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Original Study

Institutionalized Stroke Patients: Status of Functioning of an Under Researched Population

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A B S T R A C T

Objectives: In view of the development of an integrated care and treatment program for institutionalized stroke patients tailored to their needs, we aimed to explore their status of functioning in the physical, cognitive, emotional, communicative and social domains. In addition, we explored the relation between status of functioning and stroke characteristics.
Design: A cross-sectional, observational study.
Setting: Dutch nursing homes (NHs).
Participants: Residents with stroke as main diagnosis for NH-admission, who experienced a stroke ≥3 months ago and stayed ≥1 month in a long term care ward.
Measurements: Attending physicians provided information about stroke subtype, stroke location and time post-stroke. Status of functioning was measured through an observation list comprising the Barthel Index, the Neuropsychiatric Inventory Questionnaire, and sections of the Resident Assessment Instrument for Long-Term Care Facilities. The list was filled out in a structured interview with a qualified nurse assistant who knew the resident well.
Results: We included 274 residents (mean age 76.6, 58.4% female). The stroke that caused NH-dependency was in 81.3% ischemic, and in 49.8% right-sided. Median time post-stroke was 47 months; 90.9% of the residents were severely dependent in basic activities of daily living and 58% were in pain. Nearly half of the residents showed moderate (24.4%) or severe (23%) cognitive impairment. Irritability (52.9%), depressive symptoms (52.6%) and apathy (34.3%) occurred as the most frequent neuropsychiatric symptoms; 27.7% had a poor ability to express themselves and 30.3% had a low social engagement. We found more severe cognitive impairment, agitation/aggression and poor expression in left-sided strokes, more nighttime behavioral disturbances and delusions in right-sided strokes, and lower social engagement in residents with the largest time-interval post-stroke.
Conclusion: This study among institutionalized stroke patients in Dutch NHs revealed very high prevalence of impairments on all domains of functioning, above the well-known severe disabilities in basic activities of daily living. The monitoring and management of both pain and neuropsychiatric symptoms should be key elements in an integrated care and treatment program.
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There is much attention for improving integrated care for stroke patients, for example shown by the Helsingborg Declaration 2006 on Stroke Strategies.[1] However, service development and research are mainly focused on prevention, acute care and rehabilitation after stroke, whereas relatively little attention is paid to the improvement of care for chronic stroke patients.[2] Although the continuity of services for chronic stroke patients discharged to the community has gained interest,[3] there has not been an equivalent research focus on the needs of chronic stroke patients who are dependent of institutional long term care. We agree with Cowman et al[4] that there needs to be an increased societal awareness that institutionalized stroke patients are community residents whose home address happens to be a nursing home (NH). On the continuum of care for stroke patients, they are until now an under researched population.

Institutionalization after stroke occurs frequently. Previous research with large cohorts showed that approximately 15% to 20% of stroke survivors in developed countries are dependent on institutional

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long term care.[5–7] This proportion seems to be rather persistent at different times post-stroke, ranging from "completed rehabilitation" after 37 ± 41 days[7] to 5 years post-stroke.[5] Similarly, Dutch research revealed that 21% of stroke survivors at 6 months lived in a NH.[8]

In the CAre for STroke In LOng term care facilities in The Netherlands (CASTILON) study, we aim to develop guidelines for an integrated care and treatment program for this under researched group of institutionalized stroke patients, tailored to their needs. This program needs to be based on reliable data about the functioning of the residents in multiple domains, the current care they receive and their needs of care, which are all investigated in the project. The objective of the study described in this article is to explore the status of functioning of institutionalized stroke patients in the physical, cognitive, emotional, communicative, and social domains. In addition, we explored the relation between the status of functioning and the characteristics of the stroke that caused NH-dependency.

Methods

Study Design

From May 2008 to July 2009 a cross-sectional, observational study design was used to collect data about functioning of stroke patients who received long term care in Dutch NHs. We approached 22 NHs in the Northern, Middle, and Western parts of The Netherlands of which 17 agreed to participate. The study protocol was approved by the medical ethics committee of the VU University Medical Center.

