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Dimensions of informal care and quality of life among elderly family caregivers

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Dimensions of informal care and quality of life among elderly family caregivers

The aim was to investigate dimensions of caregiving activities among elderly (75+) caregivers based on Nolan's model and to study the dimensions in relation to health-related quality of life (Short Form 12). Responses to a Swedish postal survey ($n = 4278$, response rate 75–79 years old: 60%; 80–84: 56%; 85–89: 48% and 90+: 42%) showed that 783 persons (18%) were helping another person due to that person's impaired health, 41.6% women, mean age for women 81.8 years (SD 4.96) and for men 81.7 years (SD 4.32). The postal questionnaire included SF-12, demographic data and questions about caregiving activities derived from Nolan's model, social network and contacts with health care. Adapting their activities to be prepared if something happened (52%), having regular contact to prevent problems (35%), helping in contacts with the hospital (57%), helping with instrumental activities of daily living (49%), personal activities of daily living (14%), medical care (11%) and helping to improve functions (14%) were the activities reported. Adapting own activities, regular contact, weak economy and needing instrumental help with daily living oneself predicted low MCS12. The importance of early involvement on the part of the caregivers was emphasized.

Keywords: informal caregiver, gender, nursing, elderly, quality of life.

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Introduction

As the population gets older (1, 2), the need for care will increase. Due to shortage of health care personnel and decreased finances in the community, the demands on informal caregivers will increase. Thus health care staff need to support and collaborate with informal caregivers in their coping with care, both physically and emotionally. Most research on informal caregiving among older people has defined caregiving as instrumental care (IADL; i.e. help with laundry, cooking and house cleaning) or personal care (PADL; i.e. help with personal hygiene, feeding and getting dressed), which is supposed to be what the carers find least stressful (3). It may well be that caring for another person who has impaired health may include other activities and start earlier than when IADL or PADL help is required. Few studies have been designed to explore family caregiving as a whole, including other dimensions of caregiving than instrumental or personal care, although that is important for understanding informal care and its relation to strain on the caregiver (3). It is well known that the family caregiver is often an older person caring for another old person. Studies have shown that in Sweden, 14% of persons over 75 were involved in informal care of the elderly (4). Helping another person was shown to covary with low quality of life among informal caregivers in the UK [$n = 44$; 20 male (mean age 78.5) and 24 female (mean age 74.8)] (5), where 38% of the men and 65% of the women showed high levels of mortality. Thus there are reasons to further investigate the relationships between the dimensions of informal care and quality of life. Such knowledge can form the basis for outlining collaboration and support, individually and at a time when it is most needed.

Caregiving is traditionally defined in terms of aspects such as help with personal activities for daily living and/or instrumental activities for daily living, although it is likely to include other aspects as well. Bowers (6) developed a typology for intergenerational care by interviewing adult children ($n = 33$) and the parents they cared for, 62–97 years old ($n = 27$), to understand the less obvious parts of caregiving. She identified five levels (Table 1), of

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Table 1 Typology from Bowers (6) and Nolan *et al.* (3) and corresponding items from the questionnaire

Bowers' typology (levels)	*Nolan's typology (dimensions)*	*Items in questionnaire*
Anticipatory care 'Just in case'	Anticipatory care (Informative and speculative)	I adapt my own activities to be prepared if something happens
Preventive caregiving Preventing illness, injury and physical and mental deterioration	Preventive caregiving	I keep in touch every week to prevent problems (monitoring medicine intake, or checking that he or she is eating)
Supervisory caregiving Checking up, and making arrangements for the person	Supervisory caregiving	I help with practical things, such as visits to the doctor's, contacting the hospital
Instrumental caregiving Hands-on caregiving	Instrumental caregiving	I help regularly with chores, such as shopping, cooking, or cleaning
Protective caregiving Protect from consequences which cannot be avoided (cognitive decline)	Preservative care Maintaining the self-esteem of the person	I help regularly with personal care, such as eating, getting dressed, personal hygiene
	(Re)constructive care Rebuilding an identity on the person's past history	I help regularly with technical tasks, such as catheter, wound dressing and medicine
	Reciprocal care	I help with improving physical functions (walking together, moving his or her legs, training memory)
		Other things

