992), 'Hispanic familism in caretaking of older adults: is it functional?', *Journal of Gerontological Social Work*, 19(2), 29-43.

'The role of familism in elderly adults has been professed to be the central institution in their lives. Though, Hispanic caretakers have provided high levels of informal care, it is the purpose of this paper to give evidence that current under utilization of formal services by the Hispanic family has dysfunctional side-effects. Reliance solely upon informal familial support increases dependency upon children which has been correlated with depression. Reliance also perpetuates a cycle of poverty as

children's economic opportunities are sacrificed due to caregiving. Ideas for how to effectively intervene in this self-destructive pattern are suggested.'

DEPENDENCY; ETHNICITY; FAMILY; FINANCIAL ASPECTS;
PSYCHOLOGICAL ASPECTS; SERVICE USE; SOCIOECONOMIC STATUS;
UNITED STATES

- 582 Quadagno, Jill, Ceiba Sims, D. Anne Squier and Georgia Walker (1987), 'Long-term care, community services and family caregiving', in Timothy H. Brubaker, ed., *Aging, Health, and Family: Long-Term Care*, Sage, Newbury Park, Calif., 116-28.

'The purpose of this study is to investigate how a community-based services program interacts with family caregiving, both from the perspective of the family caregivers and from that of the elderly clients of the bureaucracy.' It is a study of the home and community based services program of the state of Kansas and interviews were conducted with clients and caregivers.

COMMUNITY SERVICES; UNITED STATES

- 583 Quayhagen, Mary P. and Margaret Quayhagen (1989), 'Differential effects of family-based strategies on Alzheimer's disease', *The Gerontologist*, 29(2), 150-5.

'Assessed was the efficacy of a home-based program of cognitive stimulation for the functional status of patients with Alzheimer's disease, as well as the well-being of caregivers. Ten family dyads (caregiver and patient) participated in the intervention and six family dyads formed the comparison group. Patients in the program maintained their levels of cognitive and behavioral functioning while improving emotionally, whereas the comparison group patients deteriorated. Similarly, the caregivers in the program maintained well-being and enhanced their coping resources.'

COMPARATIVE STUDIES; DEMENTIA; EDUCATION; METHODOLOGY;
UNITED STATES

- 584 Quine, Lyn and Helen Charnley (1987), *Evaluating the Malaise Inventory as a Measure of Stress in Carers*, Discussion Paper No.551, Personal Social Services Research Unit, University of Kent at Canterbury, 1v.(unpaged)

'The continuing trend towards caring for dependent people in the community has focussed the attention of health and social care managers, practitioners and researchers on the informal carers who provide support for those with special needs. Such care is widely acknowledged to be stressful. This paper examines the Malaise Inventory as a measure of stress in informal carers. It describes the application of the

inventory in two studies of carers; the families of severely mentally handicapped children and the principal carers of elderly people. It demonstrates the validity of the Malaise Inventory as a measure of stress which may be used in establishing levels of stress among specific populations and in measuring outcomes of service interventions.'

EVALUATION; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 585 Qureshi, Hazel (1986), 'Responses to dependency: reciprocity, affect and power in family relationships', in Chris Phillipson, Miriam Bernard and Patricia Strang, eds, *Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives*, Croom Helm, London, 167-79.

'This chapter draws upon the results of a survey of elderly people and their informal carers carried out in 1982-1983 in Sheffield'. There were 299 elderly people interviewed and 58 carers. This chapter focuses on the carers' views of responses to dependency by the elderly people to whom they gave assistance, and the factors which influenced them to provide care.

DEPENDENCY; RELATIONSHIPS; UNITED KINGDOM

- 586 Qureshi, Hazel (1990), 'Boundaries between formal and informal care-giving work', in Clare Ungerson, ed., *Gender and Caring: Work and Welfare in Britain and Scandinavia*, Harvester Wheatsheaf, Hemel Hempstead, Herts., 59-79.

'This paper commences with a discussion of the ideas underlying the distinction between formal and informal care, and continues with an investigation of the extent to which these concepts can be usefully employed to describe the actual practice of caring for elderly people in formal and informal contexts. The areas of critical interest are: first, the perception that to receive informal care is the preference of those who are cared for, and the associated belief that to attempt to "formalize" such care by, for example, offering payment, would be radically to change its nature; second, drawing upon an understanding of informal care in operation, an examination of the extent to which certain kinds of formal care can take on informal aspects, and what the consequences of this might be.' Using evidence from the Kent Community Care project, it is concluded that paid performance of practical tasks does not corrupt pre-existing informal relationships, can perform the role of relationship-building for elderly people and help generate the care they require.

CONCEPTUAL ISSUES; PAYMENT; RELATIONSHIPS; UNITED KINGDOM

- 587 Qureshi, Hazel and Alan Walker (1986), 'Caring for elderly people: the family and the state', in Chris Phillipson and Alan Walker, eds, *Ageing and Social Policy: A Critical Assessment*, Gower, Aldershot, Hants., 109-27.

'The main purpose of this chapter is to examine the relationships between the family and the state in the provision of care to elderly people.' To do this, the authors draw on the results of a study carried out in Sheffield, Britain. It discusses 'the nature of family care, the impact of state policies, particularly in the personal social services, on the care provided by families, the role of other informal carers, government policies on community care and, finally, an alternative basis for policy which does not exploit the duty felt by families and female kin in particular to provide care for elderly relatives. At the heart of this analysis is the ostensible conflict between elderly people and carers' which the study shows to be due primarily to the state failing to meet the needs of *both* the elderly people and the carers and to strike a balance between these needs.

CASE STUDIES; COMMUNITY SERVICES; FAMILY; GENDER; POLICY; RELATIONSHIPS; UNITED KINGDOM

- 588 Qureshi, Hazel and Ken Simons (1987), 'Resources within families: caring for elderly people', in Julia Brannen and Gail Wilson, *Give and Take in Families: Studies in Resource Distribution*, Allen & Unwin, London, 117-35,

This chapter focuses on two areas of resource distribution within families caring for elderly people: first, the distribution of material resources, both money and goods (relatively rare and usually flows from elderly parents to their children); and secondly, the allocation of routine domestic assistance. There appear to be very clear expectations relating to this and the authors propose a model to describe the rules governing the discharge of such kinship obligations. Women were found to be the prime givers and receivers of informal domestic assistance. Future likely directions are alluded to. The data are drawn from a survey in Sheffield, U.K.

FAMILY; FINANCIAL ASPECTS; GENDER; RELATIONSHIPS; UNITED KINGDOM

- 589 Qureshi, Hazel and Alan Walker (1989), *The Caring Relationship: Elderly People and Their Families*, Macmillan, Basingstoke, Hants., xii, 291pp.

This book takes a look at the family relationships at the end of the life cycle. 'The book begins with a description of the overall sample of elderly people, and goes on to discuss the patterns of contact which they have with their relatives and the variety of needs and sources of help which are identified. The second half of the book focuses on those who receive regular assistance with practical tasks and discusses how choices are made about who will help within the family, what effects increasing disability and dependency are seen to have on relationships, and how statutory help is seen in relation to family help. It concludes with a discussion on the ways in

which our improved knowledge of the informal sector might be better taken into account in the policy and practice of the formal sector of care.

DEPENDENCY; FAMILY; POLICY; RELATIONSHIPS; UNITED KINGDOM

- 590 Rakowski, William and Noreen M. Clark (1985), 'Future outlook, caregiving, and care-receiving in the family context', *The Gerontologist*, 25(6), 618-23.

'Future outlook was investigated as an aspect of family caregiving and care-receiving. In data from 90 caregiver/receiver pairs, restricted future outlook for both groups was found to be associated with situations of greater impairment, more extensive assistance, and greater stress. A mixed outcome emerged in regard to the congruence between views of caregivers and receivers about the health care situation. Results suggest the central role of family communication and the importance of maintaining a future orientation.'

FAMILY; UNITED STATES

- 591 Rankin, Eric D. (1990), 'Caregiver stress and the elderly: a familial perspective', *Journal of Gerontological Social Work*, 15(1/2), 57-73.

'This paper examines the activities and perceptions of 41 spouses and adult daughters seeking psychological and social intervention with a frail spouse/parent. Findings indicate that spouses were involved in more "hands-on" care and identified the marital relationship or their own physical abilities as sources of caregiver stress. Daughters were less involved in direct care, although overall levels of care remained comparable, and identified responsibilities outside the caregiving relationship as their primary source of stress. The significance of the caregiver's familial status in developing treatment strategies that address caregiver stress are examined.'

DAUGHTERS; HEALTH; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SPOUSES; UNITED STATES

- 592 Rankin, Eric D., Marc W. Haut and Robert W. Keefover (1992), 'Clinical assessment of family caregivers in dementia', *The Gerontologist*, 32(6), 813-21.

'Development of an integrated family assessment inventory based on the Double ABCX and Circumplex models of family functioning and its clinical utility was evaluated with 121 primary family caregivers from a cognitive disorders program. The proposed model predicted a significant proportion of the variance associated with caregivers stress and strain. Several aspects of the caregiving arrangement also emerged as key features in predicting caregiver depression. These findings supported the model's central premise that both dyadic (caregiver-patient) and systemic

(caregiver-family) variables are salient in assessing the impact of family caregiving with dementia.'

DEMENTIA; EVALUATION; FAMILY; METHODOLOGY; PSYCHOLOGICAL ASPECTS; THEORY DEVELOPMENT; UNITED STATES

- 593 Raphael, Dennis and Ben Schlesinger (1993), 'Caring for elderly parents and adult children living at home: interactions of the sandwich generation family', *Social Work Research & Abstracts*, 29(1), 3-8.

'The study presented here analyzed the patterns of demand made on 66 middle-aged women by their elderly parents and their adult children who were living at home. Factor analyses of the reports of family interactions revealed the presence of five adult children-middle-aged parents interaction factors and four elderly parents-middle-aged parents interactions. These patterns were considerably more complex than previous studies of the Sandwich Generation suggested. As expected, socioeconomic status and health of the elderly parents were related to these family interaction factors.'

HEALTH; MIDDLE AGED CAREGIVERS; RELATIONSHIPS; SOCIOECONOMIC STATUS; UNITED KINGDOM

- 594 Raveis, Victoria H., Karolynn Siegel and Myriam Sudit (1990), 'Psychological impact of caregiving on the caregiver: a critical review of research methodologies', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 53-75.

This chapter draws attention to the inadequacy of the research methodologies used in the study of the psychological burdens and consequences of performing the caregiver role. Concerns are raised about sample selection, sample size, the adequacy and validity of measurement instruments, and the need for multivariate analysis, comparative studies, longitudinal studies, and more appropriate outcome criteria. Solutions will require more sophisticated research methodology as well as the development of more adequate theoretical frameworks for the study of caregiving.

METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 595 Reed, Bruce R., Arthur A. Stone and John M. Neale (1990), 'Effects of caring for a demented relative on elders' life events and appraisals', *The Gerontologist*, 30(2), 200-05.

'Weekly ratings of events and appraisals were collected from 19 caregivers of dementia patients and 19 control subjects over 4 weeks. Caregivers reported more negative events overall and rated them as more undesirable than did control subjects, but significant differences were found in events of only 2 of the 11 life areas that

were measured. Caregivers' negative appraisals were more frequent and more intense than those of control subjects in virtually every area of life. These preliminary data fail to demonstrate a global disruption of caregivers' activities and suggest the importance of appraisals in determining the impact of caregiving.'

COMPARATIVE STUDIES; DEMENTIA; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 596 Reeve, Karen E. (1984), 'Self-help groups for caregivers coping with Alzheimer's disease: the ACMA model', *Pride Institute Journal of Long Term Home Health Care*, 3(4), 23-30.

'The Aid to Caregivers of the Mentally Impaired Aged (ACMA) project of the Philadelphia Geriatric Center was established in order to set up 30 support groups in greater Philadelphia over a period of 30 months. The goals of the ACMA model were to create support groups that functioned to enhance the ability of caregivers to cope and to help caregiver support groups make the transition to autonomy. This article discusses how the ACMA model was designed, the details of its operation, and its effectiveness as a service intervention strategy.'

DEMENTIA; METHODOLOGY; SUPPORT GROUPS; UNITED STATES

- 597 Richardson, Ann, Judith Unell and Beverly Aston (1989), *A New Deal for Carers*, Kings Fund, London, 95pp.

This book is about the needs of caregivers and is based on discussions with nearly 200 people all around Britain. This statement of needs provides the basis for developing policies and practices that will give a new deal for caregivers. It begins with a '10 Point Plan for Carers' which sets out essential requirements which must be met if caregivers are to lead a reasonable and worthwhile life. Each of these needs is then explored in detail in the following chapters, each of which consists of explanations and discussions of the caregivers' needs; suggestions for reviewing the way the need is being met locally; ideas for practical action at local level to meet the need more effectively; ideas for developing policy, organisation and training that will ensure the need is properly met; and examples from different parts of the country of how new initiatives are being developed.

COMMUNITY SERVICES; COUNSELLING; EMPLOYMENT; ETHNICITY;
INCOME SUPPORT; INSTITUTIONALISATION; NATIONAL STUDIES;
POLICY; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; RESPITE
CARE; UNITED KINGDOM

- 598 Richardson, Ann and Jane Ritchie (1989), *Letting Go: Dilemmas for Parents Whose Son or Daughter Has a Mental Handicap*, Open University Press, Milton Keynes, x, 96pp.

This book explores the feelings of parents who have an adult son or daughter with a mental handicap living at home and how they view the idea that he or she might move away. It looks at the parents' efforts to prepare themselves and their son or daughter for long-term separation and considers the experience of a few parents whose son or daughter has recently left home. It written using the parents' own words.

CASE STUDIES; DISABLED; PERSONAL NARRATIVES; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 599 Riddick, Carol Cutler, Jiska Cohen-Mansfield, Edith Fleshner and Gladys Kraft (1992), 'Caregiver adaptations to having a relative with dementia admitted to a nursing home', *Journal of Gerontological Social Work*, 19(1), 51-75.

'This study examined caregivers' adaptations to placing a relative, who suffers from dementia, in a nursing home. Relatives of 84 residents of a non-proprietary skilled nursing facility participated in the study. The perception of burden in caring for their relative decreased significantly following nursing home placement. The effects of the stress of having a loved one with dementia on caregiver's emotional adaptation and perceived burden was dependent on familial relationship. Care-receiver's acceptance of the nursing home placement and length of caregiving affected caregiver's burden, which, in turn, affected emotions regarding nursing home placement, satisfaction with nursing home, and social-recreational activities. Satisfaction with the nursing home was negatively related to the caregiver's sense of burden, to the care-receiver's resistance to nursing home placement, and to length of nursing home stay. Implications of the study are discussed.'

