Exploring determinants for quality of life among older people in pain and in need of help for daily living.

Jakobsson, Ulf; Rahm Hallberg, Ingalill; Westergren, Albert

Published in:
Journal of Clinical Nursing

DOI:
10.1111/j.1365-2702.2006.01584.x

2007

EXPLORING DETERMINANTS FOR QUALITY OF LIFE AMONG OLDER PEOPLE IN PAIN AND IN NEED OF HELP FOR DAILY LIVING

Ulf Jakobsson, RN [1]

Ingalill Rahm Hallberg, RNT, PhD, Professor [1, 2]

Albert Westergren, RN, PhD, Senior lecturer [1]

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

P.O. Box 157, SE-221 00 Lund, Sweden

[2] The Vårdal Institute. The Swedish Institute for Health Sciences, Lund University

P.O. Box 187, SE-221 00 Lund, Sweden

Address for correspondence:

Ulf Jakobsson, Department of Nursing, Faculty of Medicine, Lund University.

P.O. BOX 157, SE-221 00 Lund, Sweden.

E-mail: Ulf.Jakobsson@omv.lu.se

Telephone: +46 46 222 19 24, Fax: +46 46 222 19 35

Abstract

Aims and objectives: The aim of the study was to investigate quality of life and related factors among older people in pain and in need of help to manage daily living.

Background: To intervene against low quality of life in nursing care knowledge about factors affecting it is needed, and this is especially important for vulnerable people such as those who suffer from pain and in need help to manage daily living.

Methods: 526 people, aged 75–102 years participated in this study.

Results: Those in pain reported a significantly higher degree of all complaints and lower quality of life in all measures compared with those not in pain. Overall quality of life was associated with mobility problems, sleeping problems and depressed mood, while health-related quality of life was associated with living in special accommodations, walking problems, mobility problems and fatigue.

Conclusions: Those in need of help to manage daily living and in pain seem to be at higher risk of lowered quality of life than those not in pain, and the lower quality of life among those in pain is probably caused by the complex of complaints rather than pain per se.

Relevance to Clinical Practice: Daily nursing care should identify and treat the complex of complaints related to pain as well as pain itself, to improve everyday life and quality of life for older people in pain.

Key words: Aged 75 and over, quality of life, pain, fatigue, activities of daily living, special accommodations

Introduction

Knowledge is needed about factors affecting QoL in elderly people to be able to direct specific interventions in nursing care towards a good life, especially for vulnerable people. This goes especially for those who suffer from pain since they are at high risk of decreased quality of life (QoL), and when they also need help to manage daily living an even lower QoL may be the result. Functional limitations and dependency on others to manage daily life may be seen as measures of vulnerability. Functional limitations are known to increase with age and lead to dependency on others for performing tasks in daily life. For instance, a population study (general population) focusing on those aged 75+ in Sweden showed (n=448, mean age 84.1 SD 5.1) that the proportion of older people in need of help from others ranged from 18.5% in the youngest age group (aged 75–79) to 79.1% in the oldest age group (aged 90–99), (Hellström & Hallberg, 2001). An especially exposed group at risk of increased need of help from others to manage daily life and lowered QoL is older people in pain (Kendig et al., 2000). Pain tends to increase with increased age (Brochet et al., 1998) and may lead to e.g. functional limitations, impaired sleep and lowered satisfaction with life (Mobily et al., 1994; Scudds & Robertson, 1998). A study in Canada (n=887; age 65–94, 53% aged 75+) showed that those reporting musculoskeletal pain were three times more likely to have some kind of functional limitations (Scudds & Robertson, 1998). Thus, pain perhaps should be regarded not as a single health complaint but as existing in interaction with other factors.

Despite the increasing use of QoL measures in health care, there is little consensus regarding the definition of this construct (Bowling, 1997) and as to whether health-related QoL or a wider concept of QoL gives the most appropriate information. Previous studies have suggested that the differentiation between QoL and perceived health status is important, and they should not be used interchangeably (Covinsky et al., 1999; Smith et al., 1999). A meta-

analysis showed that, from the patient's perspective, QoL and health status are distinct constructs, and when rating QoL patients put more emphasis on mental health than on physical health, while this pattern was reversed for appraisal of health status (Smith et al., 1999). Thus, when measuring only health-related QoL a limited description of the person's experience of daily life might be achieved. However, a study in Sweden measured health-related QoL (SF-12) and overall QoL (the LGC instrument) among older people (n=1622; aged 85–105 years) in pain and found similar determinants for both measures (Jakobsson et al., 2004a). Knowledge about QoL in general is sparse in elderly people, and further studies focusing on elderly people and QoL are needed. This needs further investigation although it may be that older people may have a different view of QoL since health complaints play a dominant role in their life.

Obtaining knowledge about predictors of QoL in old age may provide nursing care with important means to outline and apply interventions towards a better life also in later years. Several factors such as marital status, living conditions, functional limitations, fatigue, sleeping problems and depression/depressed mood must be considered (Grimby & Wiklund, 1994; Kendig et al., 2000; Jakobsson et al., 2004a). Helplessness, disability and ill health have been described as the most frequent factors decreasing QoL mentioned by older persons (Farquhar, 1995). Dependency on others and pain have also been found to decrease QoL (Hopman-Rock et al., 1997). These previous studies indicate that those in pain and in need of help to manage daily living (perhaps because of functional limitations or other complaints) may be at high risk of lowered QoL. If this is so, they are in special need of interventions. However, few studies have focused on which factors need to be considered when handling daily life among these people to prevent lowered QoL. Such knowledge may be helpful to improve the quality of gerontological nursing care.

