

# Life satisfaction among informal caregivers in comparison with non-caregivers

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Being a caregiver with responsibility for someone with reduced health compared with not being a caregiver may mean different views of life satisfaction. Knowledge of what leads to reduced life satisfaction in caregivers may be helpful in interventions. Informal caregivers gainfully employed or not, aged 50–89 years, were studied with regard to life satisfaction depending on the extent of caregiving to identify types of social support of value for caregivers. A cross-sectional study was conducted including a sample of 151 informal caregivers with a high caregiving extent, 392 caregivers with a lower caregiving extent and 1258 non-caregivers. The sample was randomly selected to correspond with older Swedes as a whole aged 50–89 years. A questionnaire containing a modified form of Older Americans' Resources Schedule (OARS) and Life Satisfaction Index Z (LSIZ) was used; 19.6% helped someone with activities of daily living and of these 27% stated that they did so frequently. Frequent caregiving implied significantly higher age, being more often married

and retired, than less frequent caregivers and non-caregivers. Frequent caregivers also performed personal activities of daily living (PADL) to a higher extent than less frequent caregivers and had significantly lower LSIZ (mean 14.8) than less frequent caregivers (mean 17.6) and non-caregivers (mean 17.7). No significant differences were found between less frequent caregivers and non-caregivers in LSIZ. One-fourth had support from others, the commonest type being able to converse with a next of kin, and help and advice from professionals. Lower life satisfaction was associated with not being employed, low social resources, not refreshed after a night's sleep, overall poor health and frequent caregiving in the entire sample. High caregiving extent was associated with lower life satisfaction. The most important factors explaining lower life satisfaction among frequent caregivers were having low social resources and having poor health. Economic compensation or payment was the support most desired.

**Keywords:** informal care giving, life satisfaction, social resources, health, economy, nursing care.

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## Introduction

Being an informal caregiver and taking on the responsibility to care for someone with reduced health may have an impact on life satisfaction compared with non-caregivers. In addition, the extent of caregiving and being gainfully employed or not may affect their life satisfaction. There have not been much studies of life satisfaction and related factors such as social support, health and economy in adults and older people providing informal care (1).

Such knowledge will be even more important in the future because of the growing number of informal caregivers in society (2). The world's population is getting older and the need for help with daily activities increases with increasing age (3). This, together with cutbacks in resources in the public sector and public elderly care, will result in a growing number of informal caregivers. Thus, knowledge of life satisfaction in those providing care and related factors may be important for interventions as to how to support the caregivers.

Life satisfaction is supposed to be a global concept, referring to life as a whole rather than to specific aspects (4) and as such may be relevant when comparing people providing care with those not providing care. The distinction between life satisfaction, well-being and quality of life (QoL) is not clear, and the concepts are sometimes used interchangeably (5). Ryff (6) suggested that life satisfaction

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is a dimension of well-being and is the most frequently measured. The field of subjective well-being, for instance, comprises questions about how persons evaluate their lives both at present and during the previous year (7). Diener et al. (7) suggested that these evaluations include both emotional reactions to events, mood, life satisfaction, fulfilment and satisfaction with related factors such as marriage and work. Furthermore, Lawton (8) defined QoL as 'the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current, and anticipated' (p. 6). Thus, it seems that those concepts more or less measure important aspects from a broad, and not a specific, perspective, and over the life span as well as at the present time. This reasoning is confirmed by Diener et al. (7), who suggest that well-being cannot be measured with a single aspect such as personality. Accordingly, life satisfaction, well-being and QoL are all multidimensional in their construction (5-9). This also supports the idea of a strong association between life satisfaction, well-being and QoL as concepts, but at the same time it corroborates that there is a difference between the concepts, with life satisfaction being a component of well-being and QoL. In this study, a broad view of life satisfaction seems relevant.

Population-based studies of informal caregivers have shown that caregiving may affect people in different ways (10-12). For instance, Jones and Vetter (12) found in a survey of 256 informal caregivers in Wales (spouses 26%, daughters 40%, other relatives 24% and 10% were unrelated, 48% were 45-64 years old and 20% were over 75 years old), with the focus on aspects important for QoL, that 11% had decreased social relations with friends, 13% had borderline or high level of anxiety, 12% had a high level of strain and 6% felt the caregiving situation to be unbearable. A prospective study with 392 (aged 66-96 years) informal caregivers and 427 non-caregivers by Schultz and Beach (13) showed that caregiving in itself may be a health risk, i.e. caring for a spouse increased the risk of mortality by 63%. The research on informal caregiving has mainly focused on stress (14), burden (15) and coping (16), often in relation to caring for a person with dementia diseases (10, 17). Caring for a cognitively impaired older person, being a spouse caregiver, and being involved in caregiving several hours a week were all predictors of increased physical health strain among caregivers (18). There are, however, still few studies investigating informal caregiving among those under 65 years old and still employed when compared with those who are not. They may have a different situation from older caregivers, i.e. having to handle demands from work as well as from caregiving. Younger caregivers may provide less frequent care than older caregivers. Thus, it seems worthwhile to investigate caregivers' life satisfaction and related factors, e.g. in employment or not, depending on the extent of caregiving, and to compare with non-caregivers to obtain

an idea of how informal caregivers differ from non-caregivers with regard to life satisfaction.

