Coping as a caregiver: A question of strain and its consequences on life satisfaction and health-related quality of life.

Dahlrup, Beth; Ekström, Henrik; Nordell, Eva; Elmståhl, Sölve

Published in:
Archives of Gerontology and Geriatrics

DOI:
10.1016/j.archger.2015.06.007

2015

Citation for published version (APA):
Dahlrup, B., Ekström, H., Nordell, E., & Elmståhl, S. (2015). Coping as a caregiver: A question of strain and its consequences on life satisfaction and health-related quality of life. *Archives of Gerontology and Geriatrics*, *61*(2), 261-270. https://doi.org/10.1016/j.archger.2015.06.007

Total number of authors:
4

Archives of Gerontology and Geriatrics 61 (2015) 261–270

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

Coping as a caregiver: A question of strain and its consequences on life satisfaction and health-related quality of life

Beth Dahlrup*, Henrik Ekström, Eva Nordell, Sölve Elmståhl

Department of Health Sciences, Division of Geriatric Medicine, Lund University, Sweden CRC, Jan Waldenströms gata 35, Build. 28 Fl. 13, Skåne University Hospital, SE-205 02 Malmo, Sweden

ARTICLE INFO

Article history:
Received 13 March 2015
Received in revised form 10 June 2015
Accepted 11 June 2015
Available online 25 June 2015

Keywords:
Caregivers
Strain
Burden
HRQoL
Life satisfaction

ABSTRACT

A majority of us will at some point in our lives take care of family members, relatives and friends in need of assistance. How will this affect us?

Strain related to life satisfaction (LS) and health related quality of life (HRQoL) among caregivers aged 60 years and older has not been previously studied.

Objectives: The main objective was to describe characteristics of non-caregivers ($n = 2233$) and caregivers ($n = 369$). Further objectives were to examine differences in HRQoL and LS between caregivers and non-caregivers, and between caregivers stratified by level of strain.

Methods: We analyzed the differences in socio-demographics, social participation, locus of control and symptoms between groups. HRQoL was assessed by Short Form Health Survey (SF-12/PCS and MCS). LS was measured by the Life Satisfaction Index-A (LSI-A).

Results: Caregivers were younger, had more years of formal education, more often cohabiting and relied less on powerful others than non-caregivers. One hundred and thirty-three (36%) caregivers reported high strain. In a three-group comparison including non-caregivers and caregivers stratified for strain, high strain was associated with lower SF12-PCS, SF12-MCS and LSI-A (0.014, <0.001 and <0.001, respectively).

Conclusion: High strain affects caregivers' HRQoL and LS in a negative way.

Practice: It is important for the health care sector to consider the possibility that symptoms in a person acting as a caregiver can be related to high perceived strain.

Implications: A general policy program aiming to identify caregivers and their needs for support is much needed.

1. Introduction

In the span of a lifetime, a huge majority of us will take care of family members, relatives and friends in need of assistance. How will this affect our lives?

Previous studies referred to in this paper (Collins & Swartz, 2011; The National Board of Health and Welfare 2012a; The National Alliance for Caregiving, 2009; Andrén & Elmståhl, 2005; Andrén & Elmståhl, 2008a; Bruvik, Ulstein, Hylen Ranhoff, & Engedal, 2012; Roth, Perkins, Wadley, Temple, & Haley, 2009; Roth et al., 2013; Pinguart and Sörensen, 2011 Lautenschlager et al., 2012; van der Lee, Bakker, Duivenvoorden, & Dröes, 2014; Ekwall, Sivberg, Rahm, & Hallberg, 2006; Buyck et al., 2011; Broe et al.,1999; Schultz & Sherwood, 2008; Fauth et al., 2012; Iecovich, 2011) have given us some answers. In this study we aim to broaden the knowledge on this topic by discussing how perceived strain affects informal caregivers' health-related quality of life (HRQoL) and life satisfaction (LS).

Providing care for family or friends with chronic conditions is common in all societies, and it can be both emotionally rewarding and distressing. Care provided by informal caregivers consists not merely of helping someone with personal and instrumental activities of daily living (PADL and IADL); it is far more complex than that. Bowers (1987) identified five levels of informal care, of which PADL and IADL composed the fourth, preceded by three levels of care dominated mainly by acts of anticipatory, preventive and supervisory caregiving. In the fifth level, the purpose was generally to protect the identity and dignity of the person in need of care.

---

* Corresponding author. Fax: +46 391313.
E-mail addresses: beth.dahlrup@med.lu.se (B. Dahlrup), henrik.ekstrom@med.lu.se (H. Ekström), eva.nordell@med.lu.se (E. Nordell), solve.elmstahl@med.lu.se (S. Elmståhl).

http://dx.doi.org/10.1016/j.archger.2015.06.007
0167-4943/

Informal caregivers (hereafter referred to simply as caregivers) are taking a huge responsibility for the care of the elderly in ordinary living, and the number of caregivers is rising mainly due to an increasing number of elders, both in Sweden and elsewhere (Johansson, Long, & Parker, 2011; Lüdecke, Mnich, & Kofahl, 2012; Collins & Swartz, 2011). The responsibility for family and friends to provide care differs depending on the amount of care provided by society. Courtin, Jemiai, & Mossialos (2014) found large differences between the member states in the European Union (EU) in strategies to support caregivers. Furthermore, large differences were found in the number of caregivers within the EU, where the highest proportion was found in the south of Europe and the lowest in Switzerland, the Netherlands and Sweden. In spite of these facts, The Swedish National Board of Health and Welfare (2012a) found in a study based on answers from 15,000 randomly selected persons above the age of 18 that almost one in twenty persons identifies themselves as caregivers who help a person with P- and IADL due to illness, disabilities or old age. Figures from The United States (US) are similar. A report from The National Alliance for Caregiving (2009) estimates that 24% of persons age 18 and over in the US are caregivers and provide care to a family member or friend 18 years or older. The largest group of caregivers both in the Swedish and in the US reports consists of middle-aged persons, most commonly adult children, taking care of their aging parent. The Swedish report also reveals that spouses and partners compose another large group, with 77% of persons aged 81 and above identifying themselves as caregivers. Also, the amount of time spent taking care of another person is highest in the group of caregivers ages 65–80. The retired caregivers' perceived health correlates with the intensity of caregiving, where the risk of health problems increases in relation to the extent of care given. The same goes for the caregivers' opinions of their quality of life (QoL) in this Swedish report, where in addition to the extent of caregiving, a closer relationship and cohabiting seem to be associated with more strain, with consequences on QoL. Furthermore, almost 40% of caregivers state that they sometimes or often find it difficult to have time to meet friends and family (The National Board of Health and Welfare, 2012a).

Andrén and Elmståhl (2008a) studied the relationship between caregiver burden and caregiver perceived health among caregivers of persons with dementia and found a strong association between these factors. In a study by Bruvik et al., 2012, the carers' QoL was strongly affected by depression. Roth et al. (2009) conducted telephone interviews with more than 40,000 persons, including 12% caregivers, and found that caregivers reported more quality of life problems, especially those who experienced high strain. A meta-analysis by Pinquart and Sörenson (2011) of 168 studies including several thousands of caregivers of persons with various diagnoses, studied the association between relationship type and well-being. Spouses reported more symptoms of depression and lower levels of psychological well-being than children and children-in-law.

Besides these well-known conclusions, other factors such as personality traits of the caregiver may affect the experience of caring and the ability to cope. In reviews by Lautenschlager et al. (2012) and van der Lee et al. (2014) using data on caregivers of persons with chronic mental illnesses, neuroticism among caregivers was associated with increased caregiver burden, depression and poorer coping. As mentioned earlier, the extent of care, the perceived burden, the relationship and the caregiver's own health problems are important factors for coping with the situation. Caregivers are often elderly with health problems of their own to deal with, problems that might influence their ability to cope with the complex demands associated with caregiving (Ekwall et al., 2006).