It is important to optimise the conditions for older people in pain and in need of help for daily living so that interventions to maintain and/or improve perceived QoL despite various health problems (e.g. diseases and symptoms) can be applied. Pain and functional limitations may not always be possible to treat fully, and decreased QoL may be the result. Thus, identifying factors that contribute to decreased or increased QoL among these people may open up other possibilities to improve their QoL. A comprehensive view of factors that interact in relation to QoL in those that need help for daily living may provide other perspectives about how to improve nursing care and in turn daily life among elderly people in pain.

Aims

The aim was to describe and compare overall and health-related quality of life and related factors among those in pain with those not in pain in a sample of older people (aged 75 years and above) in need of help to manage daily living. Further, the aim was to examine determinants for overall and health-related quality of life among those in pain.

Methods

Sample

Some 294 people reporting pain were compared with 238 people who reported no pain, all in need of help with activities of daily living. A total of 532 people aged 75–102 years were thus included in the analysis. The sample was drawn from a larger questionnaire study with an age-stratified sample of people aged 75 years and older (c.f. Jakobsson et al., 2003; Stenzelius et al., 2005). The target population was elderly, aged 75+, living in southern Sweden which included those living in own homes as well as those living in special accommodations. The population study aimed at evaluating health, socio-economic situation, functional health

status, need of help with daily living, how much care was received, and quality of life. The respondents were randomly selected from the population (citizen census list) for each age group, to give the following numbers: 75–79; n=2500, 80–84; n=2500, 85–89; n=2000 and 90+ years; n=1500. Two reminders were sent, the last one with a new copy of the questionnaire. Of the total 8500 questionnaires, 4278 were returned in a usable form (mean age 83.7 years, SD 5.7, and 61.6% women) while 82 were returned but with too large an internal drop-out and were therefore discarded. Two hundred and fifty-five persons were missed (199 deceased, 56 address unknown), giving response rates in the age groups as follows: 75–79: 60%; 80–84: 56%; 85–89: 48%; and 90+: 42%. Non-respondents (mean age 85.7, SD 6.1) were significantly (Students t-test, p=0.005) older than those who did participate (mean age 83.7, SD 5.7), and more (Chi-square test, p=0.005) were women (69.6%) than those who did participate (61.6%).

Due to the performance of the larger population study it was possible to identify those in need of help with activities of daily living (cf. Jakobsson et al., 2004b; Stenzelius et al., 2005). Those who responded to the initial questionnaire were categorised as those in need of help for daily living and those not in need. The group of older people in need of help for daily living (n=1305) were selected based on the criteria (measured by two questions in the questionnaire from the population study): need of help for daily living because of lowered health status at least once a week with personal ADL (e.g. personal hygiene, getting dressed), and/or instrumental ADL (e.g. cooking or preparing meals), and/or medical treatment. Those identified as in need of help were contacted by phone and asked to participate in a (structured) interview. A total of 532 people agreed to participate in the interview and, hence, were included in this study. The second questionnaire was sent to those who had decided to participate in the interview, and the respondents were instructed to complete the questionnaire

as much as they could before the scheduled interview. The interview began with helping the respondents to answer parts of the questionnaire that were not fully completed. Those who did not want to participate in the interviews were significantly older (mean age: 90.3 SD 5.8; Students t-test $p<0.001$), reported significantly more hearing problems (74.3% reported any degree; Mann-Whitney U-test $p=0.018$), vision problems (69.6%; Mann-Whitney U-test $p<0.001$), speaking problems (56.6%; Mann-Whitney U-test $p<0.001$), walking problems (80.7%; Mann-Whitney U-test $p=0.01$), mobility problems (59.8%; Mann-Whitney U-test $p=0.009$), sleeping problems (52.1%; Mann-Whitney U-test $p=0.002$), and depressed mood (46.6%; Mann-Whitney U-test $p<0.001$) than those who did participate. Those who did participate had a mean age of 88.2 years SD 5.8, 68.6% reported any degree of hearing problems, 57.5% reported any degree of vision problems, 40.0% reported any degree of speaking problems, 76.3% reported any degree of walking problems, 53.4% reported any degree of mobility problems, 44.0% reported any degree of sleeping problems, and 34.0% reported any degree of depressed mood. However, there were no significant differences in the degree of pain and fatigue between those who did participate in the interviews and those who did not.

This study is a part of a larger population study that included on the one hand a questionnaire study and on the other hand structured interviews as follow-up. This design was chosen to obtain a broad view of the old and the oldest old in the general populations as well as to identify those in greatest need of help as well as go into depth in specific health complaints in relation to QoL among these elderly.

The study was approved by the Ethics Committee of the Medical Faculty at Lund University (LU 478-99).

Measurement

The initial questionnaire had questions about demographic data (Table 1) and various complaints (Figure 1). The complaints were measured by an overarching question, “Have you been troubled by one or more of the following symptoms for the last three months?”, and had four response alternative, “no, not at all”, “yes, a little”, “yes, rather much” and “yes, very much”. These questions were a modified version of questions from studies of Tibblin et al. (1990; 1993) which had as response alternative yes/no. Those who reported “no pain” were selected to the “no pain group”, and those reporting “little pain” or more were selected to the “pain group”. In the subsequent personal interview, instruments for measuring activities of daily living (measured with the ADL staircase), health-related QoL (measured with Sickness Impact Profile) and overall/present QoL (measured with the LGC instrument) were used.

