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THE ASSOCIATION BETWEEN CAREGIVING SATISFACTION, DIFFICULTIES AND COPING AMONG OLDER FAMILY CAREGIVERS

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ABSTRACT

Aims and objectives: The aim was to study the association between gender, extent and content of care, satisfaction, coping and difficulties in the caregiving situation among older (75+) caregivers and to identify clusters of caregivers. The aim was also to explore psychometrically two instruments assessing satisfaction and difficulties in family caregivers.

Background: Caregiving is a complicated phenomenon. Much of the research has focused on negative aspects, such as the burden, stress and emotional strain. Caregiving is known to affect health negatively for the caregivers. Little is known about satisfaction and motivation in voluntary work, such as informal caregiving, especially among older persons.

Design and Methods: Cross-sectional. The sample for this study consisted of 171 informal caregivers aged 75 and over, identified from an age-stratified sample in a postal survey among older people in the southern part of Sweden.

Results: Male caregivers proved to be more satisfied than female caregivers; caregiving had seemingly widened their horizon and had helped them to grow as persons. Based on satisfaction scores, those satisfied had a higher proportion of male caregivers and a significantly higher amount of caregiving hours per week. They used other coping strategies than the respondents in the other cluster, i.e. less satisfied in using more problem-solving strategies.

Conclusions: The instruments tested were appropriate for work in clinical and research settings, although the internal dropout indicates that a shorter version would be more useful. Those who found satisfaction in care used more problem-focused coping strategies and were more often men than women. From a salutogenic point of view, this may give important knowledge about factors that can promote health. The findings indicate that women deserve extra attention as informal caregivers since they did not find caregiving as rewarding as the men did. This may in turn make them less protected against the negative consequences of caregiving.

Relevance to clinical practice: Reinforcing the health-promoting qualities in caregivers who are not feeling well, with women as a particularly vulnerable group, may restrict unnecessary suffering for both the caregiver and the person cared for.

Keywords: Family caregiver, older, satisfaction, difficulties, coping, nursing

INTRODUCTION

More knowledge is needed to understand older caregivers' coping and satisfaction when providing care for a next of kin. The caregivers' personality, the cared-for persons' symptoms (Almberg *et al.*, 1998) and the caregiving hours per week (Ekwall *et al.*, 2004) are supposed to affect the caregivers' practical and emotional situation (Nolan *et al.*, 1998). Coping is also important for how the caregivers experience their situation. It may be important to provide help and support in the areas where this is possible, such as reinforcing functional coping strategies or respite care since other aspects, such as the symptoms and diseases of the person cared for, may not be possible to change.

Little is known about motivation in voluntary work, such as informal caregiving, especially among older persons, whilst the mechanisms behind motivation in the work situation for employees have been investigated. Herzberg (1959), a researcher in motivational work, identified clusters of factors that made people feel good and bad about their jobs; job satisfiers and job dissatisfiers. He also found that these clusters were related to each other and that all factors were equally beneficial to the organisation and to the individual. When the value is positive for the person positive stress arises, whilst when the value is not important to the person negative stress may appear. These work values are estimates of the worth and importance of aspects of work for the person. However, these findings may be useful in understanding satisfaction and dissatisfaction in family caregiving as well. It could increase the understanding of the interaction between stress and satisfaction in caregivers. Herzberg (1959) found that job satisfaction and job dissatisfaction were not opposites; instead, they were separate aspects produced by different factors and had their own dynamics. He also distinguished between intrinsic factors such as achievement, recognition and work itself and extrinsic factors such as working conditions, job security and technical supervision (Herzberg in (Rantz *et al.*, 1996). Money fits into both groups but had more potency as a job dissatisfier.

Using the same theory, Knoop (1994) argued that stress can be reduced if people get to work with things they value and consider important. Applying a caregiver perspective, it is important to identify both negative and positive aspects of caregiving and to study the reciprocal action between different aspects and how they correlate with the caregivers' situation.

Personal strength in the caregiver may also affect his or her situation. Antonovsky described a person with a high sense of coherence (SOC) as someone who has inner resources to cope with external strain (Antonovsky, 1987). For a caregiver with high SOC the situation may be appraised as more positive and meaningful than for a person with low SOC (Antonovsky, 1987). Another study (n=72 spouses of persons with dementia) showed that caregivers with 'hardiness' coped with the caregiving difficulties in a more problem-oriented way (DiBartolo *et al.*, 2003) and also appraised the situation more positively.

Much of the research on caregivers has focused on the negative aspects, such as burden (Edwards & Scheetz, 2002), stress (Donaldson *et al.*, 1998) and emotional strain (Almberg *et al.*, 1997; Collins & Jones, 1997). Caregiving is also known to affect health negatively for the caregivers (Almberg *et al.*, 1998). A study comparing caregivers of persons with dementia (n=52) with non-caregivers (n=66) showed women caregivers to be more burdened than both caregiving men and non-caregivers. The women had poorer health and more limits in their social life. Caregivers aged 75 or over in an Australian study (n=630) (Broe *et al.*, 1999) had lower life satisfaction and a higher degree of psychiatric symptoms than non-caregivers. There is, however, more to caring than just burden. An American study of caregiving wives (Motenko, 1989) showed that those who reported their relationship as positive also reported less strain in caregiving. Lundh (1999) has also shown satisfaction and reciprocity in the caregiving relationship to be one of the strongest buffers against negative stress. Few studies, however, have explored the positive aspects of caregiving among older people. Antonovsky (1987) criticised medical research for being too focused on pathogenesis. Looking at the positive factors in informal caregiving would be one way towards a more salutogenic view. Understanding caregiving difficulties, satisfaction from caregiving and how the older caregivers cope with their situation could help formal caregivers to create support that is adequate for the specific situation and for the individual caregiver.

