

Quality of life among older people in Sweden receiving help from informal and/or formal helpers at home or in special accommodation

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Abstract

The present study describes and compares quality of life (QoL) and factors which predict QoL among people aged 75 years and over who receive help with activities of daily living (ADLs) from formal and/or informal helpers. The subjects were living at home or in special accommodation in Sweden. A postal questionnaire was sent to a randomly selected and age-stratified sample of 8500 people. The response rate was 52.8% ($n = 4337$), and 1247 people [mean age (\pm SD) = 86.4 ± 5.9 years] received help and indicated who helped them with ADLs. The findings suggest that a greater age, being a woman, being a widow/widower, a higher number of health-related complaints, needing more help with ADLs and a lower QoL were found among those receiving help in special accommodation in comparison with those receiving help at home. The extent of help was highest among those receiving help in special accommodation. Having help with ADLs every day at home indicated having help from both informal and formal helpers, while respondents receiving help from only informal or only formal helpers received the smallest amount of help with ADLs. A need for greater help with ADLs, and a higher number of self-reported diseases and complaints determined low QoL, whilst a social network (contact with more than three people) and a greater age determined high QoL. However, who the helpers were did not have a significant influence on QoL; it was the extent of help with ADLs that influenced QoL negatively and the density of the social network that influenced QoL positively.

Keywords: formal help, health-related quality of life, informal help, living at home, living in special accommodation, quality of life

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Introduction

Not much is known about what contributes to quality of life (QoL) amongst older people receiving help from informal and/or formal helpers at home or in special accommodation (Guse & Masesar 1999, Hellström & Hallberg 2001). Nor have the characteristics of those receiving help from formal or informal helpers and living at home or in special accommodation been fully explored, especially in Sweden. Help from informal helpers may invoke feelings of loss of confidence or anxiety as a result of being a burden on the helpers, and

this might influence QoL. Help from formal helpers may also affect QoL because of the uncertainty of having partly unknown helpers around (Ellefsen 2002) and being dependent on the public sector. Knowledge is lacking about whether it makes a difference who the helpers are for older people's QoL. It is a prevalent idea that it is best for older people to remain at home (Swedish Institute 1999), but there is little evidence to support this assertion in terms of its impact on QoL when help is required with everyday activities of daily living (ADLs).

It may well be that it is the impaired functional ability and not how and by whom help is provided that

makes a difference to older people's QoL. Decreased functional ability, impaired cognitive function and comorbidity have been found to contribute to the need for help with ADLs among older people (Johansson & Thorslund 1992, Sonn 1996, Melzer *et al.* 1999, Steen *et al.* 2001). Living alone, gender, difficulties in using public transport and poor perceived health (Thorslund *et al.* 1991, Ranhoff & Laake 1995, Herlitz 1997, Stoddart *et al.* 2002) also seem to indicate a need for help with ADLs. The help may be with instrumental ADLs (IADLs), including assistance with shopping, meal preparation and housekeeping, for example, or personal ADLs (PADLs), including bathing, dressing and feeding. A study by Roe *et al.* (2001) of US subjects living at home or in special accommodation ($n = 20$, mean age = 79 years, range = 60–96 years) showed that the majority had help with IADLs from informal helpers (e.g. family, friends and neighbours), and those receiving help from formal helpers (e.g. unlicensed or licensed professionals) were those with the greatest disability who needed help with PADLs. Help with IADLs and PADLs seems to be associated with low QoL (Hellström & Hallberg 2001). Bowling & Browne (1991) and Nunley *et al.* (2000) found that the amount of help with ADLs, perception of health and type of support provided by the helpers contributed to QoL in elderly people who were in need of help and living at home. These studies do not provide sufficient information about whether QoL was related to living at home or in special accommodation, or to who provided the help. The importance of informal helpers at home, as opposed to formal helpers, and receiving help at home, as opposed to in special accommodation, needs further exploration in terms of their impact on QoL.

In Sweden, older people can have public help at home or in special accommodation (Swedish Institute 1999). Although help for older people is an issue for the public sector in Sweden, a study by Hellström & Hallberg (2001) showed that older people living at home received more help from informal helpers, such as family and friends, than from the public sector, and help was often given in combination. Previous studies in Sweden have also shown that informal helpers play a central role in enabling elderly people (Tennstedt *et al.* 1990, Johansson 1991). As the number of elderly people increases (Statistics Sweden 2001), knowledge about differences between people living in special accommodation and those at home is needed to aid service planning. Tseng & Wang (2001) showed that, for older people living in nursing homes, higher educational level, as well as better socio-economic conditions, physical functions, ADLs, social support from families and frequency of family interaction contributed positively to QoL. The impact of different helpers was not investi-

gated. Newsom & Schulz (1998) reported in a study done in the USA that negative reactions to being helped by a spouse were fairly common and these negative reactions may influence QoL.

In healthcare QoL has emerged as an important concept and outcome measure (Harrison *et al.* 1996), and one of the main goals in medical care (Nordenfelt 1991). The complexity of QoL requires using both global and health-related QoL instruments to determine which aspects play the most important role. Factors influencing older people's QoL have been investigated in various studies, but with a weak concordance in the results. Several studies have shown that multiple chronic health problems, and observed and perceived illness are significantly associated with reduced health-related QoL (Grimby & Wiklund 1994, Michelson *et al.* 2001). In a national sample ($n = 4734$) of non-institutionalised people aged 65 years or older, Newsom & Schultz (1996) showed that physical impairment was associated with fewer friendship contacts and fewer family contacts, and that lower reported social support indicated decreased life satisfaction. Social contacts as a component of QoL appeared to be just as important as health status among older people in south-east England (Farquhar 1995). These studies showed that several different aspects influence QoL, and therefore, need to be included when assessing older people's QoL. To the present authors' knowledge, no studies have focused on where or by whom help is provided to older people, and whether it makes a difference for QoL.