To be a caregiver can also be rewarding. Andrén and Elmståhl (2005) found that caregivers of persons suffering from dementia can experience great satisfaction in spite of moderate burden. In recent years, several studies have confirmed this finding and reported interesting results indicating positive effects of caregiving. Roth et al. (2009) found that caregivers reporting no strain had a better quality of life than non-caregivers. Buyck et al. (2011) found that caregivers with low burden reported better perceived general health and fewer symptoms of mental and physical tiredness than non-caregivers. Another study by Roth et al. (2013) including 3503 caregivers and propensity-matched controls showed that caregivers had a reduced risk of death compared to non-caregivers, taking into account well-known confounders such as age, relationship, sex and caregiving strain.

In assessing caregivers' situations, different instruments involving strain, perceived health and quality of life are used (Lüdecke et al., 2012; Andrén and Elmståhl,, Bruvik, 2008aAndrén and Elmståhl,, Bruvik, 2012 Roth et al., 2009; Ekwall et al., 2006).

The Life satisfaction Index A (LSI-A), by Neugarten, Havighurst, & Tobin (1961), is a multidimensional instrument intended to detect a person's previous and present experiences and the influence of these experiences on the person's overall life satisfaction (LS) as a measure of successful aging. Al-Windi (2005) found that LS, along with depression and number of symptoms, was a strong predictor of perceived health. Other factors demonstrated by Enkvist, Ekström, and Elmståhl (2012a,b) to be related to LS in persons aged 78–98 included marital status, education and functional ability. Studies of caregivers' life satisfaction using LSI-A are few. Broe et al. (1999) found that caregivers providing personal care reported lower LS caused mainly by distress in the relationship with the person they cared for.

The importance of adjusting for various factors is obvious in trying to understand which factors influence the situation of caregivers. In this study we included not only well-known socio-demographic factors such as sex, age, marital status, place of dwelling, and education, but also added other possible confounders including the caregiver's social network; consisting of social anchorage, social participation and social support. We also included data on the caregiver's health locus of control (HLC) and domains of physical and psychological symptoms.

We hypothesized that socio-demographic factors, especially age and sex of the caregivers, but also health issues and the degree of strain, would influence their HRQoL and LS negatively. We were also interested in the answers to several related questions: which factors can mitigate possible negative effects on the caregivers' HRQoL and LS? Are social networks an important factor for the caregivers' well-being? What role do different personality traits play in the individual's perception of being a caregiver?

Previous studies on caregivers are often limited to convenience samples of caregivers or selected diagnoses of the person receiving help, such as dementia, stroke and cancer. To our knowledge, studies on strain and its consequences on HRQoL and LS among caregivers drawn from a general population of persons aged 60 years and older has not been previously conducted.

The objectives of this study were to:

Describe the characteristics of caregivers and the differences in HRQoL and LS, firstly between caregivers and a control-group of non-caregivers, and secondly between caregivers stratified by level of perceived strain using the same non-caregivers as a control group.

2. Methods

2.1. Study population

Good Aging in Skåne (GÅS) (Ekström & Elmståhl, 2006; Lagergren et al., 2004) is part of the ongoing, Multicenter Swedish National Study on Aging and Care (SNAC), initiated by the government and the Ministry of Social Affairs. GÅS consists of individuals 60–96 years of age from the general population in five municipalities in southern Sweden, covering both rural and urban settings. The participants were randomly selected from a population register and invited by letter to attend the study, which aims to provide knowledge about factors affecting the health and the care needs of senior citizens.

The participants underwent medical examination performed by a physician, cognitive tests administered by a psychologist or specially trained test administrator and functional assessments taken by a registered nurse. All assessments were made according to a predefined research protocol and took place at the research outpatient clinic or in the participant's home. To avoid or minimize selection bias, home visits were offered to frail elderly and to persons that preferred home visits. The self-administered part was composed of questionnaires on socio-demographic data, informal caregiving, social network, physical and mental well-being and life satisfaction.

The first group of participants ($n = 2931$), divided into nine age cohorts 60, 66, 72, 78, 81, 84, 87, 90 and $\geq$93, were examined between the years 2001 and 2004, and re-examined with identical protocols every sixth year for participants aged 60 and 66 and every third year for participants 72 and older. The participation rate at first examination was 60% and at the re-examination of all age cohorts six years later, the participation rate was 81% ($n = 1834$). A new group of participants aged 60 and 81 years of age were included between the years 2007–2012 and the participation rate in this group was 66% ($n = 1528$). The same research protocols were used in both groups.

In our study, the population consists of participants from the re-examination and from the new group, $n = 3362$. Participants in need of formal care ($n = 255$) and/or assisted living for themselves ($n = 343$), or providing incomplete data in the outcome variables ($n = 162$), were excluded. Finally, the study population consisted of 2602 participants including 369 (14%) caregivers, in other words those helping a family member or friend with personal and/or instrumental activities of daily living.

2.2. Questionnaires

Socio-demographic variables included were informal caregiving, sex, age, marital status, place of residence, housing, education, social anchorage, social support and social participation, health locus of control and domains of symptoms.

Marital status was dichotomized into married/cohabitant or unmarried/widowed/living alone. Place of residence was dichotomized into rural or urban living, with the latter referring to participants living in a densely populated area or in the city center. Housing was divided into two categories based on whether the participants rented or owned their homes. Level of education was divided into three categories: elementary school or less, secondary school, or one or more years above secondary school.

To assess the participant's social network, a model developed by Hanson and Östergren was used (Krantz & Östergren, 2000). This model consists of three parts; social anchorage, social support and social participation.

Social anchorage was assessed by three questions: "Do you feel that you have a strong coherence with your relatives?" along with, "Are you rooted and do you feel you have a strong sense of coherence with your neighborhood?" as well as, "If you are a member of an organization, would you say that you feel a strong coherence with this organization and its members?" The alternative answers were; "very much" and "to some extent" categorized as yes, and "not particularly" and "not at all" categorized as no. If at least one answer out of the three questions was categorized as yes, the participant was regarded as socially anchored.

Social support was divided into instrumental and emotional support. Instrumental support was assessed by two questions: "Can you get help from someone in case of illness or with practical problems of any sort?" and "Do you know someone who can help you write an official letter or help you appeal decisions made by an authority?" Likewise, emotional support was assessed by two questions: "Do you feel that you have someone who can give you proper personal support and help you cope with life's stresses and problems?" and "Do you know someone that you can be yourself with, and who accepts you with your strengths and weaknesses?" The answers "very much" and "to some extent" were categorized as yes, and "not particularly" and "not at all" were categorized as no. If at least one answer was categorized as yes for instrumental or emotional support respectively, the participant was regarded as having instrumental and/or emotional support.

Social participation refers to a person's social, cultural and leisure-time activities in both formal and informal networks. The social activities included four questions regarding meeting friends/relatives, participation in study circles, non-profit organizations, and going to restaurants. Cultural activities included five questions about going to concerts, theatres/movies, museums and art exhibitions, shows/musicals and attending church services. Finally, leisure-time activities included four activities: taking long walks, gardening, repairing cars or mechanical equipment and domestic or foreign travel (Enkvist et al., 2012b; Ekström et al., 2013). Participants who had performed at least one activity during the past year were considered to be active.