Informal caregiving may be both positive and negative depending on the demands. Almgren et al. (19) found in a study investigating caregiving among older persons with dementia that poor health, limitations in social life and lack of positive outlook increased the risk of burnout among the caregivers. However, Lee et al. (20) found in a study of 140 informal caregivers (mean age 65 years, SD 11.6) that carers with a higher level of empathy appraised the caregiving situation as less stressful and less threatening, they were less depressed and reported higher life satisfaction than caregivers with a low level of empathy. Llacer et al. (21) compared well-being among caregiving spouses (mean age 75.7 years, SD 6.6) and children (mean age 60.7 years, SD 7.7) (n = 195) for community-dwelling people aged 65 years and above and found that spouses had lower socioeconomic status, poorer health and lower level of well-being than children caregivers. However, children caregivers were significantly more burdened (21). Spousal caregivers compared with children caregivers differed in age as well as in their conditions for providing care. Spouses are mainly older, often retired, whereas children are younger and are often involved in family responsibilities and work in addition to caregiving, and this may contribute to different evaluation of being a caregiver. It is well known that spousal caregivers, to a high extent, provide help with PADL (22) and some of them may be working as well as providing care. However, studies have shown that caregiving may also be positive for the caregivers' life satisfaction. For instance, Grant and Nolan (23) found in a content analysis of 522 informal caregivers (age of carer 16-65+ years) that 19% experienced feelings of appreciation and 7% experienced improved affinity in the relationship between the care recipient and the caregivers. Thus, caregiving may affect people differently, both positively and negatively, and the extent of caregiving as well as demands from being gainfully employed may be explanations for their life satisfaction.

Different types of support such as respite care, study circles, help or/and advice from professionals may improve life satisfaction among informal caregivers. Knowledge of factors contributing to low life satisfaction along with the extent of caregiving may be helpful in outlining support or interventions to improve the situation of caregivers. To meet the need for support from the caregivers' point of view, knowledge of what they desire and value is required. In an interview study with 80 family caregivers, Steffens and Bergler (24) showed that many were unprepared for the task and felt insecure. Nearly one-third of the caregivers had support from professionals and rated this aid positively. Another type of social support described in a previous study, the circle model by Jansson et al. (25), with the intention of facilitating informal caregivers' situation, showed a favourable result. Informal caregivers

of demented persons met other caregivers in the same situation. Exchanging experiences increased their spirit of community, their knowledge of caregiving and their ability to handle the situation. Combining work and caregiving was in some respects found to be difficult (26). From this knowledge, a model of support for working caregivers was developed which included care-friendly working arrangements, access to a private telephone, and supportive line managers and co-workers (26).

Knowledge from the informal caregiver's point of view is warranted. Such knowledge is important for policy-makers as well as healthcare staff in elder care, to increase understanding of informal caregivers' situation, the need of support and what may be risk factors for lower life satisfaction to them. Knowledge of what brings lower life satisfaction among caregivers with different extent of caregiving together with knowledge of what type of support is wanted may be helpful in planning interventions aimed at supporting informal caregivers.

## Aim

The aim was to investigate life satisfaction in informal caregivers aged 50–89 years, gainfully employed or not, depending on the caregiving extent and to compare with non-caregivers not receiving care themselves. Furthermore, the aim was to identify factors related to life satisfaction and also to investigate the extent, need and type of support provided or desired among informal caregivers.

## Method

### Sample and procedure

The present study included 151 frequent caregivers, 392 less frequent caregivers and 1258 non-caregivers and was a sub-sample of the Swedish part of the European Study

of Adult Well-being (ESAW) project (27). The study design was cross-sectional population-based and participants were randomly selected among people aged 50–89 years in accordance with the population distribution in four age groups (50–59, 60–69, 70–79 and 80–89 years). Of those invited to participate in the study (7034) 8.1% refused on grounds of health, 22.1% did not want to participate and 30.1% gave no reason for not participating, which resulted in 2803 useful questionnaires. New age groups 50–64, 65–74, 75–84 and 85+ years were constructed for the present study, in order to correspond with the groups used by Statistics Sweden (28), and to agree with the retirement age in Sweden. The response rate differed with regard to age (years) and gender (male/female): 50–64 (36.1%/41.7%), 65–74 (46.9%/45.1%), 75–84 (46.2%/37.8%), and 85+ (37.2%/26.0%), with an overall response rate of 41.4%. The analysis of dropouts showed that the mean age of participants was 66.9 years (SD 11.4) and of dropouts 67.1 years (SD 12.2); thus, no significant differences (*p*-value 0.4) were found between participants and dropouts as a whole. However, when the dropouts were analysed in relation to age groups, differences were found (Table 1).

In the present study, the inclusion criterion was 'help provided to someone because of that person's reduced health'. In all, 550 (19.6%) respondents fulfilled the criteria. Seven subjects were excluded because they had not stated how often they helped someone. The remaining 543 people were divided into two groups depending on the extent of caregiving. The group of frequent caregivers (*n* = 151) helped at least four to six times a week or every day (four to six times a week 4.4% and every day 23.5%) and less frequent caregivers (*n* = 392) helped three times a week or less (less than once a week 21.8%, once a week 34.9%, two to three times a week 15.4%). Inclusion criteria for non-caregivers were 'not belonging to the other

**Table 1** The sample, analysis of dropouts, response rate and persons providing informal help

| Age group (years)  | 50–64                          | 65–74                               | 75–84                            | 85–89                              |
|--|--------------------------------|-------------------------------------|----------------------------------|------------------------------------|
| Target sample, <i>n</i>                                      | 3357                           | 1401                                | 1518                             | 758                                |
| Final sample, <i>n</i>                                       | 3281                           | 1373                                | 1448                             | 698                                |
| Final sample, <i>n</i><br>(male/female)                      | 663/634                        | 344/301                             | 386/258                          | 92/133                             |
| Response rate, <i>n</i> (%)                                  | 1297 (38.6%)                   | 645 (46.0%)                         | 644 (42.4%)                      | 225 (29.6%)                        |
| Male/female  | 36.1/41.7                      | 46.9/45.1                           | 46.2/37.8                        | 37.2/26.0                          |
| Participants'/dropouts'<br>mean age (SD) ( <i>p</i> -value)* | 56.2 (4.4)/<br>56.2 (4.3) (NS) | 69.7 (3.0)/<br>69.6 (3.1) (<0.0001) | 78.7 (2.8)/78.9<br>(2.8) (0.001) | 86.5 (1.5)/86.7<br>(1.5) (<0.0001) |
| Informal caregivers, <i>n</i>                                | 310                            | 122                                 | 88                               | 23                                 |
| Frequent caregivers, <i>n</i>                                | 53                             | 40                                  | 42                               | 16                                 |
| Less frequent caregivers, <i>n</i>                           | 257                            | 82                                  | 46                               | 7                                  |
| Non-caregivers   | 705                            | 294                                 | 207                              | 52                                 |

The differences between target and final sample are due to death, address unknown and high internal dropout.