Aim

The aim of the present study was to describe and compare QoL among older people (75 years and above) who receive help with ADLs from formal and/or informal helpers, and are living at home or in special accommodation. The aim was also to investigate demographic aspects, place of living, helpers, help with ADLs, social network, self-reported diseases and complaints as predictors of QoL.

Subjects and methods

The Ethics Committee at Lund University (LU 478-99) approved the study.

Sample

The data collection ($n = 8500$) took place in southern Sweden during spring 2000 and included 33 municipalities. In total, there were 99 796 people aged 75 years and above. Subjects were randomly selected within each age group and stratified for age: (75–79 years) $n = 2500$;

(80–84 years) $n = 2500$; (85–89 years) $n = 2000$; and (≥ 90 years) $n = 1500$. The stratification was done to ensure that there were enough respondents in the younger age groups (75–79 and 80–84 years) needing help with ADLs. The final sample, which excluded instances of people having died, addresses being unknown and answers given by another person, had an overall response rate of 52.8%. A pilot study with 1000 older people (1999) preceded the present study to determine the number of people in each age group to be included. The sample included people living at home as well as in special accommodation. Two reminders were sent, with a new copy of the questionnaire in the last reminder.

Measurement

The questionnaire covered areas such as demographic data, social network, complaints and self-reported diseases. Social network was elicited by: 'Do you have someone to trust?' followed by 'If yes, how many people?' There were four possible responses: 'One person', 'Two people', 'Three to five people' and 'More than five people'. Furthermore, the questionnaire covered IADLs and PADLs with questions about who helped the respondents. The type of help that the respondents received and the extent to which they received help was elicited by: 'Because of reduced health, do you need help with personal care (e.g. to eat, get dressed, take care of your hygiene or take a bath/shower)?', i.e. PADLs; and 'Because of reduced health, do you need help with daily matters (e.g. cooking, cleaning or going shopping)?', i.e. IADLs. There were five possible responses: 'No, I do not need any help', 'Yes, but not every week', 'Yes, once a week', 'Yes, several times a week' and 'Yes, every day'. The respondents were asked who helped them. The following possible responses were used to elicit where the help came from: 'Wife, husband, cohabitant', 'Children in the same household', 'Children outside the household', 'Another relative', 'Neighbours (not relatives)', 'Friends (not relatives)', 'Home-help service, home nursing', 'Primary health-care, district nurse', 'Staff in special accommodation' and 'Others: Who? ...'.

In addition, two QoL instruments were used. Global QoL was measured with the Life-quality Gerontology Centre (LGC) scale (Nordbeck *et al.* 1993, Nordbeck 1996). The instrument was developed to measure QoL among older people, based on Neugarten's Life Satisfaction Index A (LSIA) (Neugarten *et al.* 1961), Lawton's Philadelphia Geriatric Centre Morale Scale (Lawton 1975) and Rubenowitz's life quality scale (Rubenowitz 1980), and was developed through factor analysis, revealing a 10-factor solution. The LGC has been used in previous studies among retired people in Sweden

(Nordbeck 1996, Hagberg *et al.* 2002) and also among stroke patients (Nordbeck *et al.* 1992, Elmståhl *et al.* 1996). Two factors from the LGC were used in this study: present quality of life (11 items, including questions such as 'Do you usually think life could be less monotonous?' and 'I am very satisfied with my life at present') and life span quality (four items, including questions such as 'Do you have a feeling that people normally appreciate what you are doing?' and 'Overall I have obtained what I want out of life'). The score ranged from (0) 'lowest QoL' to (1) 'highest QoL'.

The Short Form Health Survey (SF-12), a shorter version of the SF-36, was used. It is well documented as a health-related QoL instrument and validated for Swedish conditions (Ware & Sherbourne 1992, Sullivan *et al.* 1995). The SF-12 covers a Physical Component Summary (PCS) scale covering general health, physical functioning, physical role limitation and bodily pain, and a Mental Component Summary (MCS) scale covering vitality, social functioning, and role-emotional and mental health (Ware *et al.* 1996). The scores in each scale are standardised to range from (0) 'poorest well-being' to (100) 'highest well-being' (Ware *et al.* 1996). The SF-12 has been proposed as a plausible alternative to the SF-36 because the length of the questionnaire is reduced by two-thirds with a minimal loss of measurement precision (Ware *et al.* 1996). The response alternative in the SF-12 measures attitudes by value consent and includes a number of predetermined statements from agreement to contrast.

Data analysis

Variables were compared by the five combinations of place of residence (at home or in special accommodation) and source of help (informal, formal or both) occurring in the data, and also by place of residence (all sources of help combined). The chi-squared test was used when data were on nominal scale level. The Kruskal-Wallis one-way analysis of variance (ANOVA) test was used to analyse data on an ordinal level or a highly skewed interval scale between the five groups, and the Mann-Whitney *U*-test was used to compare those living at home and those living in special accommodation. A one-way ANOVA was used when analysing age and QoL in the five groups, and Student's *t*-test was used when comparing those living at home and those living in special accommodation (Altman 1991).