DEMENTIA; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 600 Rimmer, Lesley (1983), 'The economics of work and caring', in Janet Finch and Dulcie Groves, eds, *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, 131-47.

This chapter examines the economic costs of care. Firstly, in discussions about community care policies it is explicitly or implicitly assumed that they cost less. The author questions such assumptions, maintaining that such policies often appear lower in cost as they fail to recognise *all* the costs of care and fail to compensate one of the main groups of carers, married women. It then moves on to consider the private costs of care, both direct and indirect, in particular the loss of income from earnings when a carer is forced to give up paid employment or reduce hours or level of work. An attempt is made to link these private and public costs of care to provide a more

adequate assessment of the true costs of care so as to assess the adequacy of current resources directed to community care policies. Finally, it examines how changes in the future will affect the availability of informal carers and the viability of community care policies.

EMPLOYMENT; FINANCIAL ASPECTS; GENDER; POLICY; SOCIAL ASPECTS; UNITED KINGDOM

- 601 Robinson, Carol and Kirsten Stalker (1992), *Why Are We Waiting? Reducing Waiting Lists - Practical Guidance for Developing Short-Term Breaks*, HMSO, London, 39pp.

This pamphlet examines the factors which contribute to a serious shortfall in existing respite services. Many people on waiting-lists are wanting a link with another family or individual rather than a stay in a residential home. It suggests ways to recruit, train and support people who will provide short-term breaks for those on waiting-lists and proposes a number of alternative support services that can be offered to those forced to wait.

RESPITE CARE; UNITED KINGDOM

- 602 Rogerson, Barbara (1985), 'Time to ease the burden', *Community Care*, (576), August 22, 22-3.

Recent research into the role of carers of the elderly in the community in Derby, England, involved interviewing 127 people. All of those interviewed were referred to the research project because of some stress they were experiencing as carers. Most carers were women and the majority were daughters. This article gives the results of the survey. The single most important service that carers wished to receive was respite care, and policies should make services more readily available to them to enable them to continue. Further training of all staff who work with the elderly should be given priority, coupled with greater flexibility of resources to respond to crisis situations.

DAUGHTERS; GENDER; POLICY; PSYCHOLOGICAL ASPECTS; RESPITE CARE; UNITED KINGDOM

- 603 Rosenthal, Carolyn J., Sarah H. Matthews and Victor W. Marshall (1989), 'Is parent care normative? The experience of a sample of middle-aged women', *Research on Aging*, 11(2), 244-60.

'In the current literature on parent care, the assertion is made that modern women at some time in their lives may expect to be sandwiched between responsibilities to old parents and their other commitments. This article presents the distribution for a random sample of 163 women aged 40 to 69 with respect to combinations of

variables or commitment configurations that have been identified in the literature as contributing to women's being "caught in the middle." In addition, the lifetime caregiving experiences and the likelihood that those who have not yet been caregivers will be "caught" are examined for a subsample of the women. The argument is made that the adult children rather than caregivers to frail parents are the appropriate population on which to focus if the incidence and prevalence of the involvement of adult children in parent care are to be ascertained.'

DAUGHTERS; MIDDLE AGED CAREGIVERS; UNITED STATES

- 604 Rosenthal, Carolyn J., Joanne Sulman and Victor W. Marshall (1993), 'Depressive symptoms in family caregivers of long-stay patients', *The Gerontologist*, 33(2), 249-57.

'Factors contributing to depressive symptoms in a group of 67 family caregivers of hospitalized "long-stay" patients were investigated. Levels of depressive symptoms were quite high and were related to level of patient dependency, caregiver's health, feeling too many demands were being made on the caregiver, feeling torn between the patient's needs and the caregiver's own needs, not getting enough rest, amount of time spent in caregiving activities, feeling someone else could take over caregiving if necessary, and perceptions of staff. The factors contributing to depressive symptoms differed among spouses, children and other caregivers, but for all the strongest contributor was experiencing difficulty with staff.'

INSTITUTIONALISATION; LITERATURE REVIEW; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED STATES

- 605 Rossiter, Chris and Malcolm Wicks (1982), 'The future of family care', *Community Care*, September 23, 19-20.

Looking at community care policies for the elderly, the authors discuss the broad implications of changes in the family and society and what they mean for the family's capacity to continue to care for elderly relatives into the 21st century.

FAMILY; POLICY; SOCIAL ASPECTS; UNITED KINGDOM

- 606 Scharlach, Andrew E. (1987), 'Relieving feelings of strain among women with elderly mothers', *Psychology and Aging*, 2(1), 9-13.

It was 'hypothesized that feelings of strain experienced by an adult daughter are likely to interfere with the nature of her relationship with her aging mother and to have a potentially deleterious effect on the mother. To test this proposition...a study [was devised] that examined the impact of two brief interventions on 37 middle-aged women and 24 of their elderly mothers: (a) a cognitive-behavioral presentation designed to reduce the daughter's unrealistic feelings of responsibility and (b) a

supportive-educational presentation designed to increase the daughter's awareness of her mother's needs. [It was found] that the first procedure was more effective than the second in reducing the daughter's burden, improving the mother-daughter relationship, and decreasing the loneliness experienced by the elderly mother.'

DAUGHTERS; MIDDLE AGED CAREGIVERS; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED STATES

- 607 Scharlach, Andrew E. (1987), 'Role strain in mother-daughter relationships in later life', *The Gerontologist*, 27(5), 627-31.

'A role theory perspective was utilized to examine how women's perceived filial role strain can affect their relationships with their elderly mothers. Data from 40 middle-aged women and 24 of their mothers demonstrated that women who reported greater role strain had poorer quality mother-daughter relationships. Suggested by the findings is that social policies and programs which relieve the role strain experience by adult daughters may also benefit their elderly parents.'

DAUGHTERS; METHODOLOGY; POLICY; RELATIONSHIPS; UNITED STATES

- 608 Scharlach, Andrew E. (1989), 'A comparison of employed caregivers of cognitively impaired and physically impaired elderly persons', *Research on Aging*, 11(2), 225-43.

'An employee survey found that 32% of caregiving respondents were providing assistance to cognitively impaired older persons. These employees were more likely than those caring for physically impaired elders to report high levels of emotional, physical, and financial strain, and that they more often reported that caregiving had a negative effect on their personal lives and on their work. Programs considered particularly helpful by caregivers of the cognitively impaired elders included information about community resources, personal counseling, and support groups. These findings are discussed in terms of their implications for program development and for further research regarding the interface between working and caregiving.'

COMPARATIVE STUDIES; DEMENTIA; EMPLOYMENT; FINANCIAL ASPECTS; HEALTH; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 609 Scharlach, Andrew E. and Sandra L. Boyd (1989), 'Caregiving and employment: results of an employee survey', *The Gerontologist*, 29(3), 382-7.

'An employee survey (N=3,658) revealed that 23% of 1,898 respondents were assisting an elderly person. Multivariate analyses indicated that these care providers, when compared to other employees, were more likely to experience interference between their jobs and family responsibilities and more likely to miss work.'

Respondents also identified a number of employer-sponsored programs and benefits that could make it easier for them to combine work and caregiving roles.'

COMPARATIVE STUDIES; EMPLOYMENT; UNITED STATES

- 610 Scharlach, Andrew E., Eugene L. Sobel and Robert E.L. Roberts (1991), 'Employment and caregiver strain: an integrative model', *The Gerontologist*, 31(6), 778-87.

'This study examines a multifactorial model of caregiving strain and its effects in a sample of 341 employed caregivers, using a LISREL framework to estimate path coefficients. Work disruptions associated with caregiving significantly affected caregiving strain and the perceived likelihood of job termination. Work interference was in turn affected by the care recipient's level of impairment and the perceived adequacy of the support received. Respondents with more flexible job responsibilities reported lower levels of work interference than did other respondents.'

DEPENDENCY; EMPLOYMENT; METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 611 Schmidt, Gregory L. and Barbara Keyes (1985), 'Group psychotherapy with family caregivers of demented patients', *The Gerontologist*, 25(4), 347-9.

'Experience with a support group for caregivers of demented relatives led to the identification of a group defence against individual expression of painful emotions. An active psychotherapeutic approach was employed to confront this defence with no overall detriment to the group and apparent benefit to some individual members. This paper describes the dynamics of the transition from support group to therapy group.'

DEMENTIA; PSYCHOLOGICAL ASPECTS; SUPPORT GROUPS; UNITED STATES

- 612 Schneewind, Elizabeth Hughes (1990), 'The reaction of the family to the institutionalization of an elderly member: factors influencing adjustment and suggestions for easing the transition to a new life phase', *Journal of Gerontological Social Work*, 15(1/2), 121-36.

'The institutionalization of an elderly person is a crisis for the family. Using case illustrations, this article presents three major factors affecting family reactions and adjustment (the expectations of society, family roles and expectations, and the impact of the move upon daily family life), suggests that nursing home placement be

viewed as a step in the normal family life cycle, and discusses ways in which rituals could be used to ease the [transition] to the post-placement phase of the family.'

CASE STUDIES; FAMILY; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 613 Schoonover, Claire B., Elaine M. Brody, Christine Hoffman and Morton H. Kleban (1988), 'Parent care and geographically distant children', *Research on Aging*, 10(4), 472-92.

'Interviews were conducted with geographically distant adult children whose female siblings were primary caregivers for elderly widowed mothers. Female distant siblings were more likely than males to express guilt, strain, and other emotional effects deriving from the mother's situation, as well as certain intersibling tension relative to the mother's care.'

DAUGHTERS; LIVING ARRANGEMENTS; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SONS; UNITED STATES

- 614 Schott, Thomas and Bernhard Badura (1988), 'Wives of heart attack patients: the stress of caring', in Robert Anderson and Michael Bury, eds, *Living with Chronic Illness: The Experiences of Patients and Their Families*, Unwin Hyman, London, 117-36.

This chapter reports on the results of a longitudinal study. The first part presents the background, theoretical model and methodology of the study of nearly 1000 men with a first myocardial infarction. The second part considers the problems of the spouses of the heart patients and how they cope with being a main source of support for the patients. Drawing upon data from questionnaires to wives one year after the husbands' infarction, two questions are addressed: how stressful is the life-event for the patient's wife; and what conditions alleviate or aggravate the stress of caring? Conclusions drawn from the study are that research should focus more on processes within the patient's social network, and that care should be taken to involve the carers in the treatment and care of the patient.

CARDIOVASCULAR DISEASE; METHODOLOGY; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED KINGDOM

- 615 Schulz, Richard (1990), 'Theoretical perspectives on caregiving: concepts, variables, and methods', in David E. Biegel and Arthur Blum, eds, *Aging and Caregiving: Theory, Research, and Policy*, Sage, Newbury Park, Calif., 27-52.

'The central questions about caregiving are who provides what type of care to whom, and what are the costs and benefits of providing that care?...The major purpose of this chapter is to address these questions broadly and to raise a third,

often overlooked, question, namely, why do people provide informal care, despite often high costs associated with doing so? Diverse theoretical perspectives and a rich data base are brought to bear on these issues. The question of "why" is addressed first, followed by a discussion of key conceptual and methodological issues relevant to evaluating the costs and benefits of caregiving. Finally, the question of "who" is addressed by examining issues of external validity in the caregiving literature.' Measurement and sampling problems are identified in the process.

CONCEPTUAL ISSUES; LITERATURE REVIEW; METHODOLOGY; THEORY DEVELOPMENT; UNITED STATES

- 616 Schulz, Richard, Connie A. Tompkins and Marie T. Rau (1988), 'A longitudinal study of the psychosocial impact of stroke on primary support persons', *Psychology and Aging*, 3(2), 131-41.

This study 'investigated the effects of a stroke on the social support systems and well-being of the patient's primary support person, both acutely and as the condition stabilized. Individuals who had suffered a first stroke and a primary support person participated in two waves of data collection, carried out in 6-month intervals beginning 7 weeks after the stroke. [The] data show that the prevalence of depression symptoms is from 2 1/2 to 3 1/2 times higher than rates found among representative samples of middle-aged and elderly populations. Mean level of depression did not change over time, although level of optimism declined significantly. Multiple regression analyses showed that levels of depression and perceived burden in support persons are highly related to aspects of the stroke such as its severity, and that demographic variables such as age and income played a relatively minor role in attenuating these relations in the *acute* adjustment phase. However, from 7 to 9 months after the stroke, well-established demographic variables such as health, income, and age were significant predictors of depression. Individuals who were older and who had good health and higher incomes were least depressed.'

FINANCIAL ASPECTS; HEALTH; PSYCHOLOGICAL ASPECTS; STROKE; SUPPORT NETWORKS; UNITED STATES

- 617 Schulz, Richard, Paul Visintainer and Gail M. Williamson (1990), 'Psychiatric and physical morbidity effects of caregiving', *Journal of Gerontology: Psychological Sciences*, 45(5), P181-91.

'Existing empirical literature on the prolonged or cumulative consequences of exposure to the stresses of caregiving is reviewed. Specific goals are to identify psychiatric and physical morbidity effects, report the magnitude of those effects, evaluate research and analytic methods used to assess morbidity, and make recommendations for future research. Overall, the literature indicates increases in self-report psychiatric symptomatology and increases in psychiatric illness among

most caregivers when compared to population norms or appropriate control groups. However, there is very little information on the population prevalence or incidence of clinically significant psychiatric conditions attributable to caregiving. Studies of physical health effects as assessed by self-report, health care utilization, and immune function are less conclusive but, nevertheless, suggest increased vulnerability to physical illness among caregivers. We conclude with a discussion of why morbidity effects are difficult to obtain in caregiver studies and with recommendations for future research.'

EVALUATION; HEALTH; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
LITERATURE REVIEW; UNITED STATES

- 618 Scogin, Forrest, Colleen Beall, Jerry Bynum, Gretchen Stephens, Nicholas Grote, Lorin Baumhover, and John Bolland (1989), 'Training for abusive caregivers: an unconventional approach to an intervention dilemma', *Journal of Elder Abuse and Neglect*, 1(4), 73-86.

This article proposes a model of elder abuse intervention based on a recently implemented caregiver training program. 'Caregivers at-risk for abuse were offered training through mental health centers on biopsychosocial issues in aging, problem-solving, stress and anger management, and utilization of community resources...Participants experienced some reduction in symptoms of psychological distress and caregiving burden over time while symptoms worsened or remained unchanged for non-participants.'

EDUCATION; ELDER ABUSE; PSYCHOLOGICAL ASPECTS; UNITED
STATES

- 619 Scott, Jean Pearson, Karen A. Roberto and J. Thomas Hutton (1986), 'Families of Alzheimer's victims: family support to the caregivers', *Journal of the American Geriatrics Society*, 34(5), 348-54.