AIM

The aim was to study association between gender, extent and content of care, satisfaction, coping and difficulties in the caregiving situation among older people (75+) caregivers and to identify clusters of caregivers. The aim was also to psychometrically explore two instruments assessing satisfaction and difficulties in family caregivers.

METHOD

Sample

The sample for this study consisted of 171 informal caregivers and is a part of a larger study, parts of which are being published elsewhere (Ekwall et al, in press). The sample was identified from an age-stratified sample in a postal survey among older people in the southern part of Sweden. The same sample has been analyzed and described in another study The previous study consisted of 4278 respondents aged 75 years old or above (Jakobsson *et al.*, 2003; Thome *et al.*, 2003) of whom 18% stated that they were providing care (Ekwall *et al.*, 2004). The sample of caregivers identified was based on items about which caregiving activities the respondents performed and had eight response alternatives (Ekwall *et al.*, 2005). The items concerning what the caregivers did were based on a typology of care by Nolan *et al*. (1995). If the respondent answered yes to at least one of the statements, he or she was included for this study. A total of 171 (47%) of the 363 eligible questionnaires were returned in a usable form (Ekwall *et al*, in press). Of those not responding, 15% were too weak to answer, 25% did not want to participate and 4% of the questionnaires were partially completed and had less than 25 questions answered and were therefore excluded. Nine per cent did not state the reason for not participating. There were no significant differences in gender or age between the respondents, those who stated the reason for not participating and the dropouts (Ekwall *et al*, in press).

Instruments

The questionnaire covered kinship to the person cared for, economic situation, civil status and questions about living conditions (house or apartment, rural or urban) (Ekwall *et al*, in press). It also included questions about perceived information to the caregiver about the help from formal caregivers to the person cared for and about the medical treatment, where the respondent had four response alternatives (‘no information at all, some information, enough information and more than enough information’). The content; instrumental help (IADL), personal help (PADL) and/or medical help were assessed with suggested helping activities (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) and were answered with a ‘yes’ if the respondent did the suggested activity. The extent of the care was covered by two questions (frequency and hours per week). The first question was about how many hours per week they helped, which was an open question and was answered with an approximation of the number of hours per week. The second question was about how many times per week the respondent helped, which had four response alternatives (less than one hour per week, about once a week, 2–3 times per week and more than six times per week). The question about how long the person cared for could be left alone had six response alternatives (unlimited time, more than 12 hours, 6–12 hours, 2–5 hours, less than two hours and not at all). The questionnaire is also described and its results published elsewhere (Ekwall *et al*, in press)

Sense of coherence was measured with the SOC scale (Antonovsky, 1987), using the version with 13 items, with total scores from 13 (low SOC) to 91 (highest possible SOC). The items measure perceived manageability (four items), meaningfulness (four items) and comprehensibility (five items) (Antonovsky, 1993).

Health-related quality of life was measured with the Short Form 12 (SF12) (Ware *et al.*, 1996). SF12 consists of 12 questions measuring how the present health status affects life (Ware *et al.*, 1996) in two respects: physical component summary score (PCS12) and mental component summary score (MCS12). The scores in each area are standardised to range between 0 and 100, the higher the score, the higher the quality of life (Ware *et al.*, 1996).

Satisfaction in caregiving was assessed by Carer's Assessment of Satisfaction Index (CASI) (Nolan *et al.*, 1998), Coping strategies were assessed by Carer's Assessment of Managing Index (CAMI), and difficulties were assessed with Carer's Assessment of Difficulties Index (CADI) (Nolan *et al.*, 1998; Nolan *et al.*, 1990). The instruments were created to provide a detailed profile of the caregivers' situation (difficulties and satisfaction) at an individual level (Nolan *et al.*, 1995), but have also been used in research (Kuuppelomaki *et al.*, 2004; Lundh, 1999, Ekwall *et al*, in press). CASI consists of 30 items (Appendix 1a) (Nolan *et al.*, 1998), which are formulated as statements of things that give the respondent satisfaction such as 'Caring makes me feel needed and wanted' and 'Caring provides a challenge'. The statements in CASI come from content analysis of open-ended questions to informal caregivers (Grant *et al.*, 1998). In this version there were eight response alternatives for each statement; four about whether it was true for the respondent ('In the care of my next of kin I feel that this is very true for me, quite true for me, not very true for me' and 'not at all true for me') and four alternatives about how much satisfaction it gave ('very much satisfaction, quite much satisfaction, quite little satisfaction' and 'no satisfaction at all'), and both parts were supposed to be answered. In this report, only the first part was used. In the original version there were four response alternatives (Nolan *et al.*, 1998). CASI has been used in a Finnish caregiving population (n=290) and the results were described on an item level (Kuuppelomaki *et al.*, 2004).

