Pain prevalence among residents living in nursing homes and its association with quality of life and well-being

Britt-Marie Sjölund RN PhD (Senior Lecturer)[1,2] (iD), **Anna-Greta Mamhidir** RN PhD (Ass. Professor)[1,3] and **Maria Engström** RN PhD (Professor)[1,3,4] (iD)

[1]Faculty of Health and Occupational Studies, Department of Caring Sciences, University of Gävle, Gävle, Sweden, [2]Aging Research Center (ARC), Department of Neurobiology, Care Sciences and Society (NVS) Karolinska Institutet and Stockholm University, Stockholm, Sweden, [3]Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden and [4]Nursing Department, Medicine and Health College, Lishui University, Lishui, China

Pain prevalence among residents living in nursing homes and its association with quality of life and well-being

Abstract

Background: Pain is common and often more complex to assess among nursing homes residents with cognitive impairments. Thus, more research is needed of different pain assessment methods in elderly care and how these assessments outcomes are related to quality of life, as there mostly should be a negative relationship. There is a risk that pain are under diagnosed among persons with cognitive impairment.

Aim: The aim was to describe and compare pain prevalence among nursing home residents (1) using different pain assessment methods (2) in relation to cognitive status and to (3) examine associations between pain and quality of life or well-being.

Methods: A cross-sectional correlational design was used, participants were 213 nursing home residents and data were collected through interviews using standardised protocols. Instrument used were Katz index of ADL, Mini-Mental-State-Examination, Quality of Life in Late-Stage Dementia scale, WHO-5 well-being index, Numeric Rating Scale and Doloplus-2 scale.

Results: The results showed high pain prevalence, but no significant difference based on cognitive level. Pain classification at the individual level varied somewhat when different instruments are used. The results indicated that use of a single-item proxy-measure for pain tends to show higher pain prevalence and was not statistically significant related to quality of life. The relationship with quality of life was statistically significant when self-rated pain instruments or multi-component observation were used.

Conclusions: The study shows that it is difficult to estimate pain in residents living at nursing homes and that it continues to be a challenge to solve. Self-rated pain should be used primarily to assess pain, and a multi-component observation scale for pain should be used when residents are cognitively impaired. Both self-rated pain and multi-component observation also support the well-known link between pain and quality of life. Single-item proxy assessments should only be used in exceptional cases.

Keywords: pain assessment, quality of life, nursing homes, older residents.

Submitted 20 May 2020, Accepted 13 December 2020

Introduction

Pain has been shown to be common in older persons and even more common in women (1–4). The definition of pain is according to the International Association for the Study of Pain (IASP): 'Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'. Chronic pain, which is common in older persons, is defined as pain that persists longer than 3 months (5). Pain among older person can be more acute, such as angina (6), but for most older persons in nursing homes (NHs) pain is due to musculoskeletal injuries and persists over a longer time period (7). One of the most common causes of pain in older persons is musculoskeletal pain, for example fracture, myalgia, arthritis, knee and hip prostheses, and these problems together with pain are, in turn, associated with functional disability (6, 8, 9). A review also found that frail older persons are more likely to suffer from pain (10). Studies have reported pain prevalence figures from 29%

Correspondence to:
Britt-Marie Sjölund, University of Gävle, Kungsbäcksvägen 47, 801 76 Gävle, Sweden.
Email: bresjd@hig.se

up to 55% in older persons (1–4). Among residents living in NHs, the prevalence of pain is even higher 48–55% (11, 12), and one review found that the pain prevalence among residents in NHs varied between 4% and 80%. However, the 4% figure was only seen in a study on excruciating pain (13).

The reason for the great variation in pain prevalence could be the different data collection methods used, for example observation of residents, proxy assessment by staff, questionnaire responses made by residents themselves, and interviews. The gold standard should be self-reported pain, but in NHs this becomes problematic when several persons have cognitive impairments and some cannot themselves report their subjective experiences. A review by Takai et al. (2010) found that the prevalence of pain was higher when the older persons were interviewed than when other methods were used, but one limitation of this method is that it excludes cognitively impaired participants. Older persons who are cognitively intact or mildly impaired can also report whether they have experienced longer-term pain, while older persons with cognitive impairment can only report on the more recent past, which may also explain the higher prevalence of pain when using interviews. To include all older persons, both with and without cognitive impairment, using both interview and observation may be the best approach. However, when a person is not able to express him-/herself verbally due to cognitive impairment, is it important that NH staff try to assess, using multi-component observation, whether or not the person has problems with pain. Multi-component observation scales often include physical components, for example facial expression or breathing pattern, and some functional components that involve activities of daily living as well as psychosocial items, such as behavioural problems. Several multi-component observation scales exist, but these need to be used more systematically in everyday care. Self-reported pain is the most reliable instrument, but if the person is cognitively impaired, the question is whether multi-component observational pain assessment tools can be useful (14–16). However, different barriers to pain assessment in older persons have been found. The barriers can be insufficient knowledge about pain in older persons, not having routines for using standardised pain assessment tools or staff beliefs: they feel know the older person well; there is no need nor time to use what they perceive to be the more time-consuming multi-component observation scales (17, 18). Thus, it is interesting to compare these two methods: a single-item proxy-measure of pain and a multi-component observation scale. Furthermore, there is a need to compare whether there are any differences between persons with cognitive impairment (different levels) and those without such impairment when a

multi-component observation scale is used for both groups. It has been shown that pain is often underestimated, especially in persons with cognitive impairment. This indicates a risk that persons with cognitive impairment will receive too little pain medication (8, 19–22), or not receive other pain reduction treatment, for example massage, transcutaneous electrical nerve stimulation (TENS), heating/cooling or help with changing position (23, 24)