which the first was *anticipatory caregiving*, including decisions and behaviour based on the parents' possible future needs, 'just in case', and this was supposed to be often conducted from a distance. Future needs may have a powerful impact on the caregiver's actions, but were often kept invisible to the person cared for. The second category was *preventive caregiving*, with the purpose of preventing illness, injury and physical and mental deterioration. In this stage more active monitoring was involved than in the previous stages. The third category was *supervisory caregiving*, focusing on checking up, making sure and arranging things for the parents. The care was kept invisible to the parents as far as possible to protect their self-esteem and dignity. The fourth category, *instrumental caregiving*, was the hands-on caregiving mostly recognized as caregiving. This care was related to the parents' physical well-being, rather than their emotional needs and the protection of the parents' identity, which was the case for the next category, *protective caregiving*. The purpose of this fifth category was to protect the parent from consequences, which cannot be avoided, such as cognitive decline or depression (3). The parents' self-perception was retained, and much effort was put into keeping the parent from noticing that he or she was cared for. Bowers (6) argued that it is not the pure act, but the purpose and intention in the acts that defines the categories of caregiving. Caregiving is an interpretation of the situation, which cannot always be observed, and the same actions can have different meanings (6) and possibly also have an impact on the caregiver in terms of strain and decreased quality of life.

Nolan et al. (3) developed Bowers' (6) typology further, changing and extending some of the categories after analysing interviews and questionnaires from studies of informal caregivers from other studies, not designed to test the typology but to investigate caregiving, to improve the understanding of how families define care. Bowers regarded the different categories as phases, with a chronological aspect, while Nolan saw care in terms of process, with a chronological and hierarchical order between the dimensions. The first five dimensions in Nolan's work resembles those of Bowers. Nolan et al. (3), however, defined anticipatory care as a part of caregiving throughout the process. He divided Bowers' anticipatory care into two categories: speculative anticipation and informed anticipation. Nolan argued that protective care is only useful in short-term care, and not in the long run, and should include *preservative care* instead, maintaining the self-esteem of the person cared for. This dimension is also of limited use; for example, with chronic illness it is important to develop new roles, which moves preservative care into *(re)constructive care*, meaning rebuilding an identity on the foundation of a person's past history (3). Further, Nolan added the last dimension, *reciprocal care*, which was not in the work of Bowers (6). This concept unites the various dimensions in the typology and is supposed to be present throughout the caring process. The different dimensions can exist at the same time, with no explicit border between them. Nolan's and Bowers' work are models, developed from interviews and questionnaires with informal caregivers. Empirical support for the models could increase the understanding of the caregivers' situation, and how the caring actions may affect the caregivers' quality of life.

The theoretical framework for this study was the model presented by Nolan et al. (7), further suggesting that this more comprehensive view of caregiving may mean increased strain from the new situation earlier in the process of becoming a caregiver. Increased strain in turn may mean decreased quality of life. Psychological stress is a relationship between the person and the environment that is appraised as taxing or exceeding his or her resources and endangering his or her well-being (8). Being a caregiver may imply that ones resources are not enough for the caregiving situation also in the earlier phases marked by transition. Thus the comprehensive view of caregiving understood as involvement in various activities, and from the point of view of quality of life, may provide useful knowledge for outlining informal caregiving support.

Health-related quality of life can be said to be a global picture of the person's perspective of his or her well-being and health (9), and the person's ability to live a fulfilling life. Health-related quality of life, according to Bowling, is a multidimensional perspective of health as physical, social and psychological functioning and well-being. Caregiving has been shown in different studies to affect quality of life among informal caregivers. A study from Australia (10) among 630 caregivers, aged 75 and over, showed that full-time carers had lower life satisfaction than part-time carers. An Irish study (11) showed that high burden scores were associated with low quality of life and poorer well-being among the caregivers (n = 50, mean age 57.7 years), with the caring women having the lowest quality of life. Gallicchio et al. (12) used the same instrument to measure caregiver burden among 327 (259 women) informal caregivers in Canada. The caregivers were asked to rate the frequency of specific problems related to common areas of concern, such as finances, health, social life and interpersonal relationships. The results showed significantly higher burden scores among the female caregivers, who also experienced higher degrees of depressive symptoms. Caregivers in these studies were self-identified as the person who was most responsible for the provision of care (11, 12) or a person who was providing personal or instrumental care (10). Thus caregiving was mostly defined narrowly and did not cover the whole range of actions that, according to Bowers (6) and Nolan et al. (3), are included in caregiving, nor did they explore the relationships between different aspects of caregiving and quality of life.