Activities of daily living (ADL) were assessed using the ADL staircase (Sonn & Hulter-Åsberg, 1991; Sonn, 1996). The instrument is an extended version of Katz’s index of ADL (Katz & Akbom, 1976) especially developed to measure states among older people. The ADL staircase summarises an individual’s overall performance based on ten functions, personal ADL (e.g. hygiene, dressing/undressing) and instrumental ADL (e.g. cleaning, cooking), and the degree of dependency is calculated and graded from zero to ten or as “O”, in a specific hierarchical order (Sonn & Hulter-Åsberg, 1991; Sonn, 1996). The hierarchical order is originally based on a hypothesis that a patient that came to the hospital could regain his/her ability to manage activities in daily living in a specific order. For example, a person is dependent in food intake (i.e. the “lowest” category in the staircase) is most likely also dependent in all the other activities. Moreover, a person that can manage his/her hygiene (i.e. the “highest” category in the staircase) on their own is most likely independent in all other

activities. Zero signifies independent in all functions, one to nine signifies dependency in one to nine activities and ten dependency in all respects. O means “others”, i.e. being dependent on help in at least two and at most nine activities and not classifiable as 1–10 according to the hierarchical order, for example dependent in only one IADL activity or dependent in one PADL and one IADL activity but not needing any help with other activities listed (Sonn & Hulter-Åsberg, 1991).

Overall QoL was assessed using the LGC questionnaire (Nordbeck et al., 1992). The LGC questionnaire is an instrument developed at the Lund Gerontology Research Centre (Nordbeck et al., 1992). The questionnaire has been developed through a factor analysis using questions from previously used measurements (Neugarten et al., 1961; Rubenowitz, 1980; Lawton, 1983; Liang, 1984). The LGC instrument aims to measure global QoL among older people and contains 49 questions divided into 10 factors (present quality of life, psychological well-being, life-span quality, satisfaction with residential environment, psychosomatic health, relations to neighbours, satisfaction with economic situation, satisfaction with social relationship and activities, satisfaction with close relations, and outlook on life) (Hagberg et al., 2002). The scores range between 0 (lowest QoL) and 1 (highest QoL). Only one (Present quality of life) of these ten factors was used in this study (Appendix 1). The instrument measures QoL from a broad perspective and was used as a complement to the Sickness Impact Profile instrument which measures health-related QoL only.

Sickness Impact Profile (SIP) measures perceived health/health-related QoL (Bergner et al., 1981). Sickness is measured in relation to its impact on behaviour, and emphasises sickness-related dysfunction rather than diseases; hence, SIP does not measure positive function. SIP consists of 136 items, divided into 12 sub-scales/areas (e.g. mobility, intellectual function,

social interaction, and household management). Each question asked is answered by yes or no. Two sub-scores (physical and psychosocial) and an overall score can be calculated with a range of 0–100. Low scores signify better health status among the respondents. The part that emphasises work was removed in this study because the sample comprised only retired people. The instrument has been found to be especially useful for measuring perceived health status among elderly people (Fletcher et al., 1992) and has shown good validity and reliability such as test-retest reliability (r=0.75–0.92) and internal consistency (Cronbach's alpha: 0.91–0.94) (Bergner et al., 1981). Also the Swedish version has shown good validity and reliability (test-retest: r=0.87–0.95) (Sullivan et al., 1986; 1990).

Data analysis

Demographic data, ADL status, various complaints, overall (LGC) and health-related (SIP) quality of life were compared between those in pain and those without (Tables 1–2). The ADL category "O"=others was excluded from the analysis (n=48) because they did not follow the hierarchical order in the instrument. The ADL-staircase could be considered as an ordinal scale (instead of nominal) when the respondents categorised as "O" were excluded, and hence be analysed with Mann Whitney U-test. The tests were performed using Student's t-test, Mann-Whitney U-test and Chi-square test. Multiple linear regression (stepwise) was carried out to identify variables that explained the variance in the two QoL instruments (LGC & SIP). Walking problems, mobility problems, fatigue, sleeping problems and depressed mood had four response alternatives. These response alternatives were transformed into dummy variables, with "No, not at all" as reference. Marital status and economic situation were transformed into dummy variables, with "married" and "neither good or poor" respectively as reference. Living conditions, living status and the dummy variables were entered, as independent variables, in the regression analysis. Regression analysis was performed

controlling for age and gender. Collinearity tests (Tolerance, VIF) were carried out to test for high inter-correlation, and no such problems were detected. Analysis of the residuals was made using one-sample Kolmogorov-Smirnov test, and no significant differences were found compared with the normal distribution. Internal consistency for SIP, LGC, and the 10-grade ADL scale were calculated using Cronbach's alpha (Cronbach, 1951). SIP, LGC and the 10-grade ADL scale were supported by acceptable internal consistency: SIP physical index (alpha=0.77), SIP psychosocial index (alpha=0.71), SIP overall score (alpha=0.84), LGC present quality of life (alpha=0.86) and ADL (alpha=0.85). The data were computerised and analysed using SPSS for Windows 11.0 (Norusis & SPSS Inc, 1992).

Results

In the total sample (n=532) 45.2% reported no pain, 20.5% little pain, 18.4% rather much pain, and 15.8% very much pain. Of the 294 people reporting pain, 161 (56%) responded to further specific questions (e.g. diagnosis and localisation) about their pain. Median pain duration was 5.0 years (q1–q3: 2.0–15.0). Thirty-seven per cent (of the 161) reported that they had not received any diagnosis (or did not know the reason) for the pain. The reasons the respondents reported were unspecified musculoskeletal pain (1%), osteoporosis (2%), rheumatoid arthritis (6%), ostheoarthritis (34%), other rheumatic diseases (14%) such as Sjögren's syndrome, Systemic Lupus Erythematosus (SLE), fibromyalgia and unspecified rheumatic disease. Other reasons were musculoskeletal diseases/problems (27%) such as fracture, displaced intervertebral disc, joint and muscle inflammation and other non-specified musculoskeletal problems. Non-musculoskeletal diseases/problems (16%) as reasons for the pain included lowered circulation of the blood (above all in the legs), herpes zoster and damaged nerves. The location of the pain was, in descending order, legs/feet (33%), back

(22%), hip/pelvis (15%), arms/hands (14%), joints (6%), the whole body (4%) and other not specified (6%).