Four multiple linear regression analyses were performed with present QoL (LGC), life span quality (LGC), PCS (SF-12) and MCS (SF-12) as dependent variables using a backward model, where the least significant variable in each step was removed until a final model including only significant variables was reached.

Age, gender, and level of help with PADLs and IADLs were independent variables; these were never excluded from the model. Other independent variables were social network, place of birth, place of living, civil status, number of children, number of self-reported diseases, number of complaints, groups of helpers, and living at home or in special accommodation. Dummy variables were constructed for PADLs and IADLs where the reference was 'No, I do not need any help at all or less than once a week'. The other levels were 'I need help once or several times a week' and 'I need help every day'. Other references for dummy variable were 'informal helpers at home' in different helpers, 'none to trust' in social network and 'married' in civil status. For the statistical analysis, the SPSS for Windows, Version 11.0, computer program was used.

Results

A total of 4337 people responded to the postal questionnaire (52.8% of the 8220 who could be contacted); of these, 2677 (61.7%) were women. The response rate was significantly higher for men (1660/2992, 55.9%) than women (2677/5228, 51.2%) ($\chi^2 = 56.3$, d.f. = 1, P -value < 0.001). The response rate was highest for the 75–79-year-old age group and lowest for those who were 90 years of age and over (Table 1), the distribution of the age groups being significantly different between respondents and non-respondents (Mann–Whitney $Z = -11.71$, P -value < 0.001). Reasons for not participating were given for a further 483 elderly people: 219 (45.3%) did not wish to participate; 114 (23.6%) had dementia; 93 (19.3%) did not have the strength; 15 (3.1%) were too ill; nine (1.9%) had language problems; 19 (3.9%) gave other reasons; and 14 (2.9%) returned blank questionnaires. Sixty respondents were subse-

quently excluded as their questionnaires were largely incomplete. A total of 3400 people did not respond at all, and among those, 212 (6.2%) were known to have died within 6 months of the study closing.

Fifty-four non-respondents were randomly selected and interviewed by phone about 'worries about one's health' and 'experience of life as a whole' (Table 2). The non-respondents were more likely to be older, non-urban, living in special accommodation and less worried about their health, with proportionately more (3/37) reporting their experience of life as a whole to be 'rather bad or bad'. A total of 1247 respondents indicated that they had help once a week or more, and stated the source of their help; the mean age of these respondents was 86.4 years (SD = 5.9 years, range = 75–104 years); 904 (72.5%) were women. They were divided into groups depending on whom they received help from as well as their place of living: informal helpers at home ($n = 447$); formal helpers at home ($n = 195$); informal and formal helpers at home ($n = 277$); formal helpers in special accommodation ($n = 231$); and informal and formal helpers in special accommodation ($n = 97$) (Table 1).

There were significant differences in age, gender, civil status, cohabitation and number of children ($P < 0.001$), as well as in place of birth ($P < 0.05$) between those who received help from the five combinations of living and helpers (Table 3). Those who received help from informal helpers at home had a lower age, were more often married and less likely to live alone than all the other groups. Those receiving formal and/or informal help at home had a significantly lower age ($P < 0.001$), and were more often male, married and lived together with someone than those receiving help in special accommodation. The number of children was significantly higher ($P < 0.05$) among those living at home than among those living in special accommodation.

Table 1 Sample, response rate and old people receiving help with their daily living by age group*

Variable	Age group (years)				Total
	75–79	80–84	85–89	≥ 90	
Original sample (n)	2500	2500	2000	1500	8500
Final sample [n (%)]	2467 (98.7)	2445 (97.8)	1928 (96.5)	1380 (92.0)	8220 (96.7)
Response rate [n (%)]	1474 (59.7)	1368 (56.0)	913 (47.4)	582 (42.2)	4337 (52.8)
Receiving help [n (%)]	171 (11.6)	330 (24.1)	407 (44.6)	399 (68.6)	1307 (30.1)
Female:male ratio included in the present study (n)	104:60	218:94	280:112	302:77	904:343
Informal help at home (n)	98	141	138	70	447
Formal help at home (n)	19	47	73	56	195
Informal and formal help at home (n)	28	73	93	83	277
Formal help in special accommodation (n)	14	36	55	126	231
Both informal and formal help in special accommodation (n)	5	15	33	44	97

* The difference between the original sample and final sample is a result of the number of people having deceased, address being unknown and answers being given by another person. The difference between the number of people stating that they were receiving help and those included in the present study is caused by 60 who people did not explain who helped them.

Table 2 Description of telephone interviews with non-respondents compared with respondents

Variable	Telephone interviews (<i>n</i> = 54)	Total sample (<i>n</i> = 4337)
Gender: female [<i>n</i> (%)]	35 (64.8)	2677 (61.7)
Age-group (years) [<i>n</i> (%)]:		
75–79	12 (22.2)	1474 (34.0)
80–84	10 (18.5)	1368 (31.5)
85–89	13 (24.1)	913 (21.1)
≥ 90	19 (35.2)	582 (13.4)
Place of living: urban [<i>n</i> (%)]	10 (18.5)	1853 (42.7)
Living in special accommodation [<i>n</i> (%)]	8 (19.5)	523 (12.3)
Worries about one's health: never or seldom/often or very often [<i>n</i> (%)]	33 (89.2)/4 (10.8)	3007 (72.2)/1156 (27.8)
Experience of whole life: very good or good [<i>n</i> (%)]*	30 (81.1)	3572 (85.4)
Experience of whole life: neither good or bad/rather bad or bad [<i>n</i> (%)]*	4 (10.8)/3 (8.1)	549 (13.1)/64 (1.5)

* Internal dropout = 17 people.

