

Experiences of long-term home care as an informal caregiver to a spouse: gendered meanings in everyday life for female carers

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Background. One of the most common circumstances in which a woman gradually steps into a long-term caregiver role at home involves caring for a spouse suffering from dementia. Little attention has been paid to examining the experiences and motivations of such caregivers from a feminist perspective.

Aims and objectives. In this article, we explore the gender aspects of long-term caregiving from the perspective of women providing home care for a spouse suffering from dementia.

Methods. Twelve women, all of whom were informal caregivers to a partner suffering from dementia, were interviewed on the following themes: the home, their partner's disease, everyday life, their relationship and autonomy. The results of these interviews were analysed in relation to gender identity and social power structures using a feminist perspective.

Results. The findings of this study show that the informants frequently reflected on their caregiving activities in terms of both general and heteronormative expectations. The results suggest that the process of heteropolarisation in these cases can be understood as a consequence of both the spouse's illness and the resulting caring duties. Also, the results suggest that the act of caring leads to introspections concerning perceived 'shortcomings' as a caregiver. Finally, the results indicate that it is important to recognise when the need for support in day-to-day caring is downplayed.

Conclusions. Women view their caregiving role and responsibilities as paramount; their other duties, including caring for themselves, are deemed less important. We stress that the intense commitment and responsibilities that women experience in their day-to-day caring must be acknowledged and that it is important for health-care professionals to find mechanisms for providing choices for female caregivers without neglecting their moral concerns.

Implications for practice. Female carers face difficulties in always living up to gendered standards and this need to be considered when evaluating policies and practices for family carers.

Key words: female carers, feminist perspective, informal care giving, qualitative methods

Introduction

Women often act as informal caregivers in the context of a wide range of chronic, terminal and/or disabled conditions. As such, they often care for children, spouses, older family members or friends in home care settings (Pezzin & Schone, 1999; Checkovich & Stern, 2002; Spiess & Schneider, 2003). Although there is a wide body of research focusing on caregiver burden and stress for women (Lee, 1999; Ory *et al.*, 1999; Pinquart & Sorensen, 2003; Kneipp *et al.*, 2004; Savundranayagam & Montgomery, 2010), less attention has been paid to describing the experiences and motivations of older female caregivers in providing long-term care for a spouse suffering from dementia, particularly from a feminist perspective.

One of the most common circumstances in which a woman gradually steps in to a long-term caregiver responsibility in the home is related to caring for a spouse suffering from dementia (Hellström *et al.*, 2007). Dementia is a condition involving the gradual loss of cognitive function that progressively diminishes a person's ability to perform everyday activities. Memory problems are the most frequent symptoms in early dementia; other typical symptoms include difficulties with orientation, judgment and problem solving, as well as decreased participation in community affairs, home life, hobbies and personal care (Stephan & Brayne, 2008). It is important to emphasise that caring situations involving a relative suffering from dementia are likely to differ from situations involving a purely physical impairment, as the quality of the interpersonal relationship diminishes over time (Keady, 1999; Brereton & Nolan, 2000; Keady & Nolan, 2003).

As the population in Europe ages, there will be an increase in home care services for frail older people and this shift will impact on many families (Jegermalm, 2004). Although family members requiring care are both male and female, the vast majority of the carers in home care situations are women (Carmichel *et al.*, 2008). LeRoux (2008) pointed out that in state policies and public discourse, the word 'family' is often synonymous with 'mother' and/or 'woman' whenever questions concerning caring and informal caregiving are addressed. In the same underlying notion of the concept

'family care', it is assumed that the responsibility for providing home care for a family member is taken on willingly; though, it is most likely taken for granted and unpaid (Max *et al.*, 1995; Lloyd, 2000; Paun, 2003).

Jonasdottir (1994, 2011) has critiqued this assumption and claimed that the care provided by women in the home and other private settings is of central importance in (re)affirming the social positions of men and women within their communities. This assertion can be clarified by exploring the gendered meaning attributed to the concept of 'caring': although a mutual bond of love may exist between the caregiver and receiver, the caregiver is most often conceptualised as a woman. In short, Jonasdottir argues that Western society tends to exploit the ability of women to care for others and to transfer these abilities into individual and collective power structures. Paradoxically, women seem to lose control over these power structures, as exemplified by state policies and public discourse concerning 'family' and its underlying connotation of 'women'.