The World Health Organization (WHO) defined quality of life (QoL) ' as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (25). A review study analysing the concept of QoL and well-being showed that describing the differences between these two concepts is complex. Their results demonstrated that well-being seems to be more psycho-spiritual in nature, including happiness and internal energy and that QoL is more connected with life improvement, dignity and being independent (26) . Pain also affects well-being and QoL negatively, and several studies have reported this link (11, 27–29). For example, a study of older persons with chronic pain showed that persons who reported insomnia also had more severe pain compared with persons without insomnia, and it was also associated with decreased well-being and QoL (27). Associations between pain and lower QoL was also found in a study in nursing homes in Norway. Older persons with pain felt more worried, depressed, irritable and anxious than persons without pain (11). Thus, a scale for use in clinical practice should also be able to show associations between pain and QoL and well-being at the group level.

To sum up, previous findings indicate the following: Pain is common and often more complex to assess among NH residents with cognitive impairments. More research is needed on different pain assessment methods in elderly care and how these assessments outcomes are related to QoL, where the expectation is that high levels of pain will be associated with lower QoL. Furthermore, pain is often underestimated among NH residents, particularly among those who are cognitively impaired. Undetected pain is problematic for the individual, who may be at risk for, for example deficient medication or lack other pain management, for example massage TENS etc. leading to overall decreased well-being and QoL.

The aim of the present study was to describe and compare the prevalence of pain among NHs residents (1) using different pain assessment methods (self-rated as well as proxy assessments with a single-item and a multi-component observation scale), (2) in relation to cognitive status as well as to (3) examine associations between pain and QoL or well-being.

Methods

Design

A cross-sectional correlational design was used.

Setting

The study is part of a larger Swedish pain management research project performed in 2012. The main project was an intervention study (17) conducted in one municipality in central Sweden (population 25 000). The present study consists of data from the first data collection/baseline data for all included NHs prior to the intervention. Group A was the NHs included in the intervention group, and therefore we only have data from this group regarding the multi-component observation scale and the NRS Scale (residents' self-rated pain), as this was part of the intervention. In all NHs, that is both Group A and B (the comparison group), the single-item proxy-measurement of pain as well as scales for QoL, well-being, cognitive and physical functioning were used. The intervention was designed to support development of the pain assessment process and to promote systematic pain management practices and procedures. The municipality had in total 13 NHs housing about 500 residents; all NHs were run by one management office with overall responsibility. However, each NH had its own manager who was responsible for care provision and staff at his/her NH. Three NHs declined participation, and the remaining 10 were randomly assigned to the intervention or comparison group. The NHs were staffed by registered nurses (RNs) and assistant nurses (ANs). The NHs had between 20 and 50 apartments, and each NH had 1–2 RNs responsible for care provision. Occupational therapists, physiotherapists and physicians were available for all NHs in the municipality, visiting once a week or when called for to support residents or staff. NHs in Sweden are adapted to serve older persons with great care needs. The older persons rent an apartment in one of the NHs and use their own furniture. The NHs have round-the-clock staff, and the municipality is responsible for the residents' health up to the nursing level.

Participants

The inclusion criterion for residents was: permanently living in the NH for one month or more. The exclusion criteria were: short time in care and palliative care status. From the outset, a total of 213 residents participated in the study, 130 in Group A and 83 residents in Group B. Residents' characteristics at baseline are presented in Table 1. Residents received verbal and written information about the study, were informed that participation

was voluntarily and that they could withdraw at any time, without any explanations or consequences. Participants gave their written consent to participate, and for participants with cognitive impairment a proxy or legal representative was asked to give consent. At each NH the researchers obtained information from management about which participants needed consent from a proxy or legal representative due to cognitive impairment.

Data collection and study variables

Data were collected through interviews using standardised protocols by trained RNs and ANs at the NHs in Group A and by the authors (AGM and BMS) and two municipal nurses at the NHs in Group B. Swedish versions of the different instruments were included in the standardised protocols, they have been validated in different languages, but only two of the Swedish versions have been validated. The RNs and ANs in group A were trained by the authors (AGM and BMS) in how to collect data using the different instruments in the protocol. There were 1–2 trained ANs on each unit in the NHs in Group A; they collected data at the NH, with the support

Table 1 Characteristics of study population (N = 213)

Characteristics	
Age in years, mean (SD[1])	85.4 (6.9)
Female gender, n^2 (%)	146 (68.5)
MMSE[3] points, n (%)	
0–10	94 (44.1)
11–17	42 (19.7)
18–23	50 (23.5)
24–30	27 (12.7)
Katz ADL[4],*, n (%)	
Independent (0)	30 (14.2)
Partially dependent (1–2)	39 (18.4)
Dependent (3–6)	143 (67.4)
ADCS-ADL sev.scale[5], mean (SD)	19.8 (14.5)
QUALID scale[6],**, mean (SD)	23.5 (8.8)
WHO-5 well-being[7]***, mean (SD)	65.4 (21.7)

[1]Standard deviation.
[2]Number.
[3]MMSE: Mini-Mental-State-Examination.
[4]Katz index of ADL.
[5]ADCS-ADL: Alzheimer's Disease Cooperative Study Activities of Daily Living Scale.
[6]QUALID scale: Quality of Life in Dementia Scale. Minimum score is 11, indicating high QoL and maximum score is 55, indicating poor QoL.
[7]WHO-5 index: WHO-5 well-being index. Scores are transformed to a score from 0 (worst thinkable well-being) to 100 (best thinkable well-being.
*Missing data on disability in ADL for 1 person.
**QUALID scale 119 persons.
***WHO-5 well-being 96 persons.

of the two municipal nurses and the authors. The two municipal nurses had a special interest in pain management and were specialists with postgraduate degrees in geriatric nursing. They worked as RNs in the municipality, but not at the NH they were assigned to support. Proxy-NRS was estimated by the ANs at the NHs both in Group A and B.