Symptoms were recorded with a modified version of the Göteborg Quality of Life (GQoL) instrument (Tibblin, Bengtsson, Furunes, & Lapidus, 1990), which includes 30 common physical and mental symptoms experienced during the past 3 months. The symptoms were divided into the following seven domains: depressive symptoms, including exhaustion, sleep disturbance, general fatigue, feeling gloomy and down and tearful; tension, comprising symptoms of restlessness, difficulty in relaxing, impaired concentration, nervousness and irritability; gastro intestinal/urinary symptoms, including abdominal pain, constipation, diarrhea, nausea, anorexia and difficulty in passing urine; musculoskeletal symptoms comprising impaired mobility and pain in the legs, back and joints; symptoms including metabolic problems such as overweight, loss of weight, sweating and feeling cold; cardio-pulmonary symptoms comprising cough, chest-pain and breathlessness; and finally head symptoms, including dizziness, headache and impaired hearing (Tibblin et al., 1990). We added one symptom, "memory impairment" and made it a domain of its own. The answers in all eight domains were given in degrees of severity: "no, not at all," "yes, a little," "yes, quite a lot" and "yes, a lot," and dichotomized into either "no" or "yes" where "yes" included the three latter alternatives. To be categorized into a certain domain of symptoms, a participant had experienced at least one symptom from that domain during the past three months.

Health locus of control (HLC) (Wallston, Wallston, Kaplan, & Maides, 1976; Wallston, Wallston & De Vellis, 1978) refers to the extent to which a person believes that he or she can control events that affect their health. HLC contains three subscales measuring how individuals attribute their health to chance or fate (chance), to themselves (internal) or to powerful others (external). Every scale has six items and each item was assessed on a five-point rating scale ranging from 1 (do not at all agree) to 5 (agree very much), thus the total score ranged from 6 to 30, with a higher number indicating stronger beliefs in aspects of each respective subscale. One example of a statement is "If I take care of myself, I can avoid illness" (Ståhlbrand & Elmståhl, 2011).

Life satisfaction (LS) was measured by LSI-A (Neugarten et al., 1961). The LSI-A is multidimensional and consists of 20 attitude

Table 1
Comparison of numbers and proportions between (1) non-caregivers (control-group) and caregivers, and (2) between non-caregivers (control-group) and caregivers perceiving low or high strain; stratified by sex, age, marital status, place of residence, housing, education, social anchorage, social support, social participation, locus of control, domains of symptoms and time spent on caregiving.

Variables *n* (%)	Non-caregivers $n = 2233$	Caregivers $n = 369$	*p*-value[a]	Caregivers low strain $n = 236$	Caregivers high strain $n = 133$	*p*-value[a]
Sex						
Men	1013 (45)	165 (45)		110 (49)	47 (39)	
Women	1220 (55)	204 (55)	0.816	126 (51)	86 (61)	0.178
Age						
60–69 years	1278 (57)	257 (69)		168 (71)	89 (67)	
70–79 years	546 (25)	66 (18)		45 (19)	21 (16)	
≥80	409 (18)	46 (13)	<0.001	23 (10)	23 (17)	<0.001
Marital status						
Cohabiting	1399 (63)	264 (72)		166 (70)	98 (74)	
Single	834 (37)	105 (28)	0.001	70 (30)	35 (26)	0.004
Residence						
Rural	487 (22)	59 (16)		39 (17)	20 (15)	
Urban	1743 (78)	309 (84)	0.011	196 (83)	113 (85)	0.038
Housing						
Owner	1611 (72)	261 (71)		174 (74)	87 (65)	
Rental	622 (28)	108 (29)	0.576	62 (26)	46 (35)	0.199
Education						
Elementary school or less	944 (42)	121 (33)		81 (34)	40 (30)	
Secondary school	661 (30)	117 (32)		81 (34)	36 (27)	
University	613 (28)	131 (35)	0.001	74 (32)	57 (43)	<0.001
Social anchorage						
Yes	1843 (83)	316 (86)		207 (88)	109 (83)	
No	387 (17)	50 (14)	0.080	27 (12)	23 (17)	0.076
Social support						
Instrumental						
Yes	2180 (98)	363 (98)		235 (99)	128 (96)	
No	53 (2)	6 (2)	0.372	1 (1)	5 (4)	0.079
Emotional						
Yes	2185 (98)	360 (98)		231 (99)	129 (97)	
No	46 (2)	7 (2)	0.846	3 (1)	4 (3)	0.522
Social participation						
Social activities						
Yes	2146 (96)	357 (97)		232 (98)	125 (94)	
No	83 (4)	12 (3)	0.655	4 (2)	8 (6)	0.095
Cultural activities						
Yes	1971 (88)	337 (91)		218 (92)	119 (90)	
No	261 (12)	32 (9)	0.089	18 (8)	14 (10)	0.165
Leisure activities						
Yes	2048 (92)	345 (94)		224 (95)	121 (91)	
No	182 (8)	24 (6)	0.275	12 (5)	12 (9)	0.223
Locus of control						
Chance						
High	1265 (57)	174 (47)	109 (46)	65 (49)		
Low	966 (43)	194 (53)	0.001	127 (54)	67 (51)	0.003
Internal						
High	1275 (57)	202 (55)		131 (56)	71 (53)	
Low	954 (43)	167 (45)	0.377	105 (44)	62 (47)	0.626
External						
High	1165 (52)	169 (46)		106 (45)	63 (47)	
Low	1065 (48)	200 (54)	0.022	130 (55)	70 (53)	0.065
Domains of symptoms						
Depressive						
Yes	1721 (77)	300 (81)		182 (77)	118 (89)	
No	508 (23)	69 (19)	0.080	54 (23)	15 (11)	0.008
Tension						
Yes	1512 (68)	265 (72)		153 (65)	112 (84)	
No	720 (32)	104 (28)	0.119	83 (35)	21 (16)	<0.001
Gastro-intestine/urinary						
Yes	1000 (45)	173 (47)		104 (44)	69 (52)	
No	1232 (55)	195 (53)	0.430	132 (56)	63 (48)	0.232
Musculo-skeletal						
Yes	1602 (72)	260 (71)		151 (64)	109 (82)	
No	629 (28)	109 (29)	0.595	85 (36)	24 (18)	0.001
Metabolic						
Yes	1383 (62)	230 (62)		144 (61)	86 (65)	
No	849 (38)	139 (38)	0.595	92 (39)	47 (35)	0.780
Cardiopulmonary						
Yes	1051 (47)	1978 (48)		105 (45)	73 (55)	
No	1182 (53)	191 (52)	0.676	131 (55)	60 (45)	0.145
Related to head						
Yes	1353 (61)	224 (61)		140 (59)	84 (63)	
No	872 (39)	145 (39)	0.970	96 (41)	49 (37)	0.769
Memory impairment						

Table 1 (*Continued*)

Variables *n* (%)	Non-caregivers *n* = 2233	Caregivers *n* = 369	*p*-value[a]	Caregivers low strain *n* = 236	Caregivers high strain *n* = 133	*p*-value[a]
Yes	877 (39)	124 (34)		74 (31)	50 (38)	
No	1355 (61)	245 (66)	0.038	162 (69)	83 (62)	0.057
Time spent on caregiving						
Once a week or less	–	–		138 (61)	50 (39)	
Several times a week	–	–	–	88 (39)	77 (61)	<0.001

[a] Significance tested with Chi-squared test.

items covering five domains of life satisfaction: zest (vs. apathy), resolution and fortitude, congruence between desired and achieved goals in life, self-concept and mood tone. The instrument was constructed with the intention of being without time restriction, including questions covering past and present time as well as the future, for example "As I look back on my life, I am fairly well satisfied and I expect some interesting and pleasant things to happen to me in the future." Each question can be answered by "disagree," "doubtful" and "agree," and the sum score ranges from 0 to 40. A high score indicates high life satisfaction. Validity and reliability for internal consistency were established by Neugarten et al. (1961). These results have been confirmed in later studies by Lobello, Underhill, and Fine (2004) with Cronbach's α ranging from 0.85 to 0.92, and in a meta-analysis of 34 different studies using LSI instruments, where the average reliability was 0.79 with a range between 0.42 and 0.98 (Wallace & Wheeler, 2002).

