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OLDER CAREGIVERS' COPING STRATEGIES AND SENSE OF COHERENCE IN RELATION TO QUALITY OF LIFE

Anna Kristensson Ekwall[1] RN, PhD, Bengt Sivberg PhD[1], Ass Professor and Ingalill Rahm Hallberg[1, 2] RNT, PhD, Professor

[1] Department of Nursing, Faculty of Medicine, Lund University, Sweden

[2] The Vårdal Institute, the Swedish Institute for Health Sciences, Sweden

Corresponding address:

Anna K Ekwall

Dept of Nursing, Lund University

PO. Box 157

SE-221 00 Lund

Sweden

E-mail: anna.kristensson_ekwall@med.lu.se

ABSTRACT

Aim: This paper reports a study investigating coping strategies and sense of coherence in relation to gender, the extent of care, caregiving activities and health-related quality of life in a population-based sample of caregivers aged 75 and over.

Background: Caring for another person can be stressful both emotionally, and caregiver burden may affect quality of life in a negative way for the carer. Caregivers' experience of burden may depend on for example the behaviour of the person cared for, their own health and their sense of coherence. Older people takes a great part of caregiving responsibility and thus understanding of their strain and coping is required.

Methods: A postal survey was carried out in 2001 with 171 informal caregivers, aged 75 or older. The response rate was 47%. The questionnaire included the Short-Form 12, Carer's Assessment of Managing Index, and Sense of Coherence instrument.

Results: Almost 70% of the caregivers provided help every day. Higher health-related quality of life was predicted by using self-sustaining coping strategies and by high sense of coherence. Poor economic situation and demanding social and practical support predicted low scores.

Conclusion: These findings could help identify those at risk of low quality of life due to the caregiving, dysfunctional coping or lack of information about the care. Early intervention, including education about alternative coping strategies and practical information, might allow caregivers better possibilities to continue caring with less negative effects on their lives.

Key words: Informal caregiver, coping, Carer's Assessment of Managing Index, older people, nursing, sense of coherence, Short-Form12

Summary statement

What is already known about this topic:

- Older people take a great part of caregiving responsibility for informal care
- Caregiver burden affects quality of life negatively.
- Caregivers' experience of burden depends on the behaviour of the person cared for, the caregiver's own health and their sense of coherence

What this paper adds:

- Self-sustaining coping strategies, such as maintaining interests outside the caring situation, predicted better quality of life.
- Asking for social and practical support predicted worse quality of life among older caregivers.
- Knowledge about economic situation, the extent of the care, how long the care recipient can be left alone and an assessment of coping strategies used may help identify those at risk for low quality of life in the caregiving situation.

INTRODUCTION

Older people takes a great part of caregiving responsibility and thus understanding of their strain and coping is required. As the population gets older, an increasing number of people will be informal caregivers, especially among those who are elderly themselves. Knowledge about the kind of coping strategies mostly used among older caregivers and their relation to quality of life may provide professionals with ideas about how to support informal caregivers in their care provision. This in turn may improve quality of life among the caregivers, since caregiver burden is known to affect their quality of life negatively (Chappell and Reid, 2002).

BACKGROUND

Caring for another person can be stressful both emotionally and physically (Nolan et al.,1 996) and the outcome of stressful situations may to a great extent be dependent on the caregiver’s coping strategies. Increased life expectancy (SCB, 2001) and a shortage of health care personnel in the public sector may mean that a greater part of care for the older people will be provided by informal caregivers, many of whom will be old. An age-stratified Swedish study (n=4278) showed 18% of the older people (75–105 years old) to be involved in the care of others. Caregivers may be old and have health problems of their own to deal with in addition to the demands of caregiving. Coping with strain from caregiving may influence the experience of the caregiving situation as well as the quality of life of the caregiver.

Gender needs to be considered when evaluating caregiving since it has been shown to affect men and women differently. Women may use different coping strategies and experience the caregiver strain differently than men. Higher levels of burden were shown among women than men in a study among informal caregivers in Brazil (n=82) (Scazufca et al., 2002), aged 60 and over. Collins and Jones (1997) showed that women experienced a higher level of strain and lower life satisfaction than the men did (24 women and 24 men in the UK, mean age 74.6 years). Female caregivers (565 women and 486 men) in the USA were more likely to experience difficulty in providing care (Navaie-Waliser et al., 2002), and it was also found that women experienced greater emotional challenges than the men did. Also health among female caregivers was found to be worse than for males in a Swedish study (n=129) (Almberg et al., 1998). Since experiences and perceived strain differ between men and women, support needs to be individualised taking women's specific situation into consideration and a deeper understanding of the differences between men and women caregivers is also needed to develop effective support.

Coping and burden

Coping has been described as "realistic and flexible thoughts and acts that solve problems and thereby reduce stress" (Lazarus and Folkman, 1984). Coping is considered effective to the extent that the threat or harm is reduced. There are different strategies – emotion-focused and problem-focused – that are used depending on personality and situation. Emotion focused strategies can not change the threat, but the meaning of the situation, a way of reappraisal. It can also be about taking the mind off the problem for a while, a form of distraction. Problem-focused strategies are a way of defining the problem with the attempt to alter it. How stressful the caregiver experiences the situation is partly based on what coping strategy he or she uses, and how useful it is. Lazarus and Folkman (1984) discuss internal and external resources. In a caregiving context internal resources can be understood as the relationship to the person cared for, the caregiver's personality and knowledge about caring. External resources can be understood as the social network and the caregivers' support obtained from them, the cared-for person’s own ability to perform activities for daily living (ADL) or the formal resources available, such as public home help services.

Caregivers’ experience of burden may depend on several things, for example the behaviour of the person cared for (Coen et al., 2002), their own health (Mafullul and Morriss, 2000) and their sense of coherence (Nolan et al., 1996), which in turn may relate to coping strategies. Caregivers of older persons with stroke and Alzheimer’s disease (n=84) showed a higher frequency of depression than the non-caregiving controls (Wright et al., 1999). Highly burdened caregivers (perceived burden, measured with Zarit Burden Inventory (Zarit et al., 1980) had lower quality of life than the less burdened caregivers in a study with 72 primary caregivers in Ireland (Coen et al., 2002), and there were also more women in the highly burdened group than among those with low burden. A Swedish study (Ekwall et al., 2004) tested a care typology (Nolan et al., 1995b) and found the early phases of caregiving, i.e. to be prepared in case of problems, to affect quality of life negatively among the caregivers. Thus the extent of caregiving as well as the transition to becoming a caregiver may be stressful. In addition, the person’s strategies for handling the demands may relate to a successful outcome.