Social characteristics. Sociodemographic factors collected were age and gender.

Cognitive functioning. The Mini-Mental-State-Examination (MMSE) (30), which consists of 11 questions (maximum of 30 points), was used (severe decreased ability ≤ 10 points, moderate decreased ability 11–17 points, mild decreased ability 18–23 points and no cognitive impairment 24–30 points). MMSE has good validity and reliability (31)

Physical functioning. Physical functioning was measured by interviewing and observing the residents by the interview using the Katz index of Activities of Daily Living (ADL) (32), and for persons with MMSE 0–15 also the Alzheimer's Disease Cooperative Study-Activities of Daily Living (ADCS-ADL-sev.scale) (33) was used. The Katz index of ADL is a hierarchical scale that assesses the individual's functional dependency in relation to six basic activities of daily living (bathing, dressing, going to the toilet, transferring, continence, and feeding). Disability was defined as a need for assistance with one or more activities (34). ADCS-ADL-sev. scale consists of 19 statements measuring basic and complex functions (personal care, communication and interaction with others, maintain household, conducting hobbies and interests, and making judgments and decisions). Results are expressed in points between 0 and 54 (higher scores = better functioning). Both scales have shown acceptable psychometric properties (33, 34).

Quality of life (QoL) and well-being. QoL was measured using the of Quality of Life in Late-Stage Dementia scale (QUALID scale) (35) when the person was cognitively impaired and could not answer the questions. The WHO-5 well-being index was used (36, 37) when the person was able to answer. The QUALID scale measures QoL among persons with severe dementia disease; the 11-item scale concerns the prevalence of observable behaviours and the person's mood, for example smiles, seems to be sad, cries, shows signs of being dissatisfied, unhappy or having discomfort (complains, moans, shouts), is irritated or aggressive (get angry, swear, violent towards others), likes to eat and seems calm/harmonious. Five response alternatives (1–5 points) are available for each question, giving a total score between 11 and 55 points (11 = highest; 55 = lowest level of QoL). The QUALID-scale has

been translated to Swedish and has acceptable psychometric properties (35) The WHO-5 well-being index, a self-report instrument, includes five items (cheerful and in good spirits, calm and relaxed, active and vigorous, feels fresh and rested, daily life is filled with things of interest). Feelings are scored on a six-point scale, ranging between 0 and 5 (0 = not present; 5 = constantly present). The scores are transformed to a score between 0 and 100 (0 = worst; 100 = best thinkable); a score of 50 points suggests poor emotional well-being and a score of 28 points indicates depression. The validation of the WHO-5 well-being index has demonstrated acceptable psychometric properties (38).

Pain. Pain was measured using the Numeric Rating Scale (NRS) scale (39) (proxy and self-assessed) and the Doloplus-2 scale (40) (proxy). Proxy-NRS was used in both groups, while the self-rated NRS and the Doloplus-2 scale were only used in Group A, as these scales were part of the intervention.

Numeric Rating Scale is a unidimensional numeric 11-point scale measuring pain intensity within the past 24 hours, ranging between 0 and 10 (0 = no pain and 10 = worst imaginable pain). Estimation of pain using the NRS scale was conducted by proxy (the ANs at the NHs) and by residents who could report pain by themselves. Proxy-NRS was collected just before the Doloplus-2 and/or the self-reported NRS were used, in order to compare Proxy-NRS with Dolplus-2 or the self-reported NRS results. The Doloplus-2 scale is an observational scale consisting of 10 items in three subgroups: five somatic items (somatic complaints, protective body postures adopted at rest, protection of sore areas, expression, sleep patterns), two psychomotor items (washing and/or dressing, mobility) and three psychosocial items (communication, social life, behaviour problems). Each item is scored from 0 to 3 (0 = absent; 3 = highest score of behaviour). The scale ranges between 0 and 30 points (higher scores = more pain behaviours), and the cut-off score ≥ 5 points indicates risk of pain. The instruments, NRS scale and Doloplus-2, have been shown to have acceptable psychometric properties (41, 42). The Swedish version of the NRS scale has also been found to have good psychometric properties compared with a verbal scale (43).

Ethical approval

The study was approved by the Regional Ethical Review Board (Reg. no. 2012/016). Ethical guidelines for scientific work described in The Declaration of Helsinki and national ethical principles were followed (CODEX). Residents received verbal and written information about the study, were informed that participation was voluntarily and that they could withdraw at any time, without any explanations or consequences. Participants gave their

written consent to participate, and for participants with cognitive impairment a proxy or a legal representative was asked to give consent. The NH heads told the researchers which persons needed a relative or a legal representative to give consent to participate in the study. Prior to the study, the NHs had a routine for designating a legal representative for persons with cognitive impairment. The legal representative was a person appointed by the authority to help the person with cognitive impairment safeguard his/her personal right.

