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## Loneliness as a predictor of quality of life among older caregivers

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### Loneliness as a predictor of quality of life among older caregivers

**Aim.** This paper reports a study investigating quality of life in relation to loneliness, caregiving, social network, gender, age and economic status among caregiving men and women in a population-based sample aged 75 years or older.

**Background.** Because of demographic changes, in the future more care for older people will be given by informal caregivers who are themselves older. Being old and caring for another older person may affect various aspects of life, such as physical and emotional health and decreased time for respite, which may affect social life and quality of life.

**Method.** A postal questionnaire including the Short Form Health Survey was used. The sample consisted of 4278 people, aged 75 years and over, living in Sweden. Of these, 783 (18%) were caregivers.

**Findings.** Caregivers had a larger social network and reported feelings of loneliness less often than non-caregivers. Forty per cent of caregivers helped every day. There were gender differences in experiences of loneliness during the last year, with the frequency of intense feelings of loneliness being higher among women. Loneliness and a small or non-existent network were significantly associated with low quality of life among caregivers, as well as in the total sample. The results showed significant association between loneliness, weak social network and low mental quality of life.

**Conclusions.** The fact that loneliness was the most important factor predicting low quality of life among caregivers, as well as older people in general, indicates that it is crucial in the care of older people. From a nursing perspective, the findings indicate the advantage of helping older people to keep up and develop their social networks. Nursing care should involve steps to maintain the social network before an older person becomes too weak, since decreased health status makes social contacts more difficult.

**Keywords:** nursing, informal caregivers, gender, quality of life, loneliness, older people

## Introduction

Being an elder and caring for another older person may affect various aspects of life, such as physical and emotional health (Nolan *et al.* 1990) and decreased time for respite, which in turn affects social life among caregivers (Mastrian *et al.* 1996), and contributes to social isolation. According to the findings of a study by Hagedoorn *et al.* (2001) caring seems to affect men and women differently. This study, conducted in the Netherlands among older couples ( $n = 995$ ), showed that women's distress was affected not only by their own health, but also by that of their spouse, while men's distress was associated only with their own health status. Many caregivers are cohabitants, and this may protect them from feelings of loneliness (Holmen *et al.* 2000). However, they may be socially isolated, as caregiving may restrict their opportunities to socialize with others outside the home. Restriction of social contacts, which may not be voluntary, can contribute to a sense of loneliness. Declining health and major changes in living situation, such as institutionalization, may lead to limited social life among older people in general, rather than just caregivers (Tijhuis *et al.* 1999). In a Swedish study ( $n = 589$ ) conducted by Holmen *et al.* (2000), women in general reported more loneliness, both social and emotional, than men. Loneliness among caregivers, as well as older people in general, needs to be investigated further to understand the impact of social restrictions and loneliness on quality of life. No studies that compare social relationships among older people in general with those of older people providing care for next of kin have been located. This knowledge is needed to devise support programmes for those providing care to others.

The phenomenon of loneliness is complex and multidimensional. When discussing loneliness it is important to distinguish between the feeling of loneliness, which in some studies (e.g. Holmen *et al.* 2000) is referred to as emotional loneliness, and social isolation, referred to as social loneliness, which relates to social networks and contacts with friends. Bowlby and Weiss (1973) describes loneliness from a social-psychological perspective and characterizes it as two-dimensional and focused on core experience rather than the density of relationships. Weiss distinguishes between loneliness connected to emotional isolation and loneliness connected to social isolation; being socially isolated does not necessarily include the feeling of loneliness. Tornstam (1988) highlights three aspects of loneliness among people aged 15–80 years ( $n = 2795$ ) in Sweden. The first aspect is the intensity/quantity of the loneliness, based on how frequently the feeling of loneliness occurred, and how strong the feeling was. The second aspect is inner personal loneli-

ness, the feeling that one has always been lonely, is lonely today, and probably will be so in the future. The third aspect is the positive aspect of being alone, which can be desirable because it makes a person feel good (Tornstam 1988). Thus, to understand loneliness fully, assessment of the experience of loneliness, the density of social networks and the experience of social support is required.