'This study examined the instrumental and social-emotional support provided by families to the primary caregivers of Alzheimer's patients. It was anticipated that the more adequate the support provided by the family, the less sense of burden and the better the coping effectiveness of the caregiver. Ratings of instrumental assistance, social-emotional support, adequacy of support, and coping effectiveness were made by trained raters from transcribed interviews with 23 primary caregivers. Also, a second family member who was usually next closest of kin to the caregiver was interviewed in order to provide another perspective of the support the family provided. While the major caregiving tasks were performed by the primary caregiver, the types of assistance from family that seemed most appreciated were visits and having persons stay with the patient so that the caregiver could take a trip, rest, run errands, or get out of the house for social activities. The majority of caregivers felt a high degree of support from their families and reported low levels of

emotional upset resulting from family support efforts. The most common family problems reported were lack of visits, disagreement over level of patient's mental and physical functioning, and disagreement over the type of care required. The data confirmed the hypothesis that family support was positively associated with the caregiver's coping effectiveness. In addition, caregivers who did not receive enough support were most burdened; however, the group receiving the greatest amount of support was the next most burdened, a finding which was unanticipated...Implications for strengthening family support to caregivers of Alzheimer's patients are discussed.'

DEMENTIA; FAMILY; RESPITE CARE; SUPPORT NETWORKS; UNITED STATES

- 620 Seccombe, Karen (1992), 'Employment, the family, and employer-based policies', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 165-80.

'This chapter discusses the reciprocal relationship between caregiving and employment - both the impact of caregiving on women's employment and the ways in which women's employment is changing, and will continue to change, the nature of the caregiving relationship. Employer-based options and policies are being added to the agenda of caregiving discussion throughout the country', the United States, and these options are explored here. Opportunities for and constraints on women's employment and the family economy are discussed.

EMPLOYMENT; FINANCIAL ASPECTS; GENDER; POLICY; RELATIONSHIPS; UNITED STATES

- 621 Seelbach, Wayne C. (1984), 'Filial responsibility and the care of aging family members', in William H. Quinn and George A. Hughston, eds, *Independent Aging: Family and Social Systems Perspectives*, Aspen Systems Corporation, Rockville, Md.:92-105.

This chapter reviews the concept of filial responsibility in relation to the maintenance of independence for the elderly. It describes the nature of filial responsibility in industrial societies; identifies empirically validated patterns of filial responsibility; and discusses some trends and issues concerning the concept.

CONCEPTUAL ISSUES; DAUGHTERS; SONS; UNITED STATES

- 622 Seltzer, Marsha Mailick, Joann Ivry and Leon C. Litchfield (1987), 'Family members as case managers: partnership between the formal and informal support networks', *The Gerontologist*, 27(6), 722-8.

'Elderly persons (mean age=83) were randomly assigned to either an experimental group (n=81) in which family members (mean age=62) participated in a case management training program, or to a control group (n=76). Following training, family members in the experimental group performed a significantly greater number of case management tasks on behalf of their elderly relatives than family members in the control group. Further, the duration of services was significantly shorter for elderly persons in the experimental group.'

COMPARATIVE STUDIES; EDUCATION; UNITED STATES

- 623 Semple, Shirley J. (1992), 'Conflict in Alzheimer's caregiving families: its dimensions and consequences', *The Gerontologist*, 32(5), 648-55.

'This paper views conflict in Alzheimer's caregiving families as a multidimensional construct. Three conceptually distinct dimensions for family conflict are described and examined in relation to depression and anger. Regression analyses indicate that conflict involving family members' attitudes and actions toward the caregiver are associated with increased risk for depression among caregivers, whereas conflicts stemming from family members' attitudes and behaviors toward the patient are most likely to result in anger. Self-concepts and normative expectations are implicated as key explanatory variables.'

CONCEPTUAL ISSUES; DEMENTIA; FAMILY; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; UNITED STATES

- 624 Shimizu, Y., D. Maeda, H. Asano, T. Okamoto and N. Noguchi (1983), 'Factors influencing the expression of need for homehelp service among families caring for the impaired elderly', *Australian Journal on Ageing*, 2(3), 21-4.

This paper assesses the effects of various social and demographic variables on the discrepancy between objective and subjective needs for home help services in Japan. The sample for the study was 179 families in Japan caring for the impaired elderly. Among the respondents, 52 per cent expressed a need for home help and 48 per cent did not want it. Nineteen independent variables in five groupings were used: demographic and socioeconomic characteristics; family care situation; respondent's characteristics; elderly person's social roles and contacts; and elderly persons impairments and capability of the family to provide needed care. It was found that

there is a strong possibility of increase in need with familial and social changes in the future.

DEMOGRAPHIC ASPECTS; METHODOLOGY; SERVICE USE;
SOCIOECONOMIC STATUS; JAPAN

- 625 Siim, Birte (1990), 'Women and the welfare state: between private and public dependence: a comparative approach to care work in Denmark and Britain', in Clare Ungerson ed., *Gender and Caring: Work and Welfare in Britain and Scandinavia*, Harvester Wheatsheaf, Hemel Hempstead, Herts., 80-109.

'The purpose of this paper is to analyse how women's position in Denmark and Britain can be related to differences in organization of social reproduction in the modern "welfare state". The paper will focus on the institutional differences in the organization of social reproduction of individuals and households in relation to care for children, the sick, the old and the disabled.' It is argued that the differences have had important consequences for the position of women in society.

COMPARATIVE STUDIES; GENDER; SOCIAL ASPECTS; DENMARK;
UNITED KINGDOM

- 626 Silliman, Rebecca A. and Josef Sternberg (1988), 'Family caregiving: impact of patient functioning and underlying causes of dependency', *The Gerontologist*, 28(3), 377-81.

'Diseases affect the health and functional status of patients in different ways and, in turn, have variable impacts on their family caregivers. Using hip fracture, dementia, and stroke as examples, illustrated is how physical, and cognitive disabilities place different demands on caregivers.'

DEMENTIA; DEPENDENCY; HEALTH; PSYCHOLOGICAL ASPECTS;
SOCIAL ASPECTS; STROKE; UNITED STATES

- 627 Sinclair, Ian (1990), 'Carers: their contribution and quality of life', in Ian Sinclair, Roy Parker, Diana Leat and Jenny Williams, *The Kaleidoscope of Care: A Review of Research on Welfare Provision for Elderly People*, HMSO, London, 87-105.

This chapter looks at studies of the support which elderly people receive from relatives, neighbours and friends and considers: the classification of types of care; the pattern of care, who cares for whom, why, in what way and under what circumstances; and the experience of care, in particular, what are the costs and benefits of caring? 'Evidence on these matters clears the ground for a discussion of the viability of care by the community; that is, for a discussion of how far informal

care can or should be expected to cater for the needs of a high proportion of dependent elderly people, upon what terms and with what support.'

POLICY; SUPPORT NETWORKS; UNITED KINGDOM

- 628 Sinclair, Ian and Jenny Williams (1989), *Welfare Provision for the Elderly: Social and Demographic Background*, EEC Project Report 1, National Institute for Social Work, Research Unit, London, 139pp.

This report is concerned with the numbers of old people who appear to have particular kinds of problems; the impact of these problems on quality of life and coping; the willingness of carers to care, the kinds of care they provide and the rewards and burdens of caring; and the degree to which statutory services ensure community care.

COMMUNITY SERVICES; DEMOGRAPHIC ASPECTS; SOCIAL ASPECTS; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 629 Sivley, J.P. and J.J. Fiegener (1984), 'Family caregivers of the elderly: assistance provided after termination of chore services', *Journal of Gerontological Social Work*, 8(1-2), 23-34.

'Two groups of primary caregivers were interviewed: one whose older relatives received assistance from an in-home chore services program and the other whose relatives had been terminated from service owing to budget reductions. Both groups of caregivers were found to be actively involved in providing care to their older relatives. The assistance that caregivers provided was similar whether or not their relatives received chore services. No significant differences were found in the type of tasks they provided nor in the amount and length of time they have provided care. The data suggest that there may be limits to the assistance that these caregivers can provide and that care of the elderly beyond such limitations needs to be supplied by other sources.'

COMMUNITY SERVICES; COMPARATIVE STUDIES; SERVICE USE; UNITED STATES

- 630 Skaff, Marilyn M. and Leonard I. Pearlin (1992), 'Caregiving: role engulfment and the loss of self', *The Gerontologist*, 32(5), 656-64.

'"Loss of self" was examined in a sample of spouses and adult children caring for a relative with Alzheimer's disease. Defined as a loss of identity that comes about as a result of engulfment in the caregiver role, it was found to be more common among spouses, females, and younger caregivers. Limited social contact and lack of social roles outside that of the caregiver were found to be related to greater loss of self. It is

associated with lower self-esteem and mastery and with greater depressive symptomatology.'

DAUGHTERS; DEMENTIA; GENDER; PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; SONS; SPOUSES; UNITED STATES

- 631 Skelly, Margaret C., Carolyn M. McAdoo and Susan M. Ostergard (1993), 'Caregiver burden at McGuire Veterans Administration Medical Center', *Journal of Gerontological Social Work*, 19(3/4), 3-13.

'A quasi-experimental design was used to evaluate a Veterans Administration Respite Care Program's effectiveness in reducing caregiver burden. Sixteen caregivers, who had used respite care, comprised the experimental group. Fourteen caregivers, who had not received respite care, comprised the control group. A multi-dimensional perspective considering veterans' ADL impairment, veterans' memory and behavior problems, and the caregivers' perception of the situation was used. All data were gathered through telephone interviews. A T-test ($\alpha = .05$) revealed a significant difference ($p = .006$) in ADL impairment between the two groups. Pearson's Correlation ($\alpha = .05$) revealed a significant correlation ($r = .7348$, $p = .006$) between memory and behavior problems and burden among the non-respite group, but not among the respite group ($r = .4262$, $p = .100$). These findings indicate that respite care reduces caregiver burden related to memory and behavior problems.'

CONCEPTUAL ISSUES; DEMENTIA; EVALUATION; PSYCHOLOGICAL ASPECTS; RESPITE CARE; UNITED STATES

- 632 Slack, Patricia and Frank Mulville (1988), *Sweet Adeline: A Journey through Care*, Macmillan, Basingstoke, Hants., x, 209pp.

At the age of 75, Patricia Slack's mother, Adeline, suffered a stroke leaving her wheelchair-bound and unable to read, write or speak. This is a very personal account by Patricia Slack, a qualified nurse, and her partner, Frank Mulville, of their experiences in the long-term care of Adeline until her death. It tells the story 'of how they contended with poor hospital care, the bureaucracy of state services and how they decided on Adeline's long-term care.' It speaks in detail of coping with 'the practicalities and emotional traumas of severe handicap' interesting to professionals and the general reader. There is a concluding chapter of practical advice for carers, a list of useful addresses and further reading.

CASE STUDIES; COMMUNITY SERVICES; PERSONAL NARRATIVES; PSYCHOLOGICAL ASPECTS; QUALITATIVE STUDIES; STROKE; UNITED KINGDOM

- 633 Smith, Gregory C. and Sheldon S. Tobin (1989), 'Permanency planning among older parents of adults with lifelong disabilities', *Journal of Gerontological Social Work*, 14(3/4), 35-59.

'Older parents must be assisted in making permanency plans for their adult dependent offspring. Although attention has been given to the accelerating numbers of adults with life-long disabilities and the elderly parents who care for them at home, there has been a lack of attention for how these parents must cope with the future of their offspring when they can no longer continue as caregivers. As a step towards filling this lacuna, the current state of knowledge is reviewed encompassing the epidemiology of these families; residential, legal and financial options associated with permanency planning; interaction of older parents with formal service systems; factors predictive of the propensity of parents to engage in permanency planning; and the benefits derived by elderly parents from having made plans for the future well-being of their dependent offspring.'

AGED CAREGIVERS; DISABLED; FINANCIAL ASPECTS;
INSTITUTIONALISATION; LEGAL ASPECTS; LITERATURE REVIEW;
MENTAL ILLNESS; UNITED STATES

- 634 Smith, Gregory C., Mary F. Smith and Ronald W. Toseland (1991), 'Problems identified by family caregivers in counseling', *The Gerontologist*, 31(1), 15-22.

'Content analysis of the problems that caregiving daughters and daughters-in-law (N=51) elected to work on during counseling yielded seven categories: improving coping skills, meeting elder's care needs, responding to family issues, concern over the caregiver-recipient relationship, eliciting formal and informal supports, feelings of inadequacy and guilt, and planning for elder's future. Two global themes of maintaining control and increasing responsibility within the caregiver role were also evident. Case examples illustrate problems, and practice implications are considered.'

CASE STUDIES; COUNSELLING; DAUGHTERS; UNITED STATES

- 635 Smith, Jo and Max Birchwood (1990), 'Relatives and patients as partners in the management of schizophrenia: the development of a service model', *British Journal of Psychiatry*, 156, 654-60.

'Considerable advances have been made in the family management of schizophrenia but there remains a major challenge for the psychiatric services to integrate these innovations into clinical practice. A number of important issues need to be considered in developing routine clinical services: the problem of engaging families in a therapeutic programme; the utility of the concept of "expressed emotion"; and procedures for clinical practice. The latter include the needs of low-EE families; maintaining quality of intervention in a clinical context; responding to the

multiplicity of needs of the patient and family; and integrating family interventions with ongoing rehabilitation practice. A model of service provision is described.'

COMMUNITY SERVICES; FAMILY; MENTAL ILLNESS; UNITED KINGDOM

- 636 Snyder, Barbara and Kathy Keefe (1985), 'The unmet needs of family caregivers for frail and disabled adults', *Social Work in Health Care*, 10(3), 1-14.

'This study examines the efforts and needs associated with family care for disabled and frail adults. A survey of 117 primary caregivers focused on: the health problems associated with caregiving, the existence of informal, family support systems, use of formal services, and the need for additional social service programs. Most caregivers report physical and emotional problems due to caregiving ranging from hypertension and health problems to depression and mental exhaustion. The characteristics of caregivers at high risk for health problems are identified. More than half of the caregivers have family or friends to assist them in caregiving. At least one type of social service was being used by over 80% of caregivers, with utilization patterns in male and female caregivers. Based on the study's findings, several policy implications are reviewed.'

FAMILY; GENDER; HEALTH; POLICY; PSYCHOLOGICAL ASPECTS; SERVICE USE; SUPPORT NETWORKS; UNITED KINGDOM

- 637 Soldo, Beth J. and Jaana Myllyluoma (1983), 'Caregivers who live with dependent elderly', *The Gerontologist*, 23(6), 605-11.

'Although research on caregivers to impaired elderly is accumulating rapidly, most prior studies are small area analyses of non-probability samples. This study adapts a secondary but nationally representative data base to construct statistical profiles of intrahousehold caregivers in three types of households. The potential for disruption of each type of caregiving arrangement is examined in terms of the care needs of the older person and the competing demands on the caregivers. Situations where care is provided to a dependent, unmarried relative appear to be most vulnerable to dissolution.'