Short Form Health Survey (SF12) is a generic instrument including 12 items measuring health related quality of life (HRQoL). Six items are summed into a physical component summary (PCS) from the four domains of general health, physical function, physical role limitation and bodily pain, and six items are summed into a mental component summary (MCS) including the four domains of role limitation, vitality, social function and mental health. The total score for both scales ranges from 0 to 100, with a higher number indicating higher HRQoL. The SF12 is well-documented as a HRQoL instrument and it has been evaluated for both reliability and validity (Sullivan, Karlsson, & Ware, 1995; Ware, Kosinski, & Keller, 1996; Gandek et al., 1998). Sullivan, Karlsson, & Taft (1997) have established norm values stratified for age and sex for the SF12 in the general Swedish population.

Whether the participants were informal caregivers was assessed by the question; "Do you provide help to a family member or a friend because of illness?" Whether the caregiver and care recipient shared the same household was assessed, as was the amount of hours per week spent on caregiving, including assisting with IADL and PADL.

The extent of time spent on caregiving was assessed by the question: "How often do you assist the person in need of your help?" The answers were "less than once a week," "approximately once a week," "two to three times per week," "four to six times a week" and "every day." The answers "less than once a week" and "approximately once a week" were categorized as approximately once a week, and "two to three times a week," "four to six times a week" and daily were categorized as several times a week.

Caregivers' perceived strain was assessed by one question; "Do you feel strained by the caregiving situation?" The alternative answers were: "not at all," "not particularly," "to some extent," "much so" and "very much so." The answers "not at all" and "not particularly" were categorized as no and defined as low strain and "to some extent," "much so" and "very much so" were categorized as yes and defined as high strain.

2.3. Ethics

The study was conducted in accordance with the Helsinki Declaration and approved by the regional ethics committee at Lund University, registration no. LU 744-00. All participants provided a written consent to participate and to allow retrieval of information from the National Patient Register medical records.

2.4. Statistical methods

Comparisons of proportions stratified by age, sex, place of dwelling, housing, education, social anchorage, social support, social participation, health locus of control and perceived symptoms between (1) non-caregivers and caregivers and (2) non-caregivers and caregivers perceiving low or high strain, were tested with the Chi-squared test (Table 1).

Means and standard deviations of SF12-PCS, SF12-MCS and LSI-A were calculated for non-caregivers, total number of caregivers, and caregivers perceiving low or high strain respectively. Differences in means of SF12 and LSI-A between non-caregivers and total number of caregivers were tested with Student's *T*-test and between non-caregivers and caregivers perceiving low or high strain with analysis of variance (ANOVA), (Table 2). In all post hoc analyses comparing non-caregivers with caregivers, and non-caregivers with caregivers perceiving high or low strain, and finally between caregivers stratified for strain, Student's *T*-test was used.

In order to evaluate possible associations between being a caregiver (total number) and caregivers perceiving low or high strain and levels of SF12-PCS, SF12-MCS, LSI-A, two separate standard multiple linear regression models were constructed and B-coefficients calculated. All regression models were adjusted for age, sex,

Table 2

Comparison of mean scores for the Physical Component Summary (PCS) and Mental Component Summary (MCS) (total score range 0–100) of the 12-item Short Form Health Survey (SF-12), and Life Satisfaction Index-A (LSI-A) (total score range 0–40) between (1) control-group and caregivers and (2) between control group and caregivers with low or high perceived strain.

Variables	Non-caregivers *n* = 2233 Mean (SD)	Caregivers *n* = 369 Mean (SD)	*p*-value	Caregivers low strain *n* = 236 Mean (SD)	Caregivers high strain *n* = 133 Mean (SD)	*p*-value
SF-12 PCS	45.2 (9.2)	45.7 (9.3)	0.319	46.7 (8.8)^{a}	43.9 (9.9)^{a}	0.014
SF-12 MCS	54.5 (7.8)^{B}	53.6 (8.3)	0.042	55.0 (7.4)^{C}	51.2 (9.1)^{B,C}	<0.001
LSI-A	28.6 (6.7)^{d,E}	28.6 (7.1)	0.989	29.8 (6.5)^{d,F}	26.6 (7.8)^{E,F}	<0.001

Notes: post hoc analysis: lower case letters denote significance at the level of $p < 0.05$ and capital letters at a level of $p < 0.001$.

Table 3

Standard multiple linear regression analysis with the Mental Component Summary (MCS) and Physical Component Summary (PCS) of the 12-item Short Form Health Survey (SF-12), and Life Satisfaction Index-A (LSI-A) as dependent variables, and caregivers' sex, age, marital status, residence, housing, education, social participation, locus of control and domains of symptoms as independent variables ($n = 2549$).

Variables	SF-12 PCS B-coeff	*p*-value	SF-12 MCS B-coeff	*p*-value	LSI-A B-coeff	*p*-value
Caregivers	0.466	0.292	−0.620	0.114	−0.359	0.271
Sex (women)	−0.347	0.286	−0.725	0.012	0.292	0.223
Age						
70–79	2.339	<0.001	1.917	<0.001	−1.160	0.580
≥80	−1.043	0.028	1.292	0.002	−0.078	0.824
Marital status (cohabiting)	0.027	0.938	0.938	0.002	2.208	<0.001
Residence (urban)	0.312	0.417	−0.104	0.761	−0.168	0.551
Housing (rental)	−0.847	0.019	-0.819	0.011	−0.785	0.003
Education						
Secondary school	−0.384	0.311	−0.139	0.678	0.530	0.057
University	−0.109	0.797	−0.477	0.183	0.966	0.001
Social anchorage (yes)	1.065	0.012	0.905	0.016	2.276	<0.001
Social support (yes)						
Emotional	0.019	0.987	4.930	<0.001	4.102	<0.001
Instrumental	0.551	0.619	−0.886	0.367	−0.328	0.687
Social participation						
Social activities	1.260	0.167	2.560	0.002	1.418	0.034
Cultural activities	1.431	0.009	1.066	0.028	1.741	<0.001
Leisure activities	4.118	<0.001	2.461	<0.001	2.162	<0.001
Locus of control (high)						
Chance	−0.145	0.667	−0.392	0.189	−0.763	0.002
Internal	1.496	<0.001	1.109	<0.001	0.864	<0.001
Power	−0.968	0.005	0.475	0.122	0.393	0.123
Domains of symptoms						
Depression	−1.272	0.006	−0.752	0.065	−0.868	0.010
Tension	−0.131	0.743	−3.444	<0.001	−2.269	<0.001
Gastro-urinary	−1.903	<0.001	−2.344	<0.001	−1.574	<0.001
Musculoskeletal	−4.457	<0.001	0.132	0.692	−0.701	0.012
Metabolic	−1.220	0.001	−0.711	0.027	−0.633	0.017
Cardiopulmonary	−2.055	<0.001	−0.578	0.062	−0.286	0.266
Head symptoms	−1.315	<0.001	−0.479	0.134	−0.807	0.002
Memory impairment	−0.416	0.249	−1.222	<0.001	−0.882	0.001
R^2	0.299		0.247		0.307	

place of dwelling, housing, education, social anchorage, social support, social participation, health locus of control and perceived symptoms (Tables 3 and 4). Due to high collinearity between the variables "perceived strain" and "time spent on caregiving" (VIF > 5), the latter variable was excluded in the regression analysis. In all regression models the residuals were normally distributed and no multi-collinearity between explanatory variables was noted. Level of significance was set to $p < 0.05$ and all tests were two-sided. Analyses were performed using the SPSS software version 20 (IBM Corporation, Armonk, NY, US.