Loneliness has been found to be frequent among older people. In a Swedish study, 35% of the sample investigated ( $n = 1725$ ) reported feelings of loneliness; of those with subjectively reduced health, the corresponding figure was 45% (Holmen *et al.* 1992). Women in the study reported more often than men that they suffered from loneliness. Health risks, both mental and physical, were associated with feelings of loneliness and social isolation (Anderson 2001, Sorkin *et al.* 2002). Feelings of loneliness correlated with increased risk of depression among older Swedish people ( $n = 589$ ) (Anderson 2001), and were associated with the probability of having a coronary condition among 180 older adults in the United States of America (USA) (Sorkin *et al.* 2002). Tijhuis *et al.* (1999), in a study conducted in the Netherlands among 343 men born in 1920 or earlier, found that feelings of loneliness increased with age, but only among people aged 90–95 years. Loneliness was not correlated to absolute levels of health status or social relationships, but to changes in these areas. Being or becoming institutionalized increased the sense of loneliness. Holmen *et al.* (2000) showed no age differences in emotional loneliness, but higher age was related to greater social isolation. Relationships between these aspects and older caregivers' quality of life have not been rigorously investigated, nor have differences between older caregivers' and non-caregivers' experiences of loneliness and their relation to quality of life.

'Health status' and 'health-related quality of life' have been used interchangeably although they are two different conceptual terms (Bowling 2001). Health status is only one domain of health-related quality of life. Current use of the term 'health status' overlaps with the broader concept health-related quality of life. The theoretical framework of health-related quality of life is based on a multidimensional perspective of health as physical, psychological and social functioning, and well-being. This is coherent with the World Health Organization's definition of health:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. (WHO 1946)

Health-related quality of life is said to be a global picture of health and well-being from a particular person's perspective (Bowling 1997). It focuses on the impact of perceived health state on ability to live a fulfilling life. It seems likely that

caring affects quality of life among caregivers. An Australian study among carers ( $n = 630$ ) aged 75 years or over (Broe *et al.* 1999) showed that full-time carers had lower life satisfaction and a higher level of psychiatric symptoms than part-time carers. In addition to caregiving, gender and loneliness, socio-economic status (SES) has been shown to affect overall health status. Shorter life expectancy is associated with lower SES (Kapral *et al.* 2002). For instance, older women are often found to have lower quality of life than older men (Sullivan *et al.* 1997); one possible explanation for this is their poorer economic situation. Thus, to understand loneliness in older caregivers and its relation to quality of life, gender and socio-economic situation must also be considered.

In Sweden, as in other countries, informal caregiving is common but not very well investigated. The care of older people is the responsibility of the public sector in Sweden, and care is financed by taxes (Swedish Institute 2003). Informal caregivers may get some next-of-kin allowance from the authorities (National Board of Health and Welfare 2000), but this is rare for older people who already have a pension. Demands on families all over the world may increase because of the higher proportion of older people in the population, and family members will perhaps be the main source of support for older adults (Nolan *et al.* 1996, Hellstrom & Hallberg 2001), with one older person looking after another. Social networks and loneliness, as well as economic status and gender, may influence quality of life, especially for those providing care to next of kin. Knowledge about these factors may be helpful in developing support programmes for older people providing care to next of kin.

## The study

### Aim

The aim of the study was to investigate quality of life in relation to loneliness, caregiving, social network, gender, age and economic status among caregiving men and women in a population-based sample, aged 75 years or older.

### Design

A cross-sectional survey design was used.

### Participants

In an age-stratified study conducted in 2000 among people 75 years and older (75–79:  $n = 2500$ ; 80–84:  $n = 2500$ ; 85–89:  $n = 2000$ ; and 90+:  $n = 1500$ ), 783 participants (18%) stated that they helped an older person. In order to

ensure a large enough number of respondents in the younger age groups who had help with ADL or were living in special accommodation, disproportional stratification was performed. Other studies (Hellstrom & Hallberg 2001 SCB 2001) showed that 3% of those 75–79 years old, 6% of those 80–84, 20% of those 85–90, and 40% of those older than 90 years old lived in special accommodation.

The size of the randomized sample was calculated to identify significant ( $P \leq 0.05$ ) differences (alpha 5%, power 80%) in quality of life between people living in different settings who were getting help from informal and/or formal caregivers, and those who were independent of help. Power was calculated to detect significant differences (five points SD 10) in quality of life, measured with the Short Form 12 (Ware *et al.* 1996). This sample size would also include at least 400 caregivers, according to the power analysis. The distribution of respondents in the age groups was very similar to that of the population from which the sample was drawn.