LIVING ARRANGEMENTS; NATIONAL STUDIES; STATISTICS; UNITED STATES

- 638 Spitze, Glenna and John Logan (1990), 'More evidence on women (and men) in the middle', *Research on Aging*, 12(2), 182-98.

'A recent article by Rosenthal, Matthews and Marshall (1989) focused on two related questions: How typical is Brody's "women in the middle" and how "normative" is parent care? This research builds on their work by presenting similar

analyses for a somewhat larger probability sample of middle-aged women from a U.S. metropolitan area, by presenting parallel analyses for men in the same age groups, and by presenting data on more active measures for an expanded set of roles and role combinations not included in the original article. The four major roles analyzed by Rosenthal et al. (spouse, paid worker, adult child of aging parent, and parent) are found to be typical of those in their forties and early fifties, but each falls off rapidly after that point. Men are almost as likely to experience each of these as women, and more likely to be married. When measures of more active involvement in these roles are examined, much smaller percentages of women or men are seen participating at any given age, and the combination of full-time work, active parenting, and helping or living with parents is uncommon. It is suggested that the situation described by Brody is not typical of middle-aged women or men in the U.S. today at any given time, but that collection of data on histories of caregiving is needed.'

COMPARATIVE STUDIES; EMPLOYMENT; GENDER; LIVING
ARRANGEMENTS; MIDDLE AGED CAREGIVERS; UNITED STATES

- 639 Spitze, Glenna and John Logan (1990), 'Sons, daughters, and intergenerational social support', *Journal of Marriage and the Family*, 52(2), 420-30.

'This study examines the effects of the number and gender composition of children on the receipt of social support by older persons. Effects vary with type of support: having daughters is most salient for telephone contact, while frequency of visiting is affected by both gender and number of children. Living with children is influenced by the number but not gender of children. Finally, the key to receiving help is having at least one daughter, but there is no advantage of additional children of either gender. Gender effects may be most salient for types of social support that can be provided without the participation of the helper's family. Findings are discussed in relation to models previously applied to support from different types of primary groups.'

DAUGHTERS; LIVING ARRANGEMENTS; SONS; UNITED STATES

- 640 Spitze, Glenna and John R. Logan (1992), 'Helping as a component of parent-adult child relations', *Research on Aging*, 14(3), 291-312.

'Much research on intergenerational helping has focused on help from adult children to parents, but few studies have examined help in both directions. This article focuses on the frequency of several types of help between parents and adult children and the manner in which helping relationships evolve throughout the life course of adult children and their middle-aged and elderly parents. It focuses on the role of age, gender, and needs and availability of parents and children, using data from a local probability sample survey. The results show that most kinds of household help are given more frequently by parents to children than by children to parents. Parents

above age 75 receive more help than they give, but even at that age, help occurs only in the minority of cases. There is no consistent gender pattern for parent-to-child help. Older mothers, however, receive substantially more help than do fathers. Infrequent but regular help with tasks of everyday living characterizes many of these relationships, and such help is not necessarily predicated on frailty or inability to do the task oneself. Implications of the results for future data collection are discussed.'

DAUGHTERS; RELATIONSHIPS; SONS; UNITED STATES

- 641 Springer, Dianne and Timothy H. Brubaker (1984), *Family Caregivers and Dependent Elderly: Minimizing Stress and Maximizing Independence*, Sage Human Services Guide No.38, Sage, Beverly Hills, Calif., 159pp.

This book provides carers of elderly people with information about the ageing process and the caregiving relationship. Its primary focus is practical and aims at minimising stress to the carers whilst at the same time maximising independence in the elderly. It shows the caregiver ways in which to cope with the difficulties related to the caregiving role, such as communication skills, informal support systems and the formal supports which may be available. At the end of each chapter there are suggestions for practice.

EDUCATION; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 642 Staight, Paula R. and S. Marie Harvey (1990), 'Caregiver burden: a comparison between elderly women as primary and secondary caregivers for their spouses', *Journal of Gerontological Social Work*, 15(11/2), 89-104.

'The overall purpose of this research was to examine the burdens of caregiving on elderly women who serve as primary and secondary caregivers for their impaired spouses. Fifty women 60 years and older identified as spousal caregivers participated in an in-person structured interview. Data were analyzed to compare primary caregivers (caregivers living with their spouses) and secondary caregivers (caregivers with institutionalized spouses) on the following factors: loneliness, depression, time constraints, perceived health status, financial status and perceived life satisfaction. Findings suggest that both groups of women are equally susceptible to the burdens inherent in caregiving. Time constraints were identified as the one major difference between caregiver groups. In addition, the results indicate that spousal caregivers, both primary and secondary, are an at-risk population and are especially vulnerable to loneliness, mild depression, financial worries and low life satisfaction.'

AGED CAREGIVERS; COMPARATIVE STUDIES; HEALTH; INSTITUTIONALISATION; LIVING ARRANGEMENTS; PSYCHOLOGICAL ASPECTS; SPOUSES; UNITED STATES

- 643 Steinmetz, Suzanne K. (1988), *Duty Bound: Elder Abuse and Family Care*, Sage Library of Social Research Vol.166, Sage, Newbury Park, Calif., 288pp.

This book examines the impact that caring for an elderly parent had on the lives of 104 middle-aged and older caregiving offspring to their 119 elderly kin that made up the sample. 'The daily tasks that were provided for the elderly by these caregivers and the resulting stress, conflict, and abuse is detailed. The tremendous sacrifices that these 104 caregivers and their families made in order to care for the 119 elderly kin that composed the sample were remarkable. In most instances, these caregivers probably represented model caregivers, yet the psychological, verbal, and physical abuse that they perpetrated on the elders was astonishing.' Approximately 23 per cent engaged in abuse with the potential for severe physical harm to the elder.

AGED CAREGIVERS; ELDER ABUSE; MIDDLE AGED CAREGIVERS;
UNITED STATES

- 644 Steinmetz, Suzanne K. and Deborah J. Amsden (1983), 'Dependent elders, family stress and abuse', in Timothy H. Brubaker, *Family Relationships in Later Life*, Sage, Beverly Hills, Calif., 173-92.

The additional burden of caregiving for an elderly parent on top of the caregivers responsibilities for children, retirement, physical, emotional and social changes can become a source of crisis with the potential for abuse and neglect. 'The goal of this study is to ascertain the relationship between dependency measured by the frequency with which tasks or services need to be provided for the elderly, stress as perceived by the caregivers, and the abusive techniques utilized to gain or maintain control...The data clearly indicate that social/emotional and mental health dependencies are the most stress- and violence-producing.'

DEPENDENCY; ELDER ABUSE; MIDDLE AGED CAREGIVERS;
PSYCHOLOGICAL ASPECTS; UNITED STATES

- 645 Stephens, Susan and Jon Christianson (1986), *Informal Care of the Elderly*, Lexington Books, Lexington, Mass., 174pp.

This book describes the characteristics and experiences of individuals who regularly provide assistance to their elderly relatives and friends. It includes a study of 2,000 subjects who are primary caregivers to older persons at risk of institutionalisation. It covers policy and informal support of the elderly, the channeling study of informal caregivers, care by primary informal caregivers, informal caregiving networks, informal financial assistance, and the well-being of caregivers. The coded survey instrument is included.

FINANCIAL ASPECTS; METHODOLOGY; NATIONAL STUDIES;
PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 646 Stoller, Eleanor Palo (1983), 'Parental caregiving by adult children', *Journal of Marriage and the Family*, 45(4), 851-8.

'Recent research in social gerontology has highlighted the importance of family, particularly adult daughters, as caregivers for the impaired and chronically ill community-based elderly. This paper explores the impact of employment and competing familial responsibilities on the level of assistance provided to elderly parents by adult children. Data were collected through personal interviews with a probability sample of noninstitutionalized elderly persons (N=753) and their informal helpers (N=502). Analysis is restricted to informal helpers who are sons or daughters of the older respondent. Hours of assistance varied in response to the level of parental impairment. The presence of the older parent's spouse was negatively related to hours of help. Competing demands on the helper's time, particularly marital status, had a significant impact, with married children providing less help. Being employed significantly decreased the hours of assistance provided by sons but did not have a significant impact on the hours of assistance provided by daughters.'

DAUGHTERS; EMPLOYMENT; SONS; UNITED STATES

- 647 Stoller, Eleanor Palo (1985), 'Exchange patterns in the informal support networks of the elderly: the impact of reciprocity on morale', *Journal of Marriage and the Family*, 47(2), 335-42.

'Patterns of exchange of assistance within the informal helping networks of the elderly are examined through analysis of interviews with a probability sample of 753 noninstitutionalized older persons. Most elders are involved in some type of exchange, although the proportion reporting no exchange increases as one moves from children to other relatives to friends or neighbors. Older persons who receive help usually reciprocate in some way, with the prevalence of unreciprocated assistance higher in relationships with family members than with friends or neighbors. Multiple discriminant analysis of exchange patterns produced two significant functions, the first differentiating receivers from nonreceivers and the second providers from nonproviders of help. Consistent with an exchange theory perspective, the analyses suggested that the inability to reciprocate rather than the need for assistance had a greater negative effect on morale. The data also showed a negative relationship between scope of formal service use and reliance on the informal network, a result consistent with both a possible substitution effect and/or appropriate targeting of formal services.'

RELATIONSHIPS; SERVICE USE; SUPPORT NETWORKS; UNITED STATES

- 648 Stoller, Eleanor Palo (1992), 'Gender differences in the experience of caregiving spouses', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 49-64.

'This chapter examines the experiences of husbands and wives caring for disabled partners. The first section summarizes research contrasting spouses with other caregivers. The second section explores similarities and differences in the caregiving experiences of husbands and wives. Special attention is given to the ways in which gender structures the meaning and consequences of the role of caregiver. The chapter concludes with a summary of shortcomings in the available literature and offers suggestions for future research.'

COMPARATIVE STUDIES; GENDER; LITERATURE REVIEW; SPOUSES; UNITED STATES

- 649 Stoller, Eleanor Palo and Lorna M. Earl (1983), 'Help with activities of everyday life: sources of support for the noninstitutionalized elderly', *The Gerontologist*, 23(1), 64-70.

'This paper explores sources of instrumental support for older persons of varying levels of functional capacity. Data were gathered through interviews with a probability sample of 753 noninstitutionalized elderly residing in northeastern New York. The analysis suggests that spouses are the primary source of help for married elders with impaired capacity, and adds daughters are the major helpers when a spouse is not present or when the level of support provided by the spouse is not sufficient. Helping networks increase in both size and scope when functional capacity declines.'

DAUGHTERS; SPOUSES; SUPPORT NETWORKS; UNITED STATES

- 650 Stoller, Eleanor Palo and Karen L. Pugliesi (1989), 'Other roles of caregivers: competing responsibilities or supportive resources', *Journal of Gerontology: Social Sciences*, 44(6), S231-8.

'Although the majority of research has conceptualized other roles of caregivers as competing commitments, a growing body of literature views multiple roles as supportive resources. This study examined the impact of multiple roles on the caregiving experience among informal helpers of a probability sample of elderly people living in a community setting. Results indicate that other roles, particularly when caregiving involves a large time commitment, do contribute to burden. However, other roles, especially roles outside the family, are also associated with improved caregiver well-being.'

PSYCHOLOGICAL ASPECTS; SOCIAL ASPECTS; UNITED STATES

- 651 Stoller, Eleanor Palo and Stephen J. Cutler (1992), 'The impact of gender configurations of care among married elderly couples', *Research on Aging*, 14(3), 313-30.

'This article analyzes data from the Supplement on Aging in the National Health Interview Survey to examine gender differences in the configuration of care among married elderly couples living in two-person households. The rational choice model provides the conceptual framework for the analysis. Results support the hypothesis that husband caregivers are more likely to incorporate extra-household assistance than are wife caregivers. There were no gender differences, however, in the source of extra-household assistance.'

GENDER; NATIONAL STUDIES; SERVICE USE; SPOUSES; THEORY
DEVELOPMENT; UNITED STATES

- 652 Stoller, Eleanor Palo, Lorna Earl Forster and Tamara Sutin Duniho (1992), 'Systems of parent care within sibling networks', *Research on Aging*, 14(3), 28-49.

'This article examines factors related to the participation of adult children in their elderly parents' helping networks. A three-stage decision model was tested which predicts the likelihood that: (a) an adult child is named as a helper by elderly respondents who have at least one living child; (b) an adult child is chosen as the primary helper in networks including at least one adult child; and (c) among those networks containing at least one son and one daughter (one of whom was named as the primary helper), a son is selected rather than a daughter as the primary helper. The analysis revealed the importance of geographic proximity in predicting the involvement of adult children in parental helping networks. The integral role of daughters and other female family members was also highlighted. Other factors, such as parents' marital status, gender, level of functional impairment, and family structure, were also examined.'

DAUGHTERS; FAMILY; SONS; UNITED STATES

- 653 Stommel, Manfred, Charles W. Given and Barbara Given (1990), 'Depression as an overriding variable explaining caregiver burden', *Journal of Aging and Health*, 2(1), 81-102.

'This research examines the relationship between caregiver burdens and caregiver depression. Five measures of burdens were designed to capture the specificity of psychological reactions to caregiving tasks and processes. In addition, an attempt was made to develop strictly behavioral measures of caregiving processes (e.g. caregiver involvement or support from others) to explore the sensitivity of burden measures to "objective" caregiving conditions. Finally...the CES-D [was employed] as a measure of caregiver depression. Major findings include (a) Caregiving processes affect various dimensions of burdens in largely different ways; but (b)

Caregiver depression appears to dominate caregiver perceptions of burdens across all burden dimensions. The results lead us to stress that burdens express evaluations of the caregiving situation in the light of more general affective states. This analysis is based on the first wave of a longitudinal study of caregiver-patient dyads in lower Michigan (N=307).'

METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 654 Stone, Robyn, Gail Lee Cafferata and Judith Sangl (1987), 'Caregivers of the frail elderly: a national profile', *The Gerontologist*, 27(5), 616-26.

'The 1982 National Long-Term Care Survey and Informal Caregivers Survey provided data for the first national estimates of informal caregivers to noninstitutionalized disabled elders. The descriptive profile confirmed previous research findings that informal caregivers are predominantly female, that a sizeable proportion is over age 65, and that a minority use formal services. There also was evidence for competing demands: 21% reported child care responsibilities, 9% indicated that they had quit their jobs, and 20% reported other work conflict.'