To understand the impact of caregiving on quality of life, gender also has to be considered as caregiving has been shown to affect men and women differently. A study (5) among 24 women and 24 men in the UK, mean age 74.6 years, showed that the women experienced a higher level of strain and lower satisfaction in life than the men did. A study among informal caregivers in Brazil (n = 82) (13), aged 60 and over, also showed higher levels of burden among women than men. Daughters and wives who cared for an older person had a more negative experience of the deteriorated relationship with the person cared for than the male caregivers had in Beeson et al.'s (14) study (n = 242, mean age of spouses 72 and of daughters 52, USA). Health among female caregivers was shown to be worse than for males in a Swedish study (n = 129) (15). The explanation for these differences may be women's involvement in caregiving throughout the life span, socio-economic conditions, and tasks inherent in caregiving.

The models put forward by Nolan et al. (3) and Bowers (6) may be useful for deepening the understanding of caregiving. It has not to our knowledge been tested empirically before, and this broader view may contribute to a better understanding of informal caregiving and give insights into early and individually adjusted interventions.

Aim

The aim was to investigate the dimensions in caring among elderly informal caregivers provided to another person with impaired health, based on Nolan's model of informal caregiving. The aim was also to study the dimensions of caregiving in relation to gender and health-related quality of life among informal caregivers.

Method

Sample

In a postal survey questionnaire study, completed by 4278 persons aged 75 or older, in the southern part of Sweden (cf. 16, 17), 783 (18%) persons stated that they were helping another person, and among these 111 (14%) helped someone under 75 years of age, 580 (74%) helped someone over 75 and 92 (12%) did not state the age of the person cared for (Table 1). The sample was drawn from an age-stratified study among people, 75 years and older (75–79; n = 2500, 80–84; n = 2500, 85–89; n = 2000 and 90+; n = 1500), conducted in the south of Sweden. Among these, 270 persons were considered ineligible (199 dead, 56 address unknown and 25 answered by another person). The response rate in the age groups was 75–79: 60%, 80–84: 56%, 85–89: 47% and 90+: 42%. After two reminders, 4337 questionnaires were returned, of which 82 were excluded as the internal dropout was too large. Among the respondents, 2677 (61.7%) were women. The dropouts were significantly (chi-square test, $p < 0.005$) older and significantly ($p < 0.005$) more were women. Among the non-participants, 483 persons gave reasons for not participating, of which the most frequent were, in the age group 75–79: not wanting to participate or not having the strength; 80–84: not wanting to participate, not having the strength or having dementia; 85–89: not wanting to participate or dementia; and in the oldest age group: not wanting, not having the strength and dementia. Language problems were reported as a reason for not participating by 1.9%. Among those 3402 persons who did not report any reasons for not participating 6.2% (212 persons) died within 6 months after the deadline for answering the questionnaire. A telephone interview with a random sample of 50 of the non-respondents was conducted, asking about 'worries about one's health' and 'experience of life as a whole'. The non-respondents were more likely to be non-urban, older, living in special accommodations with proportionately more reporting their experience of life as a whole to be 'rather bad or bad'.

Measurement

The questionnaires covered gender, age, living alone, married, widowed, in a relationship but not cohabitant, single, social network, economy (how the income covered the expenses, economy compared with others the same age), living situation (in rural or urban areas, house or apartment) and self-reported diseases and health complaints. The questionnaire was tested in a pilot study ($n = 469$). One part of the questionnaire covered whether the respondent was helping another person because of impaired health and what they did to help. The items about what they did were based on the typology of care from Nolan et al. (7), and developed by two of the authors (IRH and AE) (Table 1). Seven alternatives were derived: adapting own activities, keeping in touch at least once a week, helping in contacts with the hospital, helping with cleaning or cooking, helping with personal care, helping with medical care and help with improving physical functions. There was also an open-ended question about other caregiving activities. If the respondent answered yes to one or more of this statements, he or she was categorized as a caregiver in the analysis. Also included were questions about the age of the person they helped (over 75 or not), how many times per week they helped the person in five alternatives: less than once a week, approximately once a week, 2–3 times a week, 4–6 times a week, and every day, and any estimate of the amount of hours per week they helped.

