RESEARCH ARTICLE

International Journal of Geriatric Psychiatry

Pain among institutionalized stroke patients and its relation to emotional distress and social engagement

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Objective: Pain is a frequent long-term consequence of stroke, but its relation to emotional and social well-being is poorly studied in stroke populations. We aimed to identify the prevalence of substantial pain among institutionalized stroke patients and to explore its relation to emotional distress (ED) and low social engagement (SE).

Methods: In a cross-sectional design, we collected data of 274 chronic stroke patients in Dutch nursing homes. Observation lists were filled out in structured interviews with qualified nurse assistants who knew the residents well. Pain and SE were measured with the Resident Assessment Instrument for Long-term Care Facilities, and ED was measured with the Neuropsychiatric Inventory Questionnaire (NPIQ).

Results: Substantial pain was present in 28% of the residents, mostly located in the affected body side (68%). Multilevel regression analyses revealed that this pain was independently related to a 60% increase in NPIQ score (β 3.18 [1.84–4.53]) and to clinically relevant symptoms of delusions (odds ratio [OR] 8.45 [1.82–39.05]), agitation/aggression (OR 3.82 [1.76–8.29]), depression (OR 3.49 [1.75–6.98]), and anxiety (OR 2.32 [1.08–4.97]). Substantial pain was associated with low SE when adjusted for clinical covariates (OR 4.25 [1.72–10.53]), but only in residents with no/mild or severe cognitive impairment. This relation disappeared when additionally corrected for NPIQ score (OR 1.95 [0.71–5.39]).

Conclusions: Pain is a serious and multidimensional problem among institutionalized stroke patients. It is related to increased ED, which in turn can be a pathway to low SE as an indicator of social vulnerability. Future research should reveal how pain management in nursing homes can be tailored to the needs of this patient group. Copyright © 2014 John Wiley & Sons, Ltd.

Key words: stroke; long-term care; nursing home; pain; neuropsychiatry
History: Received 9 April 2014; Accepted 9 December 2014; Published online 8 January 2015 in Wiley Online Library (wileyonlinelibrary.com)
DOI: 10.1002/gps.4256

Introduction

Pain is a frequent long-term consequence of stroke, encompassing hemiplegic shoulder pain, pain due to muscle stiffness or spasm, headache, and central post-stroke pain as the most common pain types (Klit *et al*., 2011). Previous research showed that chronic pain following stroke is prevalent in 11–55% of patients at 6 months to 2 years post-stroke (Appelros, 2006; Jonsson *et al*., 2006; Sackley *et al*., 2008; Lundstrom *et al*., 2009; Naess *et al*., 2010; Klit *et al*., 2011; Hansen *et al*., 2012). In a study population of institutionalized stroke patients, we even found a total of 58% suffering from some type of pain (van Almenkerk *et al*., 2012).

Suffering from pain is not only restricted to physical discomfort but also affects emotional and social well-being. With respect to emotional distress (ED), the association between pain and depression is well known and has also been demonstrated in stroke populations (Appelros, 2006; Jonsson *et al*., 2006; Lundstrom *et al*., 2009; Klit *et al*., 2011). Research in various study populations also showed a relationship with anger (in chronic pain patients; Gatchel *et al.*, 2007), agitation and aggression (in nursing home [NH] residents with dementia; Husebo *et al.*, 2011), and anxiety (in patients with fibromyalgia; Gatchel *et al.*, 2007; or osteoarthritis; Smith and Zautra, 2008; and in NH residents; Smalbrugge *et al.*, 2007; Lapane *et al.*, 2012). With regard to social well-being, pain is shown to be adversely related to participation in social activities (e.g., in osteoarthritis patients; Machado *et al.*, 2008; and in NH residents; Lapane *et al.*, 2012). Shega *et al.* (2012) demonstrated that pain in community-dwelling older adults is associated with an index of "social vulnerability" that they operationalized as a compilation of variables characterizing a person's social circumstance, including social engagement (SE).

Although the amount of pain studies in stroke populations increased in recent years, the relation of pain to emotional and social well-being in stroke patients is still poorly studied. In this study, we focus on chronic stroke patients who are dependent of institutional long-term care, as part of our aim to develop an integrated care and treatment program for this population. We aim to answer the following research questions:

(1) What is the prevalence of substantial pain among institutionalized stroke patients, and where is this pain located?
(2) Is this substantial pain independently associated with increased ED? And if so, how is this increased ED characterized?
(3) Is this substantial pain independently associated with low SE, as an indicator of social vulnerability?