CADI also consists of 30 items (Appendix 1 b) (Nolan *et al.*, 1998), with statements such as 'I no longer have a meaningful relationship with the person I care for' and 'My sleep is affected'. The response alternatives were 'In the care of my next of kin I feel that this is very true for me, quite true for me, not very true for me, not at all true for me' and 'for me, this is very trying, quite trying, less trying, not at all trying', and the respondents were supposed to fill in both parts. A factor analysis performed with CADI showed seven sub-scales with Cronbach's alpha values between 0.71 and 0.84 (Nolan *et al.*, 1998).

The descriptives of CAMI, used in this sample, is further described elsewhere (Ekwall *et al*, in press)

Analysis

Chi-square test was used when comparing nominal data. Mann-Whitney U-test was used when comparing ordinal data between men and women and between the clusters (Altman, 1994). SPSS was the statistical software used in the analysis.

A factor analysis (the extraction method was principal component analysis) was conducted with CASI and CADI, each individually. A factor analysis with the same sample as this study, was previously conducted with CAMI (Ekwall *et al*, in press), and parts of the result is presented here in order to describe the two clusters of caregivers. Missing values were replaced with mean values when calculating the scores for CAMI in order to increase the numbers of respondents eligible for the analysis. Criteria for imputation was that at least 60% of the items in each factor had to be answered (ibid.)

All items had commonalities above 0.3 and were included in the analysis. This analysis was conducted to identify underlying structures (Altman, 1994). The number of factors was chosen with regard to the number of items in each factor and the Cronbach's alpha values. Five factors emerged in CASI when using the part of the response alternatives showing how true the statement was for the respondent. Cronbach's alpha values for the factors in CASI varied from 0.76 to 0.83 (Appendix 1a). This factor solution explained 62% of the total variance. For CASI, the five factors derived from the factor analysis in this study were labelled *Fulfilling oneself by caring, A way of control by caring, Widened horizon by caring, Reciprocal engagement* and *Personal growth by caring* (Appendix 1 a).

Cronbach's alpha values for each factor in CADI, based on how true it was for the respondent, varied from 0.60 to 0.89 (Appendix 1b). This factor solution explained 56% of the total variance. For CADI the five factors in this study were labelled *The person I care for gives me problem, Caring is too demanding, Emotional strain, Social problems* and *Practical problems* (Appendix 1 b). To compare the scores on each factor, each item in the factor, range 1–4, was added and then divided by the number of items.

A two-step cluster analysis (Polit, 1996) was conducted after four cases were considered outliers since those responses were too extreme and illogical and were excluded. The cluster analysis was performed in the whole sample and was based on the scores on the five factors of CASI, excluding those with partially completed questionnaires. Euclidean distance was used. Two groups emerged, with 45 and 54 persons respectively, and were used in the further analysis. The respondents with internal dropout in CASI (n= 68) were not included in the cluster analysis, but were compared with the two clusters (One-way ANOVA, with Bonferroni correction and Mann-Whitney test post hoc) to detect systematic dropouts. Cronbach's alpha for sense of coherence was 0.85 in this sample.

RESULTS

The mean age in the sample was 81.5; 80.6 for women and 82.1 for men (p-value 0.02) (Table 1). Among the men 89% were married and 4% widowers, among the women the corresponding numbers were 73% and 17% (p-value 0.008). Seventy per cent helped the person more than six times a week and a mean 46 hours a week, with no significant gender differences. Sense of coherence was 72.9 (SD 13.6) for the women and 72.1 (SD 12.8) for the men (p-value 0.9). Eighty-five per cent of the men and 71% of the women helped a spouse (p-value 0.3). There were gender differences in the factor scores from CASI, with more men acknowledging that caregiving had widened their horizon (p-value 0.004), was a reciprocal engagement (p-value 0.02) and had helped them to grow as persons (p-value 0.04) whilst there were no gender differences with regard to carers' assessment of difficulties.

The respondents helped with different tasks, personal, instrumental and social. There were gender differences in five of the 20 different helping activities suggested in the questionnaire, with more women helping with personal care such as eating (p-value 0.045), putting on clothes or shoes (p-value 0.007) and getting up or going to bed (p-value 0.014) (Table 2). More women also helped with cooking (p-value 0.004) and contacts with the hospital or doctors (p-value 0.034). No activities were more frequently performed by men.

The cluster analysis revealed two clusters with 54 and 45 respondents respectively (Table 3). Cluster 2, the satisfied group, had significantly higher scores on each of the satisfaction factors and was characterised by significantly more men. The mean number of helping hours per week differed, with median eight hours a week in the less satisfied group and 30 hours a week in the satisfied (p-value 0.01). The coping strategies ‘solution trying’ (mean 2.5 in the less satisfied group and 2.8 in the satisfied group, p-value 0.005), ‘self-empowerment and self-control’ (mean 3.1 in the less satisfied group and 3.4 in the satisfied group, p-value 0.002) and ‘obtaining new insights’ (mean 2.0 in the less satisfied group and 2.2 in the satisfied group, p-value <0.001) were used more among those in the satisfied group. The satisfied group stated that the care was too demanding, whilst the other factors in CADI did not differ between the clusters. The two clusters did not differ in age, Sense of Coherence, perceived health, economy, perceived information about the formal help, helping times per week or factor scores on CADI. Coping strategies (factors scores on CAMI) that did not differ between the clusters were ‘control by routine and prevention’ ‘self-sustaining’, ‘asking for social and practical support’ and ‘distracting by focusing on positive activities’.