Quality of life was assessed by the Short Form Health survey (SF-12) (18), which measures health-related quality of life and includes 12 items. The items physical functioning, bodily pain and general health result in the Physical Component Summary (PCS12), while vitality, social functioning, emotional and mental health give the Mental Component Summary (MCS12) (18). The norm data for the Mental component score in the Swedish population was for the men 75 and above, mean 55.3, and for women 48.4 (m) (19). For men 75+, the norm data for the Physical component score was 41.7 (m), and for women 39.2 (m) (19).

Data analysis

Demographic data, economic situation, health complaints and caregiving activities were compared between men and women using chi-square test for nominal data. A logistic regression analysis (20) was conducted, with the lowest quartile of Mental Component Summary (MCS12) as the dependent variable, and the various tasks, adapting own activities, keeping in touch at least once a week, help in contacts with the hospital, help with cleaning or cooking, help with personal care, help with medical care and help with improving physical functions, as independent variables ($0 =$ No, I do not do that, $1 =$ Yes, I do that in order to help another person). The analysis was controlled for age and gender ($0 =$ male, $1 =$ female). The same was done with the lowest quartile of PCS12. An α level of 0.05 was used in all statistical tests.

This study was approved by the Ethics Committee (LU 478-99).

Results

The sample of caregivers was 326 (42%) women and 457 (58%) men. The mean age was 81.8 (SD 4.96) for the women and 81.7 (SD 4.32) for the men. Some 80.7% of the men and 52.9% of the women were married ($p < 0.001$). One hundred and twelve (34.5%) of the women were widowed, which was the case for 49 (10.7%) of the men ($p < 0.001$). Among the men, 388 (84.9%) lived together with someone, as did 192 (58.9%) of the women ($p < 0.001$). The majority of the respondents lived in big cities (45.2%) or in small villages (34.6%). Most of the respondents stated that they helped somebody every day (40.2%) (Table 2). One hundred and four women (31.9%) answered how many hours per week they helped; this ranged from less than 1 hour a week to 24 hours a day, mean 19.5 (SD 32.1) hours a week, and the equivalent number for the 190 men (41.6%) who answered was 15.0 (SD 23.9) hours a week ($p < 0.181$). There were significantly ($p < 0.009$) more women among the non-respondents in this question but no differences in age among the respondents and the dropouts.

Helping the person with external matters, such as contacts with and visits to the hospital was stated by 450 persons (57.4% of all), and 405 persons (51.7% of all) stated that they adapted their own activities to be prepared if something happened to the person cared for, 384 persons (49%) helped regularly with practical tasks, such as cooking or cleaning, and 276 persons (35.2%) kept in touch at least once a week to prevent problems. Training and improving physical functions and help with personal care were reported by 108 (13.7%) and 111 (14.2%)

Table 2 Characteristics in helping, demographic data and health by gender among the caregivers (n = 783)

	Male (%) (457)	*Female (%) (326)*	*p*
Age			<0.09
75–79	35.0	39.9	
80–84	40.7	35.0	
85–89	19.5	17.2	
90+	4.8	8.0	
Mean age (SD)	81.6 (4.32)	81.8 (4.96)	
Helping another person, times per week			<0.06
Less than once	8.8	15.0	
Once a week	13.1	12.6	
2–3 times a week	7.7	7.7	
4–6 times a week	4.6	2.1	
Every day	41.8	38.0	
Missing	24.1	24.5	
Caregiving activities			
Adapting own activities to be there, just in case	51.9	51.5	<0.9
Keeping in touch at least once a week to prevent problems	28.4	44.8	<0.001**
Helping in contacts with hospital and visits to the doctor's	60.4	53.4	<0.05*
Helping with cooking, cleaning or other chores (IADL)	61.5	31.6	<0.001**
Helping with personal care (PADL)	11.8	17.5	<0.02*
Helping with medical care	9.2	12.6	<0.1
Helping to improve physical or intellectual functions	12.9	15.0	<0.3
Other things	10.5	22.7	
Age of the person receiving help			<0.009**
Under 75	18.9	12.0	
Over 75	81.1	88.0	
My own health status is			<0.6
Good	22.4	24.5	
Quite good	59.6	55.1	
Quite bad	13.8	16.4	
Bad	4.2	4.0	
Mental component summary 12 (mean)	51.21	50.86	<0.9
Physical component summary 12 (mean)	41.50	38.95	<0.003**
I need help with my own personal ADL			<0.2
Never, or less than once a week	95.8	91.9	
Yes, once a week or more often	4.1	8.0	
I need help with my own medical care			
Never, or less than once a week	96.0	95.0	<0.6
Yes, once a week or more often	3.9	5.0	
I need help with my own instrumental ADL			<0.001**
Never, or less than once a week	93.3	83.6	
Yes, once a week or more often	6.7	16.2	
I need help with my own garden or my house			<0.1
Never, or less than once a week	91.3	90.1	
Yes, once a week or more often	5.2	9.9	
My own financial situation compared with others			<0.1
Better	23.1	17.4	
About the same	69.1	73.0	
Worse	7.8	9.6	