The study was conducted in the southern part of Sweden (where 13% of the Swedish population live). Two reminders were sent out, and 4360 questionnaires were returned, of which 82 were excluded because of 'internal dropout' (less than 25 questions answered). Those excluded were significantly older ( $P < 0.005$ ) and significantly more were women ( $P < 0.005$ ).

## Questionnaire

The questionnaire covered demographic data, social network, economy, where the respondents lived (in rural or urban areas, house or apartment), self-reported diseases and quality of life. It was a revised version of a questionnaire used in a previous study (Hellstrom & Hallberg 2001). There were questions about respondents' need for help to manage their daily lives, the levels of care that they needed and who provided it. Those who provided help to another person were asked about the age of the person that they helped (over 75 years or not), and to estimate how many times per week they helped the person (five alternatives) and the number of hours involved in this. Items on which caregiving activities they performed had eight different response alternatives: I adapt my own activities to be prepared if something happens; I keep in touch every week to prevent problems (monitoring medicine intake, or checking on eating); I help with practical things, such as visits to the doctor's and contacts with the hospital; I regularly help with chores, such as shopping, cooking and cleaning; I regularly help with personal care, such as eating, getting dressed and personal hygiene; I regularly help with technical tasks, such as catheter care, wound dressing and giving medicines; I help with improving

physical function and other matters. Respondents could select all alternatives that applied. These items were based on a typology of care by Nolan *et al.* (1996). Questions about respondents' contact with their families, social networks and economic situation were also included.

Loneliness was assessed by three questions with five response alternatives. The first question asked how intense feelings of loneliness were, the next assessed whether individual respondents thought they were lonelier than others of the same age, and the last enquired whether they had experienced feelings of loneliness during the last year, and if so, how often.

Quality of life was assessed by the Short Form Health Survey (SF-12) (Ware *et al.* 1996). This is based on Short Form 36 (SF-36), and measures health-related quality of life. Twelve items cover eight scales. The items cover physical functioning, bodily pain and general health in the Physical Component Summary (PCS12), while vitality, social functioning, emotional and mental health comprise the Mental Component Summary (MCS12). The higher the scores, the higher the level of health or functioning (Resnick & Nahm 2001).

### Ethical considerations

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

### Data analysis

When comparing caregivers with non-caregivers and men with women within the caregivers' group, the chi-square test was used. The *t*-test was used when comparing mean MCS12, PCS12 and age between the groups. Variables associated in bivariate analyses with MCS12 and PCS12, with *P*-values less than 0.20, were tested in a logistic regression analysis. The total scores of MCS12 and PCS12 were used and divided into quartiles. The first quartile, indicating low quality of life (MCS12: 43.6; PCS12: 30.4), was used in the logistical regression analysis (Altman 1991). This was conducted with quality of life as the dependent variable and loneliness, social network, contact with children and grandchildren, economic situation and caregiving as independent variables. Social network was used in the logistic regression analysis with dummy variables: three or more close friends (=0), one or two persons in the network (=1) or no social network (=2).

A dummy variable was constructed from the questions about children and grandchildren as follows: satisfied with the contact (= 0) and poor contact with children/grandchildren (= 1) or not having any children/grandchildren as variables (= 2). The item about respondents' economic situation was a combination of how their economic situation compared with others of the same age (better or about the same = 0, worse = 1) and how their money covered their expenses (very well, well and neither well nor badly = 0, badly or very badly = 1). In the logistic regression analysis of the MCS12, in which the mental health dimension of quality of life was the dependent variable, several independent variables were included forward stepwise. The analysis was controlled for the care that they received. The logistic regression analysis with PCS12 as the dependent variable was conducted in the same way. A logistic regression analysis including caregivers only was also conducted in the same way, with the same variables, and was also controlled for their own needs for care.

### Results

The age-related proportions of those who were helping another person with activities of daily living were: 75–79 years old, 37%; 80–84, 38.3%; 85–89, 18.5%; and 90 or over, 6.1%. The rates for needing help from others in the age groups were 75–79: 11.3%; 80–84: 24.1%; 85–90: 44.5%; and among the oldest (90+) 67.4%.

Response rates in the age groups were 75–79: 60%; 80–84: 56%; 85–89: 48%; and 90+: 42%. Reasons for dropout were reported in 483 cases, as follows: not wanting to participate (*n* = 219, 45.3%); dementia (*n* = 114, 23.6%); not having the strength (*n* = 93, 19.3%); being too sick (*n* = 15, 3.1%); questionnaire returned blank (*n* = 14, 2.9%); language problems (*n* = 9, 1.9%); and other reasons (*n* = 19, 3.9%).