AGED CAREGIVERS; EMPLOYMENT; GENDER; MIDDLE AGED
CAREGIVERS; NATIONAL STUDIES; SERVICE USE; UNITED STATES

- 655 Stone, Robyn I. and Peter Kemper (1990), 'Spouses and children of disabled elders: how large a constituency for long-term care reform?' *The Milbank Quarterly*, 67(3/4), 485-506.

As population ageing increases so does concern about financing and delivering long-term care to the elderly population. Regardless of the options pursued, the family is, and will continue to be, a critical component of the long-term care system and policy makers have begun to recognise the link between long-term care policies and family needs. 'The purpose of this article is to describe the population potentially affected by long-term care policy as family members - both the larger population of immediate kin who are potential caregivers and the smaller population of active caregivers. Specifically, the article estimates the number of persons in the United States who are spouses or children of disabled elders, describes their characteristics, and compares them to the entire United States population. The article then estimates the number of spouses and children who actually give care and estimates the prevalence of caregiving among age groups. Finally, it estimates the size of the population affected most intensely, i.e., active caregivers who have competing responsibilities for child care or employment.'

DAUGHTERS; DEMOGRAPHIC ASPECTS; EMPLOYMENT; FAMILY;
NATIONAL STUDIES; SONS; SPOUSES; UNITED STATES

- 656 Strawbridge, William J. and Margaret I. Wallhagen (1991), 'Impact of family conflict on adult child caregivers', *The Gerontologist*, 31(6), 770-7.

'Family conflict is an overlooked yet potentially critical component of the caregiving experience. In a study of 100 child caregivers, 40% were experiencing relatively serious conflict with another family member, usually a sibling. Most conflict arose because the relative failed to provide sufficient help. Path analysis revealed that caregivers experiencing family conflict had significantly higher perceived burden and poorer mental health than did caregivers without conflict, even when quality of the caregiver's relationship with the parent, extent of caregiver tasks, income, gender, and age were taken into account.'

DAUGHTERS; FAMILY; FINANCIAL ASPECTS; GENDER; METHODOLOGY; PSYCHOLOGICAL ASPECTS; RELATIONSHIPS; SONS; UNITED STATES

- 657 Strawbridge, William J. and Margaret I. Wallhagen (1992), 'Is all in the family always best? *Journal of Aging Studies*, 6(1), 81-92.

'While important, family care for frail elders is not always appropriate and should be but one option in long-term care. The present focus on expanding family care includes unsupported assumptions - that long-term care costs will be decreased, that family relationships are the main source of elderly psychological support, that all family members want to care for one another, and that family care invariably has a higher quality than institutional care. Strongly promoting family care has unintended negative consequences; it can impede efforts to promote income and employment equality for women, delay needed quality improvements in institutional care, and increase the guilt felt by relatives of institutionalized family members. Rather than a single focus on family care, we need to work for parallel improvements in the quality and acceptability of institutional care. Families could then arrange the type of care that would be most efficacious for all concerned.'

FAMILY; GENDER; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 658 Strong, Catherine (1984), 'Stress and caring for elderly relatives: interpretations and coping strategies in an American Indian and white sample', *The Gerontologist*, 24(3), 251-6.

'This study explores how families who care for their elderly relatives view their caretaking situations. The stressful event literature suggests that a variety of dimensions may influence a person's subsequent coping behavior. In semi-structured interviews with 10 white caretakers of ill elderly relatives in the rural northwest, 11 dimensions were used to define caretaking, with a focus on control. The results

imply that cultural background influences the meaning of caretaking and that both variables affect the coping strategies selected.'

ETHNICITY; PSYCHOLOGICAL ASPECTS; RURAL ASPECTS; UNITED STATES

- 659 Stull, Donald E., Karl Kosloski and Kyle Kercher (1994), 'Caregiver burden and generic well-being: opposite sides of the same coin? *The Gerontologist*, 34(1), 88-94.

'Caregiver burden is one of the most commonly used variables in caregiving research, both as a predictor and as an outcome. It has been suggested that caregiver burden can be measured in terms of discrete dimensions of well-being and that burden and well-being represent opposite sides of the same coin. The goal of this study was to explore this issue further by comparing commonly used dimensions of burden with parallel dimensions of well-being, both as outcome variables and as predictors of other outcomes, in a sample of caregivers. The findings suggest that burden may tap a unique domain of caregiving outcomes that is not represented by more objective indicators of these effects. Dismissing burden as an unnecessary or redundant construct seems premature.'

METHODOLOGY; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 660 Suitor, J. Jill and Karl Pillemer (1990), 'Transition to the status of family caregiver: a new framework for studying social support and well-being', in Sidney M. Stahl, ed., *The Legacy of Longevity: Health and Health Care in Later Life*, Sage, Newbury Park, Calif., 310-20.

'The purpose of this chapter is to develop a conceptual framework for studying the role of social support in family caregivers' well-being and to discuss the implications of utilizing this framework.' It pays particular attention to the structural dimensions of individuals' social networks which may affect the receipt of support. Although there are numerous aspects of network structure, the authors address only one here, namely, status similarity between the caregiver and members of his or her network.

SOCIAL SUPPORT NETWORKS; SOCIOECONOMIC STATUS; THEORY DEVELOPMENT; UNITED STATES

- 661 Sundström, Gerdt (1986), 'Family and state: recent trends in the care of the aged in Sweden', *Ageing and Society*, 6(2), 169-96.

'Drawing upon a variety of research data and national statistics, this paper presents a detailed analysis of the contribution made by family and informal care to the support of elderly Scandinavians. Comparative data from other countries are employed to highlight some similarities with other European, American and Far Eastern societies.'

Formal help is directed at the childless and those who live alone, but the conclusions draw attention to the dangers of this concentration if it excludes essential support to overburdened carers.'

INTERNATIONAL COMPARISONS; NATIONAL STUDIES; POLICY; STATISTICS; SWEDEN

- 662 Sung, Kyu-taik (1990), 'A new look at filial piety: ideals and practices of family-centered parent care in Korea', *The Gerontologist*, 30(5), 610-7.

'This paper presents results of the analysis of 817 stories about Koreans who exemplify filial piety, a dominant value of East Asian nations. Corollaries were identified, such as types of care and services provided to elderly parents, motives for filial piety, kinds of emphases given in filial duties, and sacrifices endured for parents. The most outstanding dimensions underlying filial piety were respect, responsibility, family harmony and sacrifice. Findings provide both conceptual and practical tools for understanding and practicing filial piety.'

DAUGHTERS; SONS; KOREA

- 663 Tennstedt, Sharon L., John B. McKinlay and Lisa M. Sullivan (1989), 'Informal care for frail elders: the role of secondary caregivers', *The Gerontologist*, 29(5), 677-83.

'Although the majority of informal care is provided by one person, most elders receive help from other caregivers as well. This paper describes the identity and activities of these secondary caregivers, who are often the spouse and children of the primary caregiver. They provide a wide variety of help, but much less than the primary caregiver. Further, this help is provided in a pattern supplementary rather than complementary to that of the primary caregiver.'

SUPPORT NETWORKS; UNITED STATES

- 664 Tennstedt, Sharon L. and John B. McKinlay (1989), 'Informal care for frail older persons', in Marcia G. Ory and Kathleen Bond, eds, *Aging and Health Care: Social Science and Policy Perspectives*, Contemporary Issues in Health, Medicine and Social Policy, Routledge, London, 145-66.

'This chapter provides an overview of empirical data on informal care as a background to understanding and analyzing current public policy questions regarding long-term care.' It begins with the historical development of empirical work. It describes study findings focusing on who receives informal care, who provides this care, types and amounts of informal care, and the effects of caregiving. Specific findings from a cross-sectional study by the authors illustrates trends and

inconsistencies in available data. The chapter concludes with a discussion of the implications of the data for current public policy questions and initiatives.

HISTORICAL ASPECTS; METHODOLOGY; POLICY; STATISTICS; UNITED STATES

- 665 Tennstedt, Sharon L., Sybil Crawford and John B. McKinley (1993), 'Determining the pattern of community care: is coresidence more important than caregiver relationship?' *Journal of Gerontology: Social Sciences*, 48(2), S74-S83.

'Researchers have previously emphasized the importance of kinship tie to explain the pattern of care received by a disabled elder. For example, it has been argued that spouses are a distinct group of caregivers, i.e., they provide more care with less help from others and experience more stress. However, based on the theory of primary group structures and functions, this study hypothesizes that coresidence rather than the kinship tie is more important in determining the pattern of caregiving. When spouses are compared with other coresiding caregivers, patterns of informal care and use of formal services are similar. Variance in amounts of informal care is explained by elder gender and frailty level rather than by caregiver relationship. Similarly, level of frailty was the only important predictor of use of formal services.'

FAMILY; LIVING ARRANGEMENTS; METHODOLOGY; RELATIONSHIPS; SERVICE USE; UNITED STATES

- 666 Teri, Linda and Paula Truax (1994), 'Assessment of depression in dementia patients: association of caregiver mood with depression ratings', *The Gerontologist*, 34(2), 231-4.

'Caregivers typically provide critical diagnostic information on patients with dementia and possible depression. Yet, their accuracy and the potential of their own mood on assessment is unknown. In this study, caregivers rated a standardized stimulus of depression and their actual patient. They were able to correctly identify depression in both. Further, their mood was unassociated with video ratings and only moderately with patient ratings. Thus, reliance on caregiver input is supported.'

PSYCHOLOGICAL ASPECTS; UNITED STATES

- 667 Thompson, Catherine (1985), *Sharing Caring: Caring, Equal Opportunities and the Voluntary Sector*, National Council for Voluntary Organisations Community Care Project and Councils for Voluntary Service National Association, London, 18pp.

'This topic paper sets out the author's views and ideas on the needs for supporting carers. It also provides examples of what voluntary organisations in England are

currently doing on this issue. It explains what community care means for women and outlines what voluntary organisations can do. The special role of generalist organisations is discussed and consideration is given to the contribution of volunteers. There is a bibliography and a list of the addresses of organisations mentioned.'

BIBLIOGRAPHIES; COMMUNITY SERVICES; GENDER; UNITED KINGDOM

- 668 Thompson, Edward H. and William Doll (1982), 'The burden of families coping with the mentally ill: an invisible crisis', *Family Relations*, 31(3), 379-88.

'With deinstitutionalization, families have acquired care-giving responsibility for their mentally ill relatives. This study examined the costs families bear after assuming their recently acquired responsibilities. A random sample of 125 families who had one post-hospital member at home revealed relatives paying a high price. The impact on the family was separated into two types of burden, objective and subjective. The significance of the high prevalence of families experiencing adjustment problems is discussed in terms of who supports the support system.'

FAMILY; MENTAL ILLNESS; PSYCHOLOGICAL ASPECTS; UNITED STATES

- 669 Thompson, Linda (1989), 'Contextual and relational morality: intergenerational responsibility in later life', in Jay A. Mancini, ed., *Aging Parents and Adult Children*, Lexington Books, Lexington, Mass., 259-82.

This chapter begins the task of conceptualising intergenerational responsibility as contextual and relational morality. It borrows these conceptual components from feminist discussions of morality and from others who criticise prevailing moral thought. It attempts to take the responsibility beyond the individual and restore its social meaning.

CONCEPTUAL ISSUES; RELATIONSHIPS; SOCIAL ASPECTS; UNITED STATES

- 670 Thompson, Linda and Alexis J. Walker (1984), 'Mothers and daughters: aid patterns and attachment', *Journal of Marriage and the Family*, 46(2), 313-22.

'In this paper we examine the association of aid exchange with attachment in two sets of mother-daughter relationships - student women and their mothers (139 pairs) and these same middle-aged mothers and their mothers (110). In each case both partners are respondents. Each pair is categorized by the pattern of aid exchange - high reciprocity, low reciprocity, mother dependent, daughter dependent. Attachment reflects emotional dependence. Mothers reported greater attachment than

daughters in the older pairs. There was a main effect for aid pattern on attachment in older pairs; high reciprocity relationships displayed greater attachment than other aid patterns. In the younger pairs, there was an interaction effect of aid pattern and generation on attachment. Mothers and daughters perceived attachment differently in nonreciprocal relationships but not in reciprocal relationships; the dependent partner reported less attachment. Different results for the two sets of intergenerational relationships are discussed in terms of individual and relationship development.'

DAUGHTERS; DEPENDENCY; RELATIONSHIPS; UNITED STATES

- 671 Thornton, Patricia (1989), *Creating a Break: A Home Care Relief Scheme for Elderly People and Their Supporters*, Age Concern, London, 204pp.

This book uses the experience of an innovatory scheme, *In Safe Hands*, Age Concern, York, to show how flexible and responsive relief care can be provided with the help of volunteers. 'After a discussion of the challenges involved in meeting relief care needs, and a review of initiatives in England which use paid or unpaid volunteers, the book focuses on approaches to setting-up, running and reviewing the scheme. The perspectives of the helpers and the users are important in reaching an overall assessment of the value of the scheme. Within a discussion of the constraints, key ingredients for successful operation are set out.'

CASE STUDIES; EVALUATION; RESPITE CARE; UNITED KINGDOM

- 672 Toseland, Ronald W., Charles M. Rossiter and Mark S. Labrecque (1989), 'The effectiveness of peer-led and professionally led groups to support family caregivers', *The Gerontologist*, 29(4), 465-71.

'Participants in both professionally led and peer-led groups experienced significant improvements in psychological functioning, increases in informal support networks, and positive personal changes in handling of the caregiving role when compared with control participants. Professionally led groups produced the greatest improvement in psychological functioning, and peer-led groups produced the greatest increases in informal support networks.'

COMPARATIVE STUDIES; SUPPORT GROUPS; UNITED STATES

- 673 Toseland, Ronald W. and Charles M. Rossiter (1989), 'Group interventions to support family caregivers: a review and analysis', *The Gerontologist*, 29(4), 438-48.

'A review of 29 evaluative studies published through 1987 reveals that no clear link has yet been established between participants' satisfaction and such other important outcomes for caregivers as improving coping skills, preventing psychological

disturbances, increasing caregiver support systems, or improving caregivers' ability to care for themselves.'

EVALUATION; LITERATURE REVIEW; SUPPORT GROUPS; UNITED STATES

- 674 Townsend, Aileen L. (1990), 'Nursing home care and family caregivers' stress', in Mary Ann Parris Stephens, et al., eds, *Stress and Coping in Later-Life Families*, Hemisphere, New York, 267-85.

This chapter presents an overview of current knowledge about family caregivers' stress and nursing home care for older relatives. It looks at the prevalence of institutional care in later life and then reviews research findings about family caregivers' stress as both a cause and a consequence of nursing home care. It reviews the literature and draws on data collected by the Margaret Blenker Research Center of the Benjamin Rose Institute which completed two studies on later-life caregiving in the greater Cleveland metropolitan area. A total of 81 family members (65 adult children and 16 spouses) experienced a parent or spouse being institutionalised during the studies. Most data come from a structured questionnaire, some qualitative data is also included.