Given that the positions of men and women in society are always gendered and connected to power structures, Haraway (2008) suggested that both physical and social embodiment of knowledge can be understood with respect to 'situatedness', the lens through which one encounters and interprets the world. This lens is shaped by one's values and ideals as well as personal experiences; any experiences of gender oppression and discrimination will impact one's sense of identity and social position, and thus one's situatedness.

In this study, we explored the gendered meaning of the female caregiver role as experienced by women with a long-term home care responsibility for a spouse suffering from dementia.

Methods

The data presented and analysed were drawn from 40 interviews conducted with 12 women over a period of 5 years, each of whom was an informal caregiver to a partner suffering from dementia. Following ethical approval, the women were recruited from an assessment unit at a hospital in South-East Sweden. Potential informants were recruited by nursing staff at a hospital-based assessment unit and those

interested in participating in the study were contacted by post and given information about the study. Approximately 1 week later, the first author contacted these couples by telephone and provided more detailed information and explanations. Interview appointments were then made for those still interested in taking part. A total of 12 participants were recruited to the study, all of whom belonged to the majority ethnic group in Sweden, were between 66 and 80 years of age and had been living with their partners for 39–54 years. Informed consent was obtained from both partners in the household before each interview and participants were again given the opportunity to ask questions, clarify issues or withdraw from the study if they so desired.

The interviews were conducted in the informants' homes and structured around the following themes: the home, the partner's disease, daily life, their relationship and autonomy. The questions were not strictly fixed but rather centred on the areas of interest with the aim of obtaining in-depth information regarding their living situation. The interviews lasted approximately 45 minutes and were tape-recorded and later transcribed verbatim.

A feminist perspective was used for the analysis, similar to that applied by Jonasdottir (1994, 2011) and Haraway (2008). According to Thomson (1992, p. 4), 'Women have certain experiences because society is structured in certain ways by gender'. Therefore, a feminist perspective analyses a woman's personal experience embedded within a broader social and political context. A feminist approach is grounded in the concept that a person's spontaneous discussion of their life is a construct of gender identity and power structures. The attitudes and experiences that form our gender identity become both verbalised and visible through talk and practice (Thomson, 1992). To employ a feminist perspective is to acknowledge the importance of situated embodied experiences. It is important to recognise that there are various forms of situatedness that influence a woman's experiences and that each of these exists within a hierarchical frame, which is at once both patriarchal and heteronormative (Butler, 1990, 1993). To best capture the women's experiences of caring, the authors were aware of their own subjective interpretations of the women's ideas and the social structures that constitute the forms of situatedness within which their experiences took place.

During the analysis, the interpretation of the data was consistently based on the content of the interviews in relation to theoretical frames of reference. Iterative reflexive discussions among the authors were integral to the analysis and continued until consensus was reached about the presented themes. Hence, recurrent issues in the interviews were

actively discussed among the authors to frame the characteristics of the women's situations in relation to our analytic framework.

Results

This study presents the experiences and motivations of older female caregivers in long-term care relations with a spouse suffering from dementia and interprets their experiences in terms of gendered meaning using a feminist perspective. The findings are presented in three main themes: (i) heteropolarisation in the relationship; (ii) introspection connected to caring activity and (iii) downplaying the need for caregiving support.

Heteropolarisation in the relationship

The informants were asked to describe their relationships with their partners prior to the onset of dementia. The divisions of labour in these relationships fell into a spectrum of relationship classifications, ranging from 'equally arranged couplehood' involving the equal sharing of chores, responsibilities, household economy, leisure and spare time to rather 'conservative patriarchal organisations' in which responsibilities are segregated into inside home and outside home responsibilities according to gender. Joan, 76 years of age, provided an example of this polarised rhetoric of inside home and outside home, which can often be verbalised with reference to ordinary day-to-day activities:

For example, this latest lunch he started saying, "Tomorrow I will not go out deer-hunting," he says. And I can't do anything else other than laugh at it, in the middle of it all. He wouldn't be able to manage himself in the woods, but he believes he can

It should be noted that heteronormativity, which presupposes distinct and complementary genders with 'natural' roles in life, is the starting point from which all the interviewed women gave their relationships significance. As illustrated in the quotation above, such concepts were also relevant for their spouses.