\*Significant differences between participants and dropouts using chi-squared test.

two groups' and 'not needing help with activities of daily living themselves'. Those included in high frequency of caregiving (27%) were significantly older (mean age 69.9 years, SD 11.1) and to a lower degree gainfully employed (21.2%) compared with less frequent caregivers (73%) (mean age 62.0 years, SD 9.5) and 50.7% were gainfully employed ( $p < 0.0001$ ) or non-caregivers (mean age 65.5 years, SD 10.9) ( $p < 0.0001$ ). Less frequent caregivers and non-caregivers were significantly younger ( $p < 0.0001$ ). In addition, frequent caregivers were significantly more often married ( $p < 0.0001$ ), more often lived together with their spouses or significant others ( $p < 0.0001$ ), did not live alone ( $p < 0.0001$ ) and were retired ( $p < 0.0001$ ) more often than less frequent caregivers and non-caregivers (Table 2).

Data were collected during the spring of 2001 and autumn of 2002 using a self-report questionnaire. The questionnaire was sent by mail together with a letter of introduction, information about the study and an emphasis on voluntariness. The persons were offered help to complete the questionnaire, if needed. Two reminders were sent, the last one with a new copy of the self-reported questionnaire. Questionnaires with a high internal drop-out were completed in telephone interviews.

### Measurements

The questionnaire was based on Older Americans' Resources Schedule (OARS) part A, Multidimensional Functional Assessment Questionnaire (OMFAQ) (29, 30) approved by Gerda Fillenbaum (pers. comm.). The OARS has been tested regarding validity and reliability in the USA among people 60 years and above (29). It has not been used in Sweden before. However, the Swedish instrument was tested in a pilot study and showed good feasibility. The questionnaire was supplemented with a standardized instrument, the Life Satisfaction Index Z (LSIZ) (31). The questionnaire (including the standardized instrument) was translated into Swedish by a native Swedish speaker (the first author) and thereafter back-translated by a bilingual person (American English) who had not read the original English version. Questions about ethnicity, education system, income and healthcare system were adapted to the Swedish system.

The OARS is a multidimensional instrument and includes background information (age, sex, education), and the following dimensions: social support resources (social contact, perception of loneliness), economic resources (employment status, income resources, housing),

**Table 2** Demographic variables as percentages among caregivers with different caregiving extent

|                               | Total caregivers<br>( <i>n</i> = 543) | Frequent caregivers<br>( <i>n</i> = 151) | Less frequent<br>caregivers ( <i>n</i> = 392) | Non-caregivers<br>( <i>n</i> = 1258) | <i>p</i> -value between<br>groups | Post hoc<br>test |
|-------------------------------|---------------------------------------|--|---|--------------------------------------|-----------------------------------|------------------|
| Gender                        |                                       |  |   |                                      |                                   |                  |
| Male                          | 48.8                                  | 50.3                                     | 48.2  | 50.6                                 | 0.6                               |                  |
| Female                        | 51.2                                  | 49.7                                     | 51.8  | 49.4                                 |                                   |                  |
| Age groups (years)            |                                       |  |   |                                      |                                   |                  |
| 49–64                         | 57.1                                  | 35.1                                     | 65.6  | 56.0                                 | <0.0001                           | A, B, C          |
| 65–74                         | 22.5                                  | 26.5                                     | 20.9  | 23.4                                 |                                   |                  |
| 75–84                         | 16.2                                  | 27.8                                     | 11.7  | 16.5                                 |                                   |                  |
| 85+                           | 4.2                                   | 10.6                                     | 1.8   | 4.1                                  |                                   |                  |
| Marital status                |                                       |  |   |                                      |                                   |                  |
| Single, divorced or separated | 18.4                                  | 12.0                                     | 20.9  | 20.2                                 | <0.0001                           | A, B, C          |
| Married                       | 73.5                                  | 82.7                                     | 69.9  | 64.6                                 |                                   |                  |
| Widow/widower                 | 8.1                                   | 5.3                                      | 9.2   | 15.2                                 |                                   |                  |
| Employment                    |                                       |  |   |                                      |                                   |                  |
| Full-time                     | 34.0                                  | 17.8                                     | 40.2  | 35.7                                 | <0.0001                           | A, B, C          |
| Part-time                     | 8.5                                   | 3.4                                      | 10.4  | 9.3                                  | 0.037                             | A, B             |
| Retired                       | 55.2                                  | 74.7                                     | 47.8  | 52.3                                 | <0.0001                           | A, B, C          |
| Education                     |                                       |  |   |                                      |                                   |                  |
| ≤Compulsory school level      | 42.7                                  | 50.3                                     | 39.8  | 43.1                                 | 0.2                               |                  |
| Upper secondary school level  | 39.6                                  | 35.8                                     | 41.1  | 37.2                                 |                                   |                  |
| University level              | 17.7                                  | 13.9                                     | 19.1  | 19.6                                 |                                   |                  |
| Type of caregiving            |                                       |  |   |                                      |                                   |                  |
| IADL                          | 64.0                                  | 76.2                                     | 59.7  |                                      | <0.0001                           |                  |
| PADL                          | 15.3                                  | 37.0                                     | 7.0   |                                      | <0.0001                           |                  |
| Medical care                  | 10.6                                  | 25.8                                     | 4.8   |                                      | <0.0001                           |                  |

A, frequent caregivers vs. less frequent caregivers; B, frequent caregivers vs. non-caregivers; C, less frequent caregivers vs. non-caregivers. Chi-squared test was used to test significant differences for nominal data.