INSTITUTIONALISATION; LITERATURE REVIEW; METHODOLOGY; PSYCHOLOGICAL ASPECTS; THEORY DEVELOPMENT; UNITED STATES

- 675 Townsend, Aileen L. and S. Walter Poulshock (1986), 'Intergenerational perspectives on impaired elders' support networks', *Journal of Gerontology*, 41(1), 101-9.

'The purpose of this paper was to compare impaired elders' and their children's reports of the elders' caregiving and decision-making support networks. The two generations (n=101 each) generally agreed on the primary person in each network and on the overall hierarchy of sources of support, but they differed on the two networks' size, specific composition, and members' relative centrality. Decision-making networks were consistently smaller, more highly centralized, and more restrictive to immediate family, suggesting the need to distinguish this network from the general caregiving network. [The] discussion focuses on possible explanations for intergenerational differences in perspectives on elders' social support and on the desirability of taking these differences into account in both research and practice.'

COMPARATIVE STUDIES; SUPPORT NETWORKS; UNITED STATES

- 676 Townsend, Aloen L. and Linda S. Noelker (1987), 'The impact of family relationships on perceived caregiving effectiveness', in Timothy H. Brubaker, ed., *Aging, Health, and Family: Long-Term Care*, Sage, Newbury Park, Calif., 80-99.

This chapter examines the importance of family relationships, rather than individual characteristics, in determining perceived caregiving effectiveness. 'When the caregiving system consists of more than an isolated dyad, the issue of interpersonal relationships becomes exponentially greater as the number of caregivers increases. In addition, the allocation and execution of caregiving responsibilities take on added complexity related to cooperation, coordination, and communication among care providers.' It is critical that these relationships be understood for successful sharing of care. Three levels of caregiving relationships are explored here: the dyadic relationship between the adult-child caregiver and the impaired parent; general family relationships, sometimes referring specifically to the child, the parent(s), and any siblings and other times leaving the term *family* undefined; and relationships among everyone involved in the elder's care, including the parent, family and nonfamily informal helpers, and formal care providers.

FAMILY; RELATIONSHIPS; SUPPORT NETWORKS; UNITED STATES

- 677 Twigg, Julia (1986), *Carers: Why Do They Pose Problems for Social Service Departments?* Discussion Paper No.433, Personal Social Services Research Unit, University of Kent at Canterbury, 21pp.

'Carers present particular problems for SSDs because of their uncertain and ambiguous status within the system. The paper outlines the tensions within the principle models SSDs have available in their relations to carers - carers as resources, carers as co-workers, carers as co-clients - and relates these to the categories of analysis in the production of welfare. The paper concludes with a discussion of some of the cross-cutting issues policy makers face in employing such models.'

COMMUNITY SERVICES; POLICY; THEORY DEVELOPMENT; UNITED KINGDOM

- 678 Twigg, Julia (1989), 'Models of carers: how do social care agencies conceptualise their relationship with informal carers?' *Journal of Social Policy*, 18(1), 53-66.

'Carers occupy an ambiguous position within the social care system. Services are predominantly structured around the dependent rather than the carer, and this has important consequences for their delivery and evaluation. Many of the problems that arise in thinking about carer issues relate to confusion over the way the relationship between social care agencies and informal carers should be perceived. The paper outlines three models that provide frames of reference for this relationship: carers as

resources; carers as co-workers; and carers as clients. The tensions between these are then used to explore the contradictions of policy in this field.'

CONCEPTUAL ISSUES; POLICY; RELATIONSHIPS; THEORY
DEVELOPMENT; UNITED KINGDOM

- 679 Twigg, Julia, ed.(1992), *Carers: Research and Practice*, HMSO, London, 153pp.

This review, commissioned by the Department of Health in the wake of the 1990 NHS and Community Care Act, examines 'the lessons of research of the last decade, concentrating in particular on their relevance for practice and planning.' It maintains that there is little to be gained from yet more repetitive studies of 'who does what for whom', or on the experience of caring, its burdens and stresses as well as its rewarding aspects. It is better to draw on the established literature and adapt it for local use and this review encourages planners to do this. 'It also aims to inform practice and to encourage a more carer-sensitive response among service providers.' It explores the principles which underlie effective service development.

LITERATURE REVIEW; POLICY; UNITED KINGDOM

- 680 Twigg, Julia (1992), 'Carers in the service system', in Julia Twigg, ed., *Carers: Research and Practice*, HMSO, London, 59-93.

This chapter discusses 'the potential role of the mainstream services in the support of carers, concentrating on some of the evaluative work that has explored the effectiveness of various interventions. The relationship between carers and mainstream service is, however, more complex than that might imply; much of the literature on services does not fit into a simple model of evaluation but requires more complex forms of understanding. The chapter also outlines briefly some of the general issues that are raised in trying to think about the proper relationship between carers and public agencies, and consequently about the effectiveness of services in support of them.' The services discussed are social work; home care; medical services, both general practitioners and hospital-based doctors; community nursing; day respite; overnight respite in institutions; and carer support groups. Finally the integration of services is examined.

COMMUNITY SERVICES; DAY CARE; EVALUATION; RELATIONSHIPS;
RESPITE CARE; SUPPORT GROUPS; UNITED KINGDOM

- 681 Twigg, Julia (1993), 'Integrating carers into the service system: six strategic responses', *Ageing and Society*, 13(2), 141-70.

'This paper discusses the mechanisms whereby the needs and interests of carers might be integrated into the service delivery system. Over the last decade, informal

care has emerged as a major subject for research and discussion, and much work has been undertaken exploring the experiences, burdens and needs of carers. Carers are increasingly recognised as central to community care, but little work has so far addressed the means whereby their needs and interests might be integrated within mainstream service provision. The mechanisms for achieving this are underdeveloped. This paper puts forward six possible strategic responses, and discusses the merits and demerits of each. The responses are: taking evaluation a step further; consumerism; case management; performance or service indicators; rights; and targets. The issues raised in the discussion have relevance beyond the subject of informal care, and address questions that are central to the provision of welfare services generally.'

COMMUNITY SERVICES; EVALUATION; UNITED KINGDOM

- 682 Twigg, Julia, Karl Atkin and Christina Perring (1990), *Carers and Services: A Review of Research*, HMSO, London in conjunction with Social Policy Research Unit, University of York, v, 93pp.

'This discussion paper reviews work that has been done in the area of evaluating support to informal carers' with the broad aim of helping policy makers develop more effective and appropriate forms of carer support. It begins with a clarification of the concept of carers. It then goes on to examine the categorisation of carers and the main client and patient groups that are covered in the review. It also discusses the problems faced in evaluating informal care. Finally, it examines 'the scope of the services studied, raising the question of what counts as a service for carers.' It is concluded that services do help sustain carers but there is a lack of evaluation studies on the comparison of different forms of provision. There is ample evidence as to the patchy and uncertain nature of carer services. Obtaining help can be a major problem. Another theme of the literature concerns the differential impact and acceptability of services on different sorts of carers. Finally, there is seen to be uncertainty in the area of policy; both in the lack of knowledge of policy among front-line operators and the uncertainty of policy-making bodies themselves as to what their relationship with carers should be.

COMMUNITY SERVICES; CONCEPTUAL ISSUES; EVALUATION; LITERATURE REVIEW; POLICY; RELATIONSHIPS; UNITED KINGDOM

- 683 Twigg, Julia and Karl Atkin (1993), *Carers Perceived: Policy and Practice in Informal Care*, Open University Press, Buckingham, 160pp.

This book explores 'the reality of how service providers like doctors, social workers, and community nurses respond to carers. It looks at which carers get help and why, analysing how age, relationship, class and gender structure the responses of service providers and carers. It examines the moral and policy issues posed by trying to incorporate carers' interests into service provision. What would services look like if

they took the needs of carers seriously? How far can they afford to do so? Is this only achieved at the expense of disabled people? What is the proper relationship between carers and services? Carers pose in acute form many of the central dilemmas of social welfare, and the account presented here has the widest significance for the analysis of community care. Focusing on the view of carers as well as service providers, the book looks at caring across a variety of relationships and conditions, including people with mental health problems and learning disabilities.'

COMMUNITY SERVICES; DISABLED; MENTAL ILLNESS; POLICY;
SOCIOECONOMIC STATUS; UNITED KINGDOM

- 684 Ungerson, Clare (1983), 'Why do women care?', in Janet Finch and Dulcie Groves, eds, *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, 31-49.

This chapter begins by defining the difference between caring *about* someone and caring *for* them, and asks why women do the latter? While 'women predominantly carry out these tasks presently, will they continue to do so given changes in their material circumstances and in the consumption of their time in other tasks such as - and particularly - paid work?' To answer this question the author discusses 'the interaction of sex role stereotyping and women's material circumstances at two interfaces - the labour market and the state.'

EMPLOYMENT; GENDER; SOCIAL ASPECTS; SOCIOECONOMIC STATUS;
UNITED KINGDOM

- 685 Ungerson, Clare (1983), 'Women and caring: skills, tasks and taboos', in Eva Gamarnikow, David H.J. Morgan, June Purvis and Daphne Taylorson, eds, *The Public and the Private*, Heinemann, London, 62-77.

This chapter examines women's dual role in paid employment and housework and caring and the implications of this for the relationships within the 'private domain'. It analyses the caring role itself: 'the actual tasks of caring, the skills involved in carrying them out, and the implications of the fact that informal caring, almost by definition, *is* private.' It suggests ways in which the relationship between carer and cared for are constrained and determined, in particular, 'the problems that might arise when carers adopt a model of tending suitable to one kind of relationship (mother/child) and transfer it, both within institutions and at home, to relationships of quite another kind.' It also suggests that domestic relationships are quite different from institutional relationships in that they have a 'history', and this might give rise to particular problems when roles have to be exchanged, as between mothers and daughters. Also, the importance of the sex of the carers and cared for is stressed.

EMPLOYMENT; GENDER; RELATIONSHIPS; UNITED KINGDOM

- 686 Ungerson, Clare (1987), *Policy is Personal: Sex, Gender, and Informal Care*, Tavistock, London, 166pp.

This book is a study of 19 people, who, in 1984, were looking after a frail aged person and is concerned with the complex relationships between carer and cared for. 'The way that particular carers in a family constellation emerge, the way that carers talk about and construe the feelings they have about their work, the impact of caring on the relationship between carer and cared for' are all important issues yet very little discussed in the literature at this time apart from the aspect of stress. All the topics discussed in this book are looked at from the perspective of sex and gender.

FAMILY; GENDER; RELATIONSHIPS; UNITED KINGDOM

- 687 Ungerson, Clare, ed. (1990), *Gender and Caring: Work and Welfare in Britain and Scandinavia*, Harvester Wheatsheaf, Hemel Hempstead, Herts., x, 197pp.

The papers in this volume come from a conference held at the University of Kent in April 1985 which brought together academics from Scandinavia and Britain who had been studying and theorising on the concept of 'care'. For abstracts of individual papers relevant to this bibliography, see also: Janet Finch, Hazel Qureshi, Birte Siim, and Kari Wærness. The last chapter by Ungerson brings together the various strands of the book and criticises present policy in Britain in comparison with Scandinavia.

CONCEPTUAL ISSUES; INTERNATIONAL COMPARISONS; SCANDINAVIA; UNITED KINGDOM

- 688 Ungerson, Clare (1990), 'The language of care: crossing the boundaries', in Clare Ungerson, ed., *Gender and Caring: Work and Welfare in Britain and Scandinavia*, Harvester Wheatsheaf, Hemel Hempstead, Herts., 8-33.

This chapter suggests 'that feminist debate about caring has been helped, in Scandinavia, by the development there of a language with which to discuss caring in all its forms and wherever it takes place and which speaks more directly to feminist analysis.' It goes on to 'suggest that this rather different language in itself makes it possible to consider policies, which until now, have been very little considered' in Britain. There is a discussion of the false dichotomy of the public/private split and how Scandinavian vocabulary and analysis crosses this divide. This analysis allows consideration of 'why and how caring, in whatever context it occurs, should be waged.' The arguments for and against paying carers are discussed but, it is pointed out, 'the most important point is that the work of carers, in whatever domain, has to be recognized' and morale must be high. This latter depends on self-esteem, working conditions and recognition of their work by others.

CONCEPTUAL ISSUES; IDEOLOGY; PAYMENT; POLICY; SCANDINAVIA; UNITED KINGDOM

- 689 Ungerson, Clare (1992), *Payment for Caring - Mapping a Territory*, Darwin College, University of Kent, Canterbury, Paper for the Social Policy Association Annual Conference, University of Nottingham, 24pp.

This paper outlines why the topic of payment for care is growing in importance within a British context and points up some of the dilemmas (including moral dilemmas) that arise from considering the issues involved. The paper examines the importance of social, economic and policy trends for which are placing strong pressures for payment as a result of perceived shortages of unpaid informal carers and the reorganisation of the financing of demand. There are also conceptual factors. One of these is feminism and the distinction between the 'public' and 'private' domains. Another is 'the way the topic raises questions traditional to mainstream social administration.

CONCEPTUAL ISSUES; GENDER; PAYMENT; POLICY; UNITED KINGDOM

- 690 United States - Congress - House of Representatives - Select Committee on Aging - Subcommittee on Human Services (1988), *Exploding the Myths: Caregiving in America*, US Government Printing Office, Washington, DC, viii, 73pp.

This report provides an overview of informal caregiving to the frail elderly. Recent empirical research indicates that family members, friends and neighbours continue to be the principal sources of care of the frail elderly. Caregivers also continue to be predominantly female. Informal caregivers represent a vulnerable population as one-third are poor or near-poor and one-third perceive their health as fair to poor. The report looks at the role of the public and private sectors in support of informal caregivers.

COUNSELLING; DEMOGRAPHIC ASPECTS; EDUCATION; EMPLOYMENT; FAMILY; FINANCIAL ASPECTS; GENDER; HEALTH; HISTORICAL ASPECTS; INCOME SUPPORT; LEGAL ASPECTS; LIVING ARRANGEMENTS; NATIONAL STUDIES; PSYCHOLOGICAL ASPECTS; RESPITE CARE; SOCIAL ASPECTS; SOCIOECONOMIC STATUS; UNITED STATES

- 691 Upshur, Carole C. (1983), 'Developing respite care: a support service to families with disabled members', *Family Relations*, 32(1), 13-20.

'Respite care is identified as a temporary relief service for families with developmentally disabled members living at home and as an essential element in preventing institutionalization of disabled persons. It helps families cope with both emergency situations and relief from the daily stress of caring for a disabled family member. Four major approaches for providing respite care are identified based on site visits and surveys conducted in Massachusetts and Indiana and through correspondence with programs in eight other states. The advantages and

disadvantages of the different approaches are discussed and recommendations are made concerning how to develop quality programs. The development of a spectrum of types of respite care to meet different family needs is recommended.'