3. Results

3.1. Characteristics of study population

Three hundred and sixty-nine caregivers and 2233 non-caregivers were included.

The proportion of women in the groups of caregivers and non-caregivers was equal (55%). A larger proportion of younger participants were found among the group of caregivers than among non-caregivers (mean 67.2 years [SD = 7.9] vs. 69.4 [SD = 8.8], $p < 0.001$). Further, caregivers were more often cohabiting than non-caregivers (72%, 63% respectively, $p = 0.001$). Urban living was more common among caregivers (84%, vs. 78%, $p = 0.011$) and a larger proportion of caregivers had attended university compared to non-caregivers (35% vs. 28%, $p = 0.001$) (Table 1).

HLC between caregivers and non-caregivers differed in the subscales of chance and powerful others, where caregivers rated a lower score compared to non-caregivers, 47% vs. 57% ($p = 0.001$) and 46% vs. 52% ($p = 0.022$), respectively (Table 1).

The proportion of individuals that experienced at least one symptom during the past three months within each respective domain did not differ significantly between caregivers and non-caregivers. However, after dichotomizing caregivers in terms of strain, 36% reported high strain. A significantly larger proportion of caregivers perceiving high strain, compared to non-caregivers, had depressive domain symptoms (89% vs. 77%, $p = 0.008$), tension (84% vs. 65%, $p < 0.001$) and musculoskeletal symptoms (82% vs. 64%, $p = 0.001$) (Table 1).

Time spent on caregiving differed between the two groups of caregivers. Highly strained caregivers spent more time on caregiving than caregivers experiencing low strain (61% vs. 39% $p < 0.001$) (Table 1).

One hundred and sixteen caregivers (37%) lived with the care recipient.

A majority (81%) of the caregivers provided IADL, and 19% provided both IADL and PADL. In the group of caregivers providing IADL, adult children assisting a parent composed the largest group (40%), followed by those assisting a spouse or partner (31%), assisting "others" such as siblings or friends (22%) and parents assisting a child (6%). Caregivers providing both IADL and PADL were mostly spouses or partners (61%). In both groups, the hours

Table 4
Standard multiple linear regression analysis with the Physical Component Summary (PCS) and Mental Component Summary (MCS) of the 12-item Short Form Health Survey (SF-12) and Life Satisfaction Index-A (LSI-A) as dependent variables, and caregivers' perceived strain, sex, age, marital status, residence, housing, education, social participation, locus of control and domains of symptoms as independent variables ($n = 2549$).

Variables	SF-12 PCS B-coeff	*p*-value	SF-12 MCS B-coeff	*p*-value	LSI-A B-coeff	*p*-value
Caregivers						
Low percived strain	0.393	0.421	−0.127	0.768	0.082	0.819
High percived strain	0.035	0.972	−3.590	<0.001	−2.791	<0.001
Sex (women)	−0.345	0.290	−0.701	0.015	0.318	0.183
Age (decade)						
70–79	2.332	<0.001	1.905	<0.001	−0.176	0.543
≥80	−1.050	0.027	1.300	0.002	−0.078	0.823
Marital status (cohabiting)	0.021	0.952	0.976	0.001	2.222	<0.001
Residence (urban)	0.320	0.404	−0.087	0.799	−0.149	0.597
Housing (rental)	−0.843	0.020	−0.791	0.013	−0.774	0.003
Education						
Secondary school	−0.379	0.317	−0.149	0.671	0.529	0.057
University	−0.100	0.804	−0.449	0.208	1.003	0.001
Social anchorage (yes)	1.068	0.012	0.860	0.022	2.244	<0.001
Social support (yes)						
Emotional	0.016	0.989	4.939	<0.001	4.113	<0.001
Instrumental	0.547	0.622	−0.997	0.309	−0.418	0.607
Social participation						
Social activities	1.249	0.171	2.502	0.002	1.368	0.041
Cultural activities	1.436	0.009	1.085	0.025	1.759	<0.001
Leisure activities	4.111	<0.001	2.391	<0.001	2.109	<0.001
Locus of control (high)						
Chance	−0.153	0.651	−0.401	0.179	−0.781	0.002
Internal	1.498	<0.001	1.126	<0.001	0.886	<0.001
Power	−0.964	0.005	0.479	0.118	0.414	0.103
Domains of symptoms						
Depression	−1.270	0.006	−0.758	0.063	−0.878	0.009
Tension	−0.122	0.760	−3.403	<0.001	−2.231	<0.001
Gastro-urinary	−1.897	<0.001	−2.329	<0.001	−1.554	<0.001
Musculoskeletal	−4.454	<0.001	0.164	0.624	−0.669	0.016
Metabolic	−1.225	0.001	−0.728	0.023	−0.644	0.015
Cardiopulmonary	−2.051	<0.001	−0.591	0.056	−0.288	0.262
Head symptoms	−1.310	<0.001	−0.463	0.147	−0.786	0.003
Memory impairment	−0.424	0.241	−1.236	<0.001	−0.906	0.001
R^2	0.299		0.251		0.313	

per week spent on caregiving were: md = 5.0 ($q1 = 2.0$, $q3 = 10.3$), range = 1–129 h, $n = 306$).

3.2. Health related quality of life and life satisfaction

The mean score for SF12-MCS was significantly lower for caregivers (53.6 [SD = 8.3]) compared to non-caregivers (54.5 [SD = 7.8], $p = 0.042$), while no significant differences were found for SF12-PCS and LSI-A (Table 2).

In a three-group comparison including non-caregivers and caregivers perceiving low or high strain, significant differences were found for all three outcome variables SF12-PCS ($p = 0.014$), SF12-MCS ($p = <0.001$) and LSI-A ($p = <0.001$), where caregivers perceiving high strain showed the lowest mean scores in all three outcome measures (Table 2).

A post hoc analysis comparing non-caregivers and caregivers perceiving low strain found no significant differences in SF12-PCS, SF12-MCS. However, for LSI-A the mean score for non-caregivers was significantly lower compared to the mean score for caregivers with low strain (d in Table 2).

Further comparing non-caregivers with caregivers perceiving high strain showed significant differences in means for SF12-MCS and for LSI-A (B and E, respectively, in Table 2).

Finally, differences between mean scores comparing caregivers with low and high strain were significant for both SF12 subscales (a and C), and LSI-A (F, Table 2).

In the adjusted regression analyses with caregiving as the explanatory variable and SF12-PCS, SF12-MCS and LSI-A as dependent variables, caregiving was not significantly associated with any of the outcome measures (Table 3).

In the adjusted regression models where caregiving as the explanatory variable was dichotomized into high or low strain, high strain was significantly associated with levels of SF12-MCS ($B = -3.59$; $p < 0.001$, $R^2 = 0.251$) and LSI-A ($B = -2.79$; $p < 0.001$, $R^2 = 0.313$) (Table 4).