*p-values < 0.05 and **p-values < 0.01.

respondents, respectively, while 83 (10.7%) of the respondents stated that they helped with medical care. The activities significantly more frequent among the women than men were keeping in touch to prevent problems (44.8% women; 28.4% men) and helping with personal care (17.5% women; 11.8% men), while helping with instrumental care was reported significantly more often among the men (61.5% men; 31.6% women). The items

Table 3 The hierarchy in the number of caregiving activities

Caring activities	*1*	*1 + 2*	*1 + 2 + 3*	*1 + 2 + 3 + 4*	*1 + 2 + 3 + 4 + 5*	*1 + 2 + 3 + 4 + 5 + 6*	*1 + 2 + 3 + 4 + 5 + 6 + 7*
Number of persons doing each task (%)	405 (51.7%)	188 (24.0%)	159 (20.3%)	116 (14.8%)	53 (6.8%)	37 (4.7%)	32 (4.1%)

1, Adapting own activities; 2, keeping in touch to prevent problems; 3, helping in contacts with the hospital and doctor; 4: helping with household tasks; 5: helping with personal care; 6: helping with medical care; 7: improving physical and intellectual functions.

named ‘other things’ were helping to mow the lawn, taking care of financial errands, cutting hair, helping with correspondence and reading books aloud, for example, and these were stated by 15.6% (n = 122, 10.5% of the men and 22.7% of the women) of the respondents.

Among the caregivers, 32.3% reported one caregiving activity, 22.3% reported two activities, 14.6% reported three activities, 9.8% reported four activities, 5.6% reported five activities, 2.6% reported six activities and 4.1% reported all of the seven caregiving activities. The respondents reported a mean of 2 (SD 1.66) helping activities. The number of persons helping in a combination of different caregiving activities formed a pattern, with fewer persons doing more activities (Table 3). There were no significant differences between men and women regarding the number of activities performed.

In the logistic regression analysis, low quality of life proved to be predicted by two of the seven items. A significant relationship with low scores on MCS 12 was found for adapting own activities to be prepared if anything happens and keeping in touch at least once a week to prevent problems (Table 4). Weak economic situation and needing help oneself with practical tasks, such as cooking or cleaning, also predicted low mental quality of life. The analysis was controlled for age and gender, which did not fit into the model.

Table 4 Logistic regression analysis of variables predicting low MCS12 for caregivers aged 75 and above

Caregiving activities and variables	*Odds ratio*	*95% CI for OR*	*p*
Gender (female)	1.089	0.732–1.619	<0.675
Age (old)	0.998	0.955–1.044	<0.940
Adapting own activities to be there just in case	1.748	1.176–2.598	<0.006**
Keeping in touch every week to prevent problems	1.594	1.070–2.375	<0.022**
Weak economic situation	5.086	2.945–8.786	<0.001**
Needing help with practical tasks oneself (IADL)	3.027	1.682–5.446	<0.001**

Hosmer and Lemeshow goodness-of-fit test, **p = 0.597. Variables not in the equation were helping in contacts with or visits to the hospital, helping with personal care, helping to improve physical functions, help with IADL, help with medical care, needing help with medical or personal care oneself, gender and age.

