Pain and its Association with Disability in Institutional Long-Term Care in Four Nordic Countries

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RÉSUMÉ

On a utilisé des données transversales (n = 6 487) de quatre pays nordiques (le Danemark, la Finlande, l'Islande et la Suède) pour établir la prévalence de la douleur quotidienne et de ses effets sur l'invalidité en milieu institutionnel de soins de longue durée. Chaque pensionnaire des établissements examinés a été évalué au moyen de la version 1.0 du Minimum Data Set. L'échantillonnage était représentatif des soins de longue durée donnés en institution à Copenhagen et Reykjavik. De plus, on a utilisé des données recueillies à Stockholm et Helsinki pour tirer des renseignements importants sur les pensionnaires de ces capitales. Les résultats indiquent qu'entre 22 et 24 pour cent des pensionnaires éprouvent des douleurs quotidiennes observables, ce qui est encore plus évident chez les sujets les plus invalides. S'ajoutant à l'invalidité et au sexe féminin, les maladies ou états associés à la douleur étaient un pronostic de maladie terminale, d'ostéoporose, de pneumonie, d'arthrite, de dépression, d'anémie, d'acrosyndrome, de cancer et de défaillance cardiaque. Le lien entre la douleur et la déficience intellectuelle grave était inexistant. Les résultats indiquent clairement que la douleur quotidienne est intimement liée à l'invalidité, celle-ci agissant sur les maladies sous-jacentes pour constituer la cause et l'effet de la douleur. On peut donc voir un cercle vicieux entre la douleur et l'invalidité.

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ABSTRACT

Cross-sectional data (n = 6,487) from four Nordic countries, Denmark, Finland, Iceland and Sweden, were utilized to determine the prevalence of daily pain and its association with disability in institutional long-term care. Every resident in each of the participating institutions was assessed with Minimum Data Set version 1.0. The sample was representative of institutional long-term care in Copenhagen and Reykjavik. In addition, the data collected from Stockholm and Helsinki provided substantial information on the residents in these capitals. The results showed that 22–24 per cent of the residents experienced daily observable pain and this was most evident in the most disabled subjects. In addition to disability and female gender, diseases or conditions independently associated with pain were terminal prognosis, osteoporosis, pneumonia, arthritis, depression, anaemia, peripheral vascular disease, cancer and cardiac heart failure. The association between pain and severe cognitive impairment was negative. The results strongly indicate that daily pain in long-term care has a complex association with disability, the latter acting together with underlying diseases as a source and/or result of pain. Thus, a vicious circle between pain and disability can be anticipated.

Introduction

Pain is a common phenomenon among institutional long-term care residents. Estimates of the prevalence of pain range from 24 to 86 per cent depending on its intensity and frequency (Ferrell, Ferrell, & Osterweil, 1990; Parmelee, Katz, & Lawton, 1991; Parmelee, Smith, & Katz, 1993; Sengstaken & King, 1993; Ferrell, 1995; Ferrell, Ferrell, & Rivera, 1995; Parmelee, 1996).

In general, data on residents in pain, have been collected mainly from individuals capable of communicating adequately; severe cognitive impairment has typically been an exclusion criterion (Parmelee et al., 1993; Sengstaken & King, 1993; Ferrell et al., 1995). Thus, data on pain are lacking concerning non-communicative residents, who most likely are also suffering from dementia and severely disabled.

According to Parmelee et al. (1993) pain reports of subjects whose cognition ranges from intact to moderate impairment are valid. Some studies indicate that pain is less frequent in subjects with severe dementia than in individuals with better cognition (Parmelee et al., 1993; Sengstaken & King, 1993; Farrell et al., 1996; Porter et al., 1996; Fisher-Morris & Gellatly, 1997; Gagliese & Melzack, 1997; Parker, Brattberg, & Thorslund, 1998).

The relationship between pain and physical disability in long-term care facilities is not well established. Even though impaired ambulation as well as impaired memory were related to pain in a study by Ferrell et al. (1990), no association between pain and Katz's ADL-index was shown. Parmelee et al. (1993) found a small but significant association between pain and functional status in nursing home residents. However, 27 per cent of the residents in the study were excluded due to communication problems.

Disability can be seen as a result of chronic pain, when pain forms a hindrance to daily pursuits or rehabilitation. Also, disability could act as a source of additional pain; for instance, immobility is known to cause constipation, which is a common source of abdominal pain in disabled long-term care residents.