There were no differences between the cluster regarding information about the cared-for person’s medical care or help with IADL or PADL except for walking inside, which 12 persons (29%) in the satisfied group did and 4 (8%) in the less satisfied group (p-value <0.027). The respondents with internal dropout (all but those in the cluster analysis) were compared with the two clusters (Table 4). Differences between those with internal dropout and the less satisfied group were found in all CASI factors, with the less satisfied group scoring lower. The more satisfied group scored higher on ‘Fulfilling oneself by caring’, Widening my horizon by caring’ and ‘Personal growth’. In CADI, the less satisfied group scored lower on ‘Caring is too demanding’ and on CAMI, lower on ‘self-empowerment and self-control’. There were differences in one item in CADI, where eight persons the group with internal dropout stated that they no longer had a meaningful relationship to the person cared for, which one in the less satisfied, and three in the more satisfied group stated. The response rate in the group with internal dropout varied between 15 respondents and 24 in the factors in CASI. The response rate for the items varied between 25 and 40 respondents per item. Only those with completed factors in CASI were included in the comparison presented in Table 4.

DISCUSSION

The main finding in this study was that men proved to be more satisfied with their situation as caregivers than the women caregivers were; they thought that caregiving had widened their horizon and had helped them grow as persons. Another important finding was that the satisfied group (see Table 3) had a higher proportion of male caregivers and a significantly higher amount of caregiving hours per week than the less satisfied. They used other coping strategies than the less satisfied respondents, i.e. using more problem solving strategies. There were thus differences between caregivers, regarding gender, coping and satisfaction, which have to be considered when designing support for older caregivers.

Limitations

A high dropout rate may be a threat to the external validity if it is systematic (Kazdin, 1998). Analysis showed no differences in age or gender between dropouts, those who gave the reasons for dropout and the respondents, but still the low response rate implies that generalisations should be made with caution. Those who stated that they were too weak to answer the questionnaire might also have been too weak to help another person, and may therefore not be representative of the target population. The internal dropout may be a consequence of the administration; postal surveys may not be the most suitable way to get a high response rate in these age groups. Structured interviews might have given a higher response rate and less internal dropout, but with a risk of answers that are socially acceptable and not true. The factor analysis gave valuable information about the psychometric properties of the instruments, both CASI and CADI. This study should be considered explorative, and a study with a larger sample is needed to fully capture the psychometric properties of CASI and CADI. The factor analysis performed in this study supports the suggestion that these instruments may be valuable for use in both clinical work and research. The internal dropout indicates that the instrument should be shorter in order to work in successful research or in a clinical setting, where a fully completed instrument is necessary for adequate assessment of the caregivers' situation. The instruments were constructed in the UK, and before using them in another Swedish study, focus group interviews may be warranted to give supplementary information about what items are missing or unnecessary in a Swedish caregiving context, such as items about economy. The cluster analysis based on CASI included only those with a fully completed instrument, which left 68 respondents outside that analysis. Comparisons were made between the two groups and those with internal dropout. Those who did not complete CASI were more like the satisfied group, which supports the interpretation that there is a group of vulnerable caregivers. Their low satisfaction in caregiving together with coping that may not be very functional contributes to their vulnerability. Still, there may be knowledge missing about those who were not included in the clusters, which make further studies important to increase knowledge about the older caregivers.

The high proportion of male caregivers in this sample differs from other studies where women have been the primary caregivers (Edwards & Scheetz 2002, Navaie-Waliser *et al.* 2002). This may be explained by the use of a wider definition of caregiving in this study. Other studies tend to define caregiver as a person helping with personal or instrumental activities of daily living (Navaie-Waliser *et al.*, 2002), while giving any kind of help due to the other person's decreased health, such as being prepared if anything happens, keeping in touch or help with contacting the hospital (Ekwall *et al.* 2004), defined caregiver in this sample. This approach is supported by the findings of Bowers (1987), who in interviews with family caregivers and the persons cared for found that care as defined by the caregivers was much more extensive than what the persons cared for apprehended.