In the total sample the help was mostly received from children not living in the household (41%), home help service (36%) and spouses (24%). In the total sample 38% of the respondents were categorised between 1 and 4 (i.e. dependent in IADL) on the ADL staircase, and 9% were categorised as O (i.e. not classified in the hierarchical order). No significant difference was found in ADL score between those in pain and those not in pain (Table 1).

No significant differences were found in age, gender, marital status, living status/conditions and economic situation between those in pain and those not (Table 1). Present QoL was found to be significantly lower and the SIP scores were significantly higher among those in pain (Table 1), indicating lower present as well as health-related QoL among those in pain. Mann-Whitney U-test was used to identify differences in complaints between those in pain and those not in pain. All complaints were found to be significantly ($p<0.001$) more common among those in pain than those without (Figure 1). Among those in pain, 60% reported rather/very much walking problems and 33% reported rather/very much fatigue, while among those not in pain only 40% reported rather/very much walking problems and 22% rather/very much fatigue. Those in pain also reported twice as often rather/very much mobility problems (40%), sleeping problems (23%) and depressed mood (16%) compared to those not in pain.

The regression analysis showed that mobility problems, sleeping problems and depressed mood were associated with low Overall QoL among those in pain (Table 2). The overall SIP score was found to be associated with living in special accommodations, functional

limitations (walking problems and mobility problems) and fatigue among those in pain (Table 3).

Discussion

Elderly people in pain and in need of help for their daily living were found to have significantly more functional limitations, fatigue, sleeping problems and depressed mood than those without pain, although there were no significant differences in ADL scores between the two groups. Further, those in pain also had significantly lower health-related as well as overall QoL than those not in pain. Thus, it is especially important to focus on people in pain in daily nursing care because of the higher risk of lowered QoL, and to take actions to improve their QoL. Differences were found between the regression models for overall QoL and health-related QoL among those in pain, indicating that different factors must be considered for intervention regarding overall QoL and health-related QoL. On the one hand, mobility problems, sleeping problems and depressed mood were found to be associated with overall QoL. On the other hand, living in special accommodations, functional limitations (walking and mobility problems), and fatigue were associated with health-related quality of life.

A high drop-out rate may be a threat to the external validity if it is systematic. The response rates in the initial questionnaire study were 75–79: 60%; 80–84: 56%; 85–89: 48%; and 90+: 42%, while 41% choose to participate in the interview study. Non-participants in the initial questionnaire and those who did not participate in the interviews (second questionnaire) were found to be significantly older than the participants. This indicates that those not responding were the oldest and frailest, and perhaps because of poor health they could not answer the questionnaire. This assumption is supported by the fact that the most frequent reasons (mostly

reported by significant others) for not participating were not having enough strength, reporting dementia disease or just not wanting to be part of the study. Further, those who did not participate in the interviews (second questionnaire) also significantly more often reported communication problems, functional limitations, sleeping problems and depressed mood than those who did participate. This might mean that the results cannot be generalised to the oldest and perhaps frailest people. However, there were no significant differences, between those who participated in the interviews and those who did not, in the degree of pain and in fatigue, which means that the results may after all be valid in this sense. The attempt to include as large as possible a number of the oldest old and frail old could be seen as a strength of this study, even if the external validity is diminished because of the low response rate especially in the oldest age groups.

When measuring QoL among elderly people, the challenge is to avoid measures that exclude or ineffectively explore areas that are important to the elderly population. In this study two instruments for measuring QoL (LGC & SIP), and one instrument for assessing the ability to perform activities in daily life (ADL staircase) were used, which have been especially developed for use among older people. However, the length of the SIP instrument, which contains 136 questions, might be of concern. This may lead to both external and internal drop-out and a lowered number of respondents included. The use of structured interviews following the postal questionnaire was an attempt to include as many as possible of the frailest old, to obtain more in-depth knowledge of what was obtained by the initial questionnaire.

Older people in need of help for daily living and especially those in pain are vulnerable because they are affected by several complaints, increasing the risk of lowered QoL. The findings demonstrated the importance of not focusing on pain as an isolated problem but

rather as a problem that occurs in a complex of problems. All complaints that were common among people in need of help for daily living were significantly more common among those in pain (Figure 1). Some of these problems have also been previously reported to be common in old age. Bowling and Browne (1991) found in their study (n=662; age: 85+, 25% were 90+) in London (UK) that 70% reported pain and stiffness in the muscles/joints, and 63% reported sleeping problems. However, in this present study all respondents were identified as in need of help for daily living, while the study of Bowling and Browne (1991) included dependent as well as independent people. In this study the higher degree of all complaints among those in pain compared to those not in pain indicates that those in pain were frailer than those without pain, although no significant difference was found in ADL status. Therefore assessments and interventions should not be isolated to ADL status because in this group (the elderly in need of help) there is heterogeneity in various complaints. Systematic pain assessment seems to be required in nursing care planning because pain was found to be related to several other complaints that are common in old age. Further, all these complaints may not only be related to pain but also to each other, and a change in one complaint could affect the other complaints negatively or positively and in turn QoL. Thus, nursing care of older people in pain should bear in mind that these people are more likely to be affected by other complaints besides pain and that those other complaints also need to be systematically assessed and intervened against in daily care. Complaints such as functional limitations, fatigue, sleeping problems and depressed mood may improve when pain is reduced. However, it may well be the other way around as well. The results of this study provide information about what complaints to focus on in providing nursing care for older people. If nursing care acknowledges that several complaints occur together and bases interventions on that knowledge, it may benefit the patients more effectively.