The women described their relationships and families as normal and functional before the onset of their spouses' illness. Most of the women then described changes in the structure of their couplehood once they began caring for their spouses; in fact, their spouses' illness seemed to shift their relationships to more conservative positions. For the majority of the women, their husbands' disease has also led to a heteropolarisation in their own lives. Mary, 78 years of age, explained:

He can get rather nasty against me, it is really scary. And it makes me really sad when it happens. It is just like he knows when he goes too far, he sort of goes into himself./.../‘Shut up!’ he says, and slams his fist on the table. ‘I’ll make the decisions.’ And it’s no use discussing with him whatsoever

As shown in this quotation, a long-term caring responsibility for a husband with degenerative cognitive disease can also lead to the reinforcement of the organised polarity between men and women; this polarity seemed to be legitimised by the illness. Many of the women were tormented by this gradual polarisation of their particular role in the relationship, claiming that it was difficult to be the one that is ‘not ill’. A recurring issue in the interviews was the sense of guilt experienced by the women, both in relation to social contacts in general and more specifically in relation to their spouse.

The women’s personal experiences influence the way they expressed this polarisation as well as how they coped with it on a daily basis. Beth, 69 years of age, said:

There is no point in arguing, to say anything. In this case, for the woman it is ordered silence in the assembly, a sense of reason doesn’t exist. I’ll think it is hard, it really is

As typified by Beth above, the women often made metaphorical references to a woman’s role in church, society or nature to justify their shift towards a more conservative organisation in their lives. Some of the women rationalised their own adjusted roles in relation to this polarisation by citing examples of really unpleasant times that had ‘gone bad’, during which stormy situations had to be avoided. Although this was something to simply tolerate in their daily strategic caring, the women often took responsibility for being complacent to the heteropolarisation in their lives, as this acceptance made it easier to avoid unpleasant situations. This adjustment of roles was illustrated by Sally, 78 years of age, as she described socialising with her husband:

It is the same as when I maybe make a comment. For example, we often watch quiz shows on TV. It’s fun when you are able to answer the questions. But I’ve also noticed that if you say something, then he doesn’t say anything. And then I say, “Did you know that?” “Yes,” or “Okay,” he grunts. So I don’t say much anymore. I don’t know. I’ve thought about this, it’s like he feels subordinated

Such compliance was apparent in many aspects of the women’s lives, especially during situations in which their husbands became suddenly difficult. For example, what to watch on TV, the management of chores, and expectations related to ‘inside home and outside home’ activities could suddenly be pursued by their husbands as very important issues.

Feeling emotionally and socially stigmatised in the relationship was one of the main problems connected to the polarisation. The women felt there were no ‘rational’ arguments they could present to their husbands, family or friends for meeting their own needs; rather, their partners’ cognitive impairment took precedence.

Introspection connected to caring activity

An overall pattern that emerged from the stories captured in the interviews was a verbalised, lifelong commitment to caring. All the women in our interviews refer to themselves, by a dint of circumstances, as being caregivers in different roles throughout their entire lifetimes. For example, an informant named Jane discussed her caregiving roles as both a mother and daughter and described her attitude as somewhat ambivalent, feeling both grateful and burdened when caring for her children as well as her frail mother for the last 15 years of her mother’s life. This ambivalence highlights one of the recurrent themes: the connection of their positions and the female identity to caring. Sara, aged 70, expressed an opinion that was common among the women in our interviews:

It is typical for women, it’s in our genes to take care of everything and constantly worrying about everything, it is like all the world’s problems are resting on your shoulders. But for men, they seem to go along no matter what, because they got the women to rely on

This self-placement into gendered categories, as indicated in the quotation above, follows a common line of reasoning that connects a nurturing responsibility to the female identity. Embedded in the women’s narratives about their lives is the commitment to caring. The personal experiences, such as that outlined by Sara above, motivate their personal sense of responsibility for caring even at this old age, and even if it restricts their own social life to a minimum.

Networks of other women are important resources for sharing the responsibility and duties of caring. The possibility for caregivers to share their embodied experiences and feelings within the network of other women seems to be important for caregivers in many different roles, such as daughters, female friends, daughters-in-law and so on. Mary, aged 78, gave an example of this kind of sharing with her daughters:

My daughters call me often, sometimes several times a day to ask me how everything is going. They have said that they can hear in my voice how I’m doing. I can’t pretend that it is okay all the time and they say that they can hear in my voice if I’m extremely tired