mental health (mental status) and physical health (self-perceived health, sleeping pattern, physical activities). The dimension of physical health was measured with self-perceived health, sleeping pattern and participating in physical activities. The dimension of social resources was measured including six items constructed to an index according to Fillenbaum's original algorithm (29) consisting of contact and family satisfaction. The new ordinal variable, social resources index, describes the extent of and satisfaction with contacts in terms of low, medium and high. The financial resources index includes four items and was constructed in the same way, resulting in an ordinal variable with the levels poor, fair and good. The instrument was supplemented with an item about caregiving: 'Do you regularly provide help to a next of kin or friends due to his/her reduced health?' and type of help provided, e.g. instrumental activities of daily living (IADL), PADL and help with medical treatment. Furthermore, a question about frequencies of caregiving was included with the alternatives less than once a week, once a week, 1–3 days a week, 4–6 days a week and daily. The respondents providing help were also asked, in open-ended questions, if they had support, for example, someone to talk with, ask for help or advice. If they responded 'yes', they were asked to describe the support, and the frequency. Those not having support were asked if they wanted some; if 'yes', they were asked to describe what kind of support and the frequency.

Life satisfaction was measured using LSIZ (31), a shortened version including 13 items from the original Life Satisfaction Index A (32). LSIZ has been found to correlate strongly ( $r = 0.94$ ) with the longer version (31). The total score ranges from 0 to 26, with higher scores indicating higher overall life satisfaction. The LSIZ is a overall life satisfaction instrument with items such as 'As I grow older, things seem better than I thought they would be', 'Most of the things I do are boring or monotonous', 'As I look back on my life, I am fairly well satisfied', 'This is the dreariest time of my life'. Norm value based on the average score for LSIZ has been computed in a study of  $n = 1042$  people aged 65+ years in the UK. The mean score for LSIZ differed between the age groups 17.1 for 65–74 years and 16.4 for 75+ years (33). Cronbach's alpha (34) was 0.81 in this study and thus in agreement with the original version (31). The LSIZ was previously used in a Swedish context among older people of 90+ years which resulted in a Cronbach's alpha of 0.60 and mean value of 15.3 (35).

#### Statistical analysis

Most of the variables included in the questionnaire were of nominal and ordinal level and non-parametric statistics were therefore used (36). Chi-squared test was used to test significant differences for nominal data and Kruskal–Wallis was used for ordinal data (36). Mann–Whitney *U*-test was

used as the *post hoc* test. A *p*-value of 0.05 was regarded as significant and with a reduced *p*-value of 0.017 in the *post hoc* test. Multiple logistic regression forward conditional analyses were performed using LSIZ as the dependent variable to determine variables explaining low life satisfaction among caregivers. The logistic regression analysis was chosen, as all the independent variables were at the nominal or ordinal level (36). The dependent variable LSIZ was transformed into categorical variables using 25th percentiles (cut-off point for LSIZ 14.0). Independent variables were age, gender, living alone (Table 2), feeling lonely, not refreshed after a night's sleep, difficulty falling asleep, participating in physical activity, health, financial resources in relation to needs, money to buy luxuries and enough money for the future (Table 4). The regression analysis was performed controlling for age and gender. The alternative with the expected smallest membership with high life satisfaction was chosen as reference for categorical variables (37), i.e. high social resources, feeling refreshed after a night's sleep, no difficulty falling asleep, not participating in physical activities, overall health good, financial resources good and low extent of caregiving. The model was significant at the  $<0.0001$  level. Hosmer and Lemeshow goodness-of-fit test was used to test the models and all models were non-significant thus showed a good model fit. Hosmer and Lemeshow goodness-of-fit test is a comprehensive measurement indicating how well the model predicts the dependent variable (38). Statistical analyses were carried out using SPSS 12.0 for Windows.

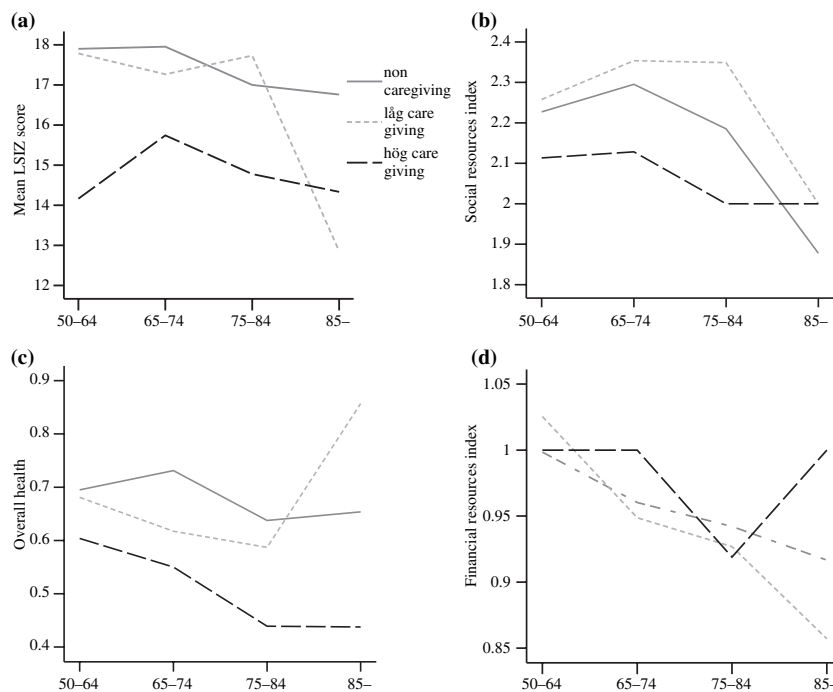
## Results

### Caregiving tasks

Frequent caregivers helped to a significantly higher extent with PADL ( $p < 0.0001$ ), 37% compared with 7% among less frequent caregivers. They also more often performed help with IADL ( $p < 0.0001$ ), 76.2% compared with 59.7%, and helped with medical care ( $p < 0.0001$ ), 25.8% compared with 4.8%, to a greater extent than less frequent caregivers (Table 2).