Methods

This study is part of the Care for Stroke in Long-term Care Facilities in the Netherlands study. From May 2008 to July 2009, a cross-sectional, observational study design was used to collect data of chronic stroke patients who received long-term care in 17 Dutch NHs (van Almenkerk *et al.*, 2012). Attending physicians (in Dutch NHs delivered by specifically trained physicians, referred to as elderly care physicians [ECPs]) were asked to select their patients according to the following inclusion criteria: (1) stroke was the main diagnosis for NH admission; (2) the last stroke occurred ≥3 months ago; (3) the need for long-term care was indicated by the multidisciplinary stroke team and discussed with the stroke patient and his or her relatives; and (4) the resident stayed ≥1 month on a long-term care ward. We collected data of each resident through an observation list that was filled out in a structured interview with a qualified nurse assistant who knew the resident well. The use of observation instruments enabled us to include also residents with severe cognitive and/or communicative impairments. All nurse assistants were interviewed by the same trained research assistant. As we will describe in the following measurements section, additional information was provided by the attending ECP. A total of 284 residents were included (ranging from 3 to 31 residents per NH), of which 10 cases were excluded because of incomplete questionnaires. The study protocol was approved by the medical ethics committee of the VU University Medical Center.

Measurements

Pain. Pain was measured with the pain scale of the Dutch version of the Minimum Data Set of the Resident Assessment Instrument for Long-term Care Facilities (MDS-RAI-LTCF), which is easy to administer and commonly used in NH studies (e.g., Achterberg *et al.*, 2010). It defines pain as "any type of physical pain or discomfort of the body. Pain may be localized to one area, or be more generalized. It may be acute or chronic, continuous or intermittent (comes and goes), occur at rest or with movement." The validity and precision of pain measurement with the MDS-RAI-LTCF items have been established against the visual analogue scale in a study involving 95 US NH residents (Fries *et al.*, 2001).

The MDS-RAI-LTCF pain scale addresses the following pain characteristics: *pain frequency*, coded as no pain (0), less than daily pain (1), and daily pain (2) in the last 7 days; *pain intensity*, categorized as no pain, mild pain (0), moderate pain (1), and severe pain (2, defined as "times when pain is horrible or excruciating") in the last 7 days; and *pain location*, with the following categories: (i) back pain; (ii) bone pain; (iii) chest pain while doing usual activities; (iv) headache; (v) hip pain; (vi) incisional pain; (vii) joint pain, other than hip; (viii) soft tissue pain (e.g., lesion and muscle); (ix) stomach pain; and (x) other pain. For the purpose of this study, we added the category "pain in the affected body side." For additional information, researchers M. S., J. E., and C. H. reviewed medication lists to identify the prescription of analgesics and psychotropics, coded as yes/no.

We defined pain as substantial when the product of pain frequency and pain intensity was ≥2, referring to severe or daily moderate pain (Pieper *et al.*, 2011).

Emotional distress. The amount of ED was assessed using the NPIQ (de Jonghe *et al*., 2003), which covers a broad range of neuropsychiatric (NP) symptoms in 12 domains. Each domain is assessed by a screening question that covers core symptom manifestations. When these symptoms are present in the last month, symptom severity is evaluated on a 3-point scale (1: *mild*, 2: *moderate*, 3: *severe*).

The total NPIQ score is the sum of individual symptom scores and represents the amount of ED, ranging from 0 (no NP symptoms present) to 36 (all NP symptoms present with maximum severity).

We defined an individual NP symptom to be clinically relevant when its severity was ≥2 (moderate or severe; Kaufer *et al*., 2000).

Social engagement. SE was measured by the MDS-RAI-LTCF Revised Index for Social Engagement (RISE; Gerritsen *et al*., 2008), which is constructed from the following six items: (i) easily interacts with others; (ii) easily does planned or structured activities; (iii) accepts invitations into most group activities; (iv) pursues involvement in life of facility; (v) initiates interaction(s) with others; and (vi) reacts positively to interactions initiated by others. The RISE ranges from 0 (*lowest level*) to 6 (*highest level of SE*).

We considered a RISE score of 0–2 to be indicative of low SE (Achterberg *et al*., 2003).

Clinical covariates. ***Demographics.*** A resident's age, gender, and marital status were administered.

Stroke characteristics. Elderly care physicians provided information about stroke subtype (hemorrhagic or ischemic), stroke location (left sided or right sided; the category "other location" is not included in the analyses), and time post-stroke.

Comorbidity. Elderly care physicians provided information about the presence of diagnoses other than stroke that influenced a resident's current status of functioning. We counted the total number of different diagnoses according to the *International Statistical Classification of Diseases and Related Health Problems*, 10th revision, coding system (Quail *et al*., 2011) and dichotomized it on the median.

Physical functioning. Performance in basic activities of daily living (ADL) was measured by the 20-point Barthel Index (BI). We categorized ADL dependence as *very severe* (BI 0–4; de Haan *et al*., 1993), *severe* (BI 5–11), and *moderate/mild* (BI ≥ 12; Sulter *et al*., 1999). To the best of our knowledge, there is no valid observation instrument to measure fatigue (Lerdal *et al*., 2009). To have an indication of the amount of fatigue, we asked the nurse assistant how many hours in a 24-h day the resident stayed in bed.