Data analysis

Differences between having and not having pain measured by Doloplus-2 and Proxy-NRS scores, were compared using Pearsons chi-square test. Chi-square was also used to compare pain prevalence measured by Proxy-NRS and Doloplus-2 score and stratified by cognitive level. Data are from the available NH residents in the organisation who were interested in participating in the upcoming intervention study. The estimates were calculated for the intervention study. However, for regression analysis, the sample size is sufficient regarding the recommended number of independent variables, which is $N \geq 50 + 8m$ (m is the number of independent variables) (44) Linear regression was used to estimate the association between the dependent variable QoL (QUALID-scale) and the independent variables Doloplus-2 scale and Proxy-NRS, and between the dependent variable well-being (WHO-5) and the independent variables Doloplus-2 scale, Proxy – NRS and NRS. The associations were first evaluated unadjusted and then adjusted for age and gender. In addition, generalised estimating equation (GEE) was used to study associations and to control for possible nesting effects within the NHs. GEE is used when there is a risk for a nesting effect, for example that people think and behave in a similar manner because they are in the same context. An exchangeable working correlation matrix structure were used in the GEE, based on tests with different structures and their Goodness of Fit values. The results from the linear regression and the GEE analysis are presented with Beta coefficients and 95% confidence interval (Cls) (45) Statistical significance level was set at $p < 0.05$ (2-tailed). Statistical analyses were performed using IBM SPSS Statistics version 22.0 (IBM SPSS Inc. Chicago, IL).

Results

Prevalence of pain using different pain assessment scales, self-rated as well as proxy-rated

Estimated with proxy-NRS, 84.4% (179/212) of the residents were assessed as having pain: 80.6% of the men vs. 86.2% of the women. Estimation of pain using

Doloplus-2 (Group A) showed that 73.6% (81/110) of residents were at risk for pain or had pain: 80.6% of the men vs. 70.7% of the women. Among the 31 residents in Group A who self-rated their pain using the NRS, 61.3% (19/31) reported pain: 50.0% of the men vs. 66.7% of the women.

Proxy-rated pain vs. Doloplus-2 and self-rated pain

The NH staff rated that 92 of 110 residents were experiencing pain (proxy-NRS), while the Doloplus-2 scores showed that 81 of 110 residents might have pain (score ≥ 5 points). When pain was rated using Proxy-NRS, 12 of the 81 residents classified with pain using Doloplus-2 were rated as having no pain, and 23 of 29 residents classified with 'no pain' according to Doloplus-2 were rated as having pain using Proxy-NRS. However, the results were nonsignificant, see Table 2

Self-rated NRS was done by 31 residents. Of these 31 residents, 19 (61.2%) rated that they had pain. Proxy-NRS for these 31 residents indicated that 24 (77.4 %) had pain. However, two residents who reported pain, 5 and 7 points according to the NRS scale, were rated with no pain by the staff. These residents had 23 vs. 21 points on the MMSE scale.

Estimation of pain using Proxy-NRS and Doloplus-2 in relation to cognitive status

Of the residents in Group A, a Doloplus-2 score was obtained for 110 of the 130 residents at baseline. These 110 residents were divided into four groups depending on their cognitive status. The proxy-NRS estimation of pain in these four groups varied between 75.0% and 86.7%, and the estimation using Doloplus-2 varied between 59.3% and 80.0%. Comparing Proxy-NRS estimation of pain in these four groups with the Doloplus-2 results showed that Proxy-NRS estimation of pain prevalence was higher or approximately the same as the

Table 2 Comparison of Doloplus 2-score and the proxy rating for pain, Proxy-NRS (n = 110)

	Proxy-NRS[2], n[3] (%)	
	No pain	Pain
Doloplus 2 score[1]	n = 18	n = 92
<5 ('No pain')	6 (33.3)	23 (25.0)
≥5 ('Pain')	12 (66.7)	69 (75.0)

[1]Doloplus-2 scale is an observational scale ranging between 0 and 30 points.
[2]Proxy-NRS: Proxy-Numeric Rating Scale consisting of integers from 0 (no pain) through 10 (worst imaginable pain).
[3]Number.

results from the Doloplus-2 in all four cognitive groups, see Table 3.

Quality of Life and well-being

The results of linear regression analysis revealed statistically significant associations between pain scores using Doloplus-2 and QoL/QUALID and well-being/WHO-5 (unadjusted and adjusted for gender and age). Furthermore, self-rated pain was statistically significantly associated with well-being/WHO-5, while for proxy-NRS the results were nonsignificant for both QoL/QUALID and well-being/WHO-5 (unadjusted and adjusted), see Table 4. Because there is a risk of nesting effects when staff working at different NHs estimate pain, we also tested the above relationships using GEE to adjust for nesting effect. Results obtained in the earlier analyses were supported using GEE except for proxy-NRS and WHO-5 where the results from GEE revealed a statistically significant association; see Table 4.

Discussion

The results showed high prevalence of pain, but no significant difference based on cognitive level. They also showed that classification of pain at the individual level varies somewhat when different instruments are used. The highest prevalence of pain was measured with proxy-NRS compared with Doloplus-2 and self-rated pain. Pain was associated with lower QoL and well-being when it was measured with Doloplus-2 and self-rated NRS. For proxy-NRS the results were more complicated. No association was found between pain and QoL, while for pain and well-being a significant association was found when clustering effects within units were controlled for.

