

Informal home caregiving in a gender perspective: A selected literature review

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ABSTRACT

An informal home caregiver is a person (family member or friends) who takes care of or participates to some degree in the care of a person in the home. This study provides a selected review of literature published 1982–2003 of the informal home caregiving from a gender perspective. A computer-aided search using MEDLINE and CINAHL was carried out. The final number of articles was 45. The main findings were that there are differences in informal caregiving due to gender. Gender differences were found in categories such as affected lifeworld, health problems, managing ability and caregivers experience from caring for a care receiver with different diseases. It is of importance that the informal caregiver is involved in the planning and that a planning act takes place. If society involves the informal home caregiver we can avoid the caregiver being the hidden victim of illness and disability. It is known that burdensome caregiving can result in encroachment due to exhaustion.

KEY WORDS: *Informal home caregivers, gender, literature review.*

Introduction

Sweden has today 1.55 million people who are 65 years or older. This is equivalent to 17.4% of the population. Between the years 2010 and 2020 we will experience the largest increase of elderly in Sweden (1). In the future there will be more people over 65 years of age and to be able to handle this situation society has to change structure. Informal home caregiver is the person who takes care of, or participates to some degree in the care of a person in the home. Informal home caregivers include family members and friends without family ties (2).

Support is needed on different levels both psychically and physically when people grow old and frail. Informal caregiving is one of the oldest types of care systems, but it is important that it happens in concert and on a voluntary basis. All the responsibility cannot be put solely on the relatives (3). Informal home caregivers give double the amount of help compared with official care. Society has failed to comprehend this problem.

It is also important to change our attitude and views of the elderly to be able to meet their requirements. There is a tendency for women more often than men to report deteriorating health and a variety of health related symptoms. There have been varying explanations for this; one is that women are more sensitive to changes in their bodies and can feel every change (3). Another is that women find it easier to report different health related diseases in an interview situation.

Men have a tendency to neglect weakness due to body health (4). There is also a tradition that women assume the main responsibility for informal home caregiving. The research in a gender perspective in informal home caregiving is limited both in Sweden and internationally (5).

Aim

The goal of this literature review was to examine informal home caregiving from a gender perspective.

Method of review

By using database MEDLINE and CINAHL a literature search was conducted. The review was confined to papers written from 1982–2003. The selected language was English. The search strategies used the search terms «home» «caregivers» and «informal», gender, social support, quality of life, burden, stress, abuse and neglect, multiple diseases. The main focus was one informal home caregivers and gender. The exclusion criteria were the person who received the informal help, newborn babies, children and youth's, literature reviews, editorials and letters (6). The initial literature search resulted in 217 articles, of which 65 met the inclusion criteria with reference to gender and read as a whole.

Goodman's, Willman's & Stoltz and Polit & Hungler's model was used to compile and evaluate the articles (6, 7, 8). Each article was judged with strict criteria and this addressed the methodological quality. The scientific qualities of the studies are judged from a three-grade scale: High quality/low risk of bias=1, Moderate quality/medium risk of bias=2, Low quality/high risk of bias=3.

In the final judgement, studies receiving grade 1 and 2 are included in the final literature review (6). To increase the reliability and validity the first two authors evaluated a number of randomly selected articles independently. The final number of articles was 45 which met the criteria for inclusion.

Analysis

After evaluation of the methodological quality of the studies the content was examined in relation

to the aim of the study. The articles were read several times and analysed by the content in the text, it became apparent that certain topics reoccurred often in the various studies. By using Burnads steps for analysing qualitative data, the data generated different categories regarding content. Similar categories were put together to create broader categories and compiled to a new completeness (9).

Findings

Affected lifeworld Daughters and sons

Daughters were significantly more physically and psychologically affected than sons due to the caregiving role (10, 11). Daughters were more likely to be affected than the sons in relation to friends and family members. Daughters reported a higher percent of deteriorating health. Within all sibling network categories, daughters were more likely than sons to be providing care to an impaired parent. Sons and daughters from only-child and single-gender network reported similar numbers of hours per day (12). Interference between caregiving and the caregiver's personal and social life created emotional strain both for daughters and sons. The most important predictors to create emotional strain for daughters were interference with work and quality of relationship with the parent. For sons it was behavioural problems of the parent and few informal helpers (10). Daughters are more likely than sons to provide ADL (Activity of daily living) and IADL (Instrumental activity of daily living) to their parents (13). Sons take on the role as primary caregiver only if there are no female siblings. The sons tend to provide less extensive support compared to daughters. They don't have the same stressful caregiving experiences. Sons provide the same proportion of

services as daughters but are less likely to help with hands-on service (14).