4. Discussion

4.1. Results

Looking at the first objective of this paper, we found several socio-demographic differences between non-caregivers and caregivers. The caregivers were younger, more often cohabiting, had a higher level of education and lived more often in urban settings than non-caregivers. Some of these characteristics might mitigate the difficulty of being a caregiver for persons aged 60 and over. In a study by McCann, Herbert, Bienias, Morris, and Evans (2004) on predictors of beginning and ending the role of being a caregiver, marital status, age and sex were associated with the decision to become a caregiver, and these factors were also important for continuing as a caregiver.

We found no differences between sexes in our study; the percentages of men and women among non-caregivers and caregivers were identical. Neither did we find any differences between the groups regarding social network, which surprised us. Findings from The National Alliance for Caregiving (2009) revels that more than 50% of all caregivers feel that they have less time to spend with family and friends. In the report from The Swedish National Board of Health and Welfare (2012a), almost 40% of the caregivers stated that they sometimes or often find it difficult to have the time to meet friends and family. We had anticipated a similar pattern among the caregivers in our study group. The fact that the caregivers referred to in the reports from the US and Sweden were ages 18 and older might be one possible explanation of these different findings.

McCann et al. (2004) also found that persons in good physical health were more likely to become caregivers and to continue being caregivers. We found no significant differences between non-caregivers and caregivers in perceived symptoms except for the domain including memory impairment, in which a larger proportion of non-caregivers reported symptoms. When dichotomizing caregivers in terms of strain, 36% reported high strain, and a significantly larger proportion of caregivers perceiving high strain reported depressive symptoms, tension and musculoskeletal symptoms (Table 1). This is in line with findings by Buyck et al. (2011) demonstrating that caregivers experiencing high burden also report worse general health and more mental and physical symptoms.

In identifying the differences in HRQoL and LS between non-caregivers and caregivers, the only significant difference found was in SF12-MCS (Table 2), indicating poorer perceived mental health related quality of life among caregivers. These results are consistent with numerous previous findings. Bruvik et al. (2012) found that depression in caregivers to persons with dementia negatively affected the caregivers' quality of life, especially if the caregiver was living with the care recipient. Findings by Pinquart and Sörenson (2011) based on a meta-analysis comparison between spouses, adult children and children-in-law acting as caregivers to persons with different diagnoses revealed that spouse caregivers reported more symptoms of depression and lower levels of psychological well-being compared to adult children and children-in-law. One explanation given was that caregivers living with the care recipient provided more care. Schultz and Sherwood (2008) state that depression is common and has a negative effect on the caregiver, especially among spouses caring for a person with dementia, and that caregiving often results in chronic stress.

Fauth et al. (2012) studied the caregivers' relationship closeness with the person with dementia before and after the onset of the disease, and its consequences for caregivers' psychological and physical well-being. They found that higher closeness before the onset of dementia was associated with higher SF12-MCS but also a worsening in the SF12-MCS over time, indicating that closeness has both positive and negative consequences for the caregiver. We have no knowledge about the closeness between caregivers and care recipients in our study, but we know that four out of ten caregivers lived with the care recipient. The lack of important information on the closeness between caregiver and care recipient could have influenced our results. Furthermore, we have no information on whether the decision to become a caregiver was made willingly and in agreement with the care recipient or whether the caregiver was retired; these factors might affect the caregiver's HRQoL and LS.

This leads us to our second objective to describe differences between non-caregivers and caregivers stratified for level of strain. In this study, perceived strain is highly correlated with time spent on caregiving. This means that time spent on caregiving could also determine levels of HRQoL and LS. However, our main objective was to study strain, although time spent on caregiving and its relation to strain, could be an interesting topic to explore in future studies.

When we dichotomized the caregivers into low (64%) vs. high (36%) perceived strain, significant differences were shown for all three outcome variables (SF12-PCS, SF12-MCS and LSI-A), (Table 2). In analyzing the relation between the outcome variables and the caregivers' perceived strain in a multiple linear regression model adjusting for confounders, the association between high perceived strain and levels of SF12-MCS and LSI-A remained significant ($p < 0.001$ vs. $p < 0.001$), (Table 4).

Furthermore, caregivers reporting high perceived strain report higher proportions of symptoms of depression, tension and musculoskeletal problems such as pain and impaired mobility (Table 1). These domains reflect different aspects of HRQoL. Enkvist et al. (2012a) found that symptoms in the above domains had a significant influence on LS in persons older than 78 years of age. The caregivers in our study are younger (mean 67.2 years of age), but nevertheless, the caregivers reporting high strain reported lower ratings in both HRQoL and LS.

Another factor that might mitigate the strain of being a caregiver is a strong sense of being in control of one's own health. We found that HLC differed between the groups in the subscales of chance and powerful others, with caregivers reporting a lower score compared to non-caregivers, indicating a more positive attitude among caregivers towards the ability to cope with health-related issues (Table 1).

When studying the differences between non-caregivers and caregivers with low reported strain, we made an interesting discovery. Caregivers with low strain reported higher scores on SF12-MCS and LSI-A compared to non-caregivers (Table 2), indicating a better HRQoL and LS. Other authors have made the same discovery regarding caregivers' quality of life. Buyck et al. (2011) and Roth et al. (2009) reported that caregiving can have a positive impact on the caregivers' health, as long as the strain is not too great. However, in a recently published study by Thomas, Saunders, Roland, and Paddison (2015) including a large sample of caregivers, no evidence for health benefits were found. More research is needed to explore these diverging results.

Life satisfaction has to our knowledge only been investigated once before in this context. Broe et al. (1999) found that caregivers providing PADL who also felt controlled by the person they cared for experienced lower levels of LS. Our results showing better self-rated LS among caregivers experiencing low strain than among non-caregivers are interesting. We can only speculate on the reasons why. Enkvist et al. (2012a) describe the associations between low LS and low functional ability in terms of self-rated activities of daily living related to scores on the GQoL instrument. The post hoc analysis comparison in our study (not shown) between non-caregivers and caregivers perceiving low strain, showed a significant difference in SF12-PCS, indicating that the caregivers in this subgroup had better perceived physical health than non-caregivers. As previously discussed, McCann et al. (2004) found that persons in good physical health were more likely to become caregivers and to continue being caregivers. It is possible that in our study the caregivers perceiving low strain were healthier before they began to provide care, and that this characteristic was essential to the decision to become a caregiver. Another possible explanation mentioned by Pinquart and Sörenson (2011) is that caregivers who are spouses are "a positively selected group of relatively healthy older adults who are physically able to provide care" (Pinquart & Sörenson, 2011). These findings stress the importance of assessing different aspects of caregiving strain such as physical and psychological strain, emotional involvement and social factors. Further, they highlight the importance of helping caregivers to maintain activities of importance for them and to find strategies to mitigate strain.

Previous studies by Andrén and Elmståhl (2008b) and Dahlrup, Nordell, Andrén, and Elmståhl (2011), including results of an intervention consisting of psychosocial education and support groups of caregivers to persons with dementia, have shown positive outcomes regarding the caregivers' perceived burden, satisfaction and knowledge. A systematic review by The Swedish National Board of Health and Welfare (2012b) including sixteen international studies on the effects of interventions aimed to support caregivers, endorses these findings.

5. Methods

To our knowledge, this is the first cross-sectional study of an elderly population addressing caregiver's perceived strain and its influences on both their HRQoL and LS.

The study sample was randomly selected from the National Population Registry with participants from different parts of the district of Skåne in southern Sweden, covering both rural and urban areas. All assessments were made according to a predefined research protocol.

The study is based on a group of persons ages 60 and older. This age limit excludes a large number of younger caregivers, mainly adult children caring for elderly parents and parents-in-law, and this must be taken into consideration. In studies including a younger population, adult children are the largest group of family caregivers (Lüdecke et al., 2012; The National Board of Health and Welfare, 2012a; The National Alliance for Caregiving, 2009; Pinquart & Sörenson, 2011).