Both pain and disability could also be explained by a third factor, an underlying disease. Diseases or conditions associated with pain are arthritis, vasculitis, peripheral neuropathies, atherosclerotic vascular disease, fractures and herpes zoster (Guccione, Meenan, & Anderson, 1989; Ferrell et al., 1990; Sengstaken & King, 1993; Stein & Ferrell, 1996). Even though prevalence of malignant diseases is usually not very high, in the institutional long-term care settings, Bernabei et al. (1998) remarked that cancer patients who are older and belong to minorities are often untreated.

The objective of this study is to determine the prevalence of frequently occurring pain in institutional long-term care residents in four Nordic countries when no residents are excluded. The second aim is to describe the factors associated with pain and disability in these settings.

Our hypothesis is that daily complaints of pain are associated with increased level of disability in functions requiring high levels of nursing care. The presence or absence of pain and its relationship with disability will also persist in the groups with or without dementia after accounting for any relative differences in the proportion of age groups, genders and medical conditions.

Methods

The data were collected from Denmark, Finland, Iceland and Sweden. They were derived from projects using the Resident Assessment Instrument (RAI) to assess elderly residents of long-term care institutions (see details on the assessment approach: Morris et al., 1990).

The Danish data (n = 3,451) included all nursing home residents in 65 of 75 nursing homes in Copenhagen during 1992–1993. The Icelandic data included all nursing home residents (n = 1,254) in the Greater Reykjavik area in 1994. The data from Sweden, sampled in 1995–1996, comprised all residents in 25 per cent of Stockholm nursing homes (n = 1,068). In Finland, the data were collected from two cities, Kokkola and Helsinki in 1995 (n = 714). In Kokkola a small nursing home participated, while in Helsinki a large geriatric hospital responsible for all hospital-based long-term care services of one geographical health district was included in the study.

The mean age of the 6,487 patients was 83.2 years (ranging from 26–109 years) and half the patients were aged 85 or older (Table 1). Women (74.4%) outnumbered men (n = 1,663). Mean resident time at the institution was 3.0 years (ranging from 0 days–31 years).

Every resident living in the institutions was observed and assessed by the staff working on the wards. The assessment observation period was at

Table 1
Age and country of the 6,487 institutional long-term care residents

	Samples Representative of Long-Term Care				*Samples Not Representative of Long-Term Care*				*Total*	
	Number (%)				*Number (%)*					
Age Group	*Iceland*		*Denmark*		*Sweden*		*Finland*		*Number (%)*	
≤ 64 years	23	(1.8)	146	(4.2)	38	(3.6)	45	(6.3)	252	(3.9)
65–74 years	117	(9.3)	376	(10.9)	103	(9.6)	101	(14.1)	697	(10.7)
75–84 years	468	(37.3)	1201	(34.8)	401	(37.5)	247	(34.6)	2317	(35.7)
≥ 85 years	646	(51.5)	1728	(50.1)	526	(49.3)	321	(45.0)	3221	(49.7)

least one week, according to the standard protocols for use of Minimum Data Set (MDS) version 1.0. (Morris et al., 1991). In each country, the staff was trained in how to assess the individual residents and how to complete the MDS assessment forms item by item (Bernabei, Murphy, Frijters, DuPaquir, & Gardent, 1997). The training manual tells the observing team to:

> Review the medical records (including current nursing care-plan) and consult with facility staff members. Ask resident if he/she experienced any of the listed symptoms in the last seven days. A resident may not complain to staff members because he/she may attribute symptoms to old "age". Such problems can often be remedied. Consult with family member (or other person close to resident) if resident unable to respond (Morris et al., 1991).

When assessing daily pain, all the shifts in one week were taken into account. Daily pain was recorded when the subject expressed a verbal or non-verbal complaint of pain at least once daily (6–7 days per week) during the observation week. The non-communicative patients were keenly observed (e.g., during all the shifts of the day, during caring procedures and in rest) for any non-verbal indicators of pain, such as moaning, crying, wincing, frowning or other facial expressions. Also, various posturings or guarding or protecting an area of the body were taken into account. A similar approach had previously been adapted by Bernabei et al. (1998) who studied patients in pain with cancer in institutional long-term-care settings.