Table 3 Comparison of pain prevalence between Proxy-NRS and Doloplus-2, N = 110. Distribution by cognitive status

MMSE[1]	Proxy-NRS[2] n[3] (%)	Doloplus 2[4] n (%)	p-value
0–10	41 (85.4)	38 (79.2)	0.625
11–17	23 (85.2)	16 (59.3)	1.000
18–23	15 (75.0)	15 (75.0)	1.000
24–30	13 (86.7)	12 (80.0)	0.371

[1]MMSE: Mini-Mental-State-Examination.
[2]Proxy-NRS: Proxy-Numeric Rating Scale consisting of integers from 0 (no pain) through 10 (worst imaginable pain).
[3]Number.
[4]Doloplus-2 scale is an observational scale ranges between 0 and 30 points.

Prevalence of pain

In the present study, the prevalence of pain about residents living in NHs as estimated by the staff /proxy-NRS was 84.4%, using the Doloplus-2 scale 73.6%, and the self-rated NRS 61.3%. The reason the staff estimated a higher pain prevalence could be because they were aware of the upcoming study and were affected by it. Our study showed a higher prevalence of pain in NHs compared with figures from other studies, where pain prevalence varies between 4% and 80% (11–13). One reason for the difference in prevalence figures may be that different methods and or scales were used to estimate pain and also different definitions of pain. The study by Torvik et al. (2010), showing a pain prevalence of 55%, measured pain using a 4-point Verbal Rating Scale asking whether they had 'pain right now' (11), while Bjork et al. (2016), showing a pain prevalence of 48%, used the Pain Assessment in Advanced Dementia (PAINAD) scale, which is an observational scale for measuring pain (12). In the review (13), the included study showing low (4%) pain prevalence only measured excruciating pain. In the present study, both self-reported pain measured on the NRS scale and observed pain on the Doloplus-2 scale were used. The observation scale may overestimate the prevalence of pain, as it only indicates that the person may have pain. Difficulties in estimating pain in older persons were also revealed in another study from Taiwan (46). Their study examined the prevalence of pain in older persons with dementia as reported by different raters; the highest pain prevalence measured by the verbal descriptor scale (VDS) was reported by the older persons themselves (30%), the RNs reported 18% and the ANs 20%. When the RNs and ANs used the Doloplus-2 to estimate pain, the RNs rated 34% of the older persons with dementia as having pain and the corresponding figure for ANs was 48%. These results are in contrast to our present findings, where staff estimated higher pain prevalence in residents when using the Proxy-NRS than when using the Doloplus-2 scale.

Most studies have shown a higher prevalence of pain in women than in men (3, 4). This pattern was not seen in the present study, except for among those who self-rated their pain using the NRS scale. It is difficult to draw any conclusions, however, because the proportion of men in the present study is small.

Proxy-rated pain vs. Doloplus-2 and self-rated pain

Comparing the Proxy-NRS with the score from Doloplus-2 and the self-rated NRS at the individual level showed differences in persons who may or may not have problems with pain. This reveals how difficult it is to assess pain in elderly people even though Doloplus-2 estimates

Table 4 The association between pain and Quality of Life (QUALID-scale[1]) or well-being (WHO 5[2])

	QUALID, n = 119					
	Unadjusted		Adjusted (age, gender)		GEE (Adjusted age, gender)[6]	
	Beta (95% CIs)	p-value	Beta (95% CIs)	p-value	Beta (95% CIs)	p-value
Doloplus-2[§,3] n = 63	0.34 (0.18; 1.07)	0.007	0.34 (0.18; 1.08)	0.008	0.65 (0.52; 0.78)	<0.001
Proxy-NRS[4] n = 118	0.06 (−0.44; 0.84)	NS	0.06 (−0.46; 0.85)	NS	0.22 (−0.30; 0.73)	NS

	WHO-5, n = 96					
	Unadjusted		Adjusted (age, gender)		GEE (Adjusted age, gender)	
	Beta (95% CIs)	p-value	Beta (95% CIs)	p-value	Beta (95% CIs)	p-value
Doloplus-2[§,3] n = 48	−0.36 (−2.88; −0.36)	0.013	−0.33 (−2.73; −0.24)	0.020	−1.48 (−2.24; −0.73)	<0.001
Proxy-NRS[4] n = 96	−0.17 (−2.76; 0.26)	NS	−0.16 (−2.80; 0.38)	NS	−1.19 (−1.96; −0.43)	0.002
NRS[§,5] n = 25	−0.56 (−5.26; −1.16)	0.004	−0.55 (−5.54; −0.83)	0.010	−3.12 (−5.55; −0.68)	0.012

[1]QUALID scale: Quality of Life in Dementia Scale. Minimum score is 11, indicating high QoL and maximum score is 55, indicating poor QoL.

[2]WHO-5 index: WHO-5 well-being index. Scores are transformed to a score from 0 (worst thinkable well-being) to 100 (best thinkable well-being).

[3]Doloplus-2 scale is an observational scale ranges between 0 and 30 points.

[4]Proxy-NRS: Proxy-Numeric Rating Scale consisting of integers from 0 (no pain) through 10 (worst imaginable pain).

[5]Numeric Rating Scale consisting of integers from 0 (no pain) through 10 (worst imaginable pain).