Fatigue seems to be very common in old age and more so among those in pain, and could reduce people's ability to manage daily life as well as their QoL. A previous study has shown that non-disabled old people (n=275; 75-year-olds) who felt tired had twice the risk of being hospitalised and of being users of home help 5 years later (Avlund et al., 2001). In this study 60.4% of those in pain and 46.7% of those not in pain reported fatigue to some degree (Figure 1) and played a significant role for health-related QoL (Table 3). In spite of the high prevalence of fatigue in older people it is sparsely investigated. For example Liao and Ferell (2000) found in their study of older residents (n=199; mean age: 88) that 98% reported some degree of fatigue. Another study (n=448; age 75+) showed a prevalence of more than 50% (some degree of fatigue) among older people (Hellström & Hallberg, 2001). The high prevalence in residential home patients could be explained by the fact that nursing care tends to underestimate fatigue in older people (Tiesinga et al., 2002) and therefore does not intervene against it. Most research focusing on fatigue among people in pain is done in patients with cancer. No study has been found focusing on fatigue among older people in pain in a general population, although fatigue seems to be related to both higher age and pain. It may be difficult to intervene directly against fatigue, but by reducing the impact of other complaints such as pain and sleeping problems, fatigue may be eased. Other tools may be used, such as controlling that the required rest and nutritional intake are achieved. The main goal for nursing care should be to find a balance between demands and resources and use available tools to intervene against fatigue. From a clinical perspective, systematic assessment in daily care is essential for professional care to identify and treat fatigue and hence improve the quality of care as well as QoL. It seems obvious that more research is needed about the mechanisms as well as how to intervene against fatigue.

To improve QoL among older people in pain and in need of help for their daily living, several factors need to be considered. Only some similarities (functional limitations) were found in variables associated with overall and health-related QoL (Tables 2 & 3), and mostly differences were found. Jakobsson et al. (2004a) found that determinants of QoL are similar when assessing overall and health-related QoL (measured with SF-12 and the LGC instrument) among the oldest old (aged 85+). Living conditions (living in special accommodations & living alone), functional limitations, fatigue and depressed mood were important determinants of QoL among elderly people in pain (Jakobsson et al., 2004a). In this study mostly the same variables, together with sleeping problems, were found to be associated with QoL. The differences in results could be due to the use of different instruments and different samples, but it may also be that those needing help for daily living are a different group of people, and hence the meaning of QoL is different. In this study living in special accommodations was associated with health-related QoL. Correspondingly Grimby and Wiklund (1994) found (n=565; 76-year-olds) that living in institutions/special accommodations was correlated to health-related QoL (measured with Nottingham Health Profile). This is not unexpected because the reason for living in special accommodations is lowered health (accompanied by e.g. pain, functional limitations and fatigue). The result revealed areas that are of the utmost importance when planning nursing care and taking actions to improve QoL for older people in pain. Furthermore, the findings also indicated that nursing care should not apply too narrow a concept of QoL. Health-related QoL seems to give detailed information about factors related to poor health whilst the overall QoL gives a broader picture of how older people view their lives.

Conclusion

Older people in need of help to manage daily living and in pain seem to be at higher risk of lowered quality of life than those not in pain. Those affected by pain had significantly lower overall and health-related quality of life than those not in pain, and had a significantly higher degree of all complaints measured. The lower QoL among those in pain is probably caused by the complex of complaints rather than pain per se. However, this relationship needs to be further studied to more fully understand the nature of these relationships. Research studies with a longitudinal design would be appropriate to reveal directions of the relationships (i.e. to establish causal relationships). This is important knowledge for research as well as practice. Pain is not understood effectively if it is not viewed in the context of other problems as well. To prevent decreased QoL among those in pain and need of help for daily living, living conditions, functional limitations, fatigue, sleeping problems and depressed mood need to be considered and adequate intervention applied. By assessing and alleviating these complaints as complex rather than single complaints it may be easier for the older person to live with the pain and QoL may be improved. This study revealed areas (i.e. various complaints and socio-economic factors) to be intervened against in nursing care, but further research is needed to evaluate available methods and to develop new methods to be used for interventions in these specific areas.

Acknowledgement

The authors wish to thank all the respondents for participating in the study. We are also most grateful to Magdalena Andersson, Gunilla Borglin, Anna Ekwall, Ylva Hellström, Ann-Christine Janlöv, Karin Stenzelius, Bibbi Thomé, who were involved in the data collection, to Per Nyberg for statistical advice and to Alan Crozier for revising the English. This study was supported by grants from the Swedish Rheumatism Association, the Vårdal Foundation and the Department of Nursing, Faculty of Medicine, Lund University.

References

Avlund, K., Damsgaard, M.T., & Schroll, M. (2001). Tiredness as determinant of subsequent use of health and social services among nondisabled elderly people. *Journal of Ageing and Health* **13**, 267-286.

Bergner, M., Bobbitt, R.A., Carter, W.B., & Gilson, B.S. (1981). The sickness impact profile: development and final revision of a health status measure. *Medical Care* **19**, 787-805.

Bowling, A., & Browne, P.D. (1991). Social networks, health and emotional well-being among the oldest old in London. *Journal of Gerontology: Social Science* **46**, 20-32.