Men considered caregiving much more rewarding, although there were no gender differences as regards how difficult caring was. Significantly more men than women stated that caring had widened their horizon, which may be explained by the traditional gender roles in that generation, with women working in the household (Hirdman 2001). Extended responsibilities, such as taking care of the person's personal care, may be rewarding for male caregivers, since it may be new to them, as shown in this study. Women may have been carers in different ways for most of their grown-up life and thus may be looking forward to something else. The men also experienced personal growth more often than the women did. Feelings of reciprocal engagement were also more frequent among the men. These differences may be a result of their lives together in a time where the women often took responsibility for the home and children. This social contract for women as housewives and men as family breadwinners may have influenced men as well as women (Hirdman 2001). The women in this study did not feel their horizons widened or reciprocal engagement as the men did, which might be a reflection of living in Sweden during those years when women's labour was not highly appreciated and work at home was taken for granted. It may also as well be a sign that there was no obvious change in responsibility for the women when their normal chores turned into helping; cooking for a man who is at work may not differ from cooking for a man who, due to sickness, is incapable of cooking. A study of dementia caregivers in the UK (n=48) showed life satisfaction to be lower among caregiving wives than caregiving husbands (Collins & Jones 1997). The men in that study were also more satisfied with their informal support, and viewed their current relationship with their cared-for wife more positively than the caregiving wives did. The men found caregiving as a way of widening the horizons and a source of personal growth, which is consistent with the finding by Collins and Jones (1997), who found men to state that caregiving gave them a purpose in life. From a clinical perspective, it is important to acknowledge the gender differences in satisfaction when designing care and help to the caregivers, since satisfaction is a powerful factor for how the caregiving situation turns out. Women caregivers may need more support and encouragement to feel that they are doing something important, and that they are not taken for granted.

A cluster analysis was conducted to detect underlying properties in the caregivers, based on the sources of satisfaction. The two clusters that emerged differed significantly on some variables. There were more men in the satisfied group (82%) than in the less satisfied group, where the gender distribution was more even (44% and 56% women), p-value <0.001. There were also differences in caregiving hours per week between the two groups, which is interesting considering that those who found most satisfaction in care were those who cared most, a mean 62 hours per week in relation to a mean 30 hours per week in the less satisfied group (p-value 0.011). This result may be interpreted as a sign of a selection over time of the caregivers; only those who can handle the care stay in the caregiving situation to this extent. Several factors such as personality, coping style or the symptoms of the persons cared for contribute to this selection of caregivers. Coping is known to affect life in various ways (Lazarus & Folkman 1984), which makes the cluster differences in coping strategies interesting. The satisfied group used several problem-solving strategies more frequently than the less satisfied group did; coping may thus have a great impact on the caregiver’s life, or other factors not revealed in this study may influence the strategies for coping.

In motivation theories (Herzberg *et al.* 1959; Knoop 1994; Rantz *et al.* 1996), there is agreement that absence of satisfying factors does not automatically mean dissatisfaction. In this study, there was only one difference in difficulties and the many differences between the clusters regarding satisfaction can be interpreted in the light of

Herzberg's (1959) motivational theory, distinguishing between satisfiers and dissatisfiers. Although difficulties were almost similar between the groups (only one factor differed: 'caring is too demanding', which more people in the satisfied group stated), there were significant differences in all sources of satisfaction. The study did not focus on caregivers' motivation and thus this interpretation should be taken with caution. The similarities to the work of Hertzberg (1959), Rantz *et al.* (1996) and Knoop (1994) seem not to be coincidental and are therefore interesting to explore more. From a nursing perspective, it is important to acknowledge that satisfaction may be more important than difficulties. According to Knoop (1994), satisfaction in work can reduce stress. Knoop (1994) concluded that satisfaction could function as a stress reducer, which is important to bear in mind when thinking about the clinical implications of these results. A group of caregivers who lacked satisfaction in the caregiving situation and had coping strategies that may not be functioning was identified in this study. Due to the absence of satisfaction and less problem-oriented coping strategies, they may run a risk of being vulnerable to stress. They could be supported by early identification. Nurses tend to think that help with IADL is what stresses informal caregivers most (Nolan *et al.* 1996), but the caregivers have other stressors such as changes in the relationship with the person cared for, which they find more stressful (Beeson *et al*. 2000). In this study demanding care was one problem, but social problems following the care were almost as frequent. By helping caregivers to find satisfaction in the care and cope with difficulties that are inevitable, much may be gained for the informal older caregivers in a long-term perspective.

From a salutogenic point of view, this results show that there are caregivers who, despite having to provide extensive care, find satisfaction in the caregiving situation and seem to have a functional way of coping with the difficulties of the care. Further research is needed to identify the health-promoting factors in these persons. Reinforcing the health-promoting qualities in caregivers who do not feel well, may restrict unnecessary suffering both for the caregiver and for the person cared for. Women and those who do not find satisfaction in the caregiving need extra support in order to not get worn out.

CONCLUSION

Satisfaction and coping strategies differed between the caregivers. Differences were identified between groups in sources of satisfaction from caregiving, but not in caregiving activities. This is in accordance with the theory about motivation to work developed by Herzberg (1959), which to our knowledge has not previously been applied to older informal caregivers. Those who found satisfaction in the care used more problem-focused coping strategies. There were more men than women in the group who found satisfaction in the care despite high caregiving demands. Thus women may deserve extra attention from formal caregivers since they did not find the caregiving as rewarding as the men did, and they may be less protected against the negative consequences of caregiving. From a clinical perspective, early identification of the caregivers and their coping strategies as well as sources of satisfaction in caregiving would help to detect those who are at risk of not feeling well in the caregiving situation. Individually designed interventions may support those vulnerable caregivers and protect them from unnecessary negative consequences of caregiving.