Cognitive functioning. Cognitive functioning was measured by the MDS-RAI-LTCF Cognitive Performance Scale (CPS), which has good agreement with the Mini-mental State Examination in the detection of cognitive impairment in NH residents (Paquay *et al*., 2007). The CPS is a seven-category index, ranging from *cognitively intact* (0) to *very severely impaired* (6). We categorized the CPS by combining the three severe categories as *severe* (CPS 4–6), the middle two categories as *moderate* (CPS 2–3), and the remaining two categories as *no/mild* cognitive impairment (CPS 0–1).

Communicative functioning. Communicative functioning was measured using the RAI-LTCF items "ability to make him/herself clear" (expression) and "ability to understand others" (comprehension; Morris *et al*., 2006). Both items are evaluated on a 5-point frequency scale (*always*, *usually*, *often*, *sometimes*, and *rarely or never*). We dichotomized the scores by combining the first three categories in *good or moderate* and the last two categories in *poor*.

Statistical analyses

Descriptive statistics were firstly generated for the assessed pain characteristics and medication categories and secondly for the other variables stratified to the presence or absence of substantial pain. To explore differences in the clinical covariates between the subgroups, we performed univariable analyses using IBM SPSS Statistics version 20 (Armonk, NY, USA): an independent *t*-test for age (normally distributed), a nonparametric Mann–Whitney *U*-test for time post-stroke (not normally distributed), and χ^2-statistics for dichotomous variables (Fisher's exact test, two-sided) and categorical variables (Pearson χ^2, two-sided).

To investigate the association between substantial pain (independent variable) and ED and low SE (outcome measures), we used multilevel analyses to adjust for possible dependence of observations, due to the clustering of residents within ECPs (second level) and NHs (third level; Twisk, 2006). The relations were analyzed with linear multilevel regression techniques (pain and NPIQ score; assumptions of linearity and normality were checked with an analysis of residuals) and logistic multilevel regression techniques (pain and clinically relevant NP symptoms; pain and low SE). Possible confounders were entered into the models in two consecutive steps: (1) all clinical covariates and (2) the other outcome measure (NPIQ score or low SE). Furthermore, we investigated whether age, gender, stroke location, cognitive impairment, and poor expression modified the relations (only with respect to the outcome measures NPIQ score and low SE), by adding each interaction term separately to the crude models (significance level $p < 0.10$). All multilevel analyses were performed with second-order penalized quasi-likelihood estimation procedures, using MLwiN 2.24 (Centre for Multilevel Modeling, University of Bristol, Bristol, UK).

Results

Table 1 shows the prevalence of the assessed pain characteristics and the prescription of medication. In the total study population ($n = 274$), 58% experienced some type of pain (i.e., daily or less than daily pain). In two-thirds of these residents, pain intensity was evaluated as moderate or severe (47.2% and 18.9%). A total of 27.7% suffered from substantial pain. This was mostly located in the stroke-affected body side (68.4%), followed by soft tissue pain (23.7%) and back pain (21.1%).

Table 2 demonstrates the characteristics of the study population, stratified by the presence or absence of substantial pain. Univariable analyses only showed that residents in pain had more bed rest, relative to residents not in pain (Pearson $\chi^2[2, n = 274] = 15.39$, $p = 0.000$).

Mean NPIQ score was 8.68 (±6.12) and 5.35 (±4.50), respectively, for residents with and without substantial pain (Table 2). In the crude multilevel analysis (Table 3), substantial pain contributed 3.08 [1.81–4.34] points to the NPIQ score, without any identified effect modification. This association was sustained when the model was corrected for clinical covariates (model 1, β 3.56 [2.18–4.93]) and when additionally corrected for low SE (model 2, β 3.18 [1.84–4.53]). Relative to residents not in pain (mean NPIQ score 5.35), this indicates an increase of almost 60%.

The most occurring clinically relevant NP symptom was irritability/lability (in 52.6% and 39.4% of residents with and without substantial pain, respectively), followed by dysphoria/depression (51.3% and 34.3%) and apathy/indifference (38.2% and 23.2%; Figure 1). In the multilevel analyses (Table 3), substantial pain appeared to be independently related to the symptoms of delusions (model 2, odds ratio [OR] 8.45 [1.82–39.05]), agitation/aggression (OR 3.82 [1.76–8.29]), dysphoria/depression (OR 3.49 [1.75–6.98]), and anxiety (OR 2.32 [1.08–4.97]).