Using several different coping strategies and the ability to use the most adequate in a certain situation was described by Antonovsky (1987) as a strong Sense of Coherence (SOC). Thus, SOC includes the ability to prevent tension from transforming into stress. It is supposed to have three dimensions: comprehensibility, manageability and meaningfulness. Meaningfulness has been suggested to be the key to understanding coping (Nolan et al., 1996). Sense of coherence is supposed to develop during childhood and young adulthood, and it is not likely to change during adulthood or the later part of life (Antonovsky, 1987). A person with a high sense of coherence is expected to have a greater ability to handle stress.

The person may focus on the positive aspects of caregiving and consider the problems as solvable. From a clinical perspective, it may be useful to know how sense of coherence interacts with coping and the caregivers' vulnerability to stress, which has not seen very much investigation. In a Swedish qualitative study (Almberg et al., 1997) 46 primary caregivers of persons with a dementia disease were asked about strain and coping. Emotion-focused coping, including grief and wishful thinking, was mostly used among those at risk of burnout, while problem-focused coping, including seeking information and social support, was used among those not at risk of burnout. Many caregivers used a combination of the two (Almberg et al, 1997). Female caregivers more often used emotion-focused strategies than male caregivers did and consequently they were more likely to be burned out (Almberg et al., 1997). A study of coping strategies among family caregivers in Sweden (Lundh, 1999) (n=123) showed problem solving to be widely used and regarded as helpful. Focus group interviews with family caregivers (n=14, 2 male and 12 female) (Chambers et al., 2001) showed acceptance, taking practical actions and behavioural interventions to be recurrent coping strategies.

Knowledge of coping strategies used by the caregivers to strengthen those strategies that work or to help the caregivers to change the ones that are not helpful, requires a standardised method of assessment. Instruments have been constructed to measure burden (Zarit et al., 1980) or difficulties (Nolan et al., 1996), whilst instruments for assessing managing or coping in informal caregivers are not frequent. A literature review of non-disease-specific instruments revealed instruments for burden and for quality of life (Deeken et al., 2003) in informal caregivers. There are, however, to our knowledge, few to assess informal caregivers' coping strategies. One instrument, Carer's Assessment of Managing Index (CAMI), was developed by Nolan et al (1995), for assessing caregivers coping strategies. It has been used in clinical settings, with individual assessments of the caregivers' situation (Lundh, 1999), but has not been psychometrically tested. Knowledge about different coping strategies and their relation to quality of life in formal caregivers can help to improve the caregivers' situation through interventions and protect them from unnecessary strain.

THE STUDY

Aim

The aim of the study was to investigate coping strategies and sense of coherence in relation to gender, the extent of care, caregiving activities, economic situation and health-related quality of life in a population-based sample of caregivers aged 75 and over.

Design

A cross-sectional questionnaire survey was carried out in Sweden in 2001. The study reported here is a part of a larger study, parts of which are being published elsewhere (Ekwall and Hallberg, in press).

Participants

The respondents were 171 informal caregivers (Ekwall and Hallberg, in press), identified from an age-stratified sample in a postal survey among older people in the south of Sweden in year 2000 (Jakobsson et al., 2003, Thome et al., 2003). The stratification was done with different numbers in different age groups: 75–79 (n=2500), 80–84 (n=2500), 85–89 (n=2000), 90 and over (n=1500) in order to get a large enough group of care recipients in the younger groups (Jakobsson et al., 2003). This previous study consisted of 4278 respondents where 18% stated that they helped another person because of that person's reduced health. The data collection for this study was conducted in 2001. All of the respondents from the previous study who stated that they cared for another person received a questionnaire, which focused on informal caregivers. During the year between the two data collections, many respondents had ceased caregiving, had moved or deceased; thus, out of 363 eligible questionnaires, only 171 (47%) were available in a usable form (Ekwall and Hallberg, in press).

Questionnaire

Demographics

The questionnaire covered civil status, questions about living conditions (house or apartment) and economic situation as well as kinship to the cared for person (Ekwall and Hallberg, in press). The questions covered instrumental help (IADL), personal help (PADL) and/or medical help, and extent of help (frequency and hours per week). There was one question about how long the person cared for could be left alone. There were also questions about information regarding help from formal caregivers and the medical treatment of the care recipient (Ekwall and Hallberg, in press). The questionnaire also covered satisfaction and difficulties in the caregiving situation, which is further described elsewhere (Ekwall and Hallberg, in press).

Quality of life

Health-related quality of life was measured with the Short-Form 12 (Ware et al., 1996) which is a short version of SF 36 consisting of 12 questions measuring how the present health status affects life (Ware et al., 1996) in two aspects: mental component summary score (MCS12) and physical component summary score (PCS12). 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).

Coping strategies

Coping strategies were assessed by Carer's Assessment of Managing Index (CAMI). The theoretical framework of the instrument was Lazarus's transactional model of stress and coping (Lazarus and Folkman, 1984). CAMI was developed primarily for use when assessing individual caregivers. It has previously been tested among caregivers of persons with Alzheimer's disease in Scotland and Wales, in a non-random sample (n=266) recruited from a patient's association (Nolan et al., 1995a). This instrument was created to provide a detailed profile of the caregivers' coping strategies at an individual level (Nolan et al., 1995a). The instrument was developed from interviews with family caregivers and a literature review and comprises 38 statements concerning the caregivers' way of handling difficulties in the caregiving situation. According to Nolan (1995), the items were based on three themes: problem solving and coping, alternative perception of events and dealing with stress symptoms.

The version used in this study had two parts, one part responding to whether each statement was true for the respondent "Very often, quite often, quite seldom and never" and one part responding to whether that way of acting/being was "Very helpful, quite helpful, slightly helpful or not at all helpful". The translation from English to Swedish was done with back translation to ensure the same meaning in both languages by two bilingual persons (cf. Varricchio, 1997).

Sense of coherence

Sense of coherence was measured with the SOC scale (Antonovsky, 1987), using the version with 13 items, with a total score from 13 (low SOC) to 91 (highest possible SOC). The items measure perceived manageability (4 items), meaningfulness (4 items) and comprehensibility (5 items).