Study design: AKE and IRH
Data collection and analysis: AKE and IRH
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Table 1. Characteristics for the respondents, n =167.

	Women (40.4%)		Men (59.6%)		df	value	Total (%)		*p*-value
Age (SD) [a]	80.6	(4.6)	82.1	(3.9)			81.5	(4.3)	0.02
Helping [b]					4	6.03			0.3
Spouse	48	(70.6)	84	(84.8)			132	(79.0)	
Female relative (other than spouse)	6	(8.8)	5	(5.1)			11	(6.6)	
Male relative (other than spouse)	1	(1.5)	1	(1.0)			2	(1.2)	
Friend, not related	10	(14.7)	6	(6.1)			16	(9.6)	
Other	3	(4.4)	3	(3.0)			6	(3.6)	
Frequency of giving help [b]					3	3.12			0.4
<once/week	3	(4.7)	2	(2.3)			5	(3.3)	
Once/week	6	(9.4)	7	(8.1)			13	(8.7)	
2-3 times/week	8	(12.5)	20	(23.3)			28	(18.7)	
>6 times/week	47	(73.4)	57	(66.3)			104	(69.3)	
Helping hours/week (SD) [a]	43.4		47.0					45.6	0.4
Civil status [b]					5	15.6			0.008
Married	50	(72.5)	90	(89.1)			140	(82.4)	
Widow/widower	11	(17.4)	4	(4.0)			15	(8.9)	
Unmarried	3	(4.4)	2	(2.0)			5	(3.0)	
Divorced	1	(1.4)	5	(5.0)			6	(3.6)	
In a relationship, not cohabitant	3	(4.4)					3	(1.8)	
Economy compared to others (%) [b]					2	0.51			0.8
Better	14	20.6	24	24.5					
About the same	50	73.5	67	68.4					
Worse	4	5.9	7	7.1					
Sense of coherence; SOC, mean (SD) [a]	72.9	(13.6)	72.1	(12.8)					0.4
Carer's assessment of satisfaction index (SD)[a]									
Fulfilling oneself by caring	3.3	(0.42)	3.4	(0.45)			3.4	(0.44)	0.1
A way of control through caring	3.4	(0.50)	3.5	(0.44)			3.4	(0.46)	0.3
Widening my horizon by caring	2.4	(0.76)	2.8	(0.78)			2.7	(0.80)	0.004
Reciprocal engagement	2.8	(0.71)	3.1	(0.58)			3.0	(0.65)	0.02
Personal growth	2.4	(0.75)	2.7	(0.78)			2.6	(0.78)	0.04
Carer's assessment of difficulties index (SD) [a]									
The person I care for gives me problems	1.8	(0.66)	1.8	(0.65)			1.8	(0.65)	0.99
Caring is too demanding	2.6	(0.39)	2.7	(0.34)			2.7	(0.36)	0.3
Emotional strain	1.8	(0.69)	1.8	(0.68)			1.8	(0.68)	0.6
Social problems	1.9	(0.78)	1.9	(0.79)			1.9	(0.78)	0.9
Practical problems	1.4	(0.54)	1.7	(0.72)			1.6	(0.66)	0.07

[a] Mann-Whitney U-test, [b] Chi-square

Table 2. Percentage of men and women helping with IADL and PADL activities, and frequency of provided help

Caregiving activities	Men % (n=102)		Women % (n=69)		*p*-value
	Sometimes	Often/all the time	Sometimes	Often/all the time	
Eating 2)	8.7	10.9	24.1	11.1	0.045
Putting on clothes or shoes 2)	27.5	17.6	30.0	40.0	0.007
Getting up or going to bed 2)	9.0	11.2	27.6	15.5	0.014
Cooking 2)	29.5	50.0	8.8	70.2	0.004
Making phone calls or accompanying to the hospital 3)	23.7	35.5	27.9	50.8	0.034
Walking indoors 2)	23.3	24.4	21.8	25.5	0.98
Getting to the toilet 2)	8.9	20.0	15.5	27.6	0.2
Using the toilet 2)	3.3	17.8	14.3	21.4	0.06
Taking a bath or shower 2)	12.5	29.5	19.7	39.3	0.08
Turning in bed 2)	3.4	6.8	16.4	5.5	0.06
Remembering where things are, or what to do 3)	38.0	33.7	33.9	44.1	0.5
Weekly laundry 2)	16.3	55.4	6.7	75.0	0.06
House cleaning 2)	17.9	70.5	12.3	75.4	0.4
Shopping for groceries 2)	9.6	81.9	11.3	79.0	0.97
Housekeeping 2)*	20.6	58.8	18.2	54.5	0.1
Gardening 4)*	14.3	60.3	15.8	57.9	0.9
Maintaining the car 2)*	6.8	67.8	2.4	31.7	0.5
Helping with bank or post errands 2)	16.7	75.6	12.1	74.1	0.5
Helping to get to the bus stop 2)*	7.7	20.0	10.9	17.4	0.2
Walking outdoors 2)	34.1	41.2	31.6	36.8	0.8

Internal dropout 1) <30, 2) 21–30, 3) 11–20, 4) 1–10

*Dropout is based on those who had a car or lived in a house.