Functional disability was measured by using an ADL-score based on need of assistance in four items (bed mobility, toilet use, transfers and eating). This scale was computed from the corresponding MDS-variables in an identical approach to that used in the Resource Utilization Groups (RUG-III) classification system (Fries et al., 1994; Ikegami, Fries, Takegi, Ikeda,& Ibe, 1994; Carpenter, Main, & Turner, 1995; Carpenter, Ikegami, Ljunggren, Carrillo, & Fries, 1997; Sgadari et al., 1997; Björkgren, Häk-

kinen, Finne-Soveri, & Fries, 1998). A subject independent in all four ADL-items receives a score of four and a totally dependent individual a score of 18. This scale has shown a good validity reliability in several countries in categorizing long-term care residents according to utilization of care (Sgadari et al., 1997; Björkgren et al., 1998). To compress the tables and make them easier to read the 4–18 ADL-scale was simplified to range from 1 to 5 by combining scores of 4–6, 7–9, 10–12, 13–15 and 16–18 (table 4) after plotting the original grades.

The definition for severe cognitive impairment was derived from the Cognitive Performance Scale (CPS) embedded in the RAI instrument (Morris et al., 1994; Hartmaier, Sloane, Guess, & Koch, 1994; Frederiksen, Tariot, & DeJonghe, 1996). The scale ranges from zero to six and is based on five MDS-variables (presence of coma, short-term memory, cognitive skills for daily decision making, being understood by others, and self-performance in eating). Zero represents a cognitively intact person and six an individual with very severely impaired cognition. The two highest scores (4) were combined to represent severe cognitive impairment. Most of the residents in this category had very impaired or no communication skills. (Morris et al., 1994; Hartmaier et al., 1994; Frederiksen et al., 1996).

The clinical diagnoses (ICD-9) were taken from medical records. Diagnoses were only considered to be active if they affected the resident's current ADL status, cognitive status, mood or behaviour status, medical treatments, nursing monitoring or risk of death (Morris et al., 1991). Nursing records were checked fpr information regarding diagnoses.

The statistical analyses were conducted using SAS software (SAS Institute inc., Cary, NC). Chi-square analyses were done for dichotomous variables to identify the diagnoses or conditions associated with daily pain, and 95 per cent confidence intervals were derived for the odds ratios (see Gardner & Altman, 1989). Logistic regression analysis was used to determine the association of pain with the ADL-scale. Stepwise logistic regression was used to derive a final multivariate model based on variables with the strongest associations at the bivariate level.

Results

Of the 6,487 institutional long-term residents, 1,504 (23.2%) experienced pain every day. The prevalence of pain did not differ from country to country (22–24%) (Table 2). Women suffered more often from pain than men (25% vs. 18%, $p < .001$, OR 1.48, CI 1.28–1.70) and the same applied to the subjects 75 years of age or older ($p < .003$, OR 1.30, CI 1.10–1.55).

One of three residents (33%) had severe cognitive impairment (n = 2,147). In the Finnish sample, one in two residents (49%) suffered from this condition and the respective percentages for Sweden, Denmark, and Iceland were 43, 29, and 27. Residents with impaired communication skills

Table 2
Occurrence of pain in long-term care settings according to previous studies and the current study

Study	*Pain Type*	*Prevalence of Pain*
Previous Studies		
Ferrell et al. (1990)	All types	
	Constant	24%
	Intermittent	47%
	"daily"	48%
	Overall	71%
Ferrell et al. (1995)	All types	62%
Parmelee et al. (1993)	All types	80%
Parmelee (1996)	All types	71–86%
Sengstaken & King (1993)	Communicative	57%
	Non-communicative	17%
	Overall	47%
Current Study		
Communicative	Daily pain	26%
Poor communication skills	Daily pain	18%
	Overall	23%

Table 3
Occurrence of diseases independently associated with daily pain based on a the stepwise logistic regression analysis

Diseases and Conditions	*Subjects in Pain as a % of All the Subjects with this Condition*	*Odds Ratio*	*95% Confidence Intervals*
Terminal prognosis	32.8	2.58	1.83–3.64
Osteoporosis	40.7	2.33	1.96–2.78
Pneumonia	40.0	2.02	1.15–3.55
Arthritis	38.6	1.89	1.55–2.29
Depression	33.6	1.75	1.47–2.07
Anaemia	36.6	1.70	1.28–2.24
Peripheral vascular disease	33.2	1.58	1.16–2.15
Cancer	31.4	1.45	1.13–1.85
Cardiac heart failure	29.2	1.24	1.04–1.48

had almost five-fold risk ($p < .001$, OR 4.60, 95%CI 4.11–5.14) for severe disability (ADL-score 13–18).