Patient Selection

Institutional long term care in The Netherlands is differentiated into somatic and psychogeriatric care, mainly based on the presence or absence of dementia (as main diagnosis for NH-admission). Because the majority of stroke patients are residing in somatic wards, even when severe cognitive impairment is present,[9] we only included residents in somatic wards.

Medical care in Dutch NHs is delivered by specifically trained physicians, who are referred to as elderly care physicians (ECPs). 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 relatives, and (4) the resident stayed ≥1 month on a somatic long term care ward.

Data Collection

Information about stroke characteristics was provided by a resident's ECP through a digital questionnaire. Data of functioning were collected through an observation list that was filled out in a structured interview with a qualified nurse assistant who knew the resident well. All nurse assistants were interviewed by the same trained research assistant.

Measurements

Stroke Characteristics

ECPs provided information about stroke subtype (hemorrhagic stroke [HS] or ischemic stroke [IS]), stroke location (left-sided [L], right-sided [R], or other location) and time post-stroke.

Physical Functioning

Performance in basic activities of daily living (ADL) was measured by the 20-point Barthel Index (BI).[10] We defined a BI score <12 for the resident to be severely dependent.[11] Pain was measured using the items "pain frequency" and "pain intensity" of the Resident Assessment Instrument for Long-Term Care Facilities (RAI-LTCF).[12,13] Pain frequency is coded as "no pain," "less than daily pain," and "daily pain" in the last 7 days. Pain intensity is categorized as "no pain," "mild pain," "moderate pain," and "severe pain" (times when pain is horrible or excruciating) in the last 7 days. We defined residents with daily or less than daily pain as having "any pain." Residents with daily pain that was moderate or greater were defined as having "substantial daily pain."[14] To the best of our knowledge, there is no valid observation instrument to measure fatigue.[15] To get an indication of the amount of fatigue, we asked the nurse assistant how many hours in a 24-hour day the resident stayed in bed.

Cognitive Functioning

Cognitive functioning was measured by the RAI-LTCF Cognitive Performance Scale (CPS),[16,17] which has good agreement with the Mini Mental State Examination (MMSE)[18] in the detection of cognitive impairment in NH residents.[19,20] The CPS is a 7-category index, ranging from cognitively intact (0) to very severely impaired (6). We categorized the CPS by combining the 3 severe categories as "severe" (CPS 4–6), the middle 2 categories as "moderate" (CPS 2-3), and the remaining 2 categories as "no or mild" cognitive impairment (CPS 0–1).

Emotional Functioning

We assessed behavioral and psychological symptoms using the Neuropsychiatric Inventory Questionnaire (NPI-Q),[21,22] which covers a broad range of behavioral and psychological 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 NPI-Q score represents the sum of individual symptom scores and ranges from 0 to 36.

Communicative Functioning

Communicative functioning was measured using the RAI-LTCF items "ability to make him/herself clear" (expression) and "ability to understand others" (comprehension).[17] 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 3 categories in "good or moderate" and the last 2 categories in "poor."

Social Functioning

Social functioning was measured by the RAI-LTCF Revised Index for Social Engagement (RISE),[17,23] which is constructed from the following 6 items: (1) at ease interacting with others, (2) at ease doing planned or structured activities, (3) accepts invitations into most group activities, (4) pursues involvement in life of facility, (5) initiates interaction(s) with others, and (6) reacts positively to interactions initiated by others. The RISE ranges from 0 (lowest level of social engagement [SE]) to 6 (highest level of SE). We categorized the RISE in "low" (RISE 0–2), "moderate" (RISE 3–4) and "high" SE (RISE 5–6).[24,25]

Statistical Analyses

Descriptive statistics were generated for both the total sample and for subgroups according to the assessed stroke characteristics. To test differences of mean scores between subgroups, an independent *t*-test (2 groups) or an ANOVA test (3 groups) was used when the data were normally distributed; otherwise a nonparametric Mann-Whitney U test (2 groups) or Kruskal Wallis test (3 groups) was used. We used χ^2 statistics to compare dichotomous variables (Fisher exact test 2-sided for 2 groups and Pearson χ^2 2-sided for 3 groups) and categorical variables (Pearson χ^2 2-sided). When the Fisher exact test was used, we calculated the OR and 95% CI. Statistical analyses were performed using PASW Statistics 18 (SPSS Inc., Chicago, IL).