There was a significantly higher proportion of women in the total sample than among the caregivers. Mean age was significantly higher (*P* < 0.001) in non-caregivers (84.2; SD 5.8; caregivers 81.7; SD 4.6) (Table 1), and among non-caregivers the proportion of women (66%) was significantly higher (*P* value < 0.001) than among the caregivers (42%). Caregivers reported that they had not been lonely and not had strong feelings of loneliness significantly more often than non-caregivers (*P* < 0.001). Loneliness compared with others in the same age was more frequent among non-caregivers than among caregivers (*P* value < 0.001), feelings of loneliness during the last year were also more frequent among non-caregivers (*P* < 0.001). Economic situation did not differ between the groups. Caregivers were more likely to

**Table 1** Characteristics of the sample

|   | Caregivers ( <i>n</i> = 783)<br>(58.4% men and 41.6% women) |             |             | Non-caregivers ( <i>n</i> = 2748)<br>(34.0% men and 66.0% women) |      |                |             |        |                 |
|---|---|-------------|-------------|--|------|----------------|-------------|--------|-----------------|
|   | Men   | Women       | Per cent    | Test   | d.f. | <i>P</i> value | Test*       | d.f.*  | <i>P</i> value* |
| Age group (years)                       |   |             |             | 6.50   | 3    | 0.090          | 43.14       | 3      | <0.001          |
| 75–79                                   | 35.0  | 39.9        | 37.0        |  |      |                | 25.5        |        |                 |
| 80–84                                   | 40.7  | 35.0        | 38.3        |  |      |                | 32.0        |        |                 |
| 85–90                                   | 19.5  | 17.2        | 18.5        |  |      |                | 22.6        |        |                 |
| 90 and older                            | 4.8   | 8.0         | 6.1         |  |      |                | 19.9        |        |                 |
| Mean age (SD)                           | 81.8 (4.3)  | 81.7 (5.0)  | 81.7 (4.6)  | 0.38   | 639  | 0.706          | 84.2 (5.8)  | 12.56  | 1564 <0.001     |
| Economic situation compared with others |   |             |             | 4.11   | 2    | 0.128          |             | 5.14   | 2 0.076         |
| Better                                  | 23.1  | 17.4        | 20.7        |  |      |                | 17.2        |        |                 |
| About the same                          | 69.1  | 73.0        | 70.7        |  |      |                | 74.4        |        |                 |
| Worse                                   | 7.8   | 9.6         | 8.5         |  |      |                | 8.4         |        |                 |
| Living together with someone            | 84.9  | 58.9        | 74.1        | 67.00  | 1    | <0.001         | 34.5        | 388.81 | 1 <0.001        |
| Feeling of loneliness                   |   |             |             | 11.27  | 5    | 0.046          |             | 27.76  | 5 <0.001        |
| Never feel alone                        | 44.2  | 48.9        | 46.2        |  |      |                | 36.5        |        |                 |
| Very or quite strong                    | 14.4  | 18.8        | 16.3        |  |      |                | 21.2        |        |                 |
| Nor strong neither weak                 | 27.6  | 17.6        | 23.4        |  |      |                | 27.9        |        |                 |
| Pretty or very weak                     | 13.7  | 14.7        | 14.2        |  |      |                | 14.4        |        |                 |
| Compared with others the same age       |   |             |             | 9.37   | 5    | 0.095          |             | 37.06  | 5 <0.001        |
| Do not feel alone                       | 50.7  | 47.8        | 49.5        |  |      |                | 39.7        |        |                 |
| Much more or slightly more lonely       | 4.5   | 6.9         | 5.4         |  |      |                | 6.1         |        |                 |
| As lonely as others                     | 23.7  | 23.1        | 23.4        |  |      |                | 34.0        |        |                 |
| Less or much less lonely                | 21.2  | 22.2        | 21.6        |  |      |                | 20.1        |        |                 |
| During last year                        |   |             |             | 18.03  | 3    | <0.001         |             | 82.32  | 3 <0.001        |
| Not felt lonely                         | 66.1  | 57.3        | 62.4        |  |      |                | 44.3        |        |                 |
| Some moments of loneliness              | 28.8  | 30.1        | 29.3        |  |      |                | 39.9        |        |                 |
| Recurrent feelings of loneliness        | 2.9   | 9.8         | 5.8         |  |      |                | 10.9        |        |                 |
| Almost constant feelings of loneliness  | 2.2   | 2.2         | 2.5         |  |      |                | 4.9         |        |                 |
| Health status                           |   |             |             | 1.87   | 3    | 0.601          |             | 28.51  | 3 <0.001        |
| Good                                    | 22.4  | 24.5        | 23.3        |  |      |                | 19.6        |        |                 |
| Quite good                              | 59.6  | 55.1        | 57.7        |  |      |                | 54.6        |        |                 |
| Quite bad                               | 13.8  | 16.4        | 14.9        |  |      |                | 15.9        |        |                 |
| Bad                                     | 4.2   | 4.0         | 4.1         |  |      |                | 9.9         |        |                 |
| MCS12 mean (SD)                         | 51.2 (10.4)   | 50.9 (11.1) | 51.1 (10.7) | −0.043   | 700  | 0.669          | 50.3 (11.3) | −1.70  | 1215 0.090      |
| PCS12 mean (SD)                         | 41.5 (11.1)   | 39.0 (11.2) | 40.4 (11.2) | −2.98  | 700  | 0.003          | 36.5 (12.0) | −8.03  | 1212 <0.001     |
| Someone to trust                        |   |             |             | 0.81   | 1    | 0.367          |             | 3.10   | 1 0.078         |
| Yes                                     | 96.9  | 95.7        | 96.4        |  |      |                | 94.9        |        |                 |
| No                                      | 3.1   | 4.3         | 3.6         |  |      |                | 5.1         |        |                 |
| Persons in the social network           |   |             |             | 0.39   | 2    | 0.942          |             | 12.82  | 2 0.008         |
| 1–2                                     | 41.2  | 41.0        | 41.6        |  |      |                | 48.0        |        |                 |
| 3–5                                     | 42.4  | 40.4        | 41.6        |  |      |                | 37.2        |        |                 |
| >5                                      | 16.4  | 17.6        | 16.9        |  |      |                | 14.8        |        |                 |