Bowling, A. (1997). *Measuring health. A review of quality of life measurement scales* (2nd ed.). St Edmundsbury Press, Bury St Edmunds; Suffolk

Brochet, B., Michel, P., Barberger-Gateau, P., & Dartigues, J-F. (1998). Population-based study of pain in elderly people: a descriptive survey. *Age & Ageing* **27**, 279-284.

Covinsky, K.E., Wu, A.W., Landefeld, S., Connors, A.F., Philips, R.S., Tsevat, J. *et al.* (1999). Health status versus quality of life in older patients: does the distinction matter? *Journal of Medicine* **106**, 435-440.

Cronbach, L.J. (1951). Coefficient alpha and the internal structures of tests. *Psychometrika* **3**, 297-334.

Farquhar, M. (1995). Elderly people's definitions of quality of life. *Social Science & Medicine* **41**, 1439-1446.

Fletcher, A.E., Dickinson, E.J., & Philip, I. (1992). Review: audit measures: quality of life instruments for everyday use with elderly patients. *Age & Ageing* **21**, 142-150.

Grimby, A., & Wiklund, I. (1994). Health-related quality of life in old age. A study among 76-year-old Swedish urban citizens. *Scandinavian Journal of Social Medicine* **22**, 7-14.

Hagberg, M., Hagberg, B., & Saveman, B.-I. (2002). The significance of personality factors for various dimensions of life quality among older people. *Ageing & Mental Health* **6**, 178-185.

Hellström, Y., & Hallberg, I.R. (2001). Perspectives of elderly people receiving home help on health, care and quality of life. *Health and Social Care in the Community* **9**, 61-71.

Hopman-Rock, M., Kraaimaat, F.W., & Bijlsma, J.W.J. (1997). Quality of life in elderly subjects with pain in the hip or knee. *Quality of Life Research* **6**, 67-76.

Jakobsson, U., Klevsgård, R., Westergren, A., & Hallberg, I.R. (2003). Old people in pain: a comparative study. *Journal of Pain and Symptom Management* **26**, 625-636.

Jakobsson, U., Hallberg, I.R., & Westergren, A. (2004a). Overall and health related quality of life among the oldest old in pain. *Quality of Life Research* **13**, 125-136.

Jakobsson, U., Hallberg, I.R., & Westergren, A. (2004b). Pain management in elderly persons who require assistance with activities of daily living: a comparison of those living at home with those in special accommodations. *European Journal of Pain* **8**, 335-344.

Katz, S., & Akbom, C.A. (1976). A measure of primary sociobiological functions. *International Journal of Health Services* **6**, 493-507.

Kendig, H., Browning, C.J., & Young, A.E. (2000). Impacts of illness and disability on the well-being of older people. *Disability & Rehabilitation* **22**, 15-22.

Lawton, M.P. (1983). Environment and other determinants of well-being in older people. *Gerontologist* **23**, 349-357.

Liang, J. (1984). Dimensions of the life satisfaction and index A. A structural formulation. *Journal of Gerontology* **39**, 613-622.

Liao, S., & Ferell, B.A. (2000). Fatigue in an older population. *Journal of American Geriatric Society: JAGS* **48**, 426-430.

Mobily, P.R., Herr, K.A., Clark, M.K., & Wallace, R.B. (1994). An epidemiologic analysis of pain in the elderly. *Journal of Ageing and Health* **6**, 139-154.

Neugarten, B.L., Havighurst, R.J., & Weiner, R.S. (1961). The measurement of life satisfaction. *Journal of Gerontology* **16**, 134-143.

Nordbeck, B., Hagberg, B., Jadbeck, G., & Johansson, B. (1992). Stroke patients in Sweden. (Abstract). In XVth World Congress of Gerontology. Budapest, Hungary.

Norusis, J.M., SPSS Inc. (1992). *SPSS for Windows. Base system user's guide. Release 6.* Chicago: SPSS Inc.

Rubenowitz, S. (1980). *Development of methods to map out psychological factors which should be taken into consideration in regional planning.* [In Swedish] Department of Psychology: University of Gothenburg, Sweden.

Scudds, R.J., & Robertson, J.M. (1998). Empirical evidence of the association between the presence of musculoskeletal pain and physical disability in community-dwelling senior citizens. *Pain* **75**, 229-35.

Smith, K.W., Avis, N.E., & Assmann, S.F. (1999). Distinguishing between quality of life and health status in quality of life research: a meta-analysis. *Quality of Life Research* **8**, 447-459.

Sonn, U., & Hulter-Åsberg, K. (1991). Assessment of activities of daily living in the elderly. *Scandinavian Journal of Rehabilitation Medicine* **23**, 193-202.

Sonn, U. (1996). Longitudinal studies of dependence in daily life activities among elderly persons. *Scandinavian Journal of Rehabilitation Medicine* **Suppl 34**, 2-35.

Stenzelius, K., Westergren, A., Thorneman, G., & Hallberg, IR. (2005). Patterns of health complaints among people 75+ in relation to quality of life and need of help. *Archives of Gerontology and Geriatrics* **40**, 85-102.

Sullivan, M., Ahlmen, M., Archenholtz, B., & Svensson, G. (1986). Measuring health in rheumatic disorders by means of a Swedish version of the Sickness Impact Profile: results from a population study. *Scandinavian Journal of Rheumatology* **15**, 193-200.

Sullivan, M., Ahlmen, M., & Bjelle, A. (1990). Health status assessment in rheumatoid arthritis. Further work on the validity of the Sickness Impact Profile. *Journal of Rheumatology* **17**, 439-447.