Results

We collected data of 284 residents, of which 10 cases were excluded because of incomplete questionnaires. The number of residents per NH ranged from 3 to 31. Table 1 shows the resident and stroke characteristics of the total sample. Age was rather normally distributed (mean 76.6 ± 10.6, median 78 years). In 7.5% of the residents the stroke was not specifically located in the left or right hemisphere, due to for example bilateral or multi-infarcts. The distribution of time post-stroke was skewed to the right (mean 62.3 months ± 57.63, range 3–400 months) and, therefore, the median of 47 months is presented. Table 2 shows the functioning measures, both for the total sample and for the subgroups according to stroke subtype (HS vs IS), stroke location (L vs R) and time post-stroke. With regard to the time post-stroke, we split the sample in 3 equal proportions, which resulted in the categories ≤2.5 years, 2.5–5.5 years and ≥5.5 years. We found no differences between the subgroups on age and sex.

Physical Functioning

A total of 90.9% of the residents were severely dependent in basic ADL. The prevalence of any type of pain was 58%, and of substantial daily pain 26.6%. More than half of the residents stayed more than 12 hours a day in bed. Comparison of the subgroups showed no differences in these physical functioning measures.

Cognitive Functioning

A total of 47.4% of the residents showed moderate or severe cognitive impairment. We found a significant difference between left- and right-sided strokes (Pearson χ^2 [2, n = 245] = 16.17, $P = .000$), showing more residents with severe cognitive impairment in the subgroup of left-sided strokes.

Emotional Functioning

The most common neuropsychiatric symptoms were irritability and depressive symptoms (in more than 50% of the residents), followed by apathy (34.3%), agitation/aggression (29.6%) and disinhibition (28.5%). We found a lower prevalence of agitation/aggression (OR 0.46 [0.27–0.80], $P = .008$), and a higher prevalence of nighttime behavioral disturbances (OR 2.19 [1.14–4.21], $P = .019$) and delusions (OR 2.97 [1.14–7.72], $P = .021$) in right-sided strokes.

Table 1
Resident and Stroke Characteristics

N = 274	n (%)
Age (mean ± SD [range])	76.6 ± 10.6 [41–97]
<65	39 (14.2)
65–74	54 (19.7)
75–84	108 (39.4)
≥85	73 (26.6)
Female sex	160 (58.4)
Marital status	
Single or widowed	169 (61.7)
Education (n missing = 102)	
only primary education	65 (37.8)
Secondary education	80 (46.5)
higher education	27 (15.7)
Stroke type* (n missing = 12)	
Hemorrhagic	49 (18.7)
Ischemic	213 (81.3)
Stroke location* (n missing = 9)	
Left-sided	113 (42.6)
Right-sided	132 (49.8)
Other	20 (7.5)
Time post-stroke (median [25%–75%], months)*	47 [22–81]

*The stroke that caused nursing home dependency.

Communicative Functioning

A total of 11.7% of the residents had a poor ability to understand others, and 27.7% had a poor ability to make him/herself clear. We found a much higher prevalence of poor expression in left-sided strokes (OR 8.00 [4.12–15.63], $P = .000$).

Social Functioning

A percentage (30.3% and 36.1%) of the residents showed low, respectively high SE. We found a significant difference between the time post-stroke subgroups (Pearson χ^2 [4, n = 274] = 15.45, $P = .004$), showing more residents with low SE and less residents with high SE in the group of ≥5.5 years post-stroke.

Discussion

As part of our aim to develop an integrated care and treatment program for institutionalized stroke patients tailored to their needs, we explored the functioning of this population in multiple domains. The main findings are that (1) almost 60% of the residents are in pain, (2) nearly half of the residents have moderate or severe cognitive impairment, (3) irritability, depressive symptoms and apathy occur as the most frequent neuropsychiatric symptoms, (4) more than a quarter of the residents have poor expressive abilities, and (5) almost a third of the residents have a low social engagement (SE). The relation between status of functioning and the characteristics of the stroke that caused NH-dependency, revealed some differences with regard to stroke location (more severe cognitive impairment, agitation/aggression and poor expression in left-sided strokes; more nighttime behavioral disturbances and delusions in right-sided strokes), and with regard to time post-stroke (lower SE in residents with the largest time-interval post-stroke).