\*Test, d.f. and *P*-value between groups of non-caregivers and caregivers. MCS12, Mental Component Score; PCS12, Physical Component Score.

be cohabiting than non-caregivers. Among caregivers, men were significantly more often cohabiting (84.9% against 58.9% among women). Women caregivers reported more experiences of recurrent loneliness during the last year (9.8%) than men did (2.9%).

In the sample, 18% stated that they helped another person because of their health problems. Among these, 41.8% of the

men and 38.0% of the women helped every day. The most common action, performed by 57.4%, was to help the cared for person with external matters, such as contacts and visits to the hospital (Table 2). The activities done significantly more frequent by 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

**Table 2** Caregiving characteristics

|   | Caregivers ( <i>n</i> = 783) |           | Test  | d.f. | <i>P</i> value |
|---|------------------------------|-----------|-------|------|----------------|
|   | Men (%)                      | Women (%) |       |      |                |
| Giving help times/week                                      |                              |           | 10.50 | 4    | 0.033          |
| Less than once  | 11.5                         | 19.9      |       |      |                |
| Once  | 17.3                         | 16.7      |       |      |                |
| Two to three times  | 10.1                         | 10.2      |       |      |                |
| Four to six times   | 6.1                          | 2.8       |       |      |                |
| Every day   | 55.0                         | 50.4      |       |      |                |
| Caregiving activities                                       |                              |           |       |      |                |
| Adapting own activities                                     | 51.9                         | 51.5      | 0.008 | 1    | 0.928          |
| Keeping in touch every week                                 | 28.4                         | 44.8      | 22.26 | 1    | <0.001         |
| Helping with practical things (e.g. visits to the hospital) | 60.4                         | 53.4      | 3.84  | 1    | 0.050          |
| Helping with household tasks                                | 61.5                         | 31.6      | 67.47 | 1    | <0.001         |
| Helping with personal care (e.g. hygiene)                   | 11.8                         | 17.5      | 5.03  | 1    | 0.025          |
| Helping with medical care                                   | 9.2                          | 12.6      | 2.30  | 1    | 0.129          |
| Helping with improving physical and intellectual functions  | 12.9                         | 15.0      | 0.73  | 1    | 0.393          |

Among the respondents, 190 (24.3%) did not answer the question about the frequency of provided care.

helping with instrumental care was reported significantly more by men (61.5% men; 31.6% women). Respondents did, on average, 2.4 caregiving activities and the hours they helped ranged from < 1 hour per week to 24 hours per day, men helping 15.0 hours per week (SD 23.9) and women 19.5 hours per week (SD 32.1).