A low SE was present in 40.8% and 26.3% of residents with and without substantial pain, respectively (Table 2). In the crude multilevel analyses, the association between substantial pain and low SE appeared to be modified by the level of cognitive impairment (“moderate” versus “no/mild,” Wald χ^2 4.61, $df = 1$, $p < 0.05$; “moderate” versus “severe,” Wald χ^2 3.67, $df = 1$, $p < 0.10$; but no modification by “no/mild” versus “severe,” Wald χ^2 0.01, $df = 1$, $p > 0.10$). Therefore, we present stratified results (Table 3). Only residents with no/mild or severe cognitive impairment were more likely to have low SE when they were in pain, both in the crude model (OR 2.72 [1.44–5.15]) and when adjusted for clinical covariates (model 1, OR 4.25 [1.72–10.53]). However, when the model was additionally corrected for NPIQ score, the relationship

Table 1 Pain characteristics of institutionalized stroke patients and prescription of analgesics and psychotropics

	n (%)
Pain frequency ($n = 274$)	
No pain	115 (42.0)
Less than daily	65 (23.7)
Daily	94 (34.3)
Pain intensity ($n = 159$)[a]	
Mild	54 (34.0)
Moderate	75 (47.2)
Severe	30 (18.9)
Substantial pain ($n = 274$)[b]	76 (27.7)
Pain location ($n = 76$)[c]	
In the affected body side	52 (68.4)
Soft tissue pain	18 (23.7)
Back pain	16 (21.1)
Joint pain, other than hip	13 (17.1)
Other pain	9 (11.8)
Hip pain	9 (11.8)
Headache	6 (7.9)
Stomach pain	2 (2.6)
Chest pain	2 (2.6)
Incisional pain	1 (1.3)
Bone pain	0 (0.0)
Analgesics ($n = 274$)	
Acetaminophen	111 (40.5)
Nonsteroidal anti-inflammatory drugs	22 (8.0)
Weaker opioids	16 (5.8)
Stronger opioids	14 (5.1)
Psychotropics ($n = 274$)	
Antidepressants	101 (36.9)
Anxiolytics/hypnotics	86 (31.4)
Antiepileptics	58 (21.2)
Antipsychotics	22 (8.0)

[a]In residents with (less than) daily pain.
[b]Defined as severe or daily moderate pain.
[c]In residents with substantial pain.

Table 2 Characteristics of institutionalized stroke patients with and without substantial pain (pain+ and pain−, respectively)

	Pain+ (*n* = 76)	Pain− (*n* = 198)	
	n (%)	*n* (%)	*p*-value
Age (mean ± SD, years)	75.7 ± 10.9	77.0 ± 10.5	0.393
Female	45 (59.2)	115 (58.1)	0.892
Single/widowed	44 (57.9)	125 (63.1)	0.488
Ischemic stroke	58 (80.6)	155 (81.6)	0.860
Right-sided stroke (*n* missing = 29)	42 (63.6)	90 (50.3)	0.083
Time post-stroke (median [IQR], months)	41 [16.50–72]	49 [26.75–87.75]	0.108
≥2 comorbid diagnoses	45 (59.2)	102 (51.5)	0.280
Dependence in basic ADL			
Very severe	45 (59.2)	87 (43.9)	
Severe	27 (35.5)	90 (45.5)	0.059
Moderate/mild	4 (5.3)	21 (10.6)	
Bed rest			
<12 h	27 (35.5)	108 (54.5)	
12–16 h	30 (39.5)	73 (36.9)	0.000
>16 h	19 (25.0)	17 (8.6)	
Cognitive impairment			
No/mild	44 (57.9)	100 (50.5)	
Moderate	17 (22.4)	50 (25.3)	0.537
Severe	15 (19.7)	48 (24.2)	
Poor comprehension	9 (11.8)	23 (11.6)	1.000
Poor expression	17 (22.4)	59 (29.8)	0.231
NPIQ score (mean ± SD)	8.68 ± 6.12	5.35 ± 4.50	NT
Low social engagement	31 (40.8)	52 (26.3)	NT

Values are *n* (%) unless otherwise indicated.
NT, not tested because these characteristics are outcome measures in multilevel analyses; IQR, interquartile range; ADL, activities of daily living; NPIQ, Neuropsychiatric Inventory Questionnaire.

disappeared (model 2, OR 1.95 [0.71–5.39]). Furthermore, the model showed an independent association between the NPIQ score and low SE (OR 1.19 [1.08–1.31] per 1-point increase of the NPIQ score).

Discussion

This explorative, cross-sectional study among institutionalized stroke patients shows that a total of 28% experience substantial pain (severe or daily moderate), which is mostly located on the side of the body that is affected by the stroke. Residents with (substantial) pain have more ED as opposed to residents without pain, expressed by a 60% increase of NP symptoms. They are especially more likely to exhibit clinically relevant symptoms of delusions, agitation/aggression, depression, and anxiety. Furthermore, substantial pain is associated with social vulnerability, expressed by a four times higher prevalence of low SE. However, the results suggest that this relationship is only present in residents with no/mild or severe cognitive impairment and disappears when the amount of ED is taken into account.

Pain prevalence among institutionalized stroke patients (58% have some type of pain in our study) can be expected to be higher than in the general stroke population (11–45%). We are aware of one study with a similar study population to ours: Sackley *et al.* (2008) investigated complications in patients with severe strokes (BI score ≤ 10) and found during the first year shoulder and other types of pain in 52–55% of patients, comparable with our findings. However, they did not investigate pain frequency and intensity, so we are not able to compare our finding that 28% suffer from substantial pain.