Validity and reliability

Cronbach's alpha for the answers about how useful the suggested coping strategy were considered to be varied from .61 to .87. Cronbach's alpha value for CAMI part 1 was .86, and for part 2 .92. Cronbach's alpha for CAMI was .86 in a previous study from Great Britain (Nolan et al., 1995a). Cronbach's alpha for Sense of Coherence was 0.85 in this sample. Antonovsky reported alpha values from 0.74–0.91 in the 13-item version from 16 western countries (Antonovsky, 1993). Those with three or more missing answers on SOC were excluded, which left 136 respondents with completed SOC-scale

Ethical considerations

This study was approved by the Ethics Committee at the Faculty of Medicine, Lund University (LU 478-99). The respondents were guaranteed confidentiality. Potential participants were informed about the study in a covering letter together with the questionnaire. If they did not want to participate, they contacted the researchers or did not return the questionnaire.

Data analysis

The chi-square test was used when comparing the groups (men and women and respondents and non-respondents) regarding ordinal and nominal data, and t-test for comparisons with continuous data. Physical component summary 12 was not used in that kind of analysis, since it did not differ between genders or for high or low scores on Mental component summary 12. A factor analysis was conducted including all items in the instrument to identify underlying structures (Altman, 1994) in order to get groups of items for use in the regression analysis. A principal component analysis with varimax rotation was used. To set the number of factors in the analysis, a cut-off point of eigenvalues over 1.00 was used. Only items with commonalities above 0.3 were used in the further analysis. Stepwise linear regression analyses were conducted with the two aspects of quality of life, mental component summary (MSC12) and physical component summary (PCS12) as the dependent variables. The independent variables were the total score in each factor from the coping instrument and the usefulness of each factor, perceived information about the practical care and perceived information about the medical care (Yes, enough information =0, No information at all =1), Sense of coherence and economic situation compared to others' (Better or about the same as others=0, worse than others=1). The analysis was controlled for gender. SPSS 10.0 for windows (Norusis and SPSSInc, 1992) was used.

Results

The mean age was 82.1 (SD 3.88) for men and 80.6 (SD 4.63) for women, and the men were significantly older (p-value = .02) (Table 1).

Eighty-nine percent of the men were married and 73% of the women; 4.0% of the men were widowed, which was the case for 17.4% of the women (p-value =.005); 4.4% of the women were in a relationship but not cohabitant, which none of the men was. Five (3.3%) of the respondents helped less than once a week, 13 (9%) helped once a week, 28 (19%) helped 2–3 times a week and 104 (69%) helped more than 6 times a week, with no significant difference between men and women. Among the women, 8% could not leave the cared for person at all, and this was the case for 12% of the men. 21% of the men could leave the cared for person less than 2 hours, the corresponding number for women caregivers was 33% (p-value .547). There were no gender differences in the frequency of provided care or in how long the person cared for could be left alone. The score on SOC was 72.1 (SD 12.8) for the men and 72.9 (SD 13.6) for the women, with no significant gender difference. The scores on MCS12 and PCS12 were 45.8 and 37.0 respectively for the men and 45.8 and 35.6 respectively for the women. Among the respondents, 56.6% were men and 43.4% women (Table 1). Two reminders were sent. Seventeen percent were too weak to answer, 25% did not want to participate,4% of the questionnaires had incomplete answers (i.e. too few (<25) questions were answered) and had to be excluded and the rest of the potential respondents did not state the reason for not participating. There were no significant differences in age or gender between the respondents, and the dropouts.

Insert Table 1 about here

Helping with cooking was done often or all the time by 50% of the men and 70% of the women (p-value=.004) (Table 2). Helping with eating was done sometimes by 9% and often or all the time by 11% of the men and sometimes by 24% and often or all the time by 11% of the women (p-value =.045), putting on clothes or shoes was done often or every time by 18% of the men and 40% of the women (p-value =.007). Helping to make phone calls or contact the hospital was done often or every time by 36% of the men and 51% of the women (p-value =.034).

Insert Table 2 about here

There were more women helping with oral care and skin care than men, which was done by 15% (p=.025) and 22% (p<.001) of the female respondents respectively and by 6% and 3% of the men. The medical care given once a day or more was helping with tablets which 22% of the men and 47% of the women (p-value =.013) did.

Seven factors with Cronbach's alpha varying from .32 to .81 on the first part of the responses (if the statements were true for the respondents) were extracted (Appendix 1) from the factor analysis. This factor solution explained 59% of the total variance. The seven factors were labelled: "Testing solutions", "Self-empowerment and self-control", "Control by routine and prevention", "Reappraisal of the caregiving situation", "Self-sustaining", "Asking for social and practical support" and "Distracting by focusing on positive activities". The items "Relying on religious beliefs" and "Joining support groups" were excluded from the factor analysis because of low commonalities (<.300). The same factor structure was used for the part of the response alternatives stating how helpful the different coping strategies were.

The five most commonly used coping strategies (item level) were "Keeping my emotions tightly under control", (91.9% used that often or very often), "Taking one day at a time" (90.7%), "Remembering the good times I used to have with the person I care for" (89.2%), "Establishing priorities and concentrating on them" (87.2%) and "Realising that there is someone worse off than me" (86.8%) (Figure 1 a-f). The five most helpful strategies were "Looking for what is positive in each situation" (86.4%), "Taking one day at a time" (86.3%), "Keeping my emotions tightly under control" (86.1%), "Remembering the good times" (85.8%) and "Establishing priorities" (82.4%). There were no significant differences between men and women regarding coping strategies used, nor with regard to how useful they were considered to be. The stepwise linear regression analysis showed high scores on SOC to predict high scores on the mental component score (MCS12) (p-value <.001), as did "Self-sustaining" (p-value=.018) (Table 3) as well as an economic situation "as good or better than others’”. Gender was not a significant predictor (p-value =.386). The same analysis with physical component score (PCS12) as the dependent variable was done and no other variables were significant predictors. Two more stepwise linear regression analyses were conducted with PCS12 and MCS12 as the dependent variables respectively, and with questions about how helpful the different coping strategies were, frequency in given help, gender and kinship to the cared for person, but no significant predictors were found among the variables.

Discussion

The main finding of this study was that higher quality of life was predicted by using self-sustaining coping strategies such as keeping interests outside caring and by high sense of coherence, indicating personal strength to handle demanding situations. Poor economic situation predicted low scores on MCS12. The extent of the care which the caregiver provided was striking. Almost 70% of the caregivers were helping every day and for a mean 46 hours per week.