Loneliness was assessed by three items, which were all shown to co-vary with low quality of life in the logistic

regression analysis with the total sample (Table 3). Small (one or two people) or non-existent social network was also correlated with low scores on the MCS12. Being male and living alone was associated with high scores. Poor economic situation, meaning being worse off than others of the same age and not having enough money to cover expenses, was also associated with low scores on the MCS12. Adapting one's own activities to be prepared if

**Table 3** Factors predicting low quality of life among older people (*n* = 4278)

|   | Low mental component summary (MCS12) |               |                | Low physical component summary (PCS12) |               |                |
|---|--------------------------------------|---------------|----------------|--|---------------|----------------|
|   | Odds ratio                           | 95% CI for OR | <i>P</i> value | Odds ratio                             | 95% CI for OR | <i>P</i> value |
| Adapting own activities                       | 1.708                                | 1.248–2.339   | <0.001         |  |               |                |
| Keeping in touch                              | –                                    |               |                | 0.585                                  | 0.405–0.844   | 0.004          |
| Helping with medical matters                  | 1.824                                | 1.020–3.264   | 0.043          |  |               |                |
| Weak economic situation                       | 1.836                                | 1.411–2.390   | <0.001         | 1.927                                  | 1.475–2.516   | <0.001         |
| Intensive feelings of loneliness              | 2.244                                | 1.780–2.830   | <0.001         |  |               |                |
| More lonely than others                       | 1.618                                | 1.092–2.396   | <0.001         | 0.601                                  | 0.391–0.924   | 0.020          |
| Strong feelings of loneliness last year       | 3.418                                | 2.610–4.475   | 0.016          |  |               |                |
| Three persons or more in social network       | 1                                    |               |                |  |               |                |
| One or two persons in social network          | 1.471                                | 1.215–1.781   | <0.001         | –                                      |               |                |
| Without social network                        | 2.251                                | 1.475–3.437   | <0.001         | –                                      |               |                |
| Satisfied with the contact with grandchildren | –                                    |               |                | 1                                      |               |                |
| Wishing more contact with grandchildren       | –                                    |               |                | 1.409                                  | 1.073–1.669   | 0.010          |
| Not having grandchildren                      | –                                    |               |                | 0.677                                  | 0.0819–0.1360 | 0.677          |
| Gender (male)                                 | –                                    |               |                | 0.606                                  | 0.492–0.746   | <0.001         |
| Hosmer and Lemeshow goodness                  | 0.083                                |               |                | 0.771                                  |               |                |

Factors with no significant influence were helping with contacting the hospital, helping with personal care, helping with technical tasks, helping with improving physical functions, wishing more contact with the children being a caregiver, number of caregiving activities and frequency in caregiving.

The analysis controlled for respondents' own help with Instrumental Activities of Daily Living, Personal Activities of Daily Living, medical matters and perception of own health status.

problems occurred, together with helping with medical matters, was also significantly correlated with low quality of life, but no other caregiving activities was associated with this variable. The logistic regression analysis with the Physical Component Summary (PCS12) in the total sample showed a significant association between poor economic situation and low scores for quality of life. Wishing more contact with grandchildren correlated with low physical quality of life. Higher age correlated with lower PCS. Being male and more lonely than others were associated with high scores on PCS12.

Among caregivers, slightly different variables were significantly correlated with low scores on MCS12 (Table 3). Adapting one's own activities to be prepared in case of problems, helping with IADL and weak economic situation (i.e. not having enough to cover expenses and consider one's own economy as worse than others') correlated with low mental quality of life. Loneliness (strong feelings and feelings of loneliness during the last year), together with non-existent or small social network (one or two persons), predicted low quality of life. On the PCS12, two items correlated with physical quality of life: helping another person with cooking and cleaning (i.e. IADL) had positive effects on the PCS12 scores, while wishing more contact with the grandchildren did not.

## Discussion

The main finding of this study was that feelings of loneliness, together with small (one or two close persons) or non-existent social network, were significantly associated with low mental quality of life both in the total sample and among caregivers. Of all participants, 18% were helping another person, and most recipients were in the age group 80–84 years. There was a higher percentage of men among caregivers (58.4% vs. 34.0%,  $P$  value < 0.001) (Table 1), and this is different from other studies, in which women were a majority (Dennis *et al.* 1998, Beeson *et al.* 2000). These studies were not, however, population-based, and their definition of carers was narrower, which might explain the difference. Non-caregivers in our study were older (mean age 84.2 vs. 81.7 years,  $P$  value < 0.001) than caregivers, perceived their own health to be worse than the caregivers did and had smaller social networks. Thus, caregivers were healthier and had better quality of life than non-caregiving older people.