[6]Exchangeable working correlation matrix structure used in the GEE.

§Only in group A.

people who may have problems with pain. There were also differences in the comparison between Proxy-NRS and the self-rated NRS for residents who were able to rate their pain. These persons could express their pain, but the staff were not always aware that these residents were experiencing pain. This result was the same as in the review by Takai et al (2010), which showed that the prevalence of pain was higher with self-rated pain reported by the older persons compared with other methods. This suggests that there may be a need for staff to systematically use an instrument to assess pain in NH residents so that the proper measures can be taken and so that self-rated pain will become the golden standard.

Pain and cognitive impairment

In the present study, there was no significant difference in the Proxy-NRS or Doloplus-2 estimation of pain in residents due to cognitive status. Otherwise, it is common for staff in elderly care to underestimate pain in older persons with cognitive impairment (11, 20). In a study from the US (20), nurses' reports of pain decreased as the residents' cognitive abilities declined. Why this was not the case in our study may be because the staff had worked a long time at the NH and therefore knew the older persons well and noticed any behaviour changes – changes that may be due to pain when using the observation scale. That the training in how to use the observation scale had been fruitful and thus a good tool to use in clinical practice. Another explanation may be that the staff were aware of the study which affected the results at the group level. When pain is underestimated in people with cognitive impairment, there is a risk that they will receive less pain relief medication or other pain managements, for example massage or TENS, than cognitively intact persons receive (6, 19, 22–24, 47). There is also a risk that older persons with pain will be less active, leading to reduced mobility and increases risk of dependency in ADL, and negatively affecting well-being and QoL (17, 48)

Quality of Life and well-being

It is well known that pain affects QoL negatively (9, 49–52). In our study, pain estimated with Doloplus-2 was, as assumed, negatively associated with QoL (QUALID) and well-being (WHO-5); and self-rated pain (NRS) was associated with lower QoL. This result shows once again the importance of identifying pain in older residents so as to increase their QoL. The reason there was no association

between the Proxy-NRS and QoL may be that the staff had difficulty in identifying residents who had problems with pain using Proxy-NRS instead of Doloplus-2, once again indicating that Proxy-NRS should not be used in clinical practice. GEE analysis was used to examine whether there was any clustering, for example related to how the different NHs assessed pain in the older persons. However, when clustering effects were controlled for using GEE analysis, Proxy-NRS was associated with older residents' self-reported well-being. One explanation might be that staff at some units are better in estimating residents' pain, could also be that some units have more cognitively intact residents and thereby easier to also use a proxy-measure when you know the resident.

Limitations

The limitations of the present study may be the small sample size, which may have resulted in insufficient statistical power for some of the variables. Knowledge in the staff group of the intervention study may also have led to an overestimation of pain. The NHs were run by one management with overall responsibility for elderly care, however each NH had its own manager who was responsible for daily care and the staff at his/her NH. We think that have reduced the risk for having affected the outcome. There could be a clustering effect and, therefore, as recommended, GEE was used. Another limitation was that there were different data collectors, which might have affected the results. However, the researchers tried to reduce this impact on the results by training them in data collection. The data were collected eight years prior to writing the present article, but we do not consider this a limitation, given that estimating pain in older persons is still a problem, especially in those with cognitive impairment.

The strengths of the study were that the NHs staff who performed the measurements received joint training before the start of the study, and that validated instruments were used for the data collection and that several NHs were included.

Conclusions

The study shows high prevalence of pain among NH residents, also revealing the difficulty of estimating pain, particularly among residents with dementia. If relevant treatments are to be developed, pain detection must still be prioritised. Self-rated pain scale should be used primarily for those who can independently assess pain, and a multi-component observation scale for pain should be used when residents are cognitively impaired. Both self-rated pain and a multi-component observation scale support the well-known link between pain and QoL and well-being. Single-item proxy assessments, commonly used in clinical practice today, should only be used in exceptional cases.

Acknowledgement

Author contributions

BMS, AGM, and ME contributed to the study design. Data collection was conducted by BMS and AGM and the statistical analyses by BMS and ME. BMS wrote the first draft of the manuscript and the authors (AGM and ME) have critically revised the manuscript drafts. All authors have approved the final manuscript.

Funding

Consent for publication

The paper contains aggregated data only.

References

1 Larsson C, Hansson Ee, Sundquist K, Jakobsson U. Chronic pain in older adults: prevalence, incidence, and risk factors. *Scand J Rheumatol* 2017; 46: 317–325. Available from: https://doi.org/10.1080/03009742.2016.1218543.

2 Sandin Wranker LW, Rennemark M, Berglund J. Pain among older adults from a gender perspective: Findings from the Swedish National Study on Aging and Care (SNAC-Blekinge). *Scand J Public Health.* 2016; 44: 258–63.

3 Yu HY, Tang FI, Kuo BI, Yu S. Prevalence, interference, and risk factors for chronic pain among Taiwanese community older people. *Pain Manag Nurs* 2006; 7: 2–11.

4 dos Santos FA, de Souza JB, Antes DL, d'Orsi E. Prevalence of chronic pain and its association with the sociodemographic situation and physical activity in leisure of elderly in Florianopolis, Santa Catarina: population-based study. *Rev Bras Epidemiol* 2015; 18: 234–47.