The participation rate in the re-examination consisting of participants from all nine age-cohorts was 81%. In the group recruited later, consisting of two age cohorts, persons aged 60 and 81, the participation rate was 66%. Although home visits were offered to frail persons and to those preferring this alternative, it is often the healthiest part of a population that agrees to take part in this kind of survey. This can of course create a selection bias which might dilute observed associations.

Not everyone who cares for family and friends identify themselves as caregivers, mostly because they do not find the word "caregiver" suitable. They may see their actions as simply giving help and support to family members and friends, even though this help can be both burdensome and time consuming and may include caregiving 24 h a day, 7 days a week. This might mean that the number of caregivers among the participants in GÅS may be greater than the number detected with our questions. A report by Mori (2011) based on interviews with 386 caregivers of persons with cancer showed that only 43% consider themselves to be caregivers. This is an interesting finding and must be addressed in studies and in the way we formulate questions in questionnaires.

Perceived strain was assessed with a single question and the answers were categorized as yes (high strain) or no (low strain). This of course limits our ability to delve deeper into various aspects of strain and its consequences on LS and HRQoL. In future studies, a more extensive instrument should be used in order to detect strain and the underlying causes of strain among caregivers.

The instruments used in the study (SF12-MCS, SF12-PCS, Sullivan et al., 1995; Ware et al., 1996; Gandek et al., 1998 and LSI-A Neugarten et al., 1961), are well-known and tested for reliability and validity. When we compare the result on SF12 to the norm for the general Swedish population ages 65–74 established by Sullivan et al. (1997), we find that both caregivers and non-caregivers in our study (mean age 67.2 [SD = 7.9]), scored slightly higher in SF12-PCS; 45.7 (SD 9.3) and 45.2 (SD 9.2) compared to the norm of 44.5 (SD 10.4). Regarding the scores on SF12-MCS, caregivers and non-caregivers both had scores similar to the norm values, 53.6 (SD = 8.3), and 54.5 (SD = 7.8) vs. 53.7 (SD = 10.2), respectively (Sullivan et al., 1997). The fact that the study group scored slightly higher could be explained by better health in subjects willing to participate in studies than in the average population.

As mentioned, the number of caregivers in our study might be under-representative due to the fact that some individuals do not identify themselves as caregivers and as a consequence do not answer the questions in the survey. These undiscovered caregivers will answer questions on HRQoL and LS as non-caregivers and this may create a misclassification bias.

Other limitations are undoubtedly the lack of information about the caregivers' willingness to become a caregiver and whether they were retired, circumstances that could influence perceived strain as well as HRQoL and LS. We also lack information on the feeling of closeness between caregiver and care recipient. Fauth et al. (2012) found that closeness has both positive and negative consequences for the caregiver. In a study by Iecovich (2011), the relationship quality was the most significant variable in explaining both burden and satisfaction in the caregiver role. The quality of the relationship is often a more difficult dimension to study and requires a different methodological approach, such as a qualitative study design. Further studies using well-established instruments might be able to capture this dimension of the caregiving role.

6. Conclusions

The somewhat different approach chosen for this paper, studying the caregivers' perceived strain in relation to their HRQoL and LS and comparing the findings within the group of caregivers with a large group of matched controls, has revealed new knowledge. We found that nearly forty percent of caregivers experienced high strain. We also found an association between high strain and lower HRQoL and LS.

These findings can prompt us to intervene when caregivers express strain and help them reduce or maintain an acceptable level of strain. This could in turn reduce the demand for nursing home care or at least, delay the transition to nursing home care, which has been shown in previous studies by Andrén and Elmståhl (2008b).

In our experience, caregivers often come into contact with primary health care and hospital care for their own health problems and those of the care recipients, and much later in the process come into contact with the municipality when seeking help with caregiving. It is therefore important for the health care sector to consider the possibility that various symptoms in a person acting as a caregiver can be related to high perceived strain. A general policy program aiming to identify caregivers and their individual needs for support at an early stage is much needed. This however, requires that we are able to identify caregivers by asking the correct questions.

Financial disclosure

Good Aging in Skåne (GÅS) is supported by the Swedish Ministry of Health and Social Affairs, the county Skåne and the Medical Faculty at Lund University.

Conflict of interest

The authors declare no conflicts of interest in this study.

Acknowledgements

We would like to express our gratitude to Johanna Douhan and Zinka Tusek for their invaluable help in detecting missing data, to Ole Larsen for computer support and to Helen Legrand for revising the English.

References

Al-Windi, A. (2005). The relations between symptoms, somatic and psychiatric conditions, life satisfaction and perceived health. A primary care based study. *Health Qual Life Outcomes 3*, 28. http://dx.doi.org:10.1186/1477-7525-3-28.

Andrén, S., & Elmståhl, S. (2005). Family caregivers' subjective experiences of satisfaction in dementia care: Aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Sciences*, *19*, 157–168.

Andrén, S., & Elmståhl, S. (2008a). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing*, *17*, 790–799.

Andrén, S., & Elmståhl, S. (2008b). Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: A five-year follow-up study. *International Psychogeriatrics 20*, 1177–1192. http://dx.doi.org:10.1017/S1041610208007503.

Bowers, B. J. (1987). Intergenerational caregiving: Adult caregivers and their aging parents. *ANS Advances in Nursing Science*, *9*, 20–31.

Broe, G., Jorm, A., Creasey, H., Casey, B., Bennet, H., Cullen, J., Edelbrock, D., Waite, L., & Grayson, D. (1999). Carer distress in the general population: Results from the Sydney older persons study. *Age and Ageing*, *28*, 307–311.

Bruvik, F. K., Ulstein, I. D., Hylen Ranhoff, A., & Engedal, K. (2012). The quality of life of people with dementia and the family carers. *Dementia and Geriatric Cognitive Disorders 34*, 7–14. http://dx.doi.org:10.1159/000341584.

Buyck, J.-F., Bonnaud, S., Boumendil, A., Andrieu, S., Bonenfant, S., Goldberg, M., Zins, M., & Ankri, J. (2011). Informal caregiving and self-reported mental and physical health: Results from the gazel cohort study. *American Journal of Public Health 101*, 1971–1979. http://dx.doi.org:10.2105/AJPH2010.3000044.

Collins, L. G., & Swartz, K. (2011). Caregiver care. *American Academy of Family Physician*, *8*, 1309–1317.

Courtin, E., Jemiai, N., & Mossialos, E. (2014). Mapping support policies for informal caregivers across the European Union. *Health Policy 118*, 84–94. http://dx.doi.org:10.1016/j.healthpol.2014.07.013.

Dahlrup, B., Nordell, E., Andrén, S., & Elmståhl, S. (2011). Family caregivers' assessment of symptoms in persons with dementia using the GBS-scale, differences in rating after psychosocial intervention—An 18 month follow-up study. *Clinical Interventions in Aging 6*, 9–18. http://dx.doi.org:10.2147/CIA.S14237.

Ekström, H., & Elmståhl, S. (2006). Pain and fractures are independently related to lower walking speed and grip strength: Results from the population study Good Ageing in Sköne. *Acta Orthopedica 77*, 902–911. http://dx.doi.org:10.1080/17453670610013204.

Ekström, H., Dahlin Ivanoff, S., & Elmståhl, S. (2013). Does informal support influence social participation of fractured elderly people? *Archives of Gerontology and Geriatrics 56*, 455–457. http://dx.doi.org:10.1016/j.archger.2012.11.010.