Our finding that the most common pain location is the affected body side suggests that in many residents the pain is stroke related. This argues for further research on stroke-specific pain types in institutionalized stroke patients. For example, a recent NH study found (possible) central post-stroke pain in 10% of residents, highlighting the need for validated tools to screen and diagnose specific pain types (van Kollenburg *et al.*, 2012).

The increased ED we demonstrated in residents with substantial pain is in line with studies in various patient populations as outlined in the introduction. Because of the cross-sectional design of our study,

Table 3 Multilevel analyses of the association between substantial pain, and emotional distress and low social engagement

Outcome measure	Crude model	Model 1	Model 2
NPIQ score	β, 3.08 [1.81-4.34]*	β, 3.56 [2.18-4.93]*	β, 3.18 [1.84-4.53]*
Clinically relevant NP symptoms			
Delusions	OR, 5.71 [3.16–18.20]*	OR, 7.79 [1.86–32.71]*	OR, 8.45 [1.82–39.05]*
Hallucinations	OR, 2.67 [0.53–13.52]	OR, 3.68 [0.45–29.97]	OR, 3.32 [0.38–28.89]
Agitation/aggression	OR, 3.27 [1.78–6.00]*	OR, 4.13 [1.93–8.86]*	OR, 3.82 [1.76–8.29]*
Dysphoria/depression	OR, 2.02 [1.18–3.45]*	OR, 3.78 [1.91–7.49]*	OR, 3.49 [1.75–6.98]*
Anxiety	OR, 2.00 [1.05–3.80]*	OR, 2.30 [1.08–4.91]*	OR, 2.32 [1.08–4.97]*
Elation/euphoria	OR, 1.90 [0.78–4.65]	OR, 2.66 [0.79–8.96]	OR, 3.01 [0.88–10.31]
Apathy/indifference	OR, 1.70 [0.89–3.25]	OR, 1.95 [0.81–4.69]	OR, 1.48 [0.53–4.18]
Disinhibition	OR, 1.53 [0.51–4.61]	OR, 1.63 [0.34–7.79]	OR, 1.62 [0.39–6.70]
Irritability/lability	OR, 1.71 [1.00–2.91]*	OR, 1.42 [0.75–2.69]	OR, 1.25 [0.65–2.40]
Aberrant motor behaviors	OR, 2.85 [1.14–7.14]*	OR, 2.83 [0.95–8.40]	OR, 2.71 [0.89–8.25]
Nighttime behavioral disturbances	OR, 2.03 [1.01–4.09]*	OR, 2.09 [0.90–4.82]	OR, 2.03 [0.87–4.72]
Appetite/eating disturbances	OR, 1.18 [0.49–2.83]	OR, 1.67 [0.59–4.75]	OR, 1.67 [0.59–4.74]
Low social engagement			
• Moderate cognitive impairment	OR, 0.60 [0.17–2.12]	OR, 0.16 [0.01–1.82]	OR, 0.15 [0.01–1.77]
• No/mild or severe cognitive impairment	OR, 2.72 [1.44–5.15]*	OR, 4.25 [1.72–10.53]*	OR, 1.95 [0.71–5.39]

β and OR presented with 95% confidence interval. Model 1, adjusted for clinical covariates; model 2, additionally adjusted for low SE, or NPIQ score (with regard to low SE as outcome measure). NPIQ, Neuropsychiatric Inventory Questionnaire; NP, neuropsychiatric; SE, social engagement.
*$p < 0.05$.

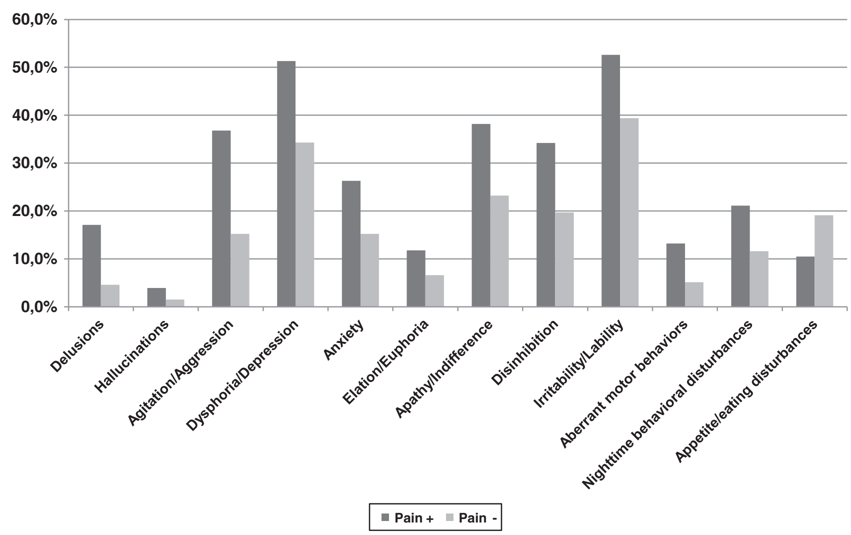

Figure 1 Prevalence of clinically relevant neuropsychiatric symptoms among institutionalized stroke patients with and without substantial pain (pain+ and pain−, respectively).