DISABLED; POLICY; RESPITE CARE; UNITED STATES

- 692 Vitaliano, Peter P., Roland D. Maiuro, Hans Ochs and Joan Russo (1990), 'A model of burden in caregivers of DAT patients', in Enid Light and Barry D. Lebowitz, eds, *Alzheimer's Disease Treatment and Family Stress: Directions for Research*, Hemisphere, New York, 267-91.

'The goal of this chapter is to encourage new research directions for studying family stress arising from caring for a victim of dementia of the Alzheimer's type (DAT). A theoretical model is offered to guide research on the biopsychosocial correlates of burden in caregivers of patients with DAT. The rationale for the model is presented along with the advantages of this multidisciplinary approach. Finally, ways to implement the model in caregiver research are presented along with preliminary data to support the model's utility.'

DEMENTIA; HEALTH; METHODOLOGY; PSYCHOLOGICAL ASPECTS;
SOCIAL ASPECTS; SPOUSES; THEORY DEVELOPMENT; UNITED STATES

- 693 Wærness, Kari (1990), 'Informal and formal care in old age: what is wrong with the new ideology in Scandinavia today?' in Clare Ungerson, ed., *Gender and Caring: Work and Welfare in Britain and Scandinavia*, Harvester Wheatsheaf, Hemel Hempstead, Herts., 110-32.

This chapter uses recent empirical data to argue that community care policy is based on myths rather than realities concerning the situation and preferences of elderly people and on an outdated understanding of women's roles in family and society. 'To develop a future-oriented social policy more related to the needs of women and the weakest members of society, we have to recognize that the welfare state is fundamentally based on the traditional division of labour between the sexes.' One way of improving the public care system in Scandinavia would be to give far better recognition to the role and significance of informal care so that services to families are more useful.

GENDER; IDEOLOGY; POLICY; SCANDINAVIA

- 694 Walker, Alan (1983), 'Care for elderly people: a conflict between women and the state', in Janet Finch and Dulcie Groves, eds, *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, 106-28.

This chapter examines family care for elderly people, which usually means care by women. The provision of care often implies a dependency relationship and both

sides of this relationship are looked at. Both women and elderly people share a dependency status. There needs to be a radical transformation in the sexual division of labour at work and within the family as well as in social policies. The physical and mental stress of women looking after an elderly relative is discussed as well as the direct and indirect costs. A range of policies is required to share care effectively. These would include action in the labour market. As well as sharing care with the family financially there is a need for community-based services which support and substitute for family-based care, some of the resources for which need to be reallocated from residential care.

DEPENDENCY; FAMILY; FINANCIAL ASPECTS; GENDER; HEALTH;
POLICY; PSYCHOLOGICAL ASPECTS; UNITED KINGDOM

- 695 Walker, Alexis J. (1992), 'Conceptual perspectives on gender and family caregiving', in Jeffrey W. Dwyer and Raymond T. Coward, eds, *Gender, Families, and Elder Care*, Sage, Newbury Park, Calif., 34-46.

This chapter 'reviews the conceptual perspectives that have been used in recent years to explain the gendered nature of family care for the elderly. Specifically, the author describes three frameworks that have informed previous research in this area (e.g., psychological/individual, sociological, and feminist) and reviews the strengths and weaknesses of these approaches. The purpose of the chapter, therefore, is not to "break new ground," but to provide a clear understanding of the conceptual perspectives that have guided much of the research in this area.'

CONCEPTUAL ISSUES; FAMILY; GENDER; UNITED STATES

- 696 Walker, Alexis J. and Linda Thompson (1983), 'Intimacy and intergenerational aid and contact among mothers and daughters', *Journal of Marriage and the Family*, 45(4), 841-9.

'We address the assumption that aid, contact, and intimacy are components of some underlying dyadic construct by examining two mother-daughter relationships - student women and their mothers (132 pairs) and middle-aged women and their mothers (107 pairs). Both partners are respondents in each case. We distinguish between proximal aid and distal aid, include all modes of contact, and measure intimacy as a multidimensional construct. Aid and contact collectively do not account for more than 11% of the variance in reports of intimacy. With small but consistent associations across relationship reports, proximal aid to mother predicts both mother's and daughter's reports of intimacy in both generational pairs. In the younger but not the older pairs, the connection between intimacy and contact by visiting and telephoning is conditional on geographic distance. Amount of contact is related negatively to mothers' reported intimacy in the younger relationship and, when proximal aid to mothers is controlled, to both mothers' and daughters' reported intimacy in the older relationship. This effect contradicts the assumption of a

positive relationship between contact and intimacy. In both mother-daughter relationships, distal aid to mother, aid in general from mother to daughter, letter writing, and child care are not related to intimacy. It is not reasonable, therefore, to infer intimacy from aid and contact. The study suggests the potential of distinguishing between discretionary and obligatory intergenerational interaction.'

DAUGHTERS; MIDDLE AGED CAREGIVERS; RELATIONSHIPS; UNITED STATES

- 697 Walker, Alexis J., Clara C. Pratt, Hwa-Yong Shin and Laura L. Jones (1989), 'Why daughters care: perspectives of mothers and daughters in a caregiving situation', in Jay A. Mancini, ed., *Aging Parents and Adult Children*, Lexington Books, Lexington, Mass., 199-212.

This chapter explores the distinction between obligatory and discretionary motives for caregiving by daughters to elderly mothers. It reports on a study of which interviewed 173 mostly white elderly mother-adult daughter pairs from western Oregon. Mothers and daughters were asked their perceptions of daughters' motives in caregiving using both quantitative and qualitative measures. Whilst 69.4 per cent of daughters reported some degree of obligation in caring for their mothers, only 31 per cent of the mothers reported that their daughters had obligatory motives. More than 90 per cent of the mothers and daughters reported that daughters were motivated to give care, at least in part, by discretion. Striking among the findings of this study is the number and diversity of motives given for caregiving, indicating complex interactions of obligation and desire, particularly for daughters.

DAUGHTERS; RELATIONSHIPS; UNITED STATES

- 698 Walker, Alexis J., Clara C. Pratt, Hwa-Yong Shin and Laura L. Jones (1990), 'Motives for parental caregiving and relationship quality', *Family Relations*, 39(1), 51-6.

'This study examines the connections between obligatory and discretionary motives for caregiving and relationship quality for caregiving daughters and their dependent older mothers. The vast majority of 174 elderly dependent mothers and their caregiving daughters believed daughters were caregiving primarily for discretionary reasons. Women who noted that daughters' motives were not highly discretionary reported lower intimacy in their relationships and mothers in this group said they had received care for more years than mothers who reported highly discretionary motives. The need for support in families wherein care is given other than discretionary motives is discussed.'

DAUGHTERS; RELATIONSHIPS; UNITED STATES

- 699 Walker, Alexis J., Hwa-Yong Shin and David N. Bird (1990), 'Perceptions of relationship change and caregiver satisfaction', *Family Relations*, 39(2), 147-52.

'Elderly pairs (133) of unmarried mothers and adult caregiving daughters were interviewed about the impact of caregiving on their relationship. Daughters also rated their satisfaction with the caregiving role. Most mothers and daughters reported no change or positive effects of caregiving on their relationship. Daughters who reported positive effects or no change had positive evaluations of, and were satisfied with, the caregiving role. The implications for family service providers are discussed.'

DAUGHTERS; RELATIONSHIPS; UNITED STATES

- 700 Walker, Alexis J., Clara C. Pratt, Louise K. Martell and Sally S.K. Martin (1991), 'Perceptions of aid and actual aid in intergenerational caregiving', *Family Relations*, 40(3), 318-23.

'Elderly mothers' and their caregiving daughters' (n=174 pairs) perceptions of aid given to the mothers were compared with reports of actual caregiving activities. Just over half of the women overestimated the amount of aid given, while most of the remainder perceived accurately. Highly educated and younger mothers had more accurate perceptions than poorly educated and older mothers. Daughters who perceived their mothers to be in better health and who lived separately from them had more accurate perceptions than daughters who saw their mothers' health as poor and who resided with them. The discussion emphasizes the high level of accurate perceptions among both mothers and daughters.'

COMPARATIVE STUDIES; DAUGHTERS; HEALTH; LIVING ARRANGEMENTS; UNITED STATES

- 701 Walker, Alexis J. and Katherine R. Allen (1991), 'Relationships between caregiving daughters and their elderly mothers', *The Gerontologist*, 31(3), 389-96.

'In this qualitative study of 29 pairs of widowed mothers and their caregiving daughters, social exchange theory [is employed] to identify three relationship types: intrinsic (45%), ambivalent (34%), and conflicted (21%). These types differ in the extent to which women receive rewards from interacting with their partner, experience the costs in their interaction, handle conflicts that arise in their relationship, and express feelings of concern for each other. They also differ in that daughters in intrinsic pairs have fewer children and shorter caregiving histories than daughters of ambivalent or conflicted pairs.'

DAUGHTERS; QUALITATIVE STUDIES; RELATIONSHIPS; THEORY DEVELOPMENT; UNITED STATES

- 702 Walmsley, Jan (1993), 'Contradictions in caring: reciprocity and interdependence', *Disability, Handicap & Society*, 8(2), 129-41.

'In this article the author draws on research into the experiences of women with learning difficulties and shows that they very often find themselves in caring roles, and, like other women find them both sustaining and frustrating. Drawing a clear distinction between carer and dependant is frequently impossible: both parties in the caring relationship both give and receive. There can be reciprocity and interdependence. Care and dependence are seen as false dichotomies. A plea is made for the interests of carers and those cared for to be considered together, not in opposition to one another.'

DEPENDENCY; DISABLED; RELATIONSHIPS; UNITED KINGDOM

- 703 Warnes, Anthony M. (1993), 'Being old, old people and the burdens of burden', *Ageing and Society*, 13(3), 297-338.

'*Burden* is today often applied to elderly people in two senses, for the fiscal load of income support and health and social care costs, and for notions and scales of care-giving effort and stress. It does not however convey straightforward meanings for its understanding is affected by two millenia of metaphorical and rhetorical usage. The use of burden tends to simplify relationships, whether between age-groups of a population or between a carer and an elderly person, and it communicates senses of a nuisance and an excessive charge. Portentous implications are invoked from biblical senses and derogatory overtones are strengthened by associations, earlier in this century, with racial stereotyping. An etymological survey reveals many sources of the word's versatility and rhetorical power. Important extensions of usage towards the two contemporary gerontological applications are then studied. A bibliometric examination of the surge in the word's social science use since the early 1980s is undertaken, and the paper concludes with a discussion of current usage as evidence of current attitudes towards, and constructions of, old age on the part of politicians and policy analysts.'

CONCEPTUAL ISSUES; UNITED KINGDOM

- 704 Wasow, Mona (1986), 'Support groups for family caregivers of patients with Alzheimer's disease', *Social Work*, 31(2), 93-8.

This article discusses some of the assumptions, dilemmas and questions that have come from the author's experience in facilitating support groups for carers whose relatives have Alzheimer's disease. She also draws on information from talking to group members themselves. Suggestions are made for a wide variety of support group models in recognition that carers have differing needs.

DEMENTIA; SUPPORT GROUPS; UNITED STATES

- 705 Wasserman, Audrey (1984), 'Coping with aging parents', *Perspectives on Aging*, 13(1), 28-9.

This article describes a support group for family carers looking after elderly parents in Detroit, USA. Bi-weekly sessions of six weeks each are offered by the group six times a year. Those who join the group do so for a variety of reasons including stress, difficulty in coping and seeking to prevent future difficulties.

CASE STUDIES; SUPPORT GROUPS; UNITED STATES

- 706 Webb, Iris (1987), *People Who Care: A Report on Carer Provision in England and Wales for the Cooperative Women's Guild*, Co-operative Women's Guild, London, 100pp.

The intention of this report was to investigate the situation of caregivers in England and Wales in order to determine how they could best be helped as a group. It involved sending out questionnaires to all Health Authorities and Social Service Departments in England and Wales to find out what provisions were made by statutory bodies (or known of by statutory bodies) for caregivers. This report presents the findings of this survey. It gives information on the range of number of schemes and their frequency, types of schemes, funding, voluntary organisations, client groups and knowledge of caregiver numbers. The final section summarises the findings and makes recommendations.

COMMUNITY SERVICES; FINANCIAL ASPECTS; METHODOLOGY; NATIONAL STUDIES; POLICY; SERVICE USE; STATISTICS; UNITED KINGDOM

- 707 Wenger, G. Clare (1989), 'Support networks in old age: constructing a typology', in Margot Jefferys, ed., *Growing Old in the Twentieth Century*, Routledge, London, 166-85.

Most care, help and support in old age comes from informal sources but research has tended to focus on relationships with adult children or, less frequently, siblings and grandchildren. 'Early network studies focused on such structural aspects as the size, density, and linkages of support networks, analysing variation in terms of intervening variables (age, gender, and marital status), but less attention has been given to different types of networks based on differences in membership and composition...This chapter, therefore, seeks to differentiate between different types of support networks and draw attention to the significance of differences for service provision...Following a brief review of the findings of earlier network research, five different types of support network are identified and described, and the predictive value of these categories is then discussed.'

SUPPORT NETWORKS; THEORY DEVELOPMENT; UNITED KINGDOM

- 708 Wenger, G. Clare (1990), 'Elderly carers: the need for appropriate intervention', *Ageing and Society*, 10(2), 197-219.

'The literature on caring and carers has tended to emphasise the care of aged parents by middle-aged daughters. A recent government survey, however, has drawn attention to the fact that a substantial proportion of all carers are themselves elderly. This paper focuses on elderly carers. It shows that at least a third of elderly people can expect to become carers during retirement. Elderly carers differ from younger carers in that they: care for shorter periods; are more likely to provide intimate personal care and heavy nursing tasks associated with terminal care; and to be caring for their most significant other, usually a spouse. It is suggested that elderly carers represent a sub-group of carers with special needs not necessarily met by present service provision. Some more appropriate interventions are suggested.'

AGED CAREGIVERS; COMMUNITY SERVICES; NATIONAL STUDIES; POLICY; UNITED STATES

- 709 Whitlatch, Carol J., Steven H. Zarit and Alexander Von Eye (1991), 'Efficacy of interventions with caregivers: a reanalysis', *The Gerontologist*, 31(1), 9-14.

'This paper presents a reanalysis of data from a previously reported study with family caregivers of dementia patients using the method of prediction analysis. Compared with subjects on a waiting list or enrolled in support groups, caregivers in individual and family counseling were more likely to have successful outcomes on all dependent measures (Brief Symptom Inventory, personal strain, and role strain).'