As exemplified by the relationship between Mary and her daughters, the women have a social support network of other women, including daughters, daughters-in-law, sisters and female friends that are either directly or indirectly connected to their caring practices. It is clear that the women appreciate their female network as it creates mental, social and physical space for personal manoeuvring and offers a crucial link to activities outside the home and beyond their caring practices. However, such networks can also be interpreted and understood as a way of disciplining the caregivers via the constant introspection and self-examination that such sharing induces. For example, Mary's sharing with her daughter in the excerpt above worked in two ways: it eased her burden, but also emphasised her shortcomings in relation her own ideals. The expectations these women have for themselves as carers seem to be related to their self-discipline in upholding their role. When Mary declared, 'I can't pretend all the time', she is aware of both the difficulty and perceived necessity of always living up to the gendered standards that female carers face. By attempting to shield her daughters from the reality of her situation, she is perpetuating the collective assumptions and ideals about women as carers. Mary, who cared for her husband for over 6 years without receiving any support from community services, provided yet another example of the importance of the connection between the carers and the network of female relatives in upholding the caregiving:

And my girls, they are coming and going like frequent flyers in our house, one of them lives a two-hour drive away and the other lives about three hours away, still they're doing everything they can to support, help and arrange our lives to the best, but it isn't easy

As shown, many different arrangements can be made to keep the personal responsibility for the caring within the 'family'. The nurturing skills associated with each of the different roles throughout a woman's lifetime, such as 'daughter', 'wife' and 'mother', provide support, maintain continuity and can be regarded as important resources for both the family and society in general.

Downplaying the need of caregiving support

Another common pattern to emerge from the interviews is the downplaying of the need for support in day-to-day caring by both the caregivers themselves and the authorities. When the question of support was raised during the interviews, it became obvious that it is a complex matter, intertwined with certain moral values rooted in the caregiver's identity. Almost every informant acknowledged the need for social services to

support family carers and was willing to accept that 1 day they might need such support. For the meantime, however, they indicated through various statements why they should be excluded from receiving such support, including 'I'd have to get sicker before...', 'Until my daughters are unable to help...', or 'As long as we can use the car...'. Such lines of reasoning seemed to postpone their perceived need for support.

An example of the reluctance to accept support is seen in a quotation below from Vera, who had problems with personal matters related to day-to-day caring activities, such as bathing and personal hygiene, in the caring for her husband and said:

It hasn't gone that far yet [referring to the husband's disease], so you still can. You need to have more severe problems to get help, to even be allowed to discuss the possibility of getting help

Vera would not allow herself to discuss the possibility of getting help; such a discussion would place a burden on support services and take support away from others with more 'severe' problems. Most importantly, Vera indicated that the solution to her problem was to have a handle installed over the bathtub to facilitate the manoeuvring of her husband in the bathroom. Like Vera, most of the interviewed women stated that they would regard accepting public support as both placing a burden on society and a failure to properly care for their husbands.

As mentioned earlier, their very 'identity' seemed to be at stake when the question of support arose. Karen, 75 years of age, gave an example of the on-going moral debates in her decision-making about accepting public support:

I haven't told him [referring to her husband] that I tried to establish contact with the community services because it might upset him, and I don't want that, I can't ... I have tried to be sneaky about it and maybe its rascal behaviour, I don't know

As demonstrated in Karen's quotation, introspection and self-examination about their day-to-day caring practices was somehow related to personal shortcomings in what would be considered a betrayal and disturbance in the caring commitment and relationship. Even when certain authorities, including their doctors, emphasised the obligation for social services to provide support, they seemed to maintain their ambivalence towards support. Sara recalled when she was encouraged by her physician to get help:

"In time I will seek support," I told her. "You should do it NOW," my doctor said and gave me a number a call. One day that was extremely bad [referring to her caring of her husband] I called the number. Later, a woman from the social services came home to us and interviewed us;

she thought we look young and healthy and didn't see any reason for why I needed any help or services from them

The caregiver is often confined by the different expectations inherent in the caregiving burden. Trapped between the encouragement to get help and the possibility of rejection, they often acknowledge that though they might need support, they are not yet ready to accept it. As demonstrated by Sara in the excerpt above, the time to receive public support for most of the women is some point in the future.

The carers' tendency to downplay their own need for support likely results from interpreting their experiences in relation to the expectations and assumptions of others. For example, the ideas of professionals about how to best provide care as well as the patriarchal and heteronormative assumptions pervasive in the discourse surrounding caring can heavily impact a carer's sense of accomplishment or failure concerning their caring duties.