Table 3. Description and comparison of the two main clusters based on the respondents' sources of satisfaction in caregiving (i.e. the five factors of CASI).

	Cluster 1 (n=54)	Cluster 2 (n=45)	df	value	*p*-value
Age, mean (SD)	81.1 (5.09)	81.6 (3.58)			0.6
Males/females %	44.4 / 55.6	82.2 / 17.8			0.001
SOC (SD)	60.3 (7.87)	61.4 (6.67)			0.5
Perceived health (%)			4	3.46	0.5
Excellent or very good	10 (18.5)	9 (20.0)			
Good	23 (42.6)	13 (28.9)			
Rather good	17 (31.5)	19 (42.2)			
Bad	4 (7.4)	4 (8.9)			
Economy compared to others			2	2.13	0.4
Better	16.7	28.9			
About the same	77.8	66.7			
worse	5.6	4.4			
Times helping per week (%)			3	6.69	0.08
Once a week or less	7 (14.0)	3 (7.3)			
2–3 times per week	10 (20.0)	6 (14.6)			
>6 times per week	33 (66.0)	32 (78.0)			
Perceived information about the help			3	3.14	0.4
Yes, enough or more than enough	60.4	68.2			
Yes, to some extent	26.4	18.2			
No, not at all	13.2	13.6			
Number of hours help per week: median (Range)	8.0 (167)	30.0 (166)			0.01
q1–q3	4–30	10–100			
Carer's assessment of satisfaction index, mean (SD) *					
Fulfilling oneself by caring	3.1 (0.39)	3.7 (0.23)			<.001
A way of control through caring	3.1 (0.41)	3.7 (0.27)			<.001
Widening my horizon by caring	2.2 (0.65)	3.2 (0.53)			<.001
Reciprocal engagement	2.6 (0.60)	3.3 (0.52)			<.001
Personal growth	2.1 (0.59)	3.1 (0.59)			<.001
Carer's assessment of difficulties index, mean (SD) *					
The person I care for gives me problems	1.9 (0.67)	1.8 (0.59)			0.4
Caring is too demanding	2.4 (0.32)	2.9 (0.21)			0.001
Emotional strain	1.9 (0.72)	1.7 (0.66)			0.4
Social problems	1.8 (0.74)	2.0 (0.81)			0.4
Practical problems	1.5 (0.56)	1.6 (0.66)			0.7
Carer's assessment of managing index, mean (SD)*, **					
Solution trying	2.5 (0.57)	2.8 (0.56)			0.005
Self-empowerment and self-control	3.1 (0.54)	3.4 (0.51)			0.002
Control by routine and prevention	2.4 (0.64)	2.6 (0.65)			0.2
Obtaining new insights	2.0 (0.53)	2.2 (0.54)			<.001
Self-sustaining	2.4 (0.70)	2.6 (0.73)			0.1
Asking for social and practical support	2.0 (0.61)	2.1 (0.69)			0.3
Distracting by focusing on positive activities	1.4 (0.51)	1.4 (0.51)			0.9

* Range 1 ('not true for me') – 4 ('very true'), ** Imputation was used when calculating the scores for CAMI, missing values were replaced with mean. Criteria for imputation was that at least 60% of the items in each factor had to be answered.

Table 4. Comparisons between the less satisfied group, the satisfied group and those with internal dropout in CASI. For comparisons between cluster 1 and 2, see table 3.

Instrument/ questions	Cluster 1 (less satisfied) n=45	Cluster 2 (more satisfied) n=54	Internal dropout in CASI (IM) n=68*	df	Value	p-value	Differences between
Men/Female (%) a)	44.4/55.6	82.2/17.8	55.9/44.1	2	15.0	<0.001	
Overall health a)				8	3.9	0.9	
Excellent	3.7	8.9	7.6				
Very good	14.8	11.1	15.2				
Good	42.6	28.9	37.9				
Fairly well	31.5	42.2	31.8				
Bad	7.4	8.9	7.6				
CASI (mean) b)							
Fulfilling oneself by caring	3.1	3.7	3.5 1)	2	10.1	<0.001	Cluster 1 and IM Cluster 2 and IM
A way of control through caring	3.1	3.7	3.6 2)	2	10.9	<0.001	Cluster 1 and IM
Widening my horizon by caring	2.2	3.2	2.8 3)	2	27.4	<0.001	Cluster 1 and IM Cluster 2 and IM
Reciprocal engagement	2.6	3.3	3.2 4)	2	11.5	<0.001	Cluster 1 and IM
Personal growth	2.1	3.2	2.6 5)	2	26.7	<0.001	Cluster 1 and IM Cluster 2 and IM
CADI (mean) b)							
The person I care for gives me problems	1.9	1.8	1.6	2	0.74	0.421	
Caring is too demanding	2.4	2.9	2.8	2	6.6	<0.001	Cluster 1 and IM
Emotional strain	1.9	1.7	1.8	2	0.30	0.725	
Social problems	1.8	2.0	2.0	2	0.52	0.658	
Practical problems	1.5	1.6	1.7	2	0.31	0.710	
CAMI (mean) b)							
Solution trying	2.4	2.8	2.7	2	2.7	0.019	
Self-empowerment and self-control	3.1	3.4	3.4	2	3.2	0.002	Cluster 1 and IM
Control by routine and prevention	2.4	2.6	2.6	2	0.96	0.273	
Obtaining new insights	2.0	2.2	2.2	2	0.67	0.273	
Self-sustaining	2.4	2.6	2.6	2	1.36	0.248	
Asking for social and practical support	2.0	2.1	2.1	2	0.52	0.541	
Distracting by focusing on positive activities	1.4	1.4	1.4	2	0.26	0.852	