The stratified population-based sampling process applied in this study resulted in an overall response rate of 52.8% of the total sample. The response rate varied between 42% and 60%, and varied inversely with age. The most common

reasons for the 483 people who stated the reason for not participating in the younger age-groups (75–79 years) were not wanting to participate or not having the strength. Among the older age groups (85–90 years and over 90 years old), the reasons for not participating were not wanting to participate, not having the strength and having dementia. Thus, dropouts may have been care recipients rather than caregivers, and would in that case not be a great threat to the reliability of this study. However, this cannot be taken for granted and therefore caution has to be applied when making generalizations. Since own need for help is known to co-vary with quality of life among older people (Hellstrom & Hallberg 2001), controlling for own need of care and perception of own health status made it possible to obtain a clearer picture of how caregiving and other aspects in older people's lives in general related to quality of life. Perception of one's own health status and quality of life was lower among non-caregivers, indicating these factors to be more important to quality of life than caregiving; however, caution must be used when making generalizations.

The logistic regression analysis showed that intense feelings of loneliness and feelings of loneliness during the last year affected mental quality of life. This study did not confirm the idea that caregivers were more lonely than non-caregivers in the age groups from 75 to over 90 years old. This can be explained by the fact that the non-caregivers were less healthy, were more often in need of help themselves and also had lower quality of life than caregivers. Thus, in an older population, those who are healthy are likely to be caregivers. However, when controlling for health in the regression analysis, being a caregiver did not mean being more lonely. Another Swedish population-based study (Holmen *et al.* 2000) among older people reported that 55% had not experienced loneliness, which is more than in this study. Loneliness in that study was assessed with only one question. Frequency of feelings of loneliness among a population-based sample of caregivers has not been much investigated. The relationship between caregivers' loneliness and risk of depression is, however, known (Beeson *et al.* 2000). These findings cannot be taken as showing that caregiving does not mean loneliness. They may, however, indicate that closeness between, for instance, a married couple, may protect them from social loneliness (Holmen *et al.* 2000). From a nursing perspective, it is important to pay attention to older people's feelings of loneliness, since identifying and decreasing these may improve their quality of life.

Adaptive care, i.e. being prepared if problems occurred, was found to correlate with low quality of life in the total sample, as well as among caregivers. Interestingly, some preventive aspects of caregiving had a significant negative



relationship to quality of life. This was the case for adapting one's own activities to be available in relation to mental quality of life, whilst keeping in touch to prevent problems was positively related to quality of life in the total sample. In the sample of caregivers, adapting one's own activities to be prepared in case of problems was also negatively related to quality of life, whilst helping with IADL was positively related to physical quality of life. These findings are unique in the sense that they have not, to our knowledge, been reported before, mainly because a narrower definition of caregiving has been applied. Being a caregiver to someone else can also mean doing something unselfish for someone else, or a way of maintaining a significant relationship (Nolan *et al.* 1996), which may explain why most caregiving activities did not correlate with low quality of life. The fact that the caregiver is needed by another person and, according to our findings, has a larger social network, may be a positive effect of caregiving and something for professional caregivers to encourage (Table 4).

In the literature, emotional loneliness is separated from social loneliness (Bowlby & Weiss 1973, Tornstam 1988, Holmen *et al.* 2000). In our study, both seemed to affect quality of life. In accordance with the idea put forward by Bowlby and Weiss (1973) and supported here, not only the emotional aspects of loneliness were important, but also density of network had a significant relationship to quality of life. Not having a social network was strongly related to mental quality of life in the total sample and also in

caregivers. Only a small portion of respondents, however, reported that they had no one to trust, and as many as 59% of caregivers and 52% of non-caregivers had three or more people to turn to. Nevertheless, those not having a network are at great risk of low quality of life and this needs to be highlighted in nursing care.