Tibblin, G., Bengtsson, C., Furunes, B., & Lapidus, L. (1990). Symptoms by age and sex. *Scandinavian Journal of Primary Health Care* **8**, 9-17.

Tibblin, G., Svärdsudd, K., Welin, L., Erikson, H., & Larsson, B. (1993). Quality of life as an outcome variable and a risk factor for mortality and cardiovascular disease: a study of men born in 1913. *Journal of Hypertension* **Suppl 4**, S81-S86.

Tiesinga, L.J., Dijkstra, A., Dassen, T.W.N., Halfens, R.J.G., & Van den Heuvel, W.J.A. (2002). Are nurses able to assess fatigue, exertion fatigue and types of fatigue in residential home patients? *Scandinavian Journal of Caring Sciences* **16**, 129-136.

Figure 1. Descriptions and comparisons of complaints among older people in need of help for daily living and being in pain or not.

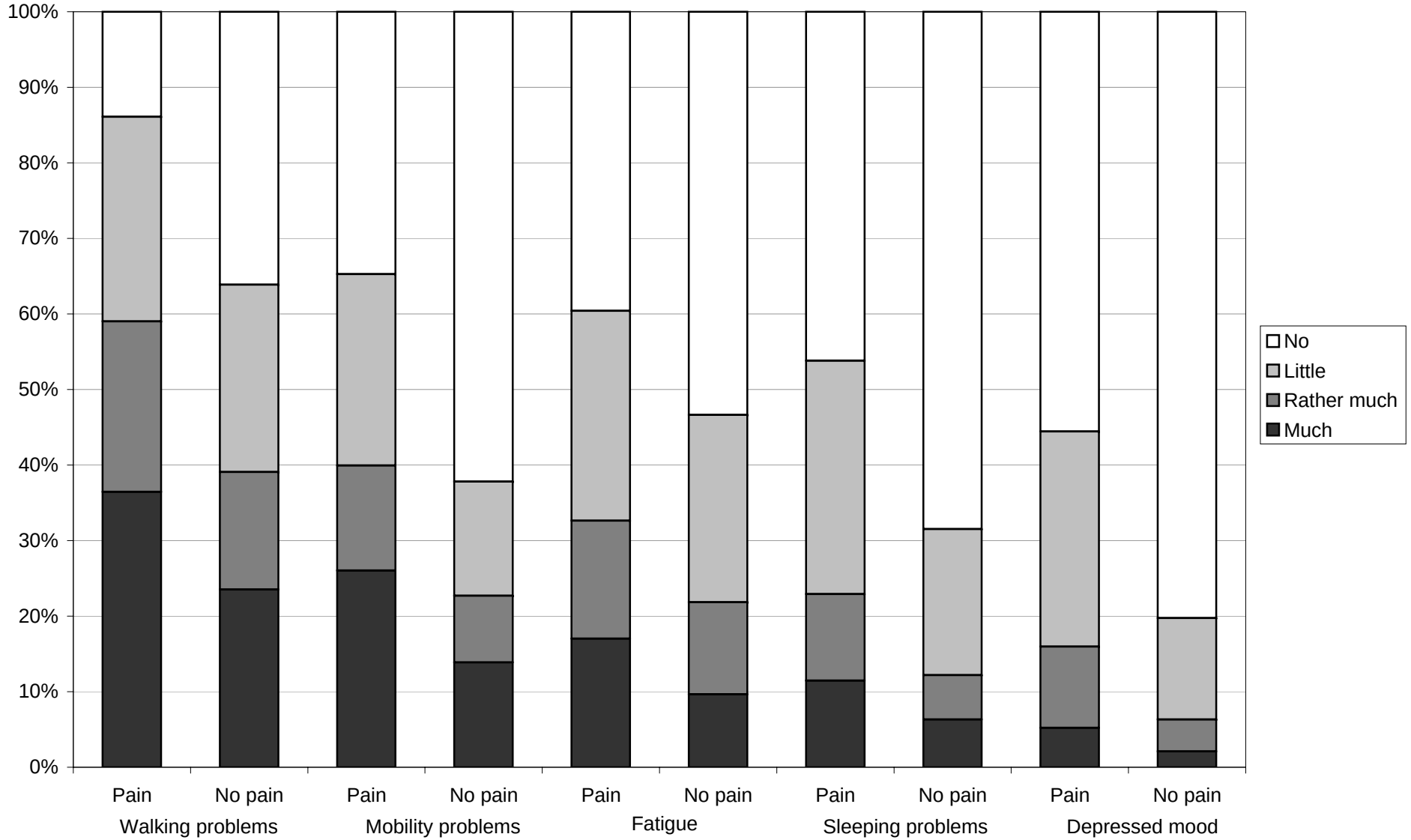
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
No
Little
Rather much
Much
Pain
No pain
Pain
No pain
Pain
No pain
Pain
No pain
Pain
No pain
Walking problems
Mobility problems
Fatigue
Sleeping problems
Depressed mood

Table 1. Description of demographic data and quality of life (LGC & SIP), and comparison between those in pain and those without pain