There was a significant ($P < 0.05$) difference in social network between the respondents who received help from various helpers, but not between those receiving help in special accommodation and those at home. There was a higher number of health complaints among those receiving help from informal and formal helpers in special accommodation (median = 16) than in all other groups, and also between those receiving help in special accommodation and those receiving help at home ($P < 0.001$). Those who received help from informal and formal helpers in special accommodation had a higher number of self-reported diseases than all other groups (Table 4).

No significant difference in help with IADLs was found between respondents receiving help from various helpers at home, nor between those receiving help from various helpers in special accommodation (Table 4). However, those receiving help in special accommodation had significantly ($P < 0.001$) more help with IADLs and PADLs than those receiving help at home. Those receiving help from only informal helpers at home had less help with PADLs than all the others. There were no significant differences in help with PADLs between those receiving help from different helpers in special accommodation.

The overall mean of physical-health-related QoL was 27.9 (SD = 8.28). Cronbach's alpha was 0.67 for physical-health-related QoL (PCS, SF-12). Lower physical-health-related QoL was found among those receiving help from informal and formal helpers at home than among those receiving help from formal helpers irrespective of housing. Those living in special accommodation who were receiving help from both informal and formal helpers had lower physical-health-related QoL than those living in special accommodation who were receiving help from only formal helpers and those living at home who were receiving help from only informal helpers or from only formal helpers (Table 4). No

significant differences in physical-health-related QoL were found between respondents living at home and those living in special accommodation. Significant variables in the multiple regression model predicting lower physical-health-related QoL were more self-reported diseases, help once or several times a week and every day in PADLs and IADLs (Table 5). Significant predictors for high physical-health-related QoL in the final model were being a widow/widower and male.

The overall mean of mental-health-related QoL was 45.5 (SD = 12.7). Cronbach's alpha was 0.76 for mental-health-related QoL (MCS, SF-12). No significant differences were found in mental-health-related QoL between any of the groups (Table 4). No significant differences were found between respondents living at home and those living in special accommodation in mental-health-related QoL. Significant predictors for low mental-health-related QoL in the final multiple regression model were more health complaints and more self-reported diseases, and help once or several times a week and every day with PADLs (Table 5). Higher age, contact with one or two, or with three or more people, and help from informal and formal helpers in special accommodation significantly predicted high mental-health-related QoL in the final model.

The overall mean of present global QoL in this study was 0.38 (SD = 0.24). Cronbach's alpha for present global QoL (LGC) was 0.68. Present global QoL was higher among respondents receiving help from only informal helpers at home than for all other groups (Table 4). Present global QoL was also found to be higher among those receiving help from both informal and formal helpers at home, compared to those receiving help from both informal and formal helpers in special accommodation. Respondents living at home had significantly ($P < 0.001$) higher present global QoL than those living in special accommodation. Significant predictors for low present global QoL in the final multiple regression

Table 3 Demographic description and comparison of the respondents receiving help from different helpers at home or in special accommodation: (K-W) Kruskal-Wallis test; (χ^2) chi-squared test; (M-W) Mann-Whitney U-test; and (t) Student's t-test

Variable	Living at home (<i>n</i> = 919)			Living in special accommodation (<i>n</i> = 328)			Comparison between helpers		Comparison between housing	
	Help from informal helper (<i>n</i> = 447)	Help from formal helper (<i>n</i> = 195)	Help from informal and formal helpers (<i>n</i> = 277)	Total help (<i>n</i> = 919)	Help from formal helper (<i>n</i> = 231)	Help from informal and formal helpers (<i>n</i> = 97)	Test statistics	d.f.	Test statistics	d.f.
Mean age (\pm SD) (years)	84.3 \pm 5.5	86.6 \pm 5.4	86.6 \pm 5.5	85.4 \pm 5.6	89.4 \pm 5.7	89.0 \pm 5.5	ANOVA <i>F</i> = 38.65	4	<i>t</i> = -10.49	1245
Gender [<i>n</i> (%)]:										
female	293 \pm 65.5	151 \pm 77.4	183 \pm 66.1	627 \pm 68.2	201 \pm 87.0	76 \pm 78.4	χ^2 = 45.03	4	χ^2 = 31.91	1
Civil status [<i>n</i> (%)]:										
married	193 \pm 43.2	10 \pm 5.1	74 \pm 26.7	277 \pm 30.1	2 \pm 0.9	4 \pm 4.1	χ^2 = 232.81	8	χ^2 = 110.52	2
unmarried, divorced or living apart	39 \pm 8.7	44 \pm 22.6	39 \pm 14.1	122 \pm 13.3	46 \pm 19.9	13 \pm 13.4				
widow/widower	215 \pm 48.1	141 \pm 72.3	164 \pm 59.2	520 \pm 56.6	183 \pm 79.2	80 \pm 82.5				
Cohabitation [<i>n</i> (%)]:										
alone	213 \pm 47.7	181 \pm 92.8	195 \pm 70.4	589 \pm 64.1	226 \pm 97.8	92 \pm 94.8	χ^2 = 279.56	4	χ^2 = 131.61	1
Place of birth [<i>n</i> (%)]:										
Sweden	406 \pm 90.8	186 \pm 95.4	264 \pm 95.3	856 \pm 93.1	225 \pm 97.4	89 \pm 91.8	χ^2 = 17.60	8	χ^2 = 2.85	2
another European country	36 \pm 8.1	8 \pm 4.1	13 \pm 4.7	57 \pm 6.2	5 \pm 2.2	8 \pm 8.2				
born outside Europe	5 \pm 1.1	1 \pm 0.5	–	6 \pm 0.7	1 \pm 0.4	–				
Place of living [<i>n</i> (%)]:										
urban	337 \pm 75.4	162 \pm 83.1	224 \pm 80.9	723 \pm 78.7	174 \pm 75.3	69 \pm 71.1	χ^2 = 9.29	4	χ^2 = 2.91	1
Children [<i>n</i> (%)]:										
0	49 \pm 11.1	50 \pm 26.7	29 \pm 10.6	128 \pm 13.9	52 \pm 22.8	11 \pm 11.5	K-W	4	M-W	
1–2	247 \pm 56.1	93 \pm 49.7	153 \pm 56.0	493 \pm 53.6	120 \pm 52.7	53 \pm 55.2	χ^2 = 30.03		<i>Z</i> = -2.05	
≥ 3	144 \pm 32.8	44 \pm 23.6	91 \pm 33.4	279 \pm 30.4	56 \pm 24.5	32 \pm 33.3				