### Life satisfaction

Frequent caregivers had significantly ( $p < 0.0001$ ) lower life satisfaction (LSIZ), (mean 14.8, SD 5.9) than less frequent caregivers (mean 17.6, SD 5.8) and non-caregivers (mean 17.7, SD 5.4). In all groups, LSIZ decreased with higher age (Fig. 1a). Significant differences were found between those 50–64 and 85+ years old ( $p$ -value 0.001) and between those 65–74 and 85+ years old ( $p$ -value 0.008). Of the frequent caregivers, 45% stated a degree of life satisfaction under the cut-off point for the 25th percentile compared with 28.6% among less



**Figure 1** LSIZ, social resources, overall health and financial resources in relation to age.

frequent caregivers and 26.6% among non-caregivers. Significant differences in life satisfaction were also found between women (mean 16.9, SD 5.4, range 13.6–17.6) and men (mean 18.0, SD 5.5, range 11.0–18.9) ( $p < 0.0001$ ). Differences in LSIZ were also found between gainfully employed frequent (mean 15.4, SD 6.4) compared with less frequent caregivers (mean 18.3, SD 5.2). Furthermore, frequent caregivers not employed had lower LSIZ (mean 14.6, SD 5.8) than less frequent caregivers (mean 16.9, SD 6.0). Thus, frequent caregivers, irrespective of if they were employed or not had a significantly lower ( $p < 0.0001$ ) LSIZ than less frequent caregivers (Table 3).

*Social resources*

Among frequent caregivers, 25.5% stated that they did not meet friends as often as they wished compared with 18.5% among less frequent caregivers and 16.6% among non-caregivers ( $p$ -value 0.011). Frequent caregivers had further significantly ( $p$ -value 0.007) higher frequency of those with low social resources (19.9%) than less frequent caregivers (13.5%) and non-caregivers (15.4%) (Table 4). The highest frequency of low social resources was found among men 85+ years old non-caregivers (36.8%), men 50–64 years frequent caregivers (33.3%) and women 85+ years frequent caregivers (28.6%). Thus, social resources declined

**Table 3** Health, social and financial resources among frequent caregivers, less frequent caregivers, non-caregivers employed or not, percentages

|                                      | Frequent caregivers employed (n = 31) | Frequent caregivers not employed (n = 115) | Less frequent caregivers employed (n = 194) | Less frequent caregivers not employed (n = 189) | Non-caregivers employed (n = 556) | Non-caregivers not employed (n = 679) |
|--------------------------------------|---------------------------------------|--|---|---|-----------------------------------|---------------------------------------|
| <b>Health</b>                        |                                       |  |   |   |                                   |                                       |
| Good                                 | 71.0                                  | 46.5                                       | 73.7  | 58.0  | 74.5                              | 65.2                                  |
| Poor                                 | 29.0                                  | 53.5                                       | 26.3  | 42.0  | 25.5                              | 34.8                                  |
| <b>Social Resources Index</b>        |                                       |  |   |   |                                   |                                       |
| High                                 | 22.6                                  | 29.1                                       | 37.4  | 47.0  | 38.1                              | 38.2                                  |
| Medium                               | 54.8                                  | 51.8                                       | 52.6  | 36.2  | 48.8                              | 44.9                                  |
| Low                                  | 22.6                                  | 19.1                                       | 10.0  | 16.8  | 13.1                              | 16.9                                  |
| <b>Financial resources</b>           |                                       |  |   |   |                                   |                                       |
| Good                                 | 3.4                                   | 5.7  | 4.4   | 8.4   | 3.7                               | 6.0                                   |
| Fair                                 | 89.7                                  | 92.5                                       | 89.0  | 87.1  | 92.5                              | 92.1                                  |
| Poor                                 | 6.9                                   | 5.7  | 6.6   | 4.5   | 3.7                               | 1.9                                   |
| Life Satisfaction Index Z, mean (SD) | 15.4 (6.4)                            | 14.6 (5.8)                                 | 18.3 (5.2)                                  | 16.9 (6.0)                                      | 18.5 (5.0)                        | 17.1 (5.5)                            |

**Table 4** Descriptions of variables related to life satisfaction as percentages among caregivers with different extent

|  | Frequent caregivers<br>(n = 151) | Less frequent<br>caregivers (n = 392) | Non-caregivers<br>(n = 1258) | p-value between<br>groups* | Post hoc<br>test |
|--|----------------------------------|---------------------------------------|------------------------------|----------------------------|------------------|
| <i>Social resources</i>                    |                                  |                                       |                              |                            |                  |
| Loneliness                                 |                                  |                                       |                              |                            |                  |
| Almost never                               | 60.0                             | 66.2                                  | 66.0                         | 0.259                      |                  |
| Sometimes                                  | 28.0                             | 26.4                                  | 25.1                         |                            |                  |
| Quite often                                | 12.0                             | 7.4                                   | 8.9                          |                            |                  |
| See friends/relations as often as wanted   | 74.5                             | 81.5                                  | 84.1                         | 0.011                      | B                |
| Someone to confide in                      | 87.9                             | 91.0                                  | 89.1                         | 0.466                      |                  |
| Social resources index                     |                                  |                                       |                              |                            |                  |
| Low  | 19.9                             | 13.5                                  | 15.4                         | 0.007                      | A, B             |
| Medium                                     | 52.7                             | 44.5                                  | 46.3                         |                            |                  |
| High                                       | 27.4                             | 41.9                                  | 38.0                         |                            |                  |
| Health                                     |                                  |                                       |                              |                            |                  |
| Refreshed after a night's sleep            | 70.9                             | 75.1                                  | 81.3                         | 0.001                      | B, C             |
| No difficulty falling asleep               | 65.8                             | 79.3                                  | 80.2                         | <0.0001                    | A, B             |
| Regularly participate in physical activity | 75.5                             | 83.9                                  | 82.1                         | 0.071                      | B                |
| Overall physical health                    |                                  |                                       |                              |                            |                  |
| Excellent                                  | 9.3                              | 19.7                                  | 20.1                         | 0.001                      | A, B             |
| Good                                       | 43.3                             | 46.3                                  | 49.1                         |                            |                  |
| Fair                                       | 42.0                             | 30.2                                  | 28.4                         |                            |                  |
| Poor                                       | 5.3                              | 3.8                                   | 2.5                          |                            |                  |
| <i>Financial resources</i>                 |                                  |                                       |                              |                            |                  |
| Financial resources meet needs             |                                  |                                       |                              |                            |                  |
| Very well                                  | 25.9                             | 26.5                                  | 27.5                         | 0.630                      |                  |
| Fairly well                                | 59.2                             | 61.9                                  | 61.0                         |                            |                  |
| Poorly                                     | 15.0                             | 11.9                                  | 11.5                         |                            |                  |
| Money to buy luxuries                      | 68.0                             | 72.2                                  | 74.8                         | 0.088                      | B                |
| Enough money for the future                | 70.9                             | 73.8                                  | 75.2                         | 0.390                      |                  |
| Financial resources index                  |                                  |                                       |                              |                            |                  |
| Good                                       | 5.0                              | 6.4                                   | 5.1                          | 0.629                      |                  |
| Fair                                       | 92.3                             | 87.8                                  | 91.9                         |                            |                  |
| Poor                                       | 2.7                              | 5.8                                   | 2.9                          |                            |                  |