we are not able to draw conclusions about the direction of the causal pathway. However, from a biopsychosocial perspective (Gatchel *et al.*, 2007), it can be expected that the relationship between pain and ED is bidirectional. In this view, biological (sensory) and emotional processes are tightly integrated in the pain experience in the brain, especially with regard to chronic pain. As a result, ED not only occurs in response to pain but also triggers, maintains, or exacerbates pain. Longitudinal research on this subject would be very desirable.

The use of the NPIQ allowed us to explore the relation of pain with a broad range of NP symptoms. For the most part though, the increased ED is characterized by symptoms known from previous research as outlined in the introduction (agitation/aggression, depression, and anxiety). With regard to depression, our result is rather in line with the mentioned stroke studies, showing ORs ranging from 2.1 to 4.1. In addition, our results demonstrated that residents in pain are much more likely to show delusions. Although this association was also revealed in a study among NH residents with cognitive impairment (Tosato *et al*., 2012), we are not able to explain it. Further research is needed to confirm or reject this result.

With respect to the relation between substantial pain and low SE, we firstly want to consider the finding that the demonstrated association in model 1 (in residents with no/mild or severe cognitive impairment) disappeared when additionally corrected for the amount of ED. This result suggests that ED acts as a pathway in the relation between pain and low SE, meaning that pain is associated with increased ED (relation A1), which in turn is related to low SE (relation A2). Our results show that the conditions for such a mediated model (Baron and Kenny, 1986) are satisfied: relations A1 and A2 are significant, and the direct relation between pain and low SE is no longer significant when it is controlled for relations A1 and A2. This suggests that substantial pain is not directly related to low SE as an indicator of social vulnerability, but only through ED. This finding is in line with a longitudinal study among patients with osteoarthritis, in which psychological (depressive) symptoms also were shown to be a pathway between physical symptoms (including pain) and subsequent participation restrictions 18 months later (Machado *et al*., 2008).

Assuming an association between pain and low SE that is mediated by ED, we want to evaluate our finding that this relation seems to be modified by cognitive functioning. Of course, we have to interpret this result very cautiously, owing to the small size of subgroups in the analyses. But in relation to what is known from the literature, this finding might be clinically relevant. Although the relation between pain and the *amount* of increased ED appeared to be similar across levels of cognitive impairment, it is still possible that the *character* of this increased ED is modified. It is known from research in NH residents that the prevalence of individual NP symptoms is related to the severity of cognitive impairment (Zuidema *et al*., 2009) and changes over time (Wetzels *et al*., 2010). For example, symptoms of depression and anxiety tend to decrease as dementia progresses. Therefore, we hypothesize that the increased ED associated with pain among institutionalized stroke patients is characterized by other (combinations of) NP symptoms across levels of cognitive impairment. In turn, the relation with low SE (relation A2) could differ across these (combinations of) individual NP symptoms.

This study has some limitations. We already mentioned the cross-sectional design that does not allow us to gain insight into the evolution of symptoms and the direction of causal pathways. Secondly, in the context of the explorative character of the study, we tested many relations and interactions, possibly affecting the robustness of the results. A third limitation is the lack of detailed information about pain management strategies, such as adequacy of drug dosing or identification of co-analgesics and non-pharmacological interventions. Although it was not the purpose of this paper to evaluate pain management, differences in treatment could bias the relation between pain and NP symptoms. We partly compensated this by performing multilevel analyses that adjust for possible differences between ECPs and NHs. A major strength of this study is the uniqueness of the study population, representing an under-researched population on the continuum of stroke care. The use of observation instruments enabled us to include all residents, even those with severe cognitive and/or communicative impairments.

Pain management is a key element to improving quality of care (Morley, 2012), and our findings underline that there still is much to improve. A critical step will be the successful implementation in NHs of existing clinical practice guidelines regarding assessment and treatment of pain (e.g., Achterberg *et al*., 2012), in which organizational and educational aspects play important roles (Swafford *et al*., 2009; Barry *et al*., 2012). In addition, future research should reveal how pain management can be tailored to the needs of institutionalized stroke patients. Firstly, accurate pain assessment needs to be optimized for those residents who are limited in self-report because of cognitive and/or communicative impairments, just as has been acknowledged for dementia patients (Achterberg *et al*., 2013). Secondly, it is of major importance that this group of chronic stroke patients will be included in research on stroke-specific pain types. Finally, gaining further insight into the interaction between pain and emotional and social well-being could open new areas of intervention. More adequate pain interventions could hopefully reduce related ED, as shown in dementia patients (e.g., Husebo *et al*., 2014). In complement, interventions targeting ED may also reduce the experience of pain, especially with regard to chronic pain. As far as we know, this has not been evaluated in stroke patients to date.