* Internal dropout in number of children = 23.

Table 4 Description and comparison of factors related to daily living among respondents receiving help from different helpers at home or in special accommodation: (ADLs) activities of daily living; (QoL) quality of life; (PCS) Physical Component Summary scale; (MCS) Mental Component Summary scale; (LGC) Life-quality Gerontology Centre scale; (K-W) Kruskal-Wallis test; (χ^2) chi-squared test; (M-W) Mann-Whitney *U*-test; (ANOVA) one-way analysis of variance; (t) Student's *t*-test; (PADLs) personal ADLs; (IADLs) instrumental ADLs; and (SF-12) Short Form Health Survey*

Variable	Living at home (<i>n</i> = 919)				Living in special accommodation (<i>n</i> = 328)				Comparison between helpers				Comparison between housing			
	Help from informal helper (<i>n</i> = 447)	Help from formal helper (<i>n</i> = 195)	Help from informal and formal helpers (<i>n</i> = 277)	Total help (<i>n</i> = 919)	Help from formal helper (<i>n</i> = 231)	Help from informal and formal helpers (<i>n</i> = 97)	Total help (<i>n</i> = 328)	Test statistics	d.f.	<i>P</i> -value	Test statistics	d.f.	<i>P</i> -value	Test statistics	d.f.	<i>P</i> -value
Social network [<i>n</i> (%)]																
no one to trust	16 ± 3.7	11 ± 5.9	5 ± 1.8	32 ± 6.5	12 ± 5.5	1 ± 1.1	13 ± 4.0	K-W	4	0.042	M-W					0.380
one or two people	192 ± 44.1	94 ± 50.5	115 ± 42.5	401 ± 43.6	102 ± 47.0	44 ± 47.3	146 ± 44.5	χ^2 = 9.91			Z = -0.878					
more than three people	227 ± 52.2	81 ± 43.6	151 ± 55.7	459 ± 49.9	103 ± 47.5	48 ± 51.6	151 ± 46.0									
Number of complaints (median)	10	9	11	10	11	16	12	K-W	4	< 0.001	M-W					< 0.001
(percentiles = 2.5–97.5)	(0.2–30.0)	(0.0–30.0)	(1.0–31.0)	(0.0–30.0)	(0.0–30.2)	(3.5–31.0)	(0.0–30.7)	χ^2 = 59.66			Z = -4.74					
Number of self-reported diseases (median)	2	2	2	2	2	3	2	K-W	4	< 0.001	M-W					0.535
(percentiles = 2.5–97.5)	(0.0–7.0)	(0.0–7.0)	(0.0–6.0)	(0.0–7.0)	(0.0–7.2)	(0.0–8.0)	(0.0–7.8)	χ^2 = 27.31			Z = -0.62					
Help with personal ADLs [<i>n</i> (%)]																
once a week	74 ± 16.7	65 ± 34.0	70 ± 25.5	209 ± 22.7	48 ± 20.8	20 ± 20.6	68 ± 20.7	K-W	4	< 0.001	M-W					< 0.001
several times a week	19 ± 4.3	16 ± 8.4	14 ± 5.1	49 ± 5.3	13 ± 5.6	6 ± 6.2	19 ± 5.8	χ^2 = 308.11			Z = -15.79					
every day	65 ± 14.7	42 ± 22.0	92 ± 33.5	199 ± 21.7	151 ± 65.4	66 ± 68.0	217 ± 66.2									
Help with instrumental ADLs [<i>n</i> (%)]																
once a week	174 ± 40.0	59 ± 30.6	81 ± 30.0	314 ± 34.2	14 ± 6.4	8 ± 8.3	22 ± 6.7	K-W	4	< 0.001	M-W					< 0.001
several times a week	52 ± 12.0	27 ± 14.0	36 ± 13.3	115 ± 12.5	10 ± 4.5	3 ± 3.1	13 ± 4.0	χ^2 = 167.50			Z = -12.79					
every day	171 ± 39.3	72 ± 37.3	121 ± 44.8	364 ± 39.6	185 ± 84.1	83 ± 86.5	268 ± 81.7									
Mean health-related QoL (± SD)																
PCS	28.3 ± 8.9	29.3 ± 8.6	27.0 ± 7.8	28.1 ± 8.5	28.2 ± 7.6	25.3 ± 6.6	27.3 ± 7.4	ANOVA	4/1014	0.002	<i>t</i> = 1.418	474.13	0.157			
								<i>F</i> = 4.21								
MCS	45.8 ± 13.3	45.8 ± 12.0	45.2 ± 12.3	45.6 ± 12.7	45.6 ± 13.0	44.2 ± 13.2	45.1 ± 13.1	ANOVA	4/1014	0.872	<i>t</i> = 0.524	1017	0.601			
								<i>F</i> = 0.31								
Mean global QoL (± SD)																
LGC Present	0.43 ± 0.23	0.40 ± 0.23	0.35 ± 0.24	0.40 ± 0.24	0.33 ± 0.24	0.27 ± 0.23	0.31 ± 0.24	ANOVA	4/975	< 0.001	<i>t</i> = 5.388	978	< 0.001			
								<i>F</i> = 12.13								
LGC Life span	0.82 ± 0.23	0.80 ± 0.23	0.80 ± 0.23	0.81 ± 0.23	0.75 ± 0.25	0.77 ± 0.25	0.76 ± 0.25	ANOVA	4/1068	0.022	<i>t</i> = 3.196	1071	0.001			
								<i>F</i> = 2.88								