*Number of respondents in the group (IM) , the number of respondents is less in the ANOVA analyses
Number of respondents with no internal dropout in the factor: 1) 15, 2) 24, 3) 18, 4) 19, 5) 16. In CASI, 2 factors completed had 10 respondents from the group IM, 3 completed had 7 respondents and 4 completed had 12 respondents.
a) Chi-square, b) One-way ANOVA. Post-hoc test Mann-Whitney

Appendix 1a. Carer’s Assessment of Satisfaction Index

	F 1	F 2	F 3	F 4	F 5	Comm.
Fulfilling oneself through caring						
I get pleasure from seeing the person I care for happy	.758					.783
It is nice to see the person I care for clean, comfortable and well turned out	.756					.768
It’s nice when something I do gives the person I care for pleasure	.742					.776
It’s good to help the person I care for overcome difficulties and problems	.694					.718
Caring enables me to fulfil my sense of duty	.585					.658
I am the sort of person who enjoys helping people	.513					.559
Caring has brought me closer to the person I care for	.450					.348
Knowing the person I care for the way I do means I can give better care than anyone else	.438					.426
It’s nice to feel appreciated by those friends and family I value	.430					.552
Caring makes me feel needed and wanted	.337					.701
A way of control through caring						
I am able to ensure that the person I care for has their needs tended to		.688				.592
At the end of the day I know I will have done the best I could		.655				.701
Maintaining the dignity of the person I care for is important to me		.647				.632
It helps to stop me from feeling guilty		.571				.548
Caring is one way of expressing my love for the person I care for		.553				.726
I m able to keep the person I care for out of an institution		.539				.408
I am able to test myself and overcome difficulties		.468				.521
Widening my horizon through caring						
Caring has provided a purpose in my life that I did not have before			.824			.764
Caring has given me the chance to widen my interests and contacts			.744			.609
Caring has strengthened close family ties and relationships			.603			.637
Caring is one way of showing my faith			.574			.696
Reciprocal engagement						
I am able to help the person I care for reach their full potential				.783		.702
I am able to repay their past acts of kindness				.653		.605
I feel that if the situation were reversed, the person I care for would do the same for me				.624		.660
The person I care for is appreciative of what I do				.555		.537
It is good to see small improvements in their condition				.491		.426
Personal growth by caring						
Caring provides a challenge					.714	.699
Despite all their problems the person I care for does not grumble or moan					.647	.488
Caring has allowed me to develop new skills and abilities					.628	.552
Caring has helped me to grow and to develop as a person					.609	.694
Eigen values after rotation	4.515	4.482	3.582	3.083	2.823	
% of variance	15.05	14.94	11.94	10.28	9.41	61.61
Cronbach’s alpha	.814	.826	.806	.765	.766	

Appendix 1 b. Carer’s Assessment of Difficulties Index

	F 1	F 2	F 3	F 4	F 5	Comm.
The person I care for gives me problems						
I can’t relax because of worry about caring	.728					.712
The behaviour of the person I care for is a problem	.680					.603
The person I care for doesn’t always appreciate what I do	.643					.578
The person I care for doesn’t help as much as they could	.611					.615
I no longer have a meaningful relationship with the person I care for	.591					.459
The person I care for can play me up	.589					.696
My physical health has suffered	.587					.638
There is no satisfaction to be gained by caring	.508					.625
The person I care for is incontinent	.500					.399
Caring is too demanding						
The person I care for needs a lot of help with personal care		.757				.669
The person I care for is immobile/has problems getting about		.718				.559
My standard of living has fallen		.715				.714
It restricts my social life/outside interests		.681				.648
It is physically tiring		.646				.587
I can’t have a break or holiday		.633				.694
I can feel helpless/not in control of the situation		.509				.582
I don’t have enough private time for myself		.508				.552
The person I care for can demand too much of me		.464				.617
Emotional strain						
Relatives don’t keep in touch as often as I’d like			.740			.760
My emotional well-being suffers			.734			.811
I can’t see friends as often as I would like			.734			.722
I feel guilty about the situation			.716			.648
I feel angry about the situation			.615			.709
My sleep is affected			.408			.427
Social problems						
I can’t devote enough time to other family members				.761		.680
It can put strain on family relationships				.612		.731
Professional workers don’t seem to appreciate the problems carers face				.584		.645
Practical problems						
Some family members don’t help as much as they could					.771	.717
I don’t get enough help from the health and social services					.643	.684
It causes financial difficulties					.506	.474
Eigen values after rotation	4.903	4.758	3.819	3.326	2.151	
% of variance	16.34	15.86	12.73	11.09	7.17	56.02
Cronbach’s alpha	.867	.893	.823	.749	.598	