A major strength of this study is the uniqueness of the study population, representing an under researched population on the continuum of stroke care. In addition, through the use of observation instruments we were able to include stroke patients with severe cognitive and/or communicative impairments. A second strength is the broad, multifocal approach we used in exploring the status of functioning. A limitation of the study is its cross-sectional design that does not allow us to gain insight in the evolution of symptoms. The fact that the residents in this study lived on average almost 4 years in the NH, indicates that longitudinal research would be very desirable in the future. A second limitation is the lack of depth in some measurement instruments, such as the CPS and the NPI-Q. However, the used measurement instruments provide good insight in the manifestation of disturbances in everyday clinical practice.

Comparison of our findings to what is known from previous stroke studies is mainly limited by our unique study population. Cowman et al[4] studied a similar population in the Republic of Ireland (n = 570), but did not use specific measurement instruments to identify functional and cognitive problems (with exception of the Barthel Index). As a consequence, we compare our findings to what is known from studies in the general stroke population, in which prevalence of impairments can be expected to be lower. Nevertheless, the prevalence of impairments found in our study population appears to be astonishingly high on all domains.

Previous research showed that post-stroke pain is prevalent in 11% to 44.6% of patients at 6 months to 2 years post-stroke,[26–30] measured through self-report. The prevalence of 58% in our study is