Conclusion

This explorative study is the first to show that pain is a serious and multidimensional problem among institutionalized stroke patients. It is related to increased ED, which in turn can be a pathway to low SE as an indicator of social vulnerability. Future research should reveal how pain management in NHs can be tailored to the needs of this patient group.

Conflict of interest

None declared.

Key points

- Substantial pain is prevalent in 28% of institutionalized stroke patients, mostly located in the stroke-affected body side.
- This pain is independently associated with increased emotional distress, characterized by clinically relevant symptoms of delusions, agitation/aggression, depression, and anxiety.
- This pain is independently associated with low social engagement, possibly mediated by the emotional distress.
- Future research should reveal how pain management in nursing homes can be tailored to the needs of these chronic stroke patients.

Ethics statement

This study was approved by the medical ethics committee of the VU University Medical Center, Amsterdam, the Netherlands.

Acknowledgements

Funding was provided by *Zonnehuisgroep Vlaardingen*, *Vereniging het Zonnehuis*, and *De Open Ankh* (Dutch healthcare organizations) and the University Network of Organizations for Care for the Elderly of the VU University Medical Center. The authors assume full responsibility for the accuracy and completeness of the ideas presented. We thank all the residents and personnel of the NHs who made this study possible and our research assistant for her help with the data collection.

References

Achterberg W, Pot AM, Kerkstra A, *et al.* 2003. The effect of depression on social engagement in newly admitted Dutch nursing home residents. *Gerontologist* **43**: 213–218.

Achterberg WP, de Ruiter CM, de Weerd-Spaetgens CM, *et al.* 2012. Multidisciplinary guideline 'Recognition and treatment of chronic pain in vulnerable elderly people'. *Ned Tijdschr Geneeskd* **155**: A4606.

Achterberg WP, Gambassi G, Finne-Soveri H, *et al.* 2010. Pain in European long-term care facilities: cross-national study in Finland, Italy and The Netherlands. *Pain* **148**: 70–74.

Achterberg WP, Pieper MJ, van Dalen-Kok AH, *et al.* 2013. Pain management in patients with dementia. *Clin Interv Aging* **8**: 1471–1482.

Appelros P. 2006. Prevalence and predictors of pain and fatigue after stroke: a population-based study. *Int J Rehabil Res* **29**: 329–333.

Baron RM, Kenny DA. 1986. The moderator–mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *J Pers Soc Psychol* **51**: 1173–1182.

Barry HE, Parsons C, Peter PA, Hughes CM. 2012. An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *Int J Geriatr Psychiatry* **27**: 1258–1266.

de Haan R, Limburg M, Schuling J, *et al.* 1993. Clinimetric evaluation of the Barthel Index, a measure of limitations in daily activities. *Ned Tijdschr Geneeskd* **137**: 917–921.

de Jonghe JF, Kat MG, Kalisvaart CJ, Boelaarts L. 2003. Neuropsychiatric inventory questionnaire (NPI-Q): a validity study of the Dutch form. *Tijdschr Gerontol Geriatr* **34**: 74–77.

Fries BE, Simon SE, Morris JN, Flodstrom C, Bookstein FL. 2001. Pain in U.S. nursing homes: validating a pain scale for the minimum data set. *Gerontologist* **41**: 173–179.

Gatchel RJ, Peng YB, Peters ML, Fuchs PN, Turk DC. 2007. The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychol Bull* **133**: 581–624.

Gerritsen DL, Steverink N, Frijters DH, *et al.* 2008. A revised Index for Social Engagement for long-term care. *J Gerontol Nurs* **34**: 40–48.

Hansen AP, Marcussen NS, Klit H, *et al.* 2012. Pain following stroke: a prospective study. *Eur J Pain* **16**: 1128–1136.

Husebo BS, Ballard C, Fritze F, Sandvik RK, Aarsland D. 2014. Efficacy of pain treatment on mood syndrome in patients with dementia: a randomized clinical trial. *Int J Geriatr Psychiatry* DOI: 10.1002/gps.4063.

Husebo BS, Ballard C, Sandvik R, Nilsen OB, Aarsland D. 2011. Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial. *BMJ* **343**: d4065. DOI: 10.1136/bmj.d4065.

Jonsson AC, Lindgren I, Hallstrom B, Norrving B, Lindgren A. 2006. Prevalence and intensity of pain after stroke: a population-based study focusing on patients' perspectives. *J Neurol Neurosurg Psychiatry* **77**: 590–595.

Kaufer DI, Cummings JL, Ketchel P, *et al.* 2000. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *J Neuropsychiatry Clin Neurosci* **12**: 233–239.

Klit H, Finnerup NB, Overvad K, Andersen G, Jensen TS. 2011. Pain following stroke: a population-based follow-up study. *PLoS One* **6**: e27607. DOI: 10.1371/journal.pone.0027607.