* Internal dropouts: social network = 45 (3.6%); PADLs = 11 (0.9%); IADLs = 33 (2.6%); QoL SF-12 PCS = 228 (18.3%); QoL SF-12 MCS = 228 (18.3%); QoL LGC Present life = 267 (21.4%); and QoL LGC Life span = 174 (14.0%).

Table 5 Predictors for health-related quality of life Short Form Health Survey (SF-12), Physical Component Summary scale (PCS) and Mental Component Summary scale (MCS) (multiple linear regression): (95% CI) 95% confidence interval; (PADLs) personal activities of daily living; and (IADLs) instrumental activities of daily living

Health-related quality of life: SF-12								
Variable	PCS*				MCS†			
	Unstandardised coefficients B	95% CI	t-test	P-value	Unstandardised coefficients B	95% CI	t-test	P-value
Age	0.035	−0.056, 0.125	0.754	0.451	0.206	0.072, 0.341	3.015	0.003
Male	1.162	0.039, 2.284	2.031	0.042	1.199	−0.447, 2.845	1.430	0.153
PADLs:								
help once or several times a week	−1.771	−2.973, −0.569	−2.891	0.004	−2.148	−4.015, −0.281	−2.258	0.024
help every day	−3.329	−4.686, −1.972	−4.815	< 0.001	−4.497	−6.677, −2.317	−4.048	< 0.001
IADLs:								
help once or several times a week	−3.185	−4.814, −1.555	−3.834	< 0.001	−1.557	−4.020, 0.905	−1.241	0.215
help every day	−3.469	−5.085, −1.854	−4.213	< 0.001	−2.068	−4.529, 0.394	−1.648	0.100
Number of complaints					−0.414	−0.509, −0.319	−8.539	< 0.001
Number of self-reported diseases	−1.192	−1.450, −0.934	−9.057	< 0.001	−1.038	−1.463, −0.614	−4.797	< 0.001
Civil status:								
unmarried/divorced/living apart	1.159	−0.519, 2.838	1.356	0.175				
widow/widower	1.398	0.087, 2.708	2.092	0.037				
Social network:								
contact with one or two people					4.870	0.541, 9.198	2.208	0.027
contact with three or more people					8.241	3.929, 12.553	3.750	< 0.001
Helper:								
only formal at home					−0.202	−2.476, 2.072	−0.175	0.861
informal and formal at home					−0.095	−1.842, 2.031	0.096	0.924
formal in special accommodation					1.808	−0.634, 4.250	1.453	0.147
informal and formal in special accommodation					3.155	0.032, 6.278	1.983	0.048

* Adjusted R^2 for PCS = 0.12. ANOVA $F = 16.789$, d.f. = 9, P -value ≤ 0.001 . The variables not included in the model were number of complaints, social network, different helpers, place of living, place of birth, cohabitation and number of children.

† Adjusted R^2 for MCS = 0.18. ANOVA $F = 16.670$, d.f. = 14, P -value ≤ 0.001 . The variables not included in the model were civil status, place of living, place of birth, cohabitation and number of children.

model were more complaints and more self-reported diseases, help once or several times a week, or every day, with PADLs and IADLs, help from informal and formal helpers at home, being a widow/widower, and living in an urban area (Table 6). Higher age, and having contact with three or more people significantly predicted high present global QoL in the final model.

The overall mean of life span global QoL was 0.80 (SD = 0.24). Cronbach's alpha for life span global QoL (LGC) was 0.65. Life span global QoL was lower among respondents receiving help from formal helpers in special accommodation than among those receiving help from informal helpers at home, and those receiving help from both informal and formal helpers at home (Table 4). Significantly lower ($P < 0.01$) life span global QoL was found among respondents living in special accommodation than among those living at home. Significant predictors for low life span global QoL in the multiple regression analysis were more complaints and more self-reported diseases, help every day with PADLs and IADLs, being born in another European country, and being unmarried, divorced, living apart or being a widow/widower (Table 6). Higher age, and contact with one or two, or with three or more people significantly predicted high life span global QoL in the final model.