5 International Association for the Study of Pain (IASP). https://www.iasp-pain.org/Taxonomy?navItemNumber=576#Pain.

6 Torvik K, Kaasa S, Kirkevold O, Rustoen T. Pain in patients living in Norwegian nursing homes. *Palliat Med* 2009; 23: 8–16.

7 Platts-mills TF, Dayaa JA. Musculoskeletal injures in older adults. *N C Med J* 2017; 78: 318–21.

8 Tse M, Leung R, Ho S. Pain and psychological well-being of older persons living in nursing homes: An exploratory study in planning patient-centred intervention. *J Adv Nurs* 2012; 68: 312–21.

9 Shah RC, Buchman AS, Boyle PA, Leurgans SE, Wilson RS, Andersson GB, Bennett DA. Musculoskeletal pain is associated with incident mobility disability in community-dwelling elders. *J Gerontol A Biol Sci Med Sci* 2011; 66A: 82–88.

10 Otones Reyes P, García Perea E, Pedraz Marcos A. Chronic pain and frailty in community-dwelling older adults: a systematic review. *Pain Manag Nurs* [Internet]. 2019; 20: 309–15. Available from: https://doi.org/10.1016/j.pmn.2019.01.003.

11 Torvik K, Kaasa S, Kirkevold O, Rustoen T. Pain and quality of life among residents of Norwegian nursing homes. *Pain Manag Nurs* 2010; 11: 35–44.

12 Bjork S, Juthberg C, Lindkvist M, Wimo A, Sandman PO, Winblad B, Edvardsson D. Exploring the prevalence and variance of cognitive impairment, pain, neuropsychiatric symptoms and ADL dependency among persons living in nursing homes; a cross-sectional study. *BMC Geriatr* 2016; 22: 154–9.

13 Takai Y, Yamamoto-Mitani N, Okamoto Y, Koyama K, Honda A. Literature review of pain prevalence among older residents of nursing homes. *Pain Manag Nurs* 2010; 11: 209–23.

14 Kim Y-S, Park J-M, Moon Y-S, Han S-H. Assessment of pain in the elderly: A literature review. *Natl Med J India* [Internet]. 2017; 30: 203. Available from: http://www.nmji.in/text.asp?2017/30/4/203/218673.

15 Hadjistavropoulos T, Herr K, Prkachin KM, Craig KD, Gibson SJ, Lukas A, Smith JH. Pain assessment in elderly adults with dementia. *Lancet Neurol* [Internet]. 2014; 13: 1216–1227. Available from: https://doi.org/10.1016/S1474-4422(14)70103-6.

16 Malara A, De Biase GA, Bettarini F, Ceravolo F, Di Cello S, Garo M et al Pain assessment in elderly with behavioral and psychological symptoms of dementia. *J Alzheimers Dis* 2016; 50: 1217–25.

17 Mamhidir Anna-Greta, Sjölund Britt-Marie, Fläckman Birgitta, Wimo Anders, Sköldunger Anders, Engström Maria. Systematic pain assessment in nursing homes: a cluster-randomized trial using mixed-methods approach. *BMC Geriatrics* 2017; 17: 61–017-0454-z.

18 McAuliffe L, Nay R, O'Donnell M, Fetherstonhaugh D. Pain assessment in older people with dementia: literature review. *J Adv Nurs* 2009; 65: 2–10.

19 Husebo BS, Strand LI, Moe-Nilssen R, Borgehusebo S, Aarsland D, Ljunggren AE. Who suffers most? Dementia and pain in nursing home patients: a cross-sectional study. *J Am Med Dir Assoc* 2008; 9: 427–33.

20 Reynolds KS, Hanson LC, DeVellis RF, Henderson M, Steinhauser KE. Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *J Pain Symptom Manage* 2008; 35: 388–96.

21 Monroe TB, Misra SK, Habermann RC, Dietrich MS, Cowan RL, Simmons SF. Pain reports and pain medication treatment in nursing home residents with and without dementia. *Geriatr Gerontol Int* 2014; 14: 541–8.

22 Monroe TB, Parish A, Mion LC. Decision factors nurses use to assess pain in nursing home residents with dementia. *Arch Psychiatr Nurs* 2015; 29: 316–20.

23 Blomqvist K. Older people in persistent pain: Nursing and paramedical staff perceptions and pain management. *J Adv Nurs* 2003; 41: 575–84.

24 Abdulla A, Adams N, Bone M, Elliott AM, Gaffin J, Jones D, Knaggs R, Martin D, Sampson L, Schofield P, British Geriatric Society. Guidance on the management of pain in older people. *Age Ageing* 2013; 42(Suppl): 1.

25 The World Health Organization Quality of Life (WHOQOL). 2012; https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/.

26 Pinto S, Fumincelli L, Mazzo A, Caldeira S, Martins JC. Comfort, well-being and quality of life: Discussion of the differences and similarities among the concepts. *Porto Biomed J* [Internet]. 2017; 2: 6–12. Available

from: https://doi.org/10.1016/j.pbj.2016.11.003.

27 Dragioti E, Bernfort L, Larsson B, Gerdle B, Levin Lå. Association of insomnia severity with well-being, quality of life and health care costs: A cross-sectional study in older adults with chronic pain (PainS65+). *Eur J Pain* [Internet]. 2018; 22: 414–425. Available from: http://doi.wiley.com/10.1002/ejp.1130.

28 O'Sullivan K, Kennedy N, Purtill H, Hannigan A. Understanding pain among older persons: Part 1-the development of novel pain profiles and their association with disability and quality of life. *Age Ageing* 2017; 46: 46–51.