Table 5 Logistic regression analysis of variables predicting low PCS12 for caregivers aged 75 and older

Caregiving activities and variables	*Odds ratio*	*95% CI for OR*	*p*
Gender (female)	0.756	0.470–1.214	<0.247
Age (old)	1.037	0.988–1.088	<0.145
Helping regularly with cooking, shopping, cleaning	0.543	0.333–0.885	<0.014**
Weak economic situation	2.005	1.030–3.901	<0.041**
Need own help with practical tasks (IADL)	3.617	1.958–6.681	<0.001**

Hosmer and Lemeshow goodness-of-fit test, **p = 0.496. Variables not in the equation were helping in contacts with or visits to the hospital, helping with personal care, helping with medical care helping to improve physical functions, keeping in touch to prevent problems, adapting own activities to be prepared, needing help with medical care or personal care, gender and age.

In the logistic regression analysis with the PCS12, weak economic situation and needing help oneself with practical tasks, such as cooking or cleaning, predicted low scores on the physical quality of life (Table 5). Helping with IADL (cooking, shopping and cleaning) correlated positively with physical quality of life. None of the other caregiving activities fitted into this model, nor did age or gender.

Discussion

Methodological considerations

This study should be considered as explorative, with the aim of studying what has not previously been studied (21). The validity can be assessed with regard to internal validity, i.e. the extent to which alternative explanations of the results can be ruled out; perhaps the most important of these is the issue of systematic dropout. The stratified population-based sampling process applied in this study resulted in a response rate that varied between 42 and 60%; the lower the rate, the older the respondents were. As dropout was most frequent among the oldest old it may well be that these were the ones not involved in caregiving. The reasons given for not participating were, for example, in the younger age groups, not wanting to participate or not having the strength, whilst in the older age groups not wanting to participate, not having the strength and being demented were given as reasons. Perhaps these people were care recipients rather than caregivers. However, this cannot be taken for granted and thus caution has to be applied when generalizations are made. Another threat to external validity is the risk of having a high internal dropout (22). This risk is especially high when addressing older people. However, SF-12 proved to be well adapted for this sample in that the internal dropout was quite low. SF-12 (18) was chosen because it is easy to complete and covers the concept of health-related quality of life fairly well (23). In addition, the internal dropout was fairly low in other items as well minimizing this threat to internal validity. Another consideration regarding the sample was the high rate of male respondents, which is different from the results of other international studies (14, 24).

Population-based studies on this topic, and in countries with the same social security system and home help service as in Sweden, are sparse, which makes comparisons difficult. Thus no reasons for the high number of men in this study can be ascertained. However, when looking at what men as compared with women did, men were over-represented in tasks such as instrumental care and accompanying the person to the hospital or doctor, whilst women were over-represented in activities such as personal care and regularly keeping in touch. Previous studies on informal caregiving have mainly defined it as help with personal care (10), whilst in this study a broader perspective was applied. Applying a narrower definition of caregiving may disfavour men. The seven items developed from Nolan's model of dimensions of informal caregiving need further development. For this study, which can be regarded as explorative in that sense, there was only one item per category, which may not adequately cover the particular category. Thus further development is needed, which can be done through focus groups and further on to develop new items. Especially focus group discussions of the different phases and dimensions in caregiving would be valuable to further understand the meaning of it. However, it seems fair to state that the seven items did work satisfactorily in terms of revealing differences between men and women, identifying a pattern of involvement, and some items explaining quality of life, whilst other items did not work well. Hence, it seems worthwhile to continue the development of a measure that is more appropriate for assessing informal caregiving than just assessing involvement in IADL and/or PADL.

