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ORIGINAL RESEARCH:
EMPIRICAL RESEARCH - QUANTITATIVE

The prevalence and determinants of inappropriate sexual behaviour in people with acquired brain injury in nursing homes

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Funding Information

The study is supported and funded by Vivent and Livio both long-term care/nursing home organizations in Den Bosch/Rosmalen and Enschede/Haaksbergen area, respectively, the Netherlands, but this research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Abstract

Aims: Establishing the prevalence of inappropriate sexual behaviour, concurrent challenging behaviours and the determinants of inappropriate sexual behaviour among patients with acquired brain injury ≤ 65 years of age in Dutch nursing homes.

Design: Cross-sectional, observational study in acquired brain injury special care units spreads throughout the