Table 2
Status of Functioning in Relation to Stroke Characteristics

	Total Sample	Stroke Type*		Stroke Location**		Time Interval Post-Stroke		
	n = 274	HS	IS	L	R	≤2.5 y	2.5-5.5 y	>5.5 y
		n = 49	n = 213	n = 113	n = 132	n = 90	n = 93	n = 91
	n (%)	*n(%)*	n(%)	*n(%)*	n(%)	n(%)	n(%)	n(%)
Age (mean ± SD)	76.6 ± 10.6	74.2 ± 11.3	76.9 ± 10.4	76.7 ± 9.6	76.9 ± 10.9	77.3 ± 9.8	76.5 ± 11.3	76.1 ± 10.8
Female sex	160 (58.4)	27 (55.1)	124 (58.2)	64 (56.6)	78 (59.1)	57 (63.3)	57 (61.3)	46 (50.5)
Physical functioning								
Barthel Index (mean ± SD)	5.28 ± 3.95	5.69 ± 4.52	5.16 ± 3.86	5.39 ± 4.17	5.21 ± 3.64	5.46 ± 4.18	5.24 ± 4.04	5.15 ± 3.67
severely dependent (BI<12)	249 (90.9)	42 (85.7)	196 (92.0)	99 (87.6)	124 (93.9)	82 (91.1)	84 (90.3)	83 (91.2)
Pain								
any type of pain	159 (58.0)	29 (59.2)	125 (58.7)	64 (56.6)	81 (61.4)	53 (58.9)	55 (59.1)	51 (56.0)
substantial daily pain	73 (26.6)	12 (24.5)	57 (26.8)	23 (20.4)	41 (31.1)	30 (33.3)	23 (24.7)	20 (22.0)
Bed rest								
<12 h	135 (49.3)	30 (61.2)	100 (46.9)	61 (54.0)	61 (46.2)	47 (52.2)	48 (51.6)	40 (44.0)
12–16 h	103 (37.6)	13 (26.5)	84 (39.4)	38 (33.6)	55 (41.7)	35 (38.9)	29 (31.2)	39 (42.9)
>16 h	36 (13.1)	6 (12.2)	29 (13.6)	14 (12.4)	16 (12.1)	8 (8.9)	16 (17.2)	12 (13.2)
Cognitive functioning								
Cognitive impairment								
no or mild (CPS 0-1)	144 (52.6)	25 (51.0)	112 (52.6)	**49 (43.4)**	**77 (58.3)**	50 (55.6)	49 (52.7)	45 (49.5)
moderate (CPS 2-3)	67 (24.4)	13 (26.5)	53 (24.9)	**25 (22.1)**	**38 (28.8)**	24 (26.7)	20 (21.5)	23 (25.3)
Severe (CPS 4-6)	63 (23.0)	11 (22.4)	48 (22.5)	**39 (34.5)**	**17 (12.9)**	16 (17.8)	24 (25.8)	23 (25.3)
Emotional functioning								
NPIQ score (mean ± SD)	6.27 ± 5.21	6.10 ± 5.76	6.40 ± 5.13	6.17 ± 5.13	6.62 ± 5.44	5.83 ± 4.83	6.70 ± 5.76	6.27 ± 5.00
Irritability/ability	145 (52.9)	23 (46.9)	115 (54.0)	58 (51.3)	72 (54.5)	40 (44.4)	50 (53.8)	55 (60.4)
Dysphoria/Depression	144 (52.6)	23 (46.9)	117 (54.9)	58 (51.3)	71 (53.8)	49 (54.4)	45 (48.4)	50 (54.9)
Apathy/Indifference	94 (34.3)	12 (24.5)	80 (37.6)	40 (35.4)	45 (34.1)	24 (26.7)	36 (38.7)	34 (37.4)
Agitation/ aggression	81 (29.6)	13 (26.5)	66 (31.0)	**44 (38.9)**	**30 (22.7)**	18 (20.0)	31 (33.3)	32 (35.2)
Disinhibition	78 (28.5)	16 (32.7)	60 (28.2)	31 (27.4)	43 (32.6)	18 (20.0)	32 (34.4)	28 (30.8)
Anxiety	65 (23.7)	13 (26.5)	50 (23.5)	26 (23.0)	35 (26.5)	24 (26.7)	21 (22.6)	20 (22.0)
Nighttime behavioral disturbances	57 (20.8)	11 (22.4)	44 (20.7)	**16 (14.2)**	**35 (26.5)**	21 (23.3)	17 (18.3)	19 (20.9)
Appetite/eating disturbances	38 (13.9)	3 (6.1)	34 (16.0)	16 (14.2)	21 (15.9)	18 (20.0)	10 (10.8)	10 (11.0)
Elation/euphoria	38 (13.9)	9 (18.4)	27 (12.7)	15 (13.4)	19 (14.4)	13 (14.4)	17 (18.5)	8 (8.8)
Delusions	27 (9.9)	7 (14.6)	18 (8.5)	**6 (5.4)**	**19 (14.4)**	9 (10.1)	12 (12.9)	6 (6.6)
Aberrant motor behaviors	25 (9.1)	6 (12.2)	19 (8.9)	11 (9.7)	13 (9.8)	9 (10.0)	7 (7.5)	9 (9.9)
Hallucinations	10 (3.6)	2 (4.1)	8 (3.8)	4 (3.5)	6 (4.5)	3 (3.3)	5 (5.4)	2 (2.2)
Communicative functioning								
Poor comprehension	32 (11.7)	6 (12.2)	25 (11.7)	18 (15.9)	13 (9.8)	6 (6.7)	16 (17.2)	10 (11.0)
Poor expression	76 (27.7)	10 (20.4)	63 (29.6)	**55 (48.7)**	**14 (10.6)**	17 (18.9)	31 (33.3)	28 (30.8)
Social functioning								
Social engagement								
low (RISE 0-2)	83 (30.3)	9 (18.4)	69 (32.4)	40 (35.4)	34 (25.8)	**25 (27.8)**	**23 (24.7)**	**35 (38.5)**
moderate (RISE 3-4)	92 (33.6)	18 (36.7)	71 (33.3)	37 (32.7)	46 (34.8)	**23 (25.6)**	**32 (34.4)**	**37 (40.7)**
high (RISE 5-6)	99 (36.1)	22 (44.9)	73 (34.3)	36 (31.9)	52 (39.4)	**42 (46.7)**	**38 (40.9)**	**19 (20.9)**

Bold = $P < 0.05$, HS, hemorrhagic stroke; IS, ischemic stroke; L, left-sided; R, right-sided; CPS, Cognitive Performance Scale; NPIQ, Neuropsychiatric Inventory Questionnaire; RISE, Revised Index for Social Engagement.