Wives and husbands

Brody (15) studied daughters who were either married, remarried, separated/divorced, widowed or spinsters. Married women considered caregiving easier than single women. Married women had more socio-emotional support, higher incomes and less depression. Husbands as caregivers were more likely than wives to seek help from formal carers and receive more support (16).

To be a caregiver in old age can be different from being a caregiver at an earlier age (17). Wenger found that isolation and loneliness were more stressful for women than for men. The evidence shows that there are gender differences both in who does the caring and who is cared for, that men and women experience the care for spouses differently, and that the caregiving experience for daughters is affected by the history of their relationship and shared residence. What many studies have shown is that most carers value the caring role and do not find it unrewarding (17).

Cossette (18) examined gender and kinship with regard to caregiver's use of informal and formal support. For most of the comparisons, husbands, wives and daughters shared more similarities than differences. Daughters were different from spouses with respect to conflicts, husband and wife caregivers were much the same. Kinship rather than gender seemed to explain this difference.

Neufelds and Harrison (19) show in a study limited to women that they have four variations in reciprocity. Women use a process of monitoring to build reciprocity. Relationship with friends and family is described as «give-and-take».

Reciprocity with the care receiver in a situation where the care receiver was unable to communi-

cate verbally, took a different form. They often constructed reciprocity, built through monitoring and included the sub process of observation.

For women, age, years of caregiving and socio-economic status was not significantly related to the size of their social network. Older men and those who had lower socio-economic status had fewer available sources of support. These gender differences in network size provide important knowledge for nurse's ability to identify caregivers who may be at risk of inadequate support (20).

Parris Stephens (21) research indicates that both positive and negative spillover effects are related to caregiver's well-being. Positive spillover is more related to well-being than negative spillover. Both husbands and wives reported that their marital relationship had been both negatively and positively affected, by their wives parent-care responsibilities. Husbands reported less negative spillover and more positive spillover than their wives.

Malone Beach (22) examined family social support and social conflict to stressors and depression among caregivers. Three dimensions were assessed; instrumental, informational and affective.

Social support was helpful for men, and sense of control was helpful for women (23). Limited social contacts and roles outside the home create a loss of self and self-esteem, which leads to depression. Good health is related to social support for family caregivers. Women reported more sources of conflict in their social network than men (24).

Women taking care of husbands with chronic obstructive pulmonary disease were dissatisfied because they had no time for recreation.

They were also dissatisfied with friends, families and health care providers who didn't give them the support they needed (25).

In a study limited to interviews with mothers, daughters and granddaughters, Sörensen (26) found that few made plans and organised for the future but those who did were more satisfied than non-planners. Caregiving involves four major dimensions or preparatory behaviour; anticipation, decision-making, concrete planning and role socialisation.

Health problems

Kramer (27) found that women provide more intensive care such as assistance with personal care and hands-on activities. Women reported higher levels of burden. Women experienced more secondary role strain and had greater household size than men. Data on health were collected from 51 older caregivers. Most of them were women 66,7 % and they have been caregivers for more than 20 years. Poor health was reported from 50% and decline in their health reported 33,3% (28). Informal caregivers especially women reported considerable stress, and they felt that very little help was given from formal caregivers (29).

Wives were more likely to wish to leave the caregiving tasks. Both sexes viewed the women as the most suitable person in the caregiving role. Wives felt a greater caregiving obligation than the husbands (30).

A desire to place the care receiver at a nursing home was strongly associated with caregivers burden, and not the level of dementia of the care receiver.

The difference appeared to be related to husband's greater tolerance of memory and behaviour problems (31). Young's (32) heart disease study found consistent patterns of strain. Women and especially the daughters had the most severe after-effects. Lutzky (33) found two explanations for gender differences, male caregivers are less likely to be watchful to their emotions, they fail to notice and report distress. Women

are able to use coping styles that are less effective for mitigating distress.

Sons and daughters from only-child and single-gender networks reported the same number of hours spent in caregiving and they experienced the same levels of stress and burden. In contrast, daughters from mixed-gender networks reported higher levels of stress and burden and more hours spent caregiving (12).

Having a masculine sex-role orientation is predictive of the caregiver having greater perceived competence (34).

Barusch (35) found that care receivers cognitive and behavioural difficulties emerged as the most important predictor of burden, followed by caregiver age, unpleasant social contacts, caregiver sex and overall coping effectiveness.

Knight (36) found that wives show higher burden scores than husbands. Women used fantasy, while withdrawal was more common in men. Women reported higher levels of depression.

The most consistent predictor of a distressed condition for women was the sense of feeling out of control. This predicted depression, anxiety, and guilt among women, but among men it predicted only anxiety (31).