\*Chi-squared for significant differences for nominal data. Kruskal–Wallis for significance test for ordinal data. Mann–Whitney *U*-test was used as the *post hoc* test for ordinal data.

A, frequent caregivers vs. less frequent caregivers; B, frequent caregivers vs. non-caregivers; C, less frequent caregivers vs. non-caregivers.

with higher ages (Fig. 1b). Frequent caregivers, regardless of whether they were gainfully employed, more often had low social resources than less frequent caregivers and non-caregivers, gainfully employed or not.

#### Physical health

Frequent caregivers stated significantly poorer health (p-value 0.001) than less frequent caregivers and non-caregivers. Forty-eight per cent of frequent caregivers rated their health as poor or fair compared with 34% among less frequent caregivers and 30.9% among non-caregivers. In addition, frequent caregivers stated significantly (p < 0.0001) more often difficulty falling asleep (34.2%) than less frequent caregivers (20.7%) and non-caregivers (19.8%). They also significantly more often reported that they did not feel refreshed after a night's sleep (29.1%)

(p-value 0.004) than non-caregivers (18.7%). Moreover, non-caregivers were significantly more often refreshed after a night's sleep than less frequent caregivers (p-value 0.016) (Table 4). Gainfully employed, irrespective of whether they were frequent caregivers (good health 71.0%), less frequent caregivers (good health 73.7%) or non-caregivers (good health 74.5%) stated significantly (p < 0.0001) better health than did those who were not employed. Health declined with age among frequent caregivers (Fig. 1c).

#### Financial resources

No significant difference was found in financial resources between the three groups (Table 4), between men and women, being employed or not (Table 3). Financial resources declined in relation to retirement in all three groups (Fig. 1d).

**Table 5** Logistic regression analysis of factors related to low life satisfaction among caregivers and non-caregivers (controlled for age and gender)

|                                     | OR  | 95% CI for OR | p-value |
|-------------------------------------|-----|---------------|---------|
| Employment                          | 0.5 | 0.3–0.7       | <0.0001 |
| Social resources                    |     |               |         |
| Medium                              | 3.1 | 2.3–4.3       | <0.0001 |
| Low                                 | 8.1 | 5.4–12.0      | <0.0001 |
| Health                              |     |               |         |
| Not refreshed after a night's sleep | 2.1 | 1.6–2.9       | <0.0001 |
| Overall health fair/poor            | 2.7 | 2.1–3.5       | <0.0001 |
| Extent of caregiving                |     |               |         |
| Frequent caregivers                 | 2.2 | 1.4–3.4       | 0.001   |

Hosmer and Lemeshow goodness-of-fit test p-value of 0.425. Factors without significant influence were: difficulty falling asleep, participating in activities, financial resources index, age and gender.

#### Factors associated with life satisfaction

Limited social resources as well as poor health, and level of caregiving were risk factors for low life satisfaction (Table 5). The highest risk factors explaining low life satisfaction were low and medium social resources (OR 8.1 and 3.1), fair/poor health (OR 2.7), frequent caregivers (OR 2.2) and not feeling refreshed after a night's sleep (OR 2.1). Being gainfully employed decreased the risk of low life satisfaction (OR 0.5). The regression analysis was repeated in each group (Table 5), because frequent caregiving proved to increase the risk of low life satisfaction (OR 2.1). When the variable measuring the extent of caregiving was used without dichotomization into high

and low caregiving frequency, it was found that providing care every day increased the risk of lower life satisfaction to OR 3.1.

The three groups differed in factors that explained low life satisfaction. However, low social resources had the highest risk in all three groups, i.e. among frequent caregivers (OR 13.0), less frequent caregivers (OR 10.6) and non-caregivers (OR 7.4). In comparison with the frequent caregivers, less frequent caregivers (OR 2.1) and non-caregivers (OR 2.1) had an increased risk of not being refreshed after a night's sleep. Poor/fair overall health (OR 2.4–3.5) proved to increase the risk of low life satisfaction in all three groups. Living alone increased the risk of low life satisfaction among less frequent caregivers (OR 2.3) and among non-caregivers (OR 2.0). Being employed was shown to be positive among non-caregivers and reduced the risk of low life satisfaction (OR 0.5) (Table 6).