Dimensions in care

It seemed worthwhile to broaden the concept of caregiving to include other aspects than personal care by asking caregivers what they actually did. Caregivers were involved in a number of different tasks, of which those related to other aspects than practical personal care were most common and involvement in the activities actually formed a pyramid-shaped pattern. The majority of caregivers on the base of the pyramid were doing activities such as keeping in touch to prevent problems, monitoring the elderly person for risk behaviours, and thus being involved in preventive care (3). Following the person cared for to the doctor or contacting the hospital, i.e. supervisory care according to Nolan, together with adapting own activities to be available (preventive care) were the most frequent activities, which supports the idea that some dimensions of caregiving are present throughout the care process. Only 11.8% vs. 17.5%, men vs. women, provided help with personal care, which means that most of them would not have been recognized as caregivers if the narrower definition were applied. Although no comparable studies are available, the findings make sense and indicate the relevance of the models presented by Bowers (6) and Nolan et al. (3). From a nursing perspective it may be worthwhile to respond to the person accompanying an older person to the hospital as someone involved in the caregiving rather than just company. The Nolan model suggesting that caregiving is a process and involves several different activities with different purposes seemed valid and useful. According to Nolan's typology, people entered into caregiving by adapting their own activities to be there 'just in case', i.e. anticipatory caregiving. This type of activity was performed by about 52% of the sample, in similar proportions for men and women. The most common type of activity, however, was supervisory care in terms of helping with practical things outside the home of the care recipient. In this type of caregiving activities men were more involved than women ($p < 0.05$). This distribution of caregiving activities does not contradict the idea of the typology as a process and an initial phase with the more subtle type of activities. The hierarchy of caregiving activities (Table 3) demonstrated that anticipatory, preventive and supervisory care was the most prevalent, and perhaps those activities are present throughout the caregiving process, suggesting that health care staff need to take a broader view of the concept of caregiving.

Interestingly, involvement in training and improving physical functions was reported by 14% of the respondents.

This emphasizes the importance of early involvement of those close to a care recipient and providing them with knowledge about how to keep up functional activities, prevent complications and other problems that may occur. The results also emphasize the importance of applying a family approach in providing care, especially to the elderly, i.e. recognizing their role at earlier stages as well. In doing so, the Nolan typology may well be useful when assessing the needs of an older person as well as when planning and providing care. It is evident from the results that, although the person does not require help with PADL or IADL, there is somebody keeping an eye on the person, helping out with other matters, prepared to take action if needed and encouraging preventive and promotive actions.

It seems fair to state that women and men are involved in different ways in informal caregiving. Women were significantly more often involved in keeping in touch to prevent problems, whereas men more often helped with cooking, cleaning or shopping. There may well be a bias risk in these results with regard to instrumental caregiving since more men (61.5%) reported involvement in such activities than women (31.6%). Traditionally, doing household tasks is a woman's activity and they may not regard themselves as helping their husband or cohabitant although he may not be able to carry out such tasks due to health problems. The different patterns of involvement in men when compared with women need further research to be understood. From a clinical perspective it is important especially since the most common attitude is that men are less often involved in caregiving.

Quality of life

Caregiving activities that seem to covary with low mental quality of life were adapting own activities to be there just in case, together with regular contact to prevent problems, i.e. supervising and anticipatory care. Perhaps these early dimensions of caregiving mean striking a difficult balance in several ways. Nolan and also Bowers suggested that keeping the care invisible to the person cared for is common in the first stages of caregiving, and that it is difficult to strike that balance. Apart from protecting the person cared for, it may be a strain that other members of the family may not recognize these activities as care; there is little chance for the caregiver to get credit or confirmation for what he or she does (7). These early dimensions of caregiving may be more straining also because they mark a transition period for the caregiver as well as for the person cared for. It may well be that it is in the transitory phase that the environmental demands exceed the personal resources (cf. 8) and that the balance will improve along with the adaptive process. Altogether these aspects may explain why these dimensions of caregiving turned out negatively in terms of quality of life for the caregivers in this study. As the two caregiving activities, which affected quality of life the most, were the ones early in the process, there are reasons to recognize these early phases of caregiving and the people involved because of the transitory character. Nurses can support adaptation by exploring the problems, listening and helping out with practical problems as well as by providing knowledge about caregiving.

Gender

From a cross-sectional study of this kind causal relationships cannot be established. The differences between men and women in terms of physical quality of life (41.50 vs. 38.95, $p < 0.003$), however, seemed more to be explained by their own need of help than their involvement in caregiving. It may also be explained by their higher level of involvement in PADL help (17.5% vs. 11.8%, $p < 0.02$) and their higher involvement in supervisory care (44.8% vs. 28.4%, $p < 0.001$). Several studies (25, 26) have reported women to be under more strain from caregiving than men. However, it may not be gender *per se* that explains those differences but the caregiving involvement, the physical activities of the women and perhaps also other external aspects such as economic conditions and social support, which tend to be weaker in elderly women (27, 28). The men in this study seemed to be lower in mental quality of life than Swedish norm values (MCS norm value 55.3, in this study 51.21, PCS norm value 41.7; in this study 41.5) and similar in physical quality of life, whilst the women were higher in mental quality of life (MCS norm value 48.4; in this study 50.9, PSC norm value 39.2; in this study 38.9) and about the same on the physical quality of life score. Compared with norm values, then, women had slightly better quality of life and men slightly poorer. These differences may not be explained by caregiving at all but by the fact that our sample is older than those from which the norm values stem. Gender, however, did not covary with quality of life (MCS12, PCS12) among the caregivers in this study, which is different from other studies showing women to be more burdened by care (12, 13) and suffering more often from depression. Other studies tend to measure depressive symptoms (14, 29), perceived burden (13) or health in the caregiver, not focusing directly on quality of life among the caregivers. Perhaps further research should apply a broader view of caring and also differentiate the type of caregiving activities people are involved in before the different outcome in terms of quality of life in men and women can be fully understood. It seems worthwhile also to use a broader approach like this in practice to be able to support caregivers at an individual level and at different stages.