Coping

The characteristics of the various factors obtained from the factor analysis apply well to the coping strategies described by Folkman and Lazarus (1988), and thus support the validity of the instrument. There may, however, be some differences with regard to content, explaining, for instance, the fact that asking for social and practical support predicted low QOL and also was more common in the group with low QOL, suggesting that it was not an effective coping strategy or it could as well be that asking for social support was the last thing to do in that group, with no more alternatives to try. Lazarus did provide knowledge about the risk of using coping strategies that are not functional, i.e. that do not reduce stress, which can be applied in this context with caregivers as well, since there may be caregivers using dysfunctional coping strategies such as escaping from the problems. The factor “Testing solutions”, corresponds well with Lazarus’s description of a problem solving strategy, whereby creating a structure and analysing the problems gives a general view which can reduce stress. As the name suggests, the factor “Self-empowerment and self-control” (self-control in Lazarus’s terminology) aims at reducing stress by improved self-control and attention. “Control by routine and prevention” aims at the source of the stress to find a solution that reduces it. “Reappraising the caregiving situation” is a way to alter the meaning of the situation, not by adjusting but by re-evaluating earlier understandings. Coping strategies named “Self-sustaining” and “Distracting by focusing on positive activities” can be compared to distancing/escaping according to Lazarus. “Asking for social and practical support” may resemble social support as described by Lazarus, which implies that support is requested from family and professionals. In this study, the factor did not only include social, but also practical support, which differs from Lazarus. It may well be that the meaning of the factor obtained in this study puts more emphasis on the demanding aspect and not as much on what actually is received from others and thus it may not be an effective strategy, if the demands can not be met by professionals or next of kin.

The use of coping strategies

From a clinical perspective, the risk of increased stress when using a coping strategy that is not effective in reducing it is important to acknowledge when assessing coping in caregivers. It may well be that although the strategy is regarded as helpful it may not give any longstanding release of stress and is thus not effective from an outsider’s perspective. The respondents frequently used strategies included in the factor “self-empowerment”. One item in this factor was “Keeping feelings and emotions tightly under control”, which was done by 92%. “Establishing priorities and concentrating on them” was done by 87%, showing that these were two of the most frequently used strategies in this factor and also altogether. Those with low quality of life used the factor “Control by routine and prevention” with letting steam off as one way of coping. This was considered helpful by 33% but was done by fewer; 9% which indicates that letting steam off may be a reaction to too tight control or not being able to influence daily life. The factor “Asking for social and practical support” covered asking for help from others, with an obvious negative relation to the caregiver’s quality of life. Social support is regarded as a helpful strategy since it gives a sense of community according to Lazarus (Folkman and Lazarus, 1988). In this case it may rather reflect that not enough social support was obtained and thus the person had to ask for it. The most used strategy in this factor was getting as much help as possible from professionals and others (35%, and considered helpful for 57%), which may indicate that the situation was out of hand for the caregiver. An alternative interpretation could be that the lack of information contributed to feelings of frustration and asking for help from professionals was one way of getting more information. This interpretation is further supported by the fact that those who reported that they used this strategy reported higher caregiver extent in terms of hours per week and in terms of being able to leave the person cared for. The findings support the importance of not only discussing the use of various strategies to handle the caregiving situation but also discussing their effectiveness in the short term and the long term. This may well be an important task for professionals in their relation to informal caregivers.

Need for support and sense of coherence

The use of self-empowerment together with reappraisal of the caregiving situation was the most frequently used coping strategies (on factor level) in both groups. Those with high quality of life considered self-empowerment to be more helpful than the others did, while getting control by routine and prevention were considered to be the most helpful strategy among those with low quality of life. Asking for social and practical support was used by both groups, but significantly more often and considered more helpful among those with low quality of life. This could be seen as an expression of different attitudes or be explained by their sense of coherence. Having a need for emotional support may in some parts of the society be seen as a weakness, and expressing that need may not be socially accepted. The cultural norm in society may not encourage people to ask for help, and this may explain why this strategy was not used very often. The formal caregivers have an important role for these caregivers since they can address those needs without adding to the stigma the care givers already may experience if they feel they are not being able to handle the situation. Asking for social and practical support may be an expression of unmet needs, practical, social or medical, which in turn can increase the caregiver’s frustration. It may also be the last alternative of coping, after trying everything else, indicating that those with low quality of life may be almost worn out. Having needs that are not supported by family, professionals or the person cared for can make the caregiver vulnerable and force him or her to act in a more extrovert way (have a good cry or talk the problems over with someone else) to get attention. It may, however, also be an expression of sense of coherence, which can be regarded as an expression of the person's ability to handle stressful situations effectively. The findings from this study showed that high SOC correlated with high mental quality of life, indicating that personality influences how the difficulties in the caregiving situation are handled and the use of coping strategies. Seemingly those with low quality of life used more emotion-focused strategies and fewer problem solving strategies. Since SOC is supposed to be stable from young adulthood (Antonovsky, 1987), it is important to identify those with low SOC, since they may be more vulnerable to difficulties and strain from caregiving. This can perhaps be explored by assessing their coping strategies and their effectiveness.

Study limitations of the

In this study, low response rate and incomplete answers were the greatest threats to external validity. The response rate was 47%, which calls for caution when making generalisations, especially among the oldest caregivers. The sample was drawn from a larger sample and the caregivers were identified through a question about whether they helped or cared for someone due to that person's health problems (Ekwall et al., 2004). One possible explanation for the dropout could be that not all respondents from the first study felt that the questions applied to their situation, since the care or help they gave was not comprehensive. Those reporting themselves to be too weak to answer (17%) may also have been too weak to help or care for someone and thus should perhaps not have been included in the sample. Another problem was the internal dropout, which was analysed to find out how it might have affected the results. The percentage of fully answered questions (response to all 12 items) in Short-Form 12 was 43%, in Sense of Coherence (13 items) 21% and the question about caregiving hours 40%. Comparison of those who did not answer all items in SF12 and those who did showed statistically significant ($p<.001$) differences between the two groups regarding overall health status, with the latter having better health. Comparisons between those who completed SOC and those who did not, and between those with or without missing answers to the question about number of hours' help per week did not reveal any statistically significant differences between the groups. It may be that those with the least caregiving involvement were the ones least represented in the sample.

Factor analysis of CAMI has not to our knowledge been done before, and the study should be considered explorative, aiming to investigate what has not previously been done (Brink and Wood, 1998). Further analysis with a larger sample is needed to fully understand the items' relationships to each other. Cultural differences, especially religious beliefs, and differences in the social security system may affect the items chosen for CAMI and may not fully fit into a Swedish context. To minimise the risk of missing items that could be appropriate for Swedish caregivers, focus groups interviews might be a helpful way to identify differences and add items relevant for a Swedish context. It could also be a way of validating the existing items. An easily-administered instrument is required for use in a clinical setting. It has been found that the use of an instrument like this increases nurses' awareness of the complexity of the care (Guberman et al., 2003). It may also lead to more appropriate interventions, since practitioners become aware of previously neglected areas. The fact that there were differences in both frequency of use and perceived helpfulness of the coping strategies supports the use of a two-dimensional response alternative in the instrument. From a clinical perspective, the subjective feeling of how helpful a coping strategy is may be important in understanding the way caregivers cope with their situation. This can also be valuable knowledge when designing educative programmes, for instance, covering information and strategies for problem-solving and coping, as well as about practical and medical difficulties of informal caregivers.