#### Support for caregiving

Among the informal caregivers (n = 134; 25.9%) reported that they had support from others. This was more common among frequent caregivers (n = 51; 34.9%), than less frequent caregivers (n = 83; 22.2%) (p-value 0.003). Frequent caregivers who were gainfully employed (n = 17) reported higher frequency of support from others (56.7%) than less frequent caregivers in gainful employment (n = 44, 23.7%). The most common type of support was conversation with a next of kin (n = 43; 41.0%), help from the district nurse (n = 12; 11.4%), or other nursing staff (n = 42; 40.0%), while 7.6% (n = 8) stated that they participated in organizations such as church, study circle,

**Table 6** Logistic regression factors related to low life satisfaction among caregivers with different extent as well as non-caregivers (controlled for age and gender)

|   | Frequent caregivers |         | Less frequent caregivers |         | Non-caregivers |         |
|---|---------------------|---------|--------------------------|---------|----------------|---------|
|   | OR (95% CI)         | p-value | OR (95% CI)              | p-value | OR (95% CI)    | p-value |
| Living alone  |                     |         | 2.3 (1.2–4.2)            | 0.009   | 2.0 (1.4–2.7)  | <0.0001 |
| Employment  |                     |         |                          |         | 0.5 (0.3–0.7)  | 0.001   |
| Social resources                                    |                     |         |                          |         |                |         |
| Medium  | 3.0 (1.0–8.5)       | 0.004   | 3.1 (1.5–6.1)            | 0.001   | 3.1 (2.1–4.6)  | <0.0001 |
| Low   | 13.0 (3.1–54.7)     | <0.0001 | 10.6 (4.4–25.4)          | <0.0001 | 7.4 (4.6–12.0) | <0.0001 |
| Health  |                     |         |                          |         |                |         |
| Refreshed after a night's sleep                     |                     |         | 2.1 (1.1–4.0)            | 0.025   | 2.1 (1.4–3.0)  | <0.0001 |
| Overall health fair/poor                            | 3.5 (1.5–8.3)       | 0.004   | 2.4 (1.3–4.2)            | 0.003   | 2.9 (2.1–4.0)  | <0.0001 |
| Hosmer & Lemeshow<br>goodness-of-fit test (p-value) | 0.449               |         | 0.851                    |         | 0.873          |         |

Factors without significant influence were:

*Frequent caregivers:* living alone, refreshed after a night's sleep, difficulty falling asleep, participating in physical activities, financial resources, age and gender.

*Less frequent caregivers:* difficulty falling asleep, participating in physical activities, financial resources, age and gender.

*Non-caregivers:* difficulty falling asleep, financial resources, age and gender.



etc. Moreover, of those not stating that they had any support, 11.6% ( $n = 51$ ) desired support, and this was more common among frequent caregivers ( $n = 26$ ; 23.1%), than less frequent caregivers ( $n = 25$ ; 7.7%) ( $p < 0.0001$ ). No significant difference in LSIZ was found between those who had support, mean 16.6 (SD 5.9), and those who did not, mean 16.9 (SD 5.9). The support caregivers desired represented five areas: economy ( $n = 9$ ; 30%) (from being salaried to receiving economic compensation), respite care ( $n = 5$ ; 16.7%) (the caregivers wanted time for themselves, from 1 h to 1–2 days per week), someone to talk with about caregiving and advice ( $n = 8$ ; 26.7%) (contact with others in the same situation, support groups, someone to call), nursing-help service (practical help with caring) ( $n = 5$ ; 16.7%), and home-help service (help with daily activities such as cleaning and shopping) ( $n = 3$ ; 10.0%).

## Discussion

### *Methodological considerations*

One limitation of this study is the low response rate. This sample covered a broad age range, 50–89 years, with differing ability to participate. It is well known that the response rate decreases with age (39), probably as a consequence of poorer health, and that could be one explanation for the low response rate. Increased age may bring more health problems, particularly cognitive impairment (40), which in turns gives raise to problems in participating in this type of postal self-reported studies. However, the response rate was low also among the youngest, 50–59 years old, and lower than among the members of the two middle-age groups, 60–69 and 70–79 years, which cannot be explained by poorer health. Possible reasons for the dropouts from these ages could be that they were still working and too busy and/or that there is a negative trend in society towards participation in this type of studies (41). Other possible reasons could be the comprehensiveness of the postal questionnaire, which was due to the broad approach the study had in measuring life satisfaction. A response rate higher than 60% is preferable in order to avoid response bias, but lower response rates are common (42). Generalizations need to be considered in the light of the low response rate. However, the purpose of this study was not to investigate prevalence, but to explore factors of importance for life satisfaction among informal caregivers. Nearly 20% of the total sample helped someone with ADL because of reduced health, which is similar to another Swedish population study (75+ years) which reported that 14% helped someone (43). The results of this study could be generalised with caution to the area of informal caregiving, especially for understanding the impact of caregiving extent on life satisfaction. The strength of this study, in spite of the low response rate, is the random selection of

the sample. Even though the differences in age and gender between those included and the dropouts were significant, there is reason to believe that these small differences did not have large clinical significance (44). The section on caregiving support had an undesired high internal dropout, which might affect the result negatively in that the real need for support in caregiving was not revealed. These questions were open-ended and thus took more time to respond to than the questions with fixed response alternatives. More research with a qualitative approach is needed in the area of caregiving support for a deeper understanding of which type of support is preferable for those persons.

The instruments used in this study, LSIZ and OARS, with the focus on life satisfaction and psychological well-being, have shown good reliability and validity (29, 31). The LSIZ instrument proved to have high Cronbach's alpha, 0.81, which indicates that it worked well among adults aged 50 years and above as well (45) and the internal consistency was similar to that in the original publication (31). Further psychometric testing, for instance, a factor analysis exploring the underlying structure as well as validity of the instrument is needed. The internal dropout for questions included in OARS was low for items belonging to background, social factors and health below 1% and for economic matters between 2.2% and 5.4%. Thus, as a whole, the low internal dropout indicated that the questions were easy to understand and answer.