Managing ability

Coping strategies (37) such as time management and stress reduction was a major problem, they had trouble with enjoying leisure time. Smith (37) found that the major categories of pressing problems had to do with coping techniques. Sibling conflicts were very common among family caregivers. The majority were focused around problems such as emotional and behavioural needs. Wilson (38) examined the mental well-being and special problems of wives who were caring for their disabled husbands. Women who care for a disabled spouse can suffer stress that

severely affects their sense of well-being and satisfaction. The major problem concerned the need for constant medical care and supervision to ensure that the care receiver's needs were met.

Paun (39) found five major themes in the structure of women's experience of taking care of their spouses diagnosed with Alzheimer's, one was making sense of the situation. Braudy Harris (40 page 346) interviewed sons caring for a parent with dementia. Common themes were sense of duty «You got to do what you got to do», and acceptance. Taking charge of the situation was a major role for the sons. Common emotions were love, pain and anguish, anger and/or resentment, sadness and guilt. Common issues were loss, affected sibling relationships.

Sons seemed to use four major coping strategies; problem solving approach, immersing themselves in their work, confiding in their wives, and finding solace and support in their religious convictions.

Borden (41) found that gender emerged as a significant correlate of well-being, women reporting higher levels of distress. The data provided no evidence of differences between men and women in age, partner's illness, characteristics, distress in response to dementia symptoms, or reliance on formal support service.

H De Vries (42) found no significant difference between male and female caregivers in coping strategies. Women were more likely than men to use avoidant coping. Women more frequently used cognitive strategies such as «prayed for guidance-strength». Women more often than men followed a pattern of seeking out social and recreational support.

If spare time was available on the weekends it's varied by gender how they used it (43). Saveman (44) investigated patterns of abuse of the elderly in their own home. Psychological abuse was

the most common type. Saveman (45) interviewed home service personnel about abuse of the elderly; in 75 percent it was a woman who was abused. Male abusers were reported to abuse physically more often than female abusers; threats were also more common amongst male abusers. Reasons behind the abuse were very often financial profit for the abuser, alcohol/drugs, mental disease and family conflicts. Kramer (46) found that social resources and health were important for understanding the variation in both negative and positive appraisals.

Experience in a gender perspective from caring care receiver with different diseases

Harris (47) studied 15 male caregivers caring for their wives with Alzheimer's disease. She found four types of male caregivers; the worker, the labourer of love, the sense of duty and the crossroads.

Parson (48) investigated the male experience of caregiving for a family member with Alzheimer's disease. Eight themes were identified; enduring hard work, vigilance, constant watchfulness, a sense of loss, aloneness and loneliness, taking away, searching to discover something about the disease.

Rose-Rego (49) examined differences in subjective psychological well-being between husband and wife caregivers of persons with Alzheimer's disease in comparison to the psychological states of husband and wives who were non-caregivers. They found that gender differences in psychological, social and physical well-being are specifically associated with the caregiver role.

More negative psychological states were reported from caregiver wives than caregiver husbands. Williamson (50) studied relationship orientation among caregivers of Alzheimer's patients. Highest level of depression among men was found in those of

low communal orientation and poor prior relationship. Higher levels of depression among women low in communal orientation were related to having a close relationship with the patient. Female caregivers to a relative with Alzheimer have experienced greater reaction to disruptive and depressive behaviour. Robinson found that there was a need for individualized education and training to understand persons with Alzheimer's especially for female caregivers (51). Eight family caregivers to elderly demented care receivers reported heavy burden. Husbands reported heaviest burden, and they expressed worry, weariness, guilt, distress and isolation Samuelsson (52). In a study of male caregivers to a relative with mental illness three themes were found, expression of burden, duration and depth of commitment and role affirmation (53).

Karmilovich (54) examined levels of burden and stress experienced by spouses of patients with heart failure. Taking care of a relative with heart failure is burdensome and stressful. Cossette (55) examined caregiving tasks as predictors of mental health in the wives of men with chronic obstructive pulmonary disease. She found two factors that stand out as related to mental health- the number of supervision tasks and the amount of disturbance associated with difficult emotional support.

Discussion

The research in a gender perspective in informal home caregiving is limited both in Sweden and international (2) and this literature review can only agree about that. The results from this literature review show that there is a need for more research in this area. When informal home caregivers perform great amount of support to a relative it doesn't mean that the professionals has to reduce it.

Instead the professional has to support and give the help they are asking for, and have a sensitive approach to gender differences.