CONCLUSION

From a nursing perspective, valuable information was obtained about the informal caregivers' situation can be captured by simple questions about the economic situation, the extent of the care and how long the care recipient can be left alone, together with an assessment of coping strategies used and their perceived helpfulness which seems to work in a Swedish as well as in an international context. Such knowledge could help identify those at risk of low quality of life due to the caregiving, dysfunctional coping or lack of information about the care. Early interventions, including education about alternative coping strategies and practical information, might give caregivers better opportunities to continue caring with less negative effects on their lives.

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Table 1. Respondent demographics

	Men n= 102 (59.6%)		Women N=69 (40.4%)		Total (%) n =171		*p*-value
Age (SD)	82.1	(3.9)	80.6	(4.6)	81.5	(4.3)	.022
Civil status 1)							.033
Married or in an relationship	90	(89.1)	52	(76.5)	142	(84.0)	
Widow/widower/ Unmarried	11	(10.9)	16	(23.5)	27	(16.0)	
Helping 2)							.254
Spouse	84	(84.8)	48	(70.6)	132	(79.0)	
Female relative (other than spouse)	5	(5.1)	6	(8.8)	11	(6.6)	
Male relative (other than spouse)	1	(1.0)	1	(1.5)	2	(1.2)	
Friend, not related	6	(6.1)	10	(14.7)	16	(9.6)	
Other	3	(3.0)	3	(4.4)	6	(3.6)	
Frequency of help given 3)							.358
<Once/week	2	(2.3)	3	(4.7)	5	(3.3)	
Once/week	7	(8.1)	6	(9.4)	13	(8.7)	
2-3 times/week	20	(23.3)	8	(12.5)	28	(18.7)	
>6 times/week	57	(66.3)	47	(73.4)	104	(69.3)	
Helping hours/week 4)	47.0		43.4		45.6		.737
Number of hours the person could be left alone 5)							.547
Not at all	11	(12.1)	5	(7.6)	6	(10.2)	
Less than two hours	19	(20.9)	22	(33.3)	41	(26.1)	
2–5 hours	17	(18.7)	12	(18.2)	29	(18.5)	
6–12 hours	11	(12.1)	6	(9.1)	17	(10.8)	
>12 hours	14	(15.4)	7	(10.6)	21	(13.4)	
Unlimited	19	(20.9)	14	(21.2)	33	(21.0)	
Sense of coherence (SOC) 6)	72.1	12.8	72.9	13.6			.860
Health related quality of life (SF-12)							
Mental component summary (MCS)	45.7		45.8				.959
Physical component summary (PCS)	37.0		35.6				.452
Self-rated overall health status 7)							.773
Excellent or very good	21	(21.0)	13	(28.8)	11	(6.5)	
Good	37	(37.0)	24	(34.8)	61	(36.1)	
Fairly good	35	(35.0)	26	(37.7)	61	(36.1)	
Bad	7	(7.0)	6	(8.7)	13	(7.7)	

Note: Internal dropout 1) 1, 2) 3, 3) 20, 4) 68, 5) 13, 6) 35, 7) 2.

Table 2. Percentage of the men and women helping with instrumental and personal activities of daily living, and frequency of provided help

	Men % (n=102)		Women % (n=69)		p-value**
Caregiving activities	Sometimes	Often/all the time	Sometimes	Often/all the time	
Instrumental help					
Weekly laundry 2)	16.3	55.4	6.7	75.0	.060
House cleaning 2)	17.9	70.5	12.3	75.4	.404
Shopping for groceries 2)	9.6	81.9	11.3	79.0	.970
Cooking 3)	29.5	50.0	8.8	70.2	.004
Helping with bank or post errands 3)	16.7	75.6	12.1	74.1	.595
Walking outdoors 3)	34.1	41.2	31.6	36.8	.819
Housekeeping 1)*	20.6	58.8	18.2	54.5	.124
Gardening 1)*	14.3	60.3	15.8	57.9	.926
Maintaining the car 2)*	6.8	67.8	5.0	55.0	.455
Helping to get to the bus stop 4)*	2.4	9.5	16.7	5.6	.213
Social help					
Remembering where things are, or what to do 2)	38.0	33.7	33.9	44.1	.491
Making phone calls or accompanying to the hospital 2)	23.7	35.5	27.9	50.8	.034
Personal help					
Walking indoors 3)	23.3	24.4	21.8	25.5	.981
Getting to the toilet 3)	8.9	20.0	15.5	27.6	.236
Using the toilet 3)	3.3	17.8	14.3	21.4	.056
Eating 3)	8.7	10.9	24.1	11.1	.045
Taking a bath or shower 3)	12.5	29.5	19.7	39.3	.080
Putting on clothes or shoes 2)	27.5	17.6	30.0	40.0	.007
Turning in bed 3)	3.4	6.8	16.4	5.5	.060
Getting up or going to bed 3)	9.0	11.2	27.6	15.5	.014

Internal dropout 1) 1–10, 2) 11–20, 3) 21–30, 4) >30
*Data is based on those who had a car (n=79) or lived in a house (n=61).
** The p-value refers to comparisons between men and women.
The figures for the response alternatives “never” and “seldom” to the items are in the analysis but not presented in this table.

Table 3. Multiple linear regression analysis with MCS12 as the dependent and CAMI (7 factors), sense of coherence, perceived information and economic situation compared to others' as independent variables. The analysis was controlled for gender. Is this correct? It is not clear how it relates to the table The variables that fitted into the model and gender is presented in the table.

	Health-related quality of life: MCS12		
	B	95% CI	*p-value*
Gender	1.703	–2.598 – 6.00	.431
Sense of coherence	0.344	0.152 – 0.535	**<.001**
Self-sustaining	0.986	0.178 – 1.795	**.018**
Economic situation compared to others'	-9.884	–18.525 – –1.244	**.026**

The following factors were not statistically significant predictors: Gender, factors named "testing solutions", "self-empowerment and self-control", "control by routine and prevention", "reappraisal of the caregiving situation", "asking for social and practical support" and "distracting by focusing on positive activities", enough information about the practical care, enough information about the medical care.