Discussion

How can the experiences and motivations of older female caregivers caring for a spouse be understood in relation to gendered meanings through a feminist perspective? Although the sample size used in this study precludes any claims of traditional forms of generalisability, several insights can be gained by demonstrating that the caregiving experience relates to society's expectations about women's caregiving roles. The results of this study's analysis paint a picture of women who constantly reflect on their caring activities in terms of general and heteronormative expectations (Butler, 1990, 1993).

The findings highlight specific concerns that are intertwined in the process of caring for their spouse. Firstly, we suggest that the process of heteropolarisation can be understood as consequence of the spouse's illness and the caring process related to the illness. Secondly, we suggest that caring itself is related to introspections and impressions of 'short-comings' of the caregiver. Thirdly, we suggest that the tendency of carers to downplay their need for support in day-to-day caring situations must be acknowledged. These three patterns can be related to expressions of moral concerns connected to caregiving, such as distress concerning personal short comings and the fear of being a burden on society.

As suggested by Gilligan (1982) and Lewis (2007), there is an important connection between a woman's sense of morality and the choices she makes as a caregiver, as the consideration of the welfare of others is a central imperative. However, associated with their choices is the risk that they

will become overwhelmed by physical, emotional and social distress as a result of their caregiving burden (Colli & Jones, 1997; Donelan *et al.*, 2001; Kneipp *et al.*, 2004).

We argue that the gendered meanings in the everyday life of female carers, as addressed in this study, have important implications for healthcare professionals in understanding the views and level of engagement of female carers. We also acknowledge that this study's presentation of the women's experiences could be seen to imply that such experiences are common for all women; this is not the case. However, the findings do indicate that these patterns can exist for both individuals and groups of female carers and merit further exploration.

Although further research is needed in this area, we can nonetheless explore the potential implications of this study for practical application. In particular, when engaging with families in which women play a primary caregiving role in later life, healthcare professionals should be aware that they will encounter practices heavily influenced by collective values and ideals surrounding caring (Jonasdottir, 1994, 2011; Haraway, 2008). By evaluating our results in relation to older male caregivers' experiences of long-term care for a spouse (Kirsi *et al.*, 2000; Russel, 2007; Eriksson & Sandberg, 2008), we stress that researching the daily caregiving provided by women is equally important in terms of understanding how general and heteronormative expectations operate for women in the role of carers. To increase gender sensitivity in caring theory, it is important to realise that collective power structures must be considered and elaborated; the position of women in society is related to values and ideals in a hierarchical framework, which is at once both patriarchal and heteronormative.

Increased gender awareness has important implications for how women with a long-term caring responsibility can be supported. As shown by Bedini and Guinan (1996), women view their caregiving role and responsibilities as a paramount over other responsibilities, including the responsibility to care for themselves. We stress that the intense commitment and responsibilities that women endure in their day-to-day caring must be acknowledged and that it is important for professionals to find new mechanism for providing better choices for female caregivers without neglecting their moral concerns. By making greater efforts to carefully listen to what might be required in terms of support, as opposed to making gendered assumptions about the women's caring ability, much could be improved for the women in their daily life. In conclusion, healthcare professionals and policy makers must constantly challenge their own assumptions that the caregiving responsibility of 'families' is identical to that of 'women'.

Implications for Practice

- Provides valuable insights for increasing gender awareness in informal care giving situations.
- Highlights the difficulty and perceived necessity of always living up to the gendered standards that female carers face; this can be useful for evaluating policies and practices for family carers.
- Contributes to the critical reflection on general norms and heteronormative expectations connected to female carers in everyday life.