Also weak economic situation was significantly related to quality of life (mental and physical), which is a well-known finding in other studies (Burstrom *et al.* 2001, Lorant *et al.* 2003). The impact of a weak economic situation became even stronger in caregivers with regard to mental quality of life. The number of people reporting a poorer economic situation did not differ between the groups, although women caregivers had a slightly poorer situation, which is consistent with trends in society as a whole and especially in older women (SCB 2003). Caregivers in a British study (Schneider *et al.* 1999) reported increased expenses for the family because of the person cared for, and financial problems as one stressor in the caregiving situation. Since social security systems differ between countries, more knowledge about the economic conditions of Swedish caregivers would be valuable.

## Limitations

Dropout, especially in the older age groups and among women, may limit the possibility of drawing conclusions about the oldest people. The study was conducted in Sweden, which has a public care system for older people, and this may

**Table 4** Factors predicting low quality of life among older caregivers ( $n = 783$ )

|   | Low mental component summary (MCS12) |               |                | Low physical component summary (PCS12) |               |                |
|---|--------------------------------------|---------------|----------------|--|---------------|----------------|
|   | Odds ratio                           | 95% CI for OR | <i>P</i> value | Odds ratio                             | 95% CI for OR | <i>P</i> value |
| Adapting own activities                               | 1.697                                | 1.088–2.647   | 0.020          | –                                      |               |                |
| Helping with practical tasks (i.e. cooking, cleaning) | –                                    |               |                | 0.524                                  | 0.316–0.870   | 0.012          |
| Helping with medical matters                          | 1.898                                | 1.034–3.483   | 0.039          | –                                      |               |                |
| Weak economic situation                               | 3.644                                | 1.911–6.948   | <0.001         | –                                      |               |                |
| Intensive feelings of loneliness                      | 2.292                                | 1.327–3.960   | 0.003          | –                                      |               |                |
| Strong feelings of loneliness last year               | 3.953                                | 1.822–8.578   | <0.001         | –                                      |               |                |
| Three persons or more in social network               | 1                                    |               |                | –                                      |               |                |
| One or two persons in social network                  | 1.734                                | 1.122–2.679   | 0.013          | –                                      |               |                |
| Without social network                                | 3.920                                | 1.406–10.928  | 0.009          | –                                      |               |                |
| Satisfied with the contact with grandchildren         | –                                    |               |                | 1                                      |               |                |
| Wishing more contact with grandchildren               | –                                    |               |                | 1.797                                  | 1.056–3.059   | 0.031          |
| Not having grandchildren                              | –                                    |               |                | 0.765                                  | 0.351–1.666   | 0.500          |
| Hosmer and Lemeshow goodness                          | 0.883                                |               |                | 0.746                                  |               |                |

Factors without significant influence were keeping in touch every week to prevent problems, helping with contacting the hospital, helping with personal care, helping with technical tasks, helping with improving physical functions, wishing more contact with the children, weak social network, living alone, more lonely than others of the same age, being a caregiver, number of caregiving activities and frequency in caregiving. The analyses were controlled for the respondents' own help with Instrumental Activities of Daily Living, Personal Activities of Daily Living, medical matters and perception of own health status.

### What is already known about this topic

- Caring can restrict the social networks of informal caregivers.
- Declining health and changes in living situation lead to limited social life among older people.
- Loneliness and social isolation are associated with health risks among older people.

### What this paper adds

- Caregivers were healthier and had better quality of life than non-caregivers.
- Caregivers were not more lonely than non-caregivers.
- Small or non-existent social networks affected quality of life negatively for caregivers, as well as for older people in general, and non-caregivers had smaller social networks, possible because of their higher rates of health problems.

restrict generalizations to countries with other social systems. Some of the results, however, may be useful for nurses and health care personnel in countries with different health care systems. Those who are most strained by caregiving may have been among the dropouts, which could imply that the results are more positive than the reality. It could also be that the respondents were those who like to emphasize the strain in caregiving.

### Conclusions

The results showed significant associations between loneliness, weak social network and low mental quality of life. Being aware of the negative effects that loneliness and small social networks may have on quality of life is important for those who work with older people, as it indicates the importance of helping them to maintain or create a social network and to try to reduce their experiences of loneliness. The fact that loneliness was the most important factor predicting low quality of life among caregivers, as well as older people in general, indicates that it is a crucial issue in the care of older people. From a nursing perspective, our findings indicate the advantages of identifying those at risk of decreased social networks and feeling lonely, and helping older people to create or maintain a social network, preferably before they become too weak, since decreased health status makes social contacts difficult. The study confirmed the benefits of early identification and systematic support for older caregivers, and the advantage of giving them time for respite.

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