Figure 1a-f Percentage using the suggested coping “often” and “quite often” and considering it quite or very useful (n=171).

░ Very true

▓ Quite true

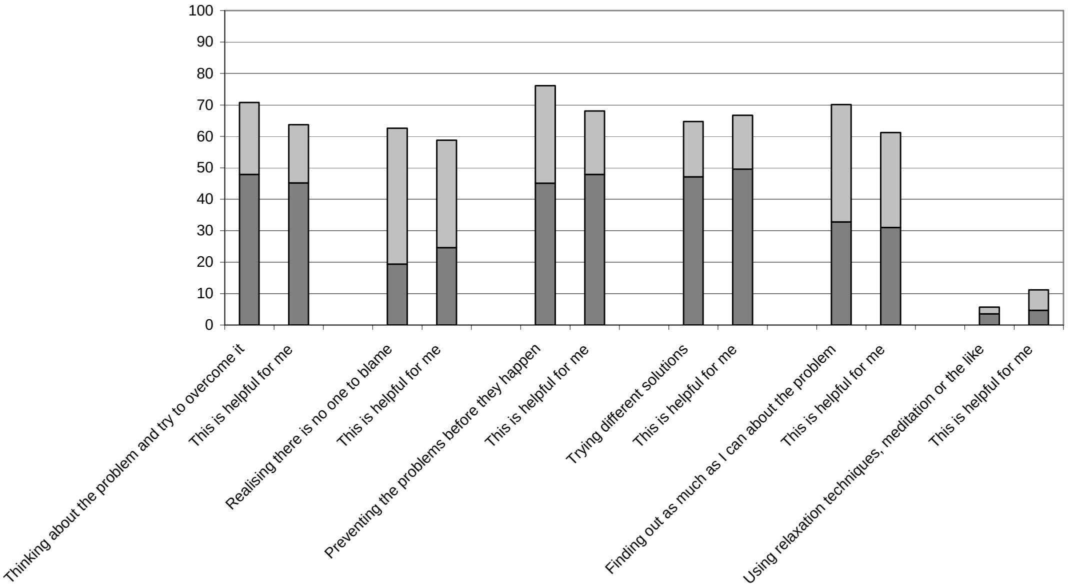


Figure 1 a. Factor 1, Testing solutions

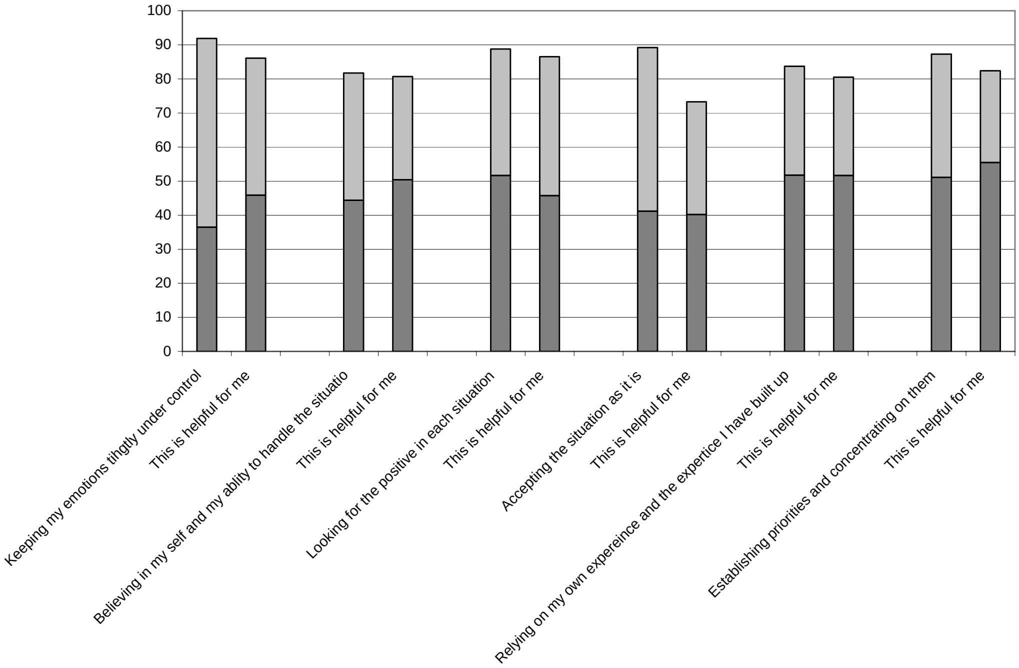


Figure 1 b. Factor 2, Self empowerment and self control

Figure 1 c. Factor 3, Control by routine and prevention

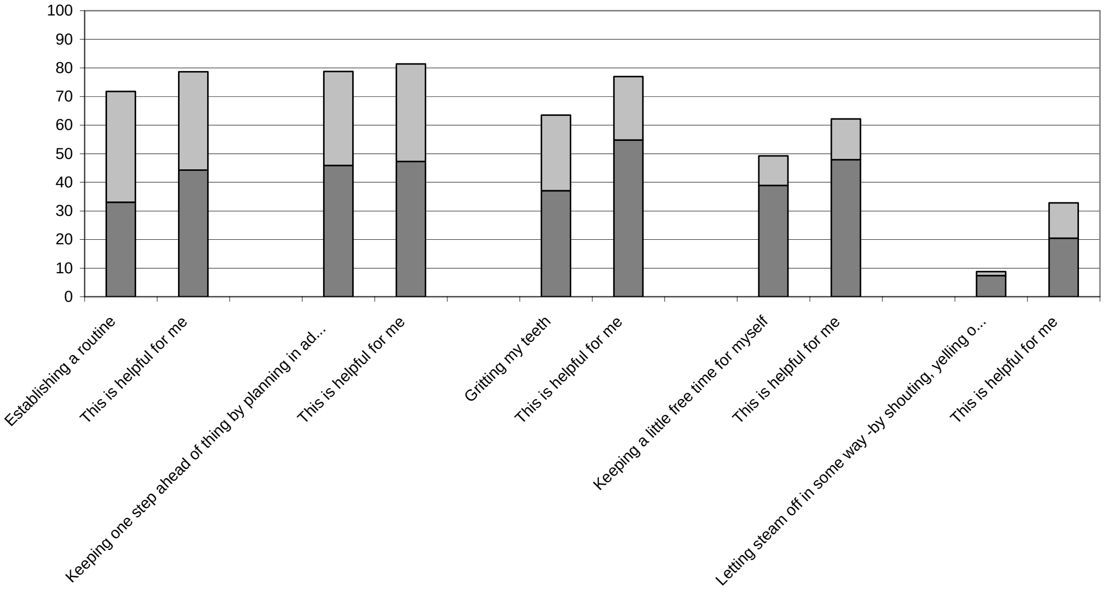


Figure 1 d. Factor 4, Reappraisal of the caregiving situation

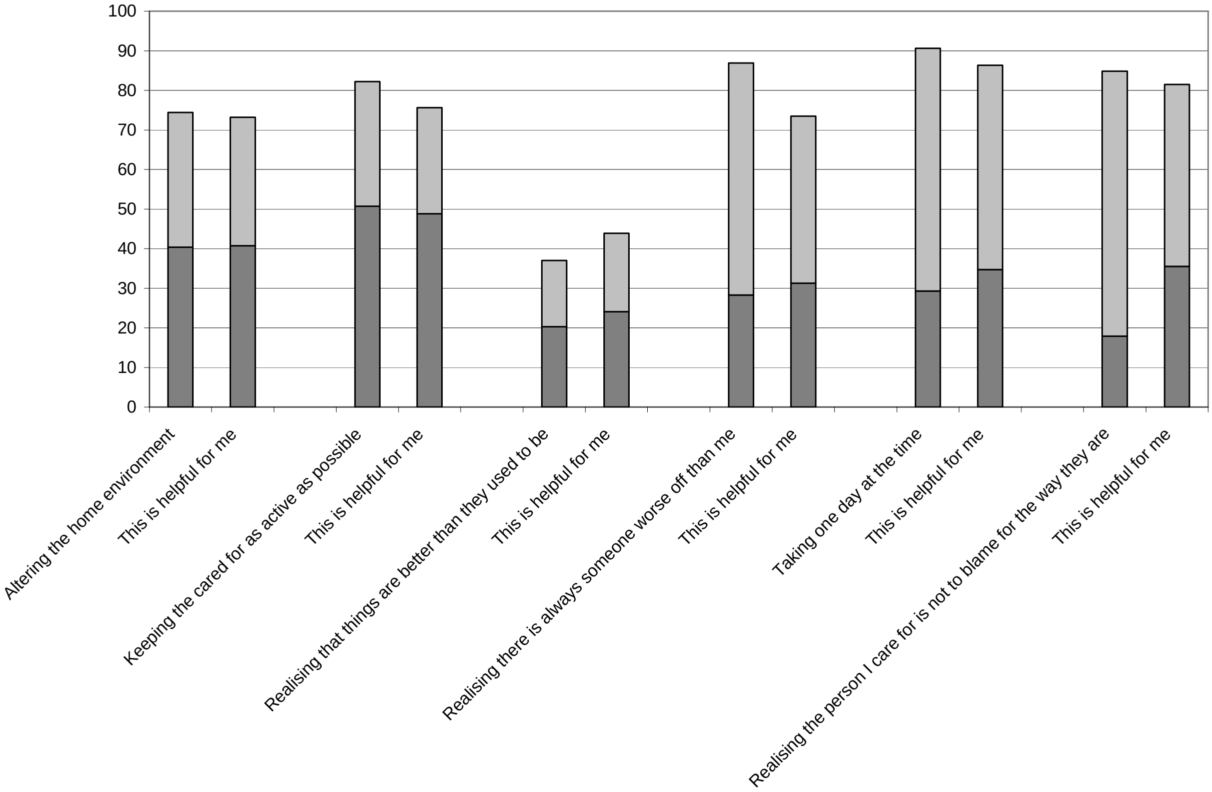


Figure 1 e. Factor 5, Self-sustaining

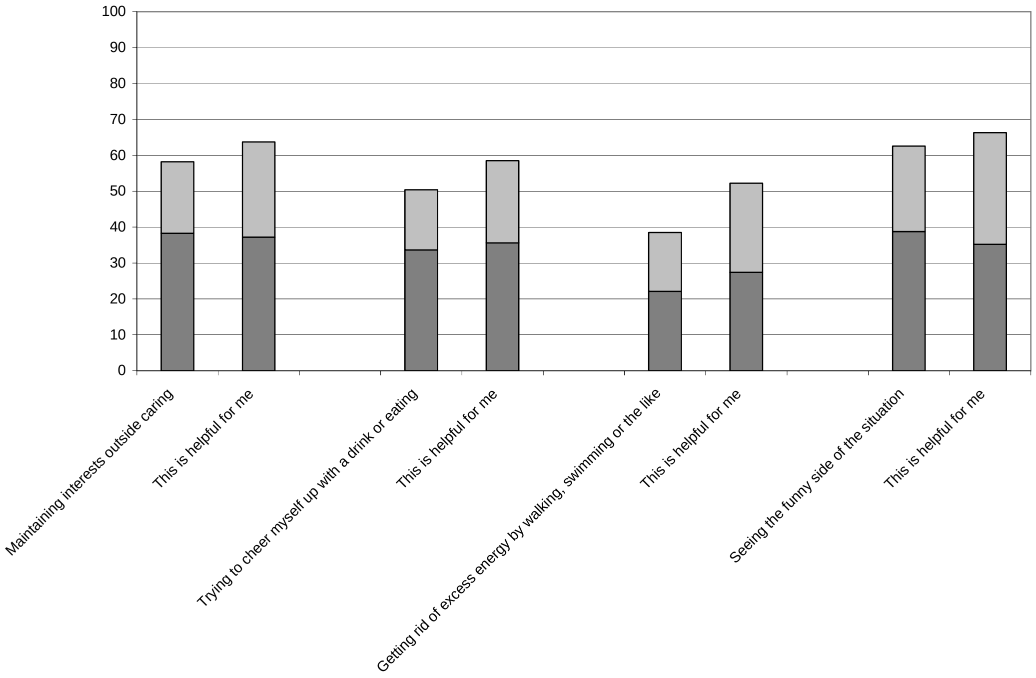


Figure 1 f. Factor 6, Asking for social and practical support

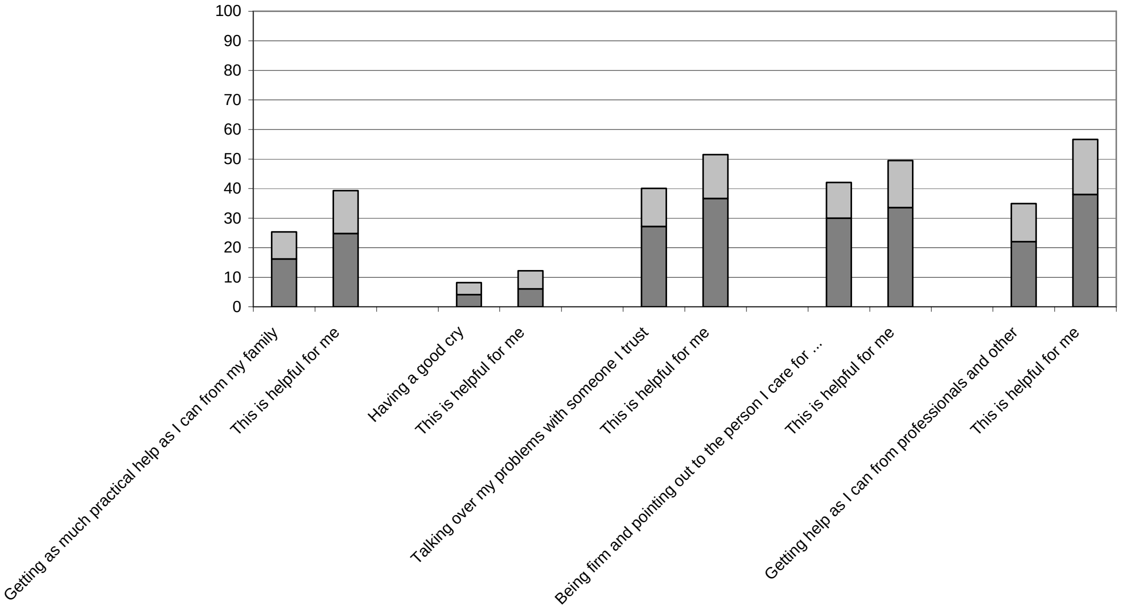
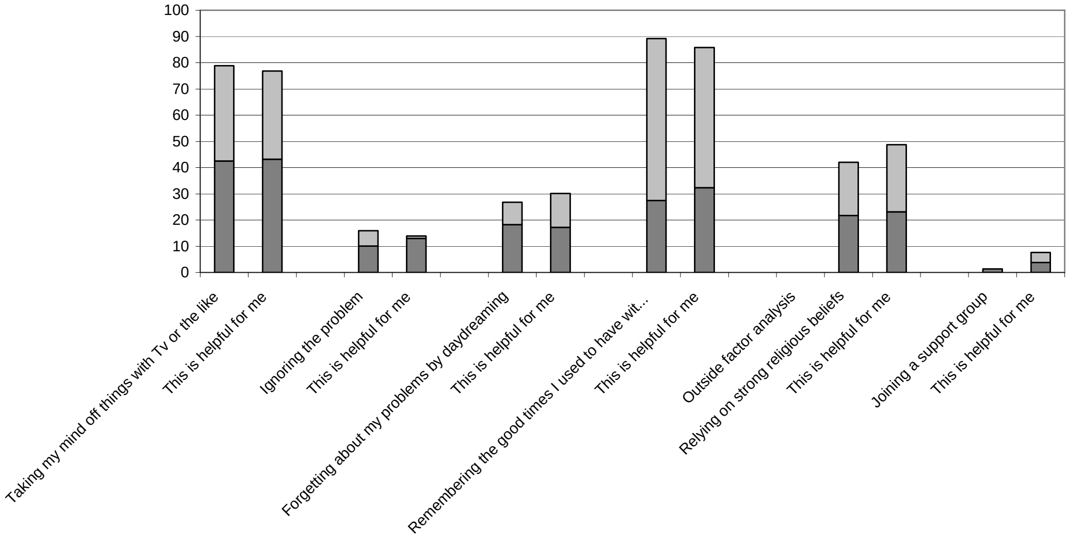


Figure 1 g. Factor 7, Distracting by focusing on positive activities & Items outside the factor analysis



Appendix 1. Factor solution with labels.

Carer's Assessment of Managing Index **(CAMI)**	Components							**Common -alities.**
	F.1	F.2	F.3	F.4	F.5	F.6	F.7	
Testing solutions								
Thinking about the problem and finding a way to overcome it	.681							.673
Realising that no one is to blame for things	.674							.612
Preventing problems before they happen	.639							.626
Trying out a number of solutions until I find one that works	.609							.541