	Pain (n=294)	No pain (n=238)	p-value
Age, median (q1-q3)	86.0 (82.0-90.0)	85.0 (81.0-91.0)	0.4 [a]
Male / Female %	31.3 / 68.7	34.0 / 66.0	0.5 [b]
Marital status %			0.7 [b]
- Married	27.6	29.8	
- Unmarried	6.5	5.9	
- widow/-er	56.8	58.4	
- divorced	5.4	3.4	
- split housing	3.7	2.5	
Living status %			0.4 [b]
- Living together with someone	30.3	33.2	
- Living alone	69.7	66.8	
Living conditions %			0.3 [b]
- own home	77.8	81.9	
- sheltered housing	22.2	18.1	
Economic situation %			0.06 [b]
- Good/very good	57.2	62.2	
- Neither good or poor	27.6	29.8	
- Poor/very poor	15.2	8,0	
ADL-staircase, median (q3-q1)	4.0 (6.0 – 3.0)	4.0 (6.0 – 2.0)	0.392 [c]
LGC			
- Present QoL, mean (SD)	0.44 (0.22)	0.49 (0.25)	**0.04**[a]
SIP			
- Physical index, mean (SD)	22.7 (14.3)	19.8 (15.2)	**0.03** [a]
- Psychosocial index, mean (SD)	12.9 (11.3)	10.6 (9.6)	**0.02** [a]
- Overall score, mean (SD)	21.7 (10.4)	19.5 (10.5)	**0.02** [a]

[a] Students t-test

[b] Chi-square test

[c] Mann-Whitney U-test

Table 2. Variables associated with overall quality of life (LGC) among old people in pain

	Final model	B	95% CI for regression coefficient	p-value
Present QoL (LGC) n=218	Age	-0.001	-0.005 to 0.005	0.999
	Gender (1=men, 0=women)	0.037	-0.020 to 0-094	0.203
	Mobility problems – little	0.014	-0.055 to 0.083	0.684
	Mobility problems – rather many	0.029	-0.056 to 0.113	0.502
	Mobility problems – very much	–0.063	–0.124 to –0.002	**0.042**
	Sleeping problems – little	0.009	-0.054 to 0.072	0.789
	Sleeping problems – rather much	-0.060	-0.146 to 0.025	0.164
	Sleeping problems – very much	–0.099	–0.186 to –0.013	**0.024**
	Depressed mood – little	–0.081	–0.141 to –0.020	**0.009**
	Depressed mood – rather much	–0.203	–0.297 to –0.109	**<0.001**
	Depressed mood – very much	–0.283	–0.419 to –0.147	**<0.001**

R^2=0.196

Variables entered in the regression analysis: Divorced, Widow/-er, Unmarried, Living alone, Sheltered housing, Economy – good/very good, Economy – poor/very poor, Walking problems – little/rather many/very much, Mobility problems – little/rather many/very much, Fatigue – little/rather much/very much, Sleeping problems – little/rather much/very much, Depressed mood – little/rather much/very much

Table 3. Variables associated with health-related quality of life (SIP) among old people in pain

	Final model	B	95% CI for regression coefficient	p-value
Overall score	Age	0.264	0.057 to 0.471	**0.013**
(SIP)	Gender (1=men, 0=women)	1.061	-1.369 to 3.490	0.391
n=269	Sheltered housing	4.779	1.906 to 7.653	**<0.001**
	Walking problems – little	0.338	-3.584 to 4.259	0.865
	Walking problems – rather many	1.466	-2.436 to 5.369	0.460
	Walking problems – very much	5.112	2.684 to 7.539	**<0.001**
	Mobility problems – little	-1.664	-4.782 to 1.495	0.303
	Mobility problems – rather many	3.498	0.174 to 6.822	**0.039**
	Mobility problems – very much	3.671	-0.537 to 6.617	0.070
	Fatigue – little	0.957	-1.919 to 3.834	0.513
	Fatigue – rather much	3.883	0.739 to 7.027	**0.016**
	Fatigue – very much	8.148	4.933 to 11.364	**0.001**

R^2=0.214

Variables entered in the regression analysis: Divorced, Widow/-er, Unmarried, Living alone, Sheltered housing, Economy – good/very good, Economy – poor/very poor, Walking problems – little/rather many/very much, Mobility problems – little/rather many/very much, Fatigue – little/rather much/very much, Sleeping problems – little/rather much/very much, Depressed mood – little/rather much/very much

Appendix 1

Items in “Present quality of life”

1) How do you feel, as a whole, about your life at present?
   (Hur tycker du, på det stora hela, att ditt liv är just nu?)

2) Do you usually think that life could be less monotonous?
   (Brukar du tänka att livet kunde vara mindre enformigt?)

3) Do you usually feel depressed about “one day being like another”?
   (Brukar du känna dig nedstämd över att “den ena dagen är den andra lik”?)

4) How would you, as a whole, rate your present state of health?
   (Hur tycker du på det hela taget att ditt hälsotillstånd är för närvarande?)

5) I am as comfortable and feel happy as when I was young: Yes/No/Doubtful
   (Jag trivs lika bra och är lika tillfreds nu som när jag var ung: Ja/Nej/Tveksam)

6) My life could be more eventful than it is now: Yes/No/Doubtful
   (Mitt liv kunde vara händelserikare än det är nu: Ja/Nej/Tveksam)

7) These are the best years in my life: Yes/No/Doubtful
   (Dessa är de bästa åren i mitt liv: Ja/Nej/Tveksam)

8) Things that I do today interest me as much as ever: Yes/No/Doubtful
   (Sådant jag gör idag intresserar mig lika mycket som någonsin förr: Ja/Nej/Tveksam)

9) I am very satisfied with my life at present: Yes/No/Doubtful
   (Jag är mycket tillfreds med mitt nuvarande liv: Ja/Nej/Tveksam)

10) This is the peak of my life: Yes/No/Doubtful
    (Detta är mitt livs höjdpunkt: Ja/Nej/Tveksam)

11) For the most part my life is hard: Yes/No/Doubtful
    (För det mesta är mitt liv svårt: Ja/Nej/Tveksam)