Discussion

All respondents, irrespective of whom they received help from, had lower health-related QoL scores on the SF-12 than the norm values based on population data in Sweden in 75 years and above age group (Sullivan *et al.* 1997). Norm values for physical- and mental-health-related QoL were 40.3 (SD = 11.6) and 51.5 (SD = 11.0), respectively. However, the study by Sullivan *et al.* (1997) included a smaller number ($n = 127$) and probably also healthier older people. Furthermore, the LGC in the present study showed a lower global QoL score than a study by Hagberg *et al.* (2002) including 100 retired people [mean age (\pm SD) = 73 \pm 5.99 years]. Hagberg *et al.* (2002) showed present and life span global QoL to be 0.74 (SD = 0.15) and 0.91 (SD = 0.13), respectively. The differences from the results of the study by Hagberg *et al.* (2002) may be because their study did not only include older people receiving help. Help from both informal and formal helpers, irrespective of housing, meant a lower mean health-related QoL score on the SF-12 than for those receiving help from only informal or only formal helpers. Those in special accommodation had lower global QoL mean scores on the LGC than those receiving help at home. Lower age, being married and living together with someone characterised those receiving help from informal helpers at home compared

to all other help receivers. They also had significantly more children than those who only had formal helpers, which may indicate a precondition for remaining at home. Those receiving help in special accommodation, irrespective of who provided it, had significantly more help with IADLs and PADLs than those receiving help at home. The predictors for health-related QoL and global QoL in the four regression models were help with PADLs and the number of self-reported diseases, irrespective of the instrument used. Furthermore, higher age and contacts with more than three people in the social network predicted high QoL (mental-health-related QoL and global QoL) in the linear regression models. An increasing number of complaints and help with IADLs were determinants of low health-related QoL and global QoL in the linear regression models.

There are threats to the internal and external validity of the present study, of which a low response rate is the largest. The dropout seemed to be systematic, as reflected by increasing dropouts in the higher age groups. Therefore, these results may give a more positive view of the oldest of the old since the dropouts in the oldest age groups might represent the frailest people. The analysis of the non-respondents regarding age, gender and living place confirmed that women and the oldest age group were less likely to answer the questionnaire, while place of living was similar compared to the respondents. However, non-respondents in the phone interviews valued their life as 'bad' or 'rather bad', but were less worried about their health than the respondents, which is a somewhat puzzling finding. The strengths of the present study were that it included older people in need of help with ADLs living both at home and in special accommodation, and the findings are likely to be generalisable to a Swedish older population receiving help, provided that one bears in mind the possible effect of the systematic dropout.

To capture as many aspects of QoL as possible, one global and one health-related instrument was chosen, i.e. the LGC and the SF-12. Similar trends were found for the mean values among the respondents with different helpers (Table 4). Thus, the use of the SF-12 (MCS and PCS) and the LGC (present life and life span) can be questioned because mental-health-related QoL (MCS) and the LGC seemed to measure almost the same aspects, and showed most predictors to be the same. Physical-health-related QoL (PCS) covers physical components, and thus, identified other predictors than mental-health-related QoL (MCS) and global QoL (LGC) (Tables 5 & 6). From these findings, it seems as though SF-12 is enough to measure QoL. Hunt (1997) suggested that there is some agreement about the components in disability, functional capacity and health status, as the present study also showed. However, a meta-analysis by Smith

Table 6 Predictors for global quality of life Life-quality Gerontology Centre (LGC) scale Present life and Life span (multiple linear regression): (QoL) quality of life; (95% CI) 95% confidence interval; (PADLs) personal activities of daily living; and (IADLs) instrumental activities of daily living

Variable	Global QoL					
	LGC Present*			LGC Life span†		
	Unstandardised coefficients B	95% CI	t-test	P-value	Unstandardised coefficients B	95% CI
Age	0.003	0.001, 0.006	2.508	0.012	0.005	0.002, 0.007
Male	0.005	-0.028, 0.038	0.314	0.753	-0.005	-0.036, 0.026
PADLs:						
help once or several times a week	-0.052	-0.088, -0.017	-2.917	0.004	-0.025	-0.058, 0.008
help every day	-0.136	-0.177, -0.094	-6.444	< 0.001	-0.071	-0.108, -0.033
IADLs:						
help once or several times a week	-0.082	-0.128, -0.035	-3.445	0.001	-0.026	-0.070, 0.017
help every day	-0.090	-0.136, -0.044	-3.834	< 0.001	-0.052	-0.095, -0.010
Number of complaints	-0.006	-0.008, -0.004	-6.935	< 0.001	-0.006	-0.007, -0.004
Number of self-reported diseases	-0.016	-0.024, -0.008	-3.956	< 0.001	-0.009	-0.016, -0.001
Civil status:						
unmarried/divorced/living apart	-0.043	-0.093, 0.006	-1.712	0.087	-0.092	-0.138, -0.046
widow/widower	-0.057	-0.098, -0.016	-2.714	0.007	-0.036	-0.073, 0.000
Social network:						
Contact with one or two people	0.059	-0.018, 0.135	1.500	0.134	0.158	0.089, 0.228
Contact with three or more people	0.098	0.022, 0.174	2.519	0.012	0.223	0.153, 0.292
Helper:						
only formal at home	-0.015	-0.060, 0.029	-0.673	0.501		
informal and formal at home	-0.041	-0.078, -0.004	-2.156	0.031		
formal in special accommodation	-0.007	-0.054, 0.041	-0.274	0.787		
informal and formal in special accommodation	-0.029	-0.086, 0.028	-0.998	0.318		
Place of living:						
urban	-0.040	-0.072, -0.007	-2.385	0.017	-0.030	-0.061, 0.001
Place of birth:						
another European country					-0.093	-0.148, -0.038
born outside Europe					-0.138	-0.300, 0.024