29 Park J, Engstrom G, Tappen R, Ouslander J. Health-related quality of life and pain intensity among ethnically diverse community-dwelling older adults. *Pain Manag Nurs* [Internet]. 2015; 16: 733–742. Available from: https://doi.org/10.1016/j.pmn.2015.04.002.

30 Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; 12: 189–198.

31 Kopecek M, Bezdicek O, Sulc Z, Lukavsky J, Stepankova H. Montreal Cognitive Assessment and Mini-Mental State Examination reliable change indices in healthy older adults. *Int J Geriatr Psychiatry* 2017; 32: 868–75.

32 Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of Illness in the Aged. the Index of Adl: a Standardized Measure of Biological and Psychosocial Function. *JAMA*. 1963; 185: 914–9.

33 Galasko D, Schmitt F, Thomas R, Jin S, Bennett D, Study ADC. Detailed assessment of activities of daily living in moderate to severe Alzheimer's disease. *J Int Neuropsychol Soc* 2005; 11: 446–53.

34 Brorsson B, Asberg KH. Katz index of independence in ADL. Reliability and validity in short-term care. *Scand J Rehabil Med* 1984; 16: 125–32.

35 Falk H, Persson LO, Wijk H. A psychometric evaluation of a Swedish version of the Quality of Life in Late-Stage Dementia (QUALID) scale. *Int Psychogeriatr* 2007; 19: 1040–50.

36 Bech P, Gudex C, Johansen KS. The WHO (Ten) Well-Being Index: validation in diabetes. *Psychother Psychosom* 1996; 65: 183–90.

37 Bonsignore M, Barkow K, Jessen F, Heun R. Validity of the five-item WHO Well-Being Index (WHO-5) in an elderly population. *Eur Arch Psychiatry Clin Neurosci* 2001; 251(Suppl): II27-31.

38 Hall T, Krahn GL, Horner-Johnson W, Lamb G, Measurement RR and TCEP on H. Examining functional content in widely used Health-Related Quality of Life scales. *Rehabil Psychol.* 2011; 56: 94–99.

39 Farrar JT, Young JP Jr, LaMoreaux L, Werth JL, Poole RM. Clinical importance of changes in chronic pain intensity measured on an 11-point numerical pain rating scale. *Pain* 2001; 94: 149–58.

40 Zwakhalen SM, Hamers JP, Abu-Saad HH, Berger MP. Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools. *BMC Geriatr* 2006; 27: 3.

41 Torvik K, Kaasa S, Kirkevold O, Saltvedt I, Holen JC, Fayers P, Rustøen T. Validation of Doloplus-2 among nonverbal nursing home patients–an evaluation of Doloplus-2 in a clinical setting. *BMC Geriatr* 2010; 20: 9.

42 Hawker GA, Mian S, Kendzerska T, French M. Measures of adult pain: Visual Analog Scale for Pain (VAS Pain), Numeric Rating Scale for Pain (NRS Pain), McGill Pain Questionnaire (MPQ), Short-Form McGill Pain Questionnaire (SF-MPQ), Chronic Pain Grade Scale (CPGS), Short Form-36 Bodily Pain Scale (SF. *Arthritis Care Res (Hoboken)* 2011; 63 (Suppl 1): S240–52.

43 Wikström L, Nilsson M, Broström A, Eriksson K. Patients' self-reported nausea: Validation of the Numerical Rating Scale and of a daily summary of repeated Numerical Rating Scale scores. *J Clin Nurs* 2019; 28: 959–68.

44 Tabachnick BG, Fidell LS. *Using Multivariate Statistics*, 5th edn. 2007, Pearson/Allyn & Bacon, Boston.

45 Fitzmaurice GM, Laird NM, Ware JH. *Applied Longitudinal Analysis*, 2nd edn. 2011, Wiley Blackwell, New York.

46 Chen YH, Lin LC, Watson R. Validating nurses' and nursing assistants' report of assessing pain in older people with dementia. *J Clin Nurs* 2010; 19: 42–52.

47 Nygaard HA, Jarland M. Are nursing home patients with dementia diagnosis at increased risk for inadequate

pain treatment? *Int J Geriatr Psychiatry* 2005; 20: 730–7.

48 Lapane KL, Quilliam BJ, Chow W, Kim M. The association between pain and measures of well-being among nursing home residents. *J Am Med Dir Assoc* 2012; 13: 344–9. https://doi.org/10.1016/j.jamda.2011.01.007.

49 Edwards RR. Age differences in the correlates of physical functioning in patients with chronic pain. *J Aging Health.* 2006; 18: 56–69.

50 Covinsky KE, Lindquist K, Dunlop DD, Yelin E. Pain, functional limitations, and aging. *J Am Geriatr Soc* 2009; 57: 1556–61.

51 Snow AL, Chandler JF, Kunik ME, Davila JA, Balasubramanyam V, Steele AB, Morgan RO. Self-reported pain in persons with dementia predicts subsequent decreased psychosocial functioning. *Am J Geriatr Psychiatry* 2009; 17: 873–80.

52 Shega J w, Weiner D k, Paice J a, Bilir S p, Rockwood K, Herr K, Ersek M, Emanuel L, Dale W. The association between noncancer pain, cognitive impairment, and functional disability: an analysis of the Canadian study of health and aging. *J Gerontol A Biol Sci Med Sci* 2010; 65A: 880–6.