Finding out as much as I can about the problem	.534							.620
Using relaxation techniques, meditation or the like	.357							.479
Self-empowerment and self-control								
Keeping my emotions and feelings tightly under control		.778						.690
Believing in myself and my ability to handle the situation		.669						.581
Looking for the positive things in each situation		.595						.657
Accepting the situation as it is		.568						.591
Relying on my own experience and the expertise I have built up		.548						.680
Establishing priorities and concentrating on them		.541						.686
Control by routine and prevention								
Establishing a regular routine and sticking to it			.688					.606
Keeping one step ahead of things by planning in advance			.685					.590
Gritting my teeth and just getting on with it			.595					.658
Keeping a little free time for myself			.549					.601
Letting steam off in some way – shouting, yelling or the like			.371					.515
Reappraisal of the caregiving situation								
Altering my home environment to make things as easy as possible				.671				.605
Keeping the person I care for as active as possible				.641				.668
Realising that things are better now than they used to be				.573				.398
Realising there is always someone worse off than me				.547				.600
Taking life one day at a time				.530				.603
Realising the person I care for is not to blame for the way they are				.484				.605
Self-sustaining								
Maintaining interests outside caring					.806			.692
Trying to cheer myself up by eating, having a drink or the like					.631			.598
Getting rid of excess energy and feelings by walking, swimming, etc.					.623			.513
Seeing the funny side of the situation					.621			.588
Asking for social and practical support								
Getting as much practical help as I can from my family						.798		.654
Having a good cry						.758		.666
Talking over my problems with someone I trust						.657		.672
Being firm and pointing out to the person I care for what I expect						.458		.408
Getting as much help as I can from professionals and others						.452		.470
Distracting by focusing on positive activities								
Taking my mind off things in some way by watching TV or the like							.629	.626
Ignoring the problem and hoping it will go away							.610	.425
Forgetting about my problems for a while by daydreaming or the like							.602	.657
Remembering all the good times I used to have with the person I care for							.486	.448
Eigenvalues after rotation	3.745	3.433	3.297	3.123	2.889	2.840	1.978	
% of variance	10.4	9.54	9.16	8.67	8.02	7.89	5.49	59.18
Cronbach's Alpha	.71	.81	.68	.71	.66	.72	.32	.86

Items outside the factor analysis were relying on strong religious beliefs and joining a support group.