COMPARATIVE STUDIES; COUNSELLING; DEMENTIA; SUPPORT GROUPS; UNITED STATES

- 710 Wilder, David E., Jeanne A. Teresi and Ruth G. Bennett (1983), 'Family burden and dementia', in Richard Mayeaux and Wilma G. Rosen, eds, *The Dementias*, Raven Press, New York, *Advances in Neurology* Vol.38, 239-51.

Home care to the demented elderly is often provided at great cost to families in terms of their psychological and physical health, social circumstances and financial resources. The term most frequently, applied to this caregiver situation is 'burden'. This chapter presents a brief review of work in this area and describes instruments used in previous research. A model of burden as it relates to those caring for the demented person is introduced and results from the authors' studies are discussed.

DEMENTIA; FINANCIAL ASPECTS; HEALTH; LITERATURE REVIEW; METHODOLOGY; PSYCHOLOGICAL ASPECTS; THEORY DEVELOPMENT; UNITED STATES

- 711 Willmott, Peter (1986), *Social Networks, Informal Care and Public Policy*, Research Report No.655, Policy Studies Institute, London, 134pp.

This report examines patterns of personal relationships in present-day Britain with an eye to their particular relevance for policy. The central policy interest is in the area of informal care. Using past survey material it looks at what is known about relationships in three categories of people - relatives, friends and neighbours - and the care and support which these informal networks provide. It identifies the distinctive contributions from the different sources and examines the informal relationships of various kinds of people who might be judged 'at risk'. This includes the elderly. Finally an assessment is made of the relevance of neighbourhood and community in contemporary Britain and suggestions are made for policy and research.

POLICY; RELATIONSHIPS; SUPPORT NETWORKS; UNITED KINGDOM

- 712 Wilson, Paul A., Stephen T. Moore, Dana S. Rubin and Pamela K. Bartels (1990), 'Informal caregivers of the chronically ill and their social support: a pilot study', *Journal of Gerontological Social Work*, 15(1/2), 155-70.

'The social support networks of 77 informal caregivers of the chronically ill are examined in relation to social participation and well-being. Correlational analyses support the propositions of the general support model that hypothesized that "robust" social networks (i.e. large size, with close relationships of long duration and frequent contact) are associated with higher levels of social participation. Social participation, in turn, is related to higher levels of well-being and life satisfaction. Dimensions of social networks are not directly associated with well-being. Satisfaction with one's health and higher levels of worry and stress are associated with higher levels of satisfaction with friends and outside activities. Contrasting social network structures and sources of support among caregivers of three types of chronically ill patients served by three different programs are compared.'

CHRONIC ILLNESS; COMPARATIVE STUDIES; HEALTH; SOCIAL ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 713 Winfield, Fairlee (1987), 'Workplace solutions for women under eldercare pressure', *Personnel*, 64(7), 31-2, 34-9.

Caring for elderly relatives is being added to women's traditional roles as wife, mother, and homemaker, as well as the new role of worker. Trends are cited, including the ageing of the population, as well as problems, such as loss of worker productivity. It presents model corporate solutions.

DEMOGRAPHIC ASPECTS; EMPLOYMENT; GENDER; UNITED STATES

- 714 Winogrand, Iris R., Albert A. Fisk, Robert A. Kirsling and Barbara Keyes (1987), 'The relationship of caregiver burden and morale to Alzheimer's disease patient function in a therapeutic setting', *The Gerontologist*, 27(3), 336-9.

'Data were collected over a six month period from 18 Alzheimer's disease patients in a day hospital program and from their caregivers who participated in an affiliated family support group. Results of analysis showed a significant decline in patient cognitive function, but with no increase in behavior problems. Significant changes also occurred over time in the relationship between patients' functioning and caregivers' perceptions of stress, suggesting an improvement in coping. Findings indicate that a therapeutic program for patients and their caregivers may slow behavior deterioration in patients and promote enhanced coping in caregivers.'

DAY CARE; DEMENTIA; PSYCHOLOGICAL ASPECTS; SUPPORT GROUPS; UNITED STATES

- 715 Wisensale, Steven K. and Michael D. Allison (1988), 'An analysis of 1987 state family leave legislation: implications for caregivers of the elderly', *The Gerontologist*, 28(6), 779-85.

'A study was completed on the 28 states that introduced family leave legislation in 1987. Shown by the findings is that only four states passed bills, and only one of those included elder care in its provisions, that advocates of the elderly did not participate in the policymaking process, and that more attention should be devoted to proposals that are intergenerational in focus and designed to aid informal supports.'

POLICY; RESPITE CARE; UNITED STATES

- 716 Wood, Juanita B. (1991), 'Caregivers as comptrollers: women and long-term care and cost containment', *Journal of Aging and Social Policy*, 3(4), 31-46.

'The emphasis on cost containment that was the hallmark of the Reagan Administration and the shifting of the burden for long-term care onto the informal sector have had a particularly negative impact on women. Women through caregiving are used to help control the public cost of long-term care. This unwritten policy is unlikely to be successful because of a number of factors: (1) the economic condition of women; (2) the lack of available and affordable community services; and (3) the types of social relationships we now have.'

COMMUNITY SERVICES; FINANCIAL ASPECTS; GENDER; POLICY; SOCIAL ASPECTS; SOCIOECONOMIC STATUS; UNITED STATES

- 717 Wright, Fay (1983), 'Single carers: employment, housework and caring', in Janet Finch and Dulcie Groves, eds, *A Labour of Love: Women, Work and Caring*, Routledge & Kegan Paul, London, 89-105.

'This chapter reports some of the findings on employment, housework and caring tasks of a small exploratory study of the experience of being a single carer.' A sample of 22 single sons and 36 single daughters was interviewed. 'Although many similarities were apparent between the daughters and sons in the study, there were major sex differences in employment, in the amount of work which had to be done in the home, in the amount of personal care tasks needing to be done for the parent, and in the amount of housework that the parent managed to do.' Sex role expectations were likely to contribute to the degree of parental dependency. Adequate support services were rarely forthcoming.

COMMUNITY SERVICES; DAUGHTERS; DEPENDENCY; EMPLOYMENT; GENDER; SONS; UNITED KINGDOM

- 718 Wright, Fay D. (1986), *Left to Care Alone*, Gower, Aldershot, Hants., viii, 205pp.

For many infirm, elderly people living in the community, the family is the principal source of support and care. 'The primary purpose of this study is to provide a picture of the effect of giving support on a sample of family members and to evaluate the relative contribution made by the wider community and the statutory health and welfare services. This small exploratory study was restricted to unmarried women or men living in the same household as at least one infirm parent. Because the women and men were in comparable situations, both with a strong incentive to maintain paid employment and a responsibility to care for their parents, it was possible to look at sex differences in the amount of housework and caring tasks which were done in the home and in the ability to maintain a paid job outside it.' It begins by examining the concept of community care and gives some demographic background to community care policies for the infirm elderly. It also examines some previous research before describing the methodology used in this research.

CONCEPTUAL ISSUES; DAUGHTERS; DEMOGRAPHIC ASPECTS; EMPLOYMENT; QUALITATIVE STUDIES; RELATIONSHIPS; SERVICE USE; SONS; SUPPORT NETWORKS; UNITED KINGDOM

- 719 York, Jonathan and Robert Caslyn (1986), 'Family involvement in nursing homes', in Lillian Troll, ed., *Family Issues in Current Gerontology*, Springer, New York, 178-88.

This reports on a study of some of the factors that affect family involvement in nursing home care. Data were collected on the extent of the problem (i.e., the quality of family-resident interactions), availability and utilisation of existing services, and willingness of family members to use services that might be offered in the future.

The findings were that families did not separate themselves from their elderly relatives, but visited and talked frequently with older relatives prior to placement in the nursing home and often helped them with a variety of household tasks. When a crisis occurred, families did not use alternatives to nursing home care, and families were not very sophisticated in choosing nursing homes. Families visited their relatives after they entered the nursing home, but often did not enjoy the visits. For emotional support, families relied on nursing home personnel, and were willing to take part in programs offered by the nursing home staff.

**FAMILY; INSTITUTIONALISATION; RELATIONSHIPS; SERVICE USE;
UNITED STATES**

- 720 Young, Rosalie F. and Eva Kahana (1989), 'Specifying caregiver outcomes: gender and relationship aspects of caregiver strain', *The Gerontologist*, 29(5), 660-6.

'The gender-specific kinship relationship of patients and their care providers has not generally been investigated in studies of caregiver burden and well-being. In this study of 183 heart patient-caregiver dyads, gender and relationship were analyzed singly and jointly with respect to the process and outcome of caregiving. Strains caregivers experienced while caring for older heart patients six weeks and one year after hospital discharge were determined. Findings showed consistent patterns of strains. Women, nonspousal caregivers, and daughters in particular, experienced the most severe after effects. These findings support a caregiving outcomes model proposing that the patient-caregiver relationship is an essential component of caregiver strain.'

**CARDIOVASCULAR DISEASE; GENDER; PSYCHOLOGICAL ASPECTS;
RELATIONSHIPS; THEORY DEVELOPMENT; UNITED STATES**

- 721 Zarit, Steven H. (1990), 'Interventions with frail elders and their families: are they effective and why?' in Mary Ann Parris Stephens, et al., eds, *Stress and Coping in Later-Life Families*, Hemisphere, New York, 241-65.

Although there is general agreement about the stressfulness of caregiving, there have been surprisingly few studies on what types of interventions can most effectively reduce stress. This chapter discusses findings about the effectiveness of various interventions and highlights the methodological limitations of current approaches to evaluating outcomes. It categorises interventions into two broad types based on their primary goal or objective. 'The first type includes programs that are designed to improve or enhance the caregiver's abilities for managing the patient or care situations. Psychoeducational interventions including support groups are the main example of this approach. The second type of intervention provides new resources that relieve the caregiver of some portion of routine care activities. Examples of this

approach include day care, in-home respite and overnight respite.' New directions for future studies are proposed.

DAY CARE; EDUCATION; EVALUATION; METHODOLOGY;
PSYCHOLOGICAL ASPECTS; RESPITE CARE; SUPPORT GROUPS; UNITED STATES

- 722 Zarit, Steven H., Karen E. Reever and Julie Bach-Peterson (1980), 'Relatives of the impaired elderly: correlates of feelings of burden', *The Gerontologist*, 20(6), 649-55.

'Factors contributing to feelings of burden of caregivers of elderly persons with senile dementia were studied. The amount of burden of caregivers was found to be less when more visits were paid to the dementia patient by other relatives. Severity of behavioral problems was not associated with higher levels of burden. The results suggest the importance of providing support to caregivers as a critical step in the community care of elderly persons with dementia.'

DEMENTIA; PSYCHOLOGICAL ASPECTS; SUPPORT NETWORKS; UNITED STATES

- 723 Zarit, Steven H. and Judy M. Zarit (1982), 'Families under stress: interventions for caregivers of senile dementia patients', *Psychotherapy*, 19(4), 461-71.

'The senile dementias are progressive brain disorders, which result in severe intellectual and behavioral decline. Although these illnesses cannot be treated medically, interventions with dementia patients and their families can be very useful. Interventions include education about the disease, problem-solving and support. Treatment modalities which have been helpful are: counseling the primary caregivers, family meetings and support groups for caregivers.'

COUNSELLING; DEMENTIA; EDUCATION; FAMILY; SUPPORT GROUPS;
UNITED STATES

- 724 Zarit, Steven H., Nancy K. Orr and Judy M. Zarit (1985), *The Hidden Victims of Alzheimer's Disease: Families under Stress*, New York University Press, New York, viii, 218pp

'This book has been written primarily for practitioners working in community settings with patients with dementing illnesses or their families.' It gives a framework for understanding dementing illnesses and describes possible intervention to assist patients and their caregivers. Two effective ways of lowering the stress on those who are responsible for providing care are to improve their skills in managing problem behaviour and to increase the social supports they receive from others.

Stress management procedures and their applications in counselling, family meetings, and support groups are described here.

COUNSELLING; DEMENTIA; EDUCATION; FAMILY; SUPPORT GROUPS;
UNITED STATES

- 725 Zarit, Steven H., Pamela A. Todd and Judy M. Zarit (1986), 'Subjective burden of husbands and wives as caregivers: a longitudinal study', *The Gerontologist*, 26(3), 260-6.

'Investigated were changes over time for caregivers of dementia patients, with a focus on factors associated with nursing home placement. Caregivers were all spouses, and at the time of the initial interview were caring for the patient at home. Subsequent nursing home placement was more strongly associated with subjective factors, particularly caregivers' perceived burden, than with objective indicators of the severity of the dementia. Although wives initially reported more burden than husbands, no differences were found at the follow-up.'

DEMENTIA; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS;
SPOUSES; UNITED STATES

- 726 Zarit, Steven H., Cheri R. Anthony and Mary Boutsellis (1987), 'Interventions with care givers of dementia patients: comparison of two approaches', *Psychology and Aging*, 3(3), 225-32.

This study 'compared the effect of two approaches, family counseling and support groups, for relieving the stress and burden experienced by care givers of dementia patients. Both treatments are designed to implement features of a stress-management model that have been identified in prior research with this population: providing information about the patient's disease and its effects on behavior, teaching behavioral problem solving for managing difficult behavior, and identifying potential support for care givers. Subjects were primary care givers of dementia patients living in the community; they included husbands, wives, daughters, and other relatives. Although subjects in the treatment groups made significant gains over time, they did not differ from wait-list subjects who showed similar improvements. One-year follow-up interviews indicated that gains made during the treatment period were maintained.'

COMPARATIVE STUDIES; DEMENTIA; EDUCATION; SUPPORT GROUPS;
UNITED STATES

- 727 Zarit, Steven H. and Ronald W. Toseland (1989), 'Current and future direction in family caregiving research', *The Gerontologist*, 29(4), 481-3.

This article suggests ways 'to improve measurement of treatment effects in studies of group interventions for family caregivers: better specification of goals and outcomes, development of measures less likely to have floor and ceiling effects, and determination of whether specific treatment processes have been implemented and goals attained. Samples too heterogeneous on key variables also make identification of change more difficult.'

FAMILY; METHODOLOGY; UNITED STATES

- 728 Zarit, Steven H. and Carol J. Whitlatch (1992), 'Institutional placement: phases of transition', *The Gerontologist*, 32(5), 665-672.

'The consequences of institutionalization were examined for a sample of caregivers to dementia patients. Consistent with the stress process model, institutionalization was hypothesized to have a large impact on the primary effects of caregiving and lesser influence on secondary effects and well-being. Following placement, relatives experienced relief from primary effects of caregiving (e.g., feelings of overload and tension) and improved well-being, whereas other indicators of stress remained unchanged.'

DEMENTIA; INSTITUTIONALISATION; PSYCHOLOGICAL ASPECTS;
UNITED STATES