The reasoning above seems to be further supported by the fact that conditions of the caregivers had a significant impact on low physical quality of life and were not determined by dimensions of caregiving but by the health and socio-economic situation of the caregiver him/herself. A weak economic situation had great impact on physical as well as mental quality of life, indicating that the financial situation is important for health care staff to consider and explore ways to strengthen. The socio-economic situation of the caregivers turned out to be the strongest predictor of low mental quality of life, and also important for physical quality of life. There are reasons to further investigate the economic consequences of caregiving, since low functional status has been shown to correlate with low socio-economic status (30). Another Swedish study ($n = 11698$, aged 16–84) (31) showed that those in the highest socio-economic group had better quality of life than those in the lower groups. Thus, negative economic consequences may imply a risk for the caregivers' health and ability to give care.

Interestingly, helping with IADL was positively related to quality of life. It may well be explained in terms of gender, i.e. more men than women reported doing such household tasks (Table 2). A certain functional status is needed to be able to perform that help, which means that caregivers who reported that they helped with IADL may have better physical status. Another explanation for the positive correlation between helping with IADL and physical quality of life could be the positive results of physical activity in general (27). Thus the caregivers' physical ability could be one explanation for the positive correlation between high scores on PCS12 and helping with IADL. In addition, under-reporting these activities by women may bias the results with regard to involvement in IADL and in turn the significant relation to quality of life. The greater dependency in women than men in IADL activities supports that interpretation. Viewing this from a gender perspective, in most families of this age this is a new task for men, but not for women, and hence it could be regarded as positive, something new added to their life experiences. The findings do, however, support the ideas put forward by for instance Nolan et al. (3), suggesting that some activities in caregiving may be straining and others a new positive experience. Thus a more differentiated view of caregivers and caregiving activities is called upon to understand how it works in terms of caregivers' quality of life.

Conclusion

The model of informal caregiving, considering it as dimensions in a process, put forward by Bowers (6) and Nolan et al. (3), was supported by the results of this study. Other caregiving activities than those related to PADL were the most common, suggesting that care starts before help with PADL is needed. Various dimensions in the informal care, especially the dimensions present in the early stages of caregiving such as anticipatory and preventive care, had a negative impact on the caregivers' quality of life. The socio-economic situation of the caregivers turned out to be the strongest predictor of low mental quality of life, and also important for the physical quality of life. Weak economic situation and own need for help with IADL also correlated with low quality of life, which may put women at greater risk of low quality of life. Gender differences were found in preventive care and helping with PADL, which the women did significantly more often than the men. From a nursing perspective it may be worthwhile to apply a family approach and respond to the person accompanying an older person as someone involved in caregiving. This study emphasizes the importance of early involvement of those close to a care recipient and providing knowledge about how to keep up functional activities, prevent complications and other problems that may occur during the caregiving process, thereby supporting the caregivers and in turn the care recipient.

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Author contribution

Anna Ekwall was involved in the study conception and design, data collection, data analysis and drafting of the manuscript.

Bengt Sivberg worked on the study conception and design, data analysis, drafting of manuscript, supervision.

Ingalill Rahm Hallberg contributed to the study conception and design, data collection, data analysis, drafting of manuscript, critical revisions of manuscript for important intellectual content, statistical expertise, obtaining funding, administrative, technical and material support and supervision.

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Ethical approval

The study was approved by the Ethics Committee of the Medical Faculty at Lund. Reference Number LU 478–99.

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