Lapane KL, Quilliam BJ, Chow W, Kim M. 2012. The association between pain and measures of well-being among nursing home residents. *J Am Med Dir Assoc* **13**: 344–349.

Lerdal A, Bakken LN, Kouwenhoven SE, *et al.* 2009. Poststroke fatigue—a review. *J Pain Symptom Manage* **38**: 928–949.

Lundstrom E, Smits A, Terent A, Borg J. 2009. Risk factors for stroke-related pain 1 year after first-ever stroke. *Eur J Neurol* **16**: 188–193.

Machado GP, Gignac MA, Badley EM. 2008. Participation restrictions among older adults with osteoarthritis: a mediated model of physical symptoms, activity limitations, and depression. *Arthritis Rheum* **59**: 129–135.

Morley JE. 2012. Pain—"God's megaphone". *J Am Med Dir Assoc* **13**: 316–318.

Morris JN, Belleville-Taylor P, Fries BE, *et al.* 2006. *InterRAI Long-term Care Facilities (LTCF) Assessment Form and User's Manual, 9.1*. interRAI: Washington D.C.

Naess H, Lunde L, Brogger J, Waje-Andreassen U. 2010. Post-stroke pain on long-term follow-up: the Bergen stroke study. *J Neurol* **257**: 1446–1452.

Paquay L, De Lepeleire J, Schoenmakers B, *et al.* 2007. Comparison of the diagnostic accuracy of the Cognitive Performance Scale (Minimum Data Set) and the Mini-mental State Exam for the detection of cognitive impairment in nursing home residents. *Int J Geriatr Psychiatry* **22**: 286–293.

Pieper MJ, Achterberg WP, Francke AL, *et al.* 2011. The implementation of the serial trial intervention for pain and challenging behaviour in advanced dementia patients (STA OP!): a clustered randomized controlled trial. *BMC Geriatr* **11**: 12. DOI: 10.1186/1471-2318-11-12.

Quail JM, Lix LM, Osman BA, Teare GF. 2011. Comparing comorbidity measures for predicting mortality and hospitalization in three population-based cohorts. *BMC Health Serv Res* **11**: 146. DOI: 10.1186/1472-6963-11-146.

Sackley C, Brittle N, Patel S, *et al*. 2008. The prevalence of joint contractures, pressure sores, painful shoulder, other pain, falls, and depression in the year after a severely disabling stroke. *Stroke* **39**: 3329–3334.

Shega JW, Andrew M, Hemmerich J, *et al*. 2012. The relationship of pain and cognitive impairment with social vulnerability—an analysis of the Canadian Study of Health and Aging. *Pain Med* **13**: 190–197.

Smalbrugge M, Jongenelis LK, Pot AM, Beekman AT, Eefsting JA. 2007. Pain among nursing home patients in the Netherlands: prevalence, course, clinical correlates, recognition and analgesic treatment—an observational cohort study. *BMC Geriatr* **7**: 3. DOI: 10.1186/1471-2318-7-3.

Smith BW, Zautra AJ. 2008. The effects of anxiety and depression on weekly pain in women with arthritis. *Pain* **138**: 354–361.

Sulter G, Steen C, De Keyser J. 1999. Use of the Barthel index and modified Rankin scale in acute stroke trials. *Stroke* **30**: 1538–1541.

Swafford KL, Miller LL, Tsai PF, Herr KA, Ersek M. 2009. Improving the process of pain care in nursing homes: a literature synthesis. *J Am Geriatr Soc* **57**: 1080–1087.

Tosato M, Lukas A, van der Roest HG, *et al*. 2012. Association of pain with behavioral and psychiatric symptoms among nursing home residents with cognitive impairment: results from the SHELTER study. *Pain* **153**: 305–310.

Twisk JWR. 2006. *Applied Multilevel Analysis. A Practical Guide*. Cambridge University Press: Cambridge.

van Almenkerk S, Depla MFIA, Smalbrugge M, Eefsting JA, Hertogh CMPM. 2012. Institutionalized stroke patients: status of functioning of an under researched population. *J Am Med Dir Assoc* **13**: 634–639.

van Kollenburg EG, Lavrijsen JC, Verhagen SC, *et al*. 2012. Prevalence, causes, and treatment of neuropathic pain in Dutch nursing home residents: a retrospective chart review. *J Am Geriatr Soc* **60**: 1418–1425.

Wetzels RB, Zuidema SU, de Jonghe JF, Verhey FR, Koopmans RT. 2010. Course of neuropsychiatric symptoms in residents with dementia in nursing homes over 2-year period. *Am J Geriatr Psychiatry* **18**: 1054–1065.

Zuidema SU, de Jonghe JF, Verhey FR, Koopmans RT. 2009. Predictors of neuropsychiatric symptoms in nursing home patients: influence of gender and dementia severity. *Int J Geriatr Psychiatry* **24**: 1079–1086.