*n missing=12

**n missing=29.

even more alarming when we realize that observation of pain by professionals often lead to underestimation.[14]

Previous studies found prevalence of cognitive impairment in 11.8% to 38% of patients at one to three years post-stroke,[31–34] compared with 47.4% in our study population. All these studies used the Mini-Mental State Examination[18] that has good agreement with the CPS we used.

A systematic review on post-stroke depression found a pooled estimate of 33% at any time during following up[35] (compared with 52.6% in our study population), and apathy following stroke has been consistently estimated between 20% to 25% of patients[36] (compared with 34.3%), although it is hazardous to compare prevalence of formal neuropsychiatric diagnoses to our results of the NPI-Q. Two other studies that also used (other versions of) the NPI in a stroke population up to 1 year post-stroke,[37,38] reported remarkably lower frequencies of irritability (12%–33%) and apathy (9%–26.6%) than our study.

The higher frequency of poor expression in left-sided strokes in our study population suggests that aphasia is the most important underlying impairment (rather than dysarthria and/or cognitive deficits[17]) because of the well-known lateralization of language in the left hemisphere. Previous research showed that aphasia is present in about one-third of stroke patients in the acute phase,[39] in 20%–25% at 3 months,[40] and in approximately 15% at 18 months.[41] A part of these patients will have a severe aphasia and neither be able to use other strategies (non-verbal or through the use of communication devices) to make themselves clear in everyday life. From this perspective it seems alarming that 27.7% of the residents in our study population can express themselves poorly.

The higher frequency of agitation we found in left-sided strokes, could be related to the higher prevalence of poor expression: Angelelli et al[37] found that patients with aphasia had a three times greater risk of becoming agitated. Our finding that severe cognitive impairment is more frequent in left-sided strokes, is supported by a study of Patel et al,[34] while other studies found no relation to stroke lateralization.[31,42] Our result could, however, also be caused by a bias in the measurement instrument (CPS) that contains an item of expression. It has been shown that such a bias toward deficits associated with left-sided lesions is also present in standard clinical scales to measure stroke severity.[43] Finally, the higher frequency of residents with low SE in the group with the largest time-interval post-stroke, might

suggest a decline of SE over time. As mentioned before, however, longitudinally research would be necessary to evaluate this evolution. As the RISE has been developed as an indicator of social well-being – itself a relevant component of quality of life (QoL)[23,44]; this hypothesized decline is supported by the results of a recent longitudinally, population-based research showing an annually decline of QoL, up to 5 years post-stroke and independent of other risk factors.[45]

The primary goal of an integrated care- and treatment program for institutionalized stroke patients is to enhance their quality of life. The data of this cross-sectional, observational study revealed clearly that the monitoring and management of both pain and neuropsychiatric symptoms should be key elements in the program. The characteristics of pain and its relation with neuropsychiatric symptoms should, therefore, be the subject of further research. With regard to cognitive functioning, the question arises whether it should be better monitored. Given the fact that we only included residents living in somatic wards as opposed to dementia special care units, the proportion of residents with severe cognitive impairment (23%) seems very high. It should be questioned whether these residents could be diagnosed as having vascular dementia. Our clinical experience is that formal assessments on the diagnosis of dementia are mostly initiated when cognitive deficits are accompanied by "challenging" behavior, often an important reason for admission to a dementia special care unit. We hypothesize that the severe cognitive deficits in our study population are related to more "silent" neuropsychiatric symptoms, such as the frequently occurring symptom of apathy. There is a great risk of ignoring such "silent" behavior without exploring the possibilities of treatment. The phenomenon of apathy and its clinical correlates should, therefore, be another subject of further research. Finally, with regard to communicative functioning the question is whether there are—at present—realistic options to improve the management of poor expressive abilities.

Conclusion

This study among institutionalized stroke patients in Dutch NHs revealed very high prevalence of impairments on all domains of functioning. Above the well-known severe disabilities in basic ADL, many residents suffered from pain and many had neuropsychiatric problems. A substantial proportion had poor expressive abilities, and there were many residents with severe cognitive impairment in the context of the somatic wards where they resided. The monitoring and management of both pain and neuropsychiatric symptoms should be key elements in an integrated care and treatment program.

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