### *Frequent caregiving meant lower life satisfaction*

Higher caregiving extent meant lower life satisfaction, i.e. frequent caregivers had significantly lower LSIZ than less frequent caregivers and non-caregivers. Nearly half of the frequent caregivers scored LSIZ under the 25th percentile, compared with one-third of the less frequent caregivers and non-caregivers. In comparison with Morgan et al.'s (33) norm values for the general population aged 65 years and above, those with high caregiving extent stated significantly lower LSIZ. LSIZ was also used in another Swedish study in a sample of people aged 90 years and above (35). In relation to the findings of that study (mean 15.5), frequent caregivers also had lower LSIZ than older persons aged 90 years and above. Thus, it seems as if providing care daily or almost daily has a negative impact on the caregiver's life satisfaction. As far as the authors know, the LSIZ instrument has not been used to evaluate life satisfaction among informal caregivers before, which makes comparisons difficult. However, Wallhagen (46) used LSIA to measure psychological well-being among elderly caregivers, and found that greater personal demands were associated with lower life satisfaction. Caregiving demands in that study were described as frequency and difficulty in relation to IADL, PADL provision, and statements such as 'I have to organise my time around

the care receiver's daily activities'. Thus, the findings of that study confirmed the findings from this study that there is an association between caregiving extent and low life satisfaction. The findings underline the importance of continuously evaluating caregivers' experience of demands and life satisfaction with the intention to take steps to prevent low life satisfaction.

### *Gainfully employed and caregiving*

Being gainfully employed was positive for life satisfaction among frequent and less frequent caregivers as well as non-caregivers. Those still gainfully employed stated higher LSIZ than did those not employed. To a certain extent, this can be a result of younger and healthier people in the groups consisting of gainfully employed. However, the regression analysis was controlled for age and gender without any explanations that can be assigned to age. There is a lack of studies investigating life satisfaction in relation to being gainfully employed in general and in particular in relation to also being caregivers. Previous research has shown that work can serve four types of needs: social contact, for example avoidance of feeling alone; personal needs, feeling pride and self-worth; financial needs; and generativity, i.e. the opportunity to pass one's knowledge and skills to the younger generation (47). Informal caregiving has many similarities to paid work and may act as something meaningful to do, i.e. it gives opportunities for social contact but also a feeling of being needed in society. It thus seems that having something to do, paid work or caregiving, can be positive for people and satisfy personal needs as long as the caregiving tasks or work do not take over their life.

### *Social resources*

Social resources may buffer low life satisfaction in caregiving. Caregiving in itself may hinder social relations. Low social resources increased the risk of low life satisfaction in all groups. One part of the social resources index was loneliness, which seems to be a common problem for people in general and among caregivers (48), being more common among women (49), and it influences older persons' life satisfaction (50). Feeling lonely quite often, for instance, was more common among frequent caregivers. Loneliness in relation to caregiving needs to be addressed in the light of social isolation, for example, not seeing friends as often as wanted, but also as emotional loneliness with feelings of loss, distress, separation and isolation (51). One-third of the frequent caregivers stated that they did not see friends as often as wanted. Mullins (51) suggested that not seeing friends as often as wanted was important for the experience of loneliness and especially social loneliness. Only a few, however, reported that they had no one to confide in, which may suggest that it

was not the loss of friends and relatives that caused their feeling of loneliness but instead an inner feeling. On the other hand, having someone to confide in is not the same as meeting friends or relatives, only that you have someone to contact if the worst comes to the worst. Irrespective of what caused low social resources, those with low social resources had a greater risk of low life satisfaction (OR 7.4–13.0). The positive effect of social resources that prevent people from being socially isolated needs to be considered in nursing care. This is especially important for informal caregivers; without social resources and support they tend to be isolated and unsatisfied with their life.

### *Support for caregiving*

Support may facilitate informal caregivers' life satisfaction positively when adequately provided. It is surprising, though, that there was a rather low frequency of support (34.9%) among frequent caregivers. Frequent caregivers in gainful employment had support from others to a higher extent. The most common type of support was talking with a next of kin about caregiving, followed by help and advice from nursing staff and district nurses, which was provided in only 11.4% of cases. The most desired support was related to economy and having someone in the same situation to talk to. Accordingly, the agreement between the support they desired and what they actually received was rather low. Economic support is not so common in Sweden and mostly occurs among caregivers aged 65 years and below. In addition, support and its relation to caregiving have seen little investigation, especially in relation to economic compensation and respite care. Having someone to talk with was shown to be important for caregivers. However, participating in support groups requires respite care if the person cared for is not capable of remaining alone at home. The positive aspect of meeting someone in the same situation has previously been described by Jansson et al. (25) in her study investigating caregivers caring for people suffering from dementia. Although that study included only informal carers of people with dementia, there is reason to believe that support groups giving an opportunity to meet other persons in the same situation are important no matter what the care receiver is suffering from. More research with an approach aimed at a deeper understanding of support is needed, especially addressing those in need of support, particularly those with a higher extent of caregiving.

### **Conclusion**

Higher caregiving extent increased the risk of low LSIZ, whereas no significant differences were found between less frequent caregivers and non-caregivers. A minority of the informal caregivers had support for their caring. The most desired support was related to economic compensa-

tion and having someone in the same situation to talk to. More research is needed in the area of social support for caregivers, and a qualitative method may provide a deeper understanding of what kind of support is needed. Low social resources caused the highest risk of low life satisfaction among caregivers. The fact that social resources and health predicted low life satisfaction among caregivers as well as non-caregivers indicated that nurses and/or healthcare professionals need to work in an interdisciplinary way, i.e. going beyond the traditional health problems and focus also on psychosocial issues.

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### Author contribution

Christel Borg was involved in the Swedish study of Ageing well in study conception and design, translation of the instruments, data collection, data analysis and drafting of the manuscript. Ingalill Rahm Hallberg was the Principal investigator (PI) for the Swedish part of the Ageing well project and the ESAW study and contributed to the study conception and design, translation of the instruments, data collection, data analysis, drafting of manuscript, and critical revision of manuscript.

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