According to the stepwise logistic regression analysis, terminal prognosis (OR 2.58 95%CI 1.83–3.64), osteoporosis (OR 2.33, 95%CI 1.96–2.78), pneumonia (OR 2.02, 95%CI 1.15–3.55), arthritis (OR 1.89, 95% CI 1.55–2.29), depression (OR 1.75, 95%CI 1.47–2.07), anaemia (OR 1.70, 95% CI 1.28–2.24), peripheral vascular disease (OR 1.58, 95%CI 1.16–2.15), cancer (OR 1.45, 95%CI 1.13–1.85) and cardiac heart failure (1.24, 95%CI 1.04–1.48) emerged as independent predictors for pain. In contrast, demen-

Table 4
Occurrence of daily pain according to functional capacity

ADL-Group (ADL-Score)	*Number of Subjects in Pain in the ADL-group*	*Percentage of Subjects in Pain in the ADL-group*
1. (4–6)	582	20.4
2. (7–9)	164	22.4
3. (10–12)	177	25.0
4. (13–15)	259	25.4
5. (16–18)	311	27.0
SUM	1493 (missing 11)	

ADL-score: range 4–18, where 4 is independent and 18 is totally dependent

Table 5
The association of daily pain and severe disability (ADL = 13–18) among 6,487 institutional long-term care residents in four Nordic countries

Country	*Number of Disabled Subjects in Pain*	*Disabled Subjects in Pain as % of All the Disabled Subjects in the Country Sample*	*P-value*	*OR*	*95% CI*
Iceland	66	22.7	0.934	0.75	0.56-1.02
Denmark	244	27.7	0.003	1.30	1.09-1.55
Sweden	142	25.0	0.013	1.47	1.08-1.99
Finland	113	27.5	0.001	2.46	1.65-3.65
All	565	26.3	0.001	1.30	1.15-1.47

tia of Alzheimer type (OR 0.49, 95%CI 0.37–0.65) and other dementias (0.71, 95% CI 0.63–0.81) associated inversely with daily pain.

The percentage of patients in pain was higher among those with more severe disability (Table 4). Residents with severe disability had significantly higher levels of pain (ADL-score = 13–18) ($p < .001$, OR 1.29 CI 1.15–1.46). Table 5 shows the results separately for each country. However, residents with severe cognitive impairment showed evidence of pain less often than those with better cognitive status (Table 2; OR 0.64, 95% CI 0.56–0.73).

The logistic regression model showed that the frequency of pain significantly increased with physical decline. The result remained unchanged when controlling for severe dementia, old age (75+) and gender (Table 6). When results for the different countries were examined separately, this relationship held true, except in Iceland. The model was also tested by adding the independent predictors for pain originating from the stepwise logistic regression analysis described above. The ADL-scale stayed significant together with all the diseases, gender and severe cognitive impairment. The odds ratio for the ADL-scale in this model declined from 1.18 to

Table 6
Multiple logistic regression analysis for pain as a dependent variable

Variables	*Odds Ratio*	*95% Confidence Intervals*
ADL-score 4–18 (divided to 5 categories)	1.18	1.13–1.23
Severe cognitive impairment (CPS=5–6)	0.50	0.43–0.58
Female gender	1.44	1.25–1.67
Old age (75 years or more)	1.24	1.03–1.17

1.17 (95%CI 1.12–1.22), which is a non-significant change based on the overlapping confidence intervals.

Discussion

To our knowledge, this is the first large international study of frequently occurring pain in institutional long-term care settings, where the non-communicative residents have not been excluded. The only method, so far, to collect information from these patients is to use proxies. Parker et al. (1998) studied the importance of proxy responses in connection with a large population-based study of pain among the oldest old in Sweden. Their conclusion was that considering the highly subjective nature of pain the responses of the proxies were both valid and reliable.

Even though the collection of data in Finland and Sweden was not based on national random samples, the large number of subjects should sufficiently describe the prevalence of pain and its relation to functional status in institutional long-term care patients in all these countries.

The data from each of the countries are likely to be comparable since in every country the assessors were educated according to clear, standardized instructions based on the RAI manual. In addition, the overall reliability of the variables included in this study has been shown to be high based on the studies including Denmark, Finland and Sweden (Sgadari et al., 1997; Björkgren et al., 1998).