This literature review shows that there is no consideration taken about gender differences in informal home caregiving. Many of these informal home caregivers are struggling with problems which could be solved if someone taking consideration of the gender aspects and that they are all individuals and ask for different kind of support. Informal home caregiving is based on deep feelings of love and care, but caring for the beloved can also change. The people who take on this important task have to be given the support to maintain that feeling. Informal caregiving can sometimes have a negative impact. That can happen when the caregiver struggles with fatigue, hopelessness, emotional stress, depression and lack of knowledge about the care receivers disease and need of care, and also when little or no help at all is given by the professionals. Today's informal caregiver is not supposed to be tomorrow's care receiver. It is important to view the whole spectrum of informal caregiving and that means to take the gender aspect into count. There is a need for gender sensitivity. Create an effective partnership between formal and informal caregivers can save one's strength. It is the caregiver and the care receiver as a whole who need the professional help. Professionals have to consider that men and women have different needs.

Since 1996 in England the «Carers Support and Services Act» (56) gives relatives the legal right to apply for help for a care receiver. The thought behind this is to involve the caregiver more in the care planning and gives the caregiver more rights. Sörensen (26) found that few made plans and organised for the future. There are few investigations

around the onset of informal home caregiving. Professionals need to proceed with caution when intervention and treatment programs are designed for men and women caregivers.

Navaie-Waliser, Mays and Robinson (29, 53, 51) found that there is a need for individualised educating and training programs for the informal home caregiver which can mean that the gender aspects are taken into account.

The vast majority of studies focus on the negative effects of providing care. There is a requirement for more research regarding positive effects of caregiving in a gender perspective. Jansson and Mui (10, 11) found that daughters significantly reported more physical and psychological destruction than sons. Also the social life of the caregiving daughters was more affected than the sons. Daughters reported a higher percentage of deteriorated health than the sons. Husbands as caregivers seek more help from formal carers and they also received more support (16). A great deal of female caregivers indicated negative impact but they don't ask for help. More research is needed. The most common informal caregiver is an elderly woman who takes care of her husband. Wenger (17) showed in her study that there are differences between young caregivers and elderly caregivers. Loneliness and isolation was more stressful for women than men, physical and unfamiliar domestic work was more stressful for men. In our society there are persons who have little or no social network and this has to be included in the planning. Women seem to have more conflict in their social network than men. Women's age, year of caregiving and socio-economic status was related to the size of their social network. Low socio-economic status and elderly men had fewer sources of support (20). Social support was helpful for men, and sense of control for women (23). Wives showed higher burden score than husbands (36).

What is the reason that women reports more negative impacts on home caregiving than men do? We really have to know what's going on, the gender aspect in home caregiving should not be an impediment instead it should be a resource that is taken care of. Lutzky (33) found that women use coping styles that are less effective for mitigating distress. Sons take on the role as primary caregiver only if there are no female siblings. Can this be due to a deep tradition or just happens to be so? Today there is very little knowledge of differences between gender's possibilities to handle difficult situations and how they react in the caregiving role. It is of importance to find out what creates the negative consequences and what can be done. The major categories of pressing problems had to do with the coping techniques (37). Caregivers cannot be seen as a homogeneous group with similar assumptions; they are individuals and should be treated as such. It is also of importance to take into account that the caregiving role can vary with the care receiver's disease, as shown by Rose-Rego and others. There has to be a caregiver plan that takes into consideration the care receiver's disease.

The informal home caregiver has to have information/education about the care receiver's disease and to make clear what responsibility the home caregiver takes on with thought on the course of events of the disease.

There is little written about abuse and neglect but Saveman (45, 46) found that psychological abuse was the most common type. Male abusers used physical abuse more than women.

There is already a knowledge that burdensome caregiving can result in encroachment due to exhaustion (57). Informal home caregivers provide a large amount of aid contribution and society has the responsibility to give them help, financial and other support. It would be a disaster if

it ends with a criminal act from the informal caregiver due to neglect from society. The informal caregiver may also become the hidden victim of illness and disability. Society has a big responsibility here; we cannot put all the responsibility on the informal caregiver.

Each informal home caregiver has his or her unique needs «gender perspective «and it falls upon society to take care of this. In Socialstyrelsens final act» Anhörig 300 (58) they don't take the gender perspective in consideration at all, in spite of studies that shows that there are differences in gender perspective in informal home caregiving. It is high time that this is taken in consideration from the professional's side.

Conclusion

Society has to pay closer attention to the needs of the informal home caregiver and take into account that there are gender differences in the caregiving role. Male and female informal caregivers have distinct needs requiring differing types of aid, and the professionals need a sensitive ear for this.

Informal caregivers have to be seen as a resource and not an impediment, and they have the right to ask for the support they need.

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