References

- Bedini L.A. & Guinan D.M. (1996) "If I could just be selfish...": caregivers perception of their entitlement to leisure. *Leisure Sciences* 18, 227–239.
- Brereton L. & Nolan M. (2000) You know, he's had a stroke don't you? Preparation for family caregiving – the neglected dimension. *Journal of Clinical Nursing* 9, 498–506.
- Butler J. (1990) *Gender Trouble: Feminism and the Subversion of Identity*. Routledge, New York, NY.
- Butler J. (1993) *Bodies that Matter. On the Discursive Limits of "Sex"*. Routledge, New York.
- Carmichel F., Humle C., Sheppard S. & Connell G. (2008) Work-life imbalance: informal care and paid employment in the UK. *Feminist Economics* 14, 3–35.
- Checkovich T.J. & Stern S. (2002) Shared caregiving responsibilities of adult siblings with elderly parents. *The Journal of Human Resources* 37, 441–478.
- Colli C. & Jones R. (1997) Emotional distress and morbidity in dementia carers: a matched comparison of husband and wives. *International Journal of Geriatric Psychiatry* 12, 1168–1173.
- Donelan K., Falik M. & Desroches C. (2001) Caregiving: challenges and implications for women's health. *Women's Health Issues* 11, 185–200.
- Eriksson H. & Sandberg J. (2008) Transitions in men's caring identities: placing a partner in a nursing home. *International Journal of Older People Nursing* 3, 131–137.
- Gilligan C. (1982) *In a Different Voice: Psychological Theory and Woman's Development*. Cambridge University Press, Cambridge, UK.
- Haraway D. (2008) Simians, cyborgs and women. *The Reinvention of Nature*. Symposium, Stockholm.
- Hellström I., Nolan M. & Lundh U. (2007) Sustaining 'couplehood'. Spouses' strategies for living positively with dementia. *Dementia: The International Journal of Social Research and Practice* 6, 383–409.
- Jegermalm M. (2004) Informal care and support for carers in Sweden: patterns of service receipt among informal caregivers and care recipients. *European Journal of Social Work* 7, 7–24.
- Jonasdottir A. (1994) *Why Women are Oppressed*. Temple University Press, Philadelphia.
- Jonasdottir A. (2011) What kind of power is love power. In: *Sexuality, Gender and Power* (Jonasdottir A., Bryson V. & Jones K.B. eds) Routledge, New York, pp. 45–60.
- Keady J. (1999) *The Dynamics of Dementia: A Modified Grounded Theory Study*. PhD thesis, University of Wales, Bangor.
- Keady J. & Nolan M. (2003) The dynamics of dementia: working together, working separately or working alone? In: *Partnerships in Family Care* (Nolan M., Lundh U., Grant G. & Keady J. eds) Open University Press, Maidenhead, pp. 15–32.
- Kirsi T., Hervonen A. & Jylhä M. (2000) A man's gotta do what a man's gotta do: husbands as caregivers to their demented wives: a discourse analytic approach. *Journal of Ageing Studies* 14, 153–169.
- Kneipp S., Casleman J. & Gailor N. (2004) Informal caregiving burden: an overlooked aspect of the lives and health of women transitioning from welfare employment. *Public Health Nursing* 21, 24–31.
- Lee C. (1999) Health, stress and coping among women caregivers: a review. *Journal of Health Psychology* 4, 27–40.
- LeRoux T. (2008) The private and the public. Family ideology & care for people with disabilities. *Women's Health and Urban Life* 7, 16–30.
- Lewis L. (2007) Epistemic authority and the gender lens. *Sociological Review* 55, 273–292.
- Lloyd L. (2000) Caring about carers: only half the picture? *Critical Social Policy* 20, 136.
- Max W., Webber P. & Fox P. (1995) Alzheimer's disease: the unpaid burden of caring. *Journal of Aging and Health* 7, 179–199.
- Ory M.G., Hoffman R.R. 3rd & Yee J.L. (1999) Prevalence and impact of caregiving: a detailed comparison between dementia and non-dementia caregivers. *Gerontologist* 39, 177–185.
- Paun O. (2003) Older women caring for spouses with Alzheimer's disease at home: making sense of the situation. *Health Care for Women International* 24, 292–312.
- Pezzin L.E. & Schone B.S. (1999) Intergenerational household formation, female labor supply and informal caregiving: a bargaining approach. *The Journal of Human Resources* 34, 475–503.
- Pinquart M. & Sorensen S. (2003) Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis. *Psychological Aging* 18, 250–267.
- Russel R. (2007) The work of elderly men caregivers: from public careers to an unseen world. *Men and Masculinities* 9, 298–314.
- Savundranayagam M.Y. & Montgomery R.J.V. (2010) Impact of role discrepancies on caregiver burden among spouses. *Research on Aging* 32, 175–199.
- Spiess C.K. & Schneider A.L. (2003) Interactions between care-giving and paid work hours among European midlife women, 1994 to 1996. *Ageing & Society* 23, 41–68.
- Stephan B. & Brayne C. (2008) Prevalence and projections of dementia. In: *Excellence in Dementia Care: Research into Practice* (Downs M. & Bowers B. eds). Open University Press, Maidenhead, pp. 9–34.
- Thomson L. (1992) Feminist methodology for family studies. *Journal of Marriage and the Family* 54, 3–18.