* Adjusted R^2 for LGC Present = 0.20, ANOVA $F = 15.892$, d.f. = 17, P -value ≤ 0.001 . The variables not included in the model were place of birth, cohabitation and number of children.
† Adjusted R^2 for LGC Life span = 0.17, ANOVA $F = 15.909$, d.f. = 15, P -value ≤ 0.001 . The variables not included in the model were different helpers, cohabitation and number of children.

et al. (1999) indicated that QoL and health status must be separated from each other and suggested that the two terms should not be used interchangeably. The LGC, especially the part covering life span quality, was stronger in identifying the social network as a predictor for global QoL in older people. Thus, the use of a global and a health-related QoL instrument showed similar results. However, it did point out that social network and its importance for QoL may be lost by using a health-related QoL instrument only.

Low QoL among older people in need of help for ADLs seems not to depend on where or from whom they get help. Rather, it seems to depend on the amount of help that they receive, and there might be other explanations too. The respondents in the present study had considerably lower QoL than the population in the same age groups. The regression analyses showed factors such as a larger range of help with ADLs, help from both informal and formal helpers at home, and a higher number of self-reported diseases and complaints to predict low QoL. The impaired functional ability was established in the present study from the amount of help with ADLs that was received. Those living in special accommodation had more complaints and more extensive help with ADLs than those living at home. A study by Noro & Aro (1996) also showed that the level of help with ADLs was associated with lower QoL among old people in institutional care. The distribution of and the number of complaints and self-reported diseases resembles that of comorbidity/multiple chronic health problems, which have been shown to be negatively associated with health-related QoL in other studies (Grimby & Wiklund 1994, Grimby & Svanborg 1997, Cuijpers *et al.* 1999, Michelson *et al.* 2001). Thus, older people's low QoL seems to be irrespective of housing and helpers, but rather, reflects the need for help with ADLs and the number of complaints, i.e. decreased functional ability.

The present findings cannot be taken as showing that it makes no difference where or by whom help with ADLs is provided. Rather, it may be that the decreased functional ability has such a strong negative impact on QoL that it conceals other important aspects. In the present study, interesting patterns emerged as to where and by whom help was provided. Respondents receiving help with ADLs every day often had help in special accommodation. The same pattern, i.e. more often receiving help with ADLs, also indicated help from both informal and formal helpers among respondents living at home. The respondents receiving help from only informal or formal helpers at home were those who received the smallest amount of help with ADLs, although the help was more extensive among those receiving help from only informal helpers compared to

only formal helpers. Trydegård (1998) found that those living in special accommodation received help with ADLs to a larger extent than those living at home, which is in line with findings from the present study. No studies were found comparing the extent of help received with ADLs from different helpers, or a combination of helpers irrespective of housing. This study indicated that a higher amount of help with ADLs is one of the most important factors for receiving help from both informal and formal helpers. However, when the extent of help increases, it is more common to receive help in special accommodation. Thus, public help is distributed in an interesting way. Older people with low functional ability and those with a small social network receive more public help. Accordingly, the priority to provide help depends on the care receiver's network and need of help, even though there is no obligation for family members in Sweden to provide care (Swedish Institute 1999). Judging from this study, the responsibility for older people's care is shared between the next of kin, and the public system of home help and special accommodation. This certainly calls for collaboration with the next of kin with regard to planning and providing care.

As expected from theories of QoL and social support networks (Birren *et al.* 1991), this study shows the social network to be significant for QoL in people receiving help in various settings. There were fewer people to trust and fewer children among respondents receiving help from only formal helpers compared to those with only informal helpers, and those with informal and formal helpers. In the present study, social network turned out to have a strong positive influence on the final regression models of mental-health-related QoL (MCS), life span and present global QoL, all independently of each other. Having help from a next of kin when living in special accommodation also had a positive influence on mental-health-related QoL (MCS) in the final model. Being a widow/widower had the opposite influence in present and life span global QoL. Thus, it was evident from the models (Tables 5 & 6) that the social network plays an important role in older people's QoL. Other studies have similarly shown low support from or interaction with family and friends to be important for decreased life satisfaction (Newsom & Schultz 1996, DuPertuis *et al.* 2001). Cohen & Syme (1985) stated that there is a positive relationship between social support and health. It has not been clarified whether this is because support enhances health and well-being, or because support protects people from stressful events as a buffering mechanism. It may be that it is a combination of these two mechanisms (Cohen & Syme 1985). The results of this study underline the importance of the social network for improving QoL among older people, irrespective of housing or helpers. Thus, older people's

QoL benefits from involving family and friends in their daily living and being careful not to cut off important relations in their networks unnecessarily. Furthermore, professionals could mediate contacts between voluntary organisations and older people to increase their social network.

Conclusion

The present study did not demonstrate that the type of helper influenced QoL among older respondents receiving help from different helpers; rather, it was the extent of help that influenced QoL. It also showed that the social network had an influence on older people's QoL. The study demonstrated very low QoL among older people receiving help compared to older people in the same age group. This, in turn, may be a sign that it is the impaired health and decreased functional ability that makes a difference with regard to QoL. Extensive help, especially with PADLs, and the number of self-reported diseases and complaints, predicted the respondent's QoL. The social network seemed to prevent low QoL, which professional helpers should be aware of, especially in collaboration with relatives with regard to planning and providing care.

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