Enkvist, Å., Ekström, H., & Elmståhl, S. (2012a). What factors affect life satisfaction (LS) among the oldest-old? *Archives of Gerontology and Geriatrics 54*, 140–145. http://dx.doi.org:10.1016/j.archger.2011.03.013.

Enkvist, Å., Ekström, H., & Elmståhl, S. (2012b). Associations between functional ability and life satisfaction in the oldest old: Results from the longitudinal population study Good Aging in Skåne. *Clinical Interventions in Aging 7*, 313–320. http://dx.doi.org/10.2147/CIA.S45382.

Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging and Mental Health 16*, 699–711. http://dx.doi.org/10.1080/13607863.2012.678482.

Gandek, B., Ware, J. E., Aaronson, N. K., Apolone, G., Bjorner, J. B., Brazier, J. E., Bullinger, M., Kaasa, S., Leplege, A., Prieto, L., & Sullivan, M. (1998). Cross-validation of item selection and scoring for SF-12 health survey in nine countries: Result from the IQOLA project. *Journal of Clinical Epidemiology*, *11*, 1171–1178.

Iecovich, E. (2011). Quality of relationships between care recipients and their primary caregivers and its effect on caregivers' burden and satisfaction in Israel. *Journal of Gerontological Social Work 54*, 570–591. http://dx.doi.org:10.1080/01634372.2011.579691.

Johansson, L., Long, H., & Parker, M. G. (2011). Informal caregiving for elders in Sweden: An analysis of current policy developments. *Journal of Aging & Social Policy 23*, 335–353. http://dx.doi.org/10.1080.08959420.2011.605630.

Krantz, G., & Östergren, P.-O. (2000). Common symptoms in middle aged women; their relation to employment status, psychosocial work conditions and social support in a Swedish setting. *Journal of Epidemiology & Community Health*, *54*, 192–199.

Ekwall, A. K., Sivberg, B., & Rahm Hallberg, I. (2006). Older caregivers' coping strategies and sense of coherence in relation to quality of life. *Journal of Advanced Nursing 57*, 584–596. http://dx.doi.org/10.1111/j.1365-2648.2006.03994.x.

Lautenschlager, N. T., Kurz, A. T., Loi, S., & Cramer, B. (2012). Personality of mental health caregivers. *Current Opinion in Psychiatry 26*, 97–101. http://dx.doi.org/10.1097/YCO.0b013e32835997b3.

Lagergren, M., Fratiglioni, L., Rahm-Hallberg, I., Berglund, J., Elmståhl, S., Hagberg, B., Holst, G., Rennemark, M., Sjölund, B.-B., Thorslund, M., Wiberg, I., Winblad, B., & Wimo, A. (2004). A longitudinal study, integrating population and care and social service data—The Swedish National study on Ageing and Care (SNAC). *Aging Clinical and Experimental Research*, *16*, 158–168.

Lobello, S. G., Underhill, A. T., & Fine, P. R. (2004). The reliability and validity of the Life Satisfaction Index-A with survivors of traumatic brain injury. *Brain Injury 18*, 1127–1132. http://dx.doi.org/10.1080/02699050410001672378.

Lüdecke, D., Mnich, E., & Kofahl, C. (2012). The impact of sociodemographic factors on the utilisation of support services for family caregivers of elderly dependents—Results from the German sample of the EUROFAMCARE study. *GMS Psycho-Social-Medicine 9*, 1–11. http://dx.doi.org/10.3205/psm000084.

McCann, J. J., Herbert, L. E., Bienias, J. L., Morris, M. C., & Evans, D. A. (2004). Predictors of beginning and ending caregiving during a 3-year period in a biracial community population of older adults. *American Journal of Public Health*, *94*, 1800–1806.

Mori, I. More than a million. Understanding the UK's carers of people with cancer—A report by Ipsos Mori for Macmillan Cancer Support. (2011). http://www.macmillan.org.uk/Documents/Cancerinfo/Ifsomeoneelsehascancer/More_than_a_million.pdf Assessed May, 2015.

Neugarten, B. L., Havighurst, R. J., & Tobin, S. S. (1961). The measurement of life satisfaction. *The Journals of Gerontology*, *16*, 134–143.

Pinquart, M., & Sörenson, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging 26*, 1–14. http://dx.doi.org/10.1037/a0021863.

Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults. *Quality of Life Research 18*, 679–688. http://dx.doi.org/10.1007/s11136-009-9482-2.

Roth, D. L., Haley, W. E., Hovater, M., Perkins, M., Wadley, V. G., & Judd, S. (2013). Family caregiving and all-cause mortality: Findings from a population-based propensity-matched analysis. *American Journal of Epidemiology 178*, 1571–1578. http://dx.doi.org/10.1093/aje/kwt225.

Schultz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing 108*, 23–27. http://dx.doi.org/10.1097/01.NAJ.0000336406.45248.4c.

Ståhlbrand, S. I., & Elmståhl, S. (2011). *The relation between personality and life satisfaction in four groups of elders. Manuscript from a doctoral dissertation.* Department of Psychology, Lund University.

Sullivan Karlsson, M. J., & Ware, J. E. Jr (1995). The Swedish SF-36Health Survey-I. Evaluation of data quality, scaling, assumptions, reliability and construct validity across general populations in Sweden. *Social Science & Medicine*, *41*, 1349–1358.

Sullivan, M., Karlsson, J., & Taft, C. (1997). *SF-12Hälsoenkät. Svensk manual. (SF-12Health Questionnaire Swedish Manual).* Göteborg: Health Care Research Unit, Medical Faculty (In Swedish)..

The National Alliance for Caregiving. Caregiving in the U.S.A. A Focused Look at Those Caring for Someone Age 50 or older. (2009). http://www.caregiving.org/data/FINALRegularExSum50plus.pdf Assessed 11.07.14.

The National Board of Health and Welfare. Anhöriga som ger omsorg till närstående—Omfattning och konsekvenser. (2012a). Available in Swedish from http://www.socialstyrelsen.se/publikationer2012/2012-8-15 Assessed 10.07.14.

The National Board of Health and Welfare. Effekter av stöd till anhöriga som vårdar äldre med demenssjukdom eller sköra äldre. (2012b) Available in Swedish with a summary in English from http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18917/2012-12-17.pdf Assessed 10.07.14.

Thomas, G., Saunders, C., Roland, M., & Paddison, C. (2015). Informal carer' health-related quality of life and patient experience in primary care: Evidence from 195,364 carers in England responding to a national survey. *BMC Family Practice*, *16*, 62 Published online 15 May 2015.

Tibblin, G., Bengtsson, C., Furunes, B., & Lapidus, L. (1990). Symptoms by age and sex. The population studies of men and women in Gothenburg, Sweden. *Scandinavian Journal of Primary Health Care*, *8*, 9–17.

van der Lee, J., Bakker, T., Duivenvoorden, H. J., & Dröes, R.-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews 15*, 76–93. http://dx.doi.org/10.1016/j.arr.2014.03.003.

Wallace, K. A., & Wheeler, A. J. (2002). Reliability generalization of the life satisfaction index. *Educational and Psychological Measurement*, *62*, 674–684.

Wallston, B. S., Wallston, K. A., Kaplan, G. D., & Maides, S. A. (1976). Development and validation of the Health Locus of Control (HLC) Scale. *Journal of Consulting and Clinical Psychology*, *44*, 580–585.

Wallston, K. A., Wallston, B. S., & De Vellis, R. (1978). Development of the multidimensional Health Locus of Control (MHLC) scales. *Health Education Monographs*, *6*, 160–170.

Ware, J. E. Jr, Kosinski, M., & Keller, S. D. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, *34*, 220–233.