The consistency of the prevalence of daily pain (22–24%) in each of the countries speaks for a mutual understanding of pain shared by the assessors.

The percentage of residents experiencing pain is consistent with previous findings of constant pain in long-term care. However, the percentage of residents identified as suffering from pain appears quite modest compared with the overall results of previous studies (Table 2). This could be explained by some limitations of MDS; namely, individuals who complain of pain on a less than daily basis are not recorded as having "daily pain" and less intensive experiences of pain not leading to spontaneous complaints fail to be recognised. Thus, using MDS does not necessarily detect

all underlying pain. The measurement of daily pain in the MDS should rather be considered as the tip of an iceberg, an index for problems with pain of such a serious, persistent and bothersome nature that they lead to repeated complaints. On the other hand, the prevalence of daily pain in this study may be lower than others because this research did not exclude the moderately or individuals with severe dementia in whom the assessment of pain may be difficult

Since the patients were observed for seven days during all shifts by the direct caregivers who knew the subjects best, it is unlikely that complaints of pain were not noticed. It was also unlikely, even though not registered, that such a constant number of patients would have refused painkillers if offered. It is also unlikely that the nurses would have neglected an elderly resident in pain after registering the fact for further observation. It is likely, in most of the cases, that the residents actually suffer from daily flares of chronic pain temporarily relieved by attempts to manage it.

Based on the speculations above, another explanation for insufficient pain management might be the fact that the physical and cognitive frailty of the patients make them prone to various side effects of medication. This fact has always to be weighed against the discomfort of one or two brief flares of pain daily.

If side-effects of the medications are expected to be a problem, serious work has to be done in basic research concerning pain in elderly frail subjects. A thorough discussion is needed concerning pain management, so as not to leave these individuals without help, as pointed out by Ferrell (1995) and Bernabei et al. (1998)

The results accord well and confirm the previous finding of Sengstaken and King (1993) that communicative residents in long-term care more often show evidence of pain than the individuals with insufficient communication skills. However, clinically and ethically it is important that one of five subjects with severe dementia shows evidence of pain daily. Since the individuals with severe cognitive impairment were often disabled and pain was associated with increasing disability, it was appropriate to control the pain-disability relationship for severe dementia, in addition to old age and gender (Table 6). The relationship between pain and disability is detectable in both the group with severe dementia and the group with better cognitive skills.

The information about the diagnoses might be biased because of the possibility that inactive diagnoses were not registered. In addition, treatment in long-term care institutions is often symptomatic and it is questionable if an official diagnosis was found in the medical records concerning various discomforts with multiple aetiology (e.g., constipation). On the other hand, in these settings, pain has also previously been associated with depression, arthritis and cancer (Guccione et al., 1989; Cohen-Mansfield & Marx, 1993; Parmelee et al., 1993; Bernabei et al., 1998).

Even when the non-communicative residents were included, pain had a clear association to disability, supporting previous findings (Guccione et al., 1989; Ferrell et al., 1990; Sengstaken & King, 1993). Accumulation of pain among the most disabled residents supports both the hypothesis of pain as a source of disability and the idea of disability as a source of pain. A vicious circle with pain leading to disability that, in turn, leads to additional pain can be anticipated. The presence of this circle was suggested by the multivariate analysis, where disability stayed significant in the model after adding all the diseases previously shown to be independent predictors for pain. Based on these analyses, managing pain would not only include the management of the underlying disease but also preventing and managing disability. Because of the cross-sectional nature of the current study, the cause-effect relationship between pain and disability cannot be speculated about further.

In institutional long-term care settings in the four Nordic countries, almost one out of four residents daily suffers from pain so bothersome that it leads to spontaneously expressed observable discomfort. Based on previous studies, there is reason to believe that these observations are only the tip of an iceberg. The residents with severe cognitive impairment are not free from this discomfort even if the proportion of residents in pain is smaller among them than among the residents with better cognition. The origin of pain in these settings is multifactorial and pain is independently associated with disability. The other variables associated with pain are terminal prognosis, osteoporosis, pneumonia, arthritis, depression, anaemia, peripheral vascular disease, cancer, cardiac heart failure and female gender. A vicious circle from pain to disability and back to pain can be the result for long-term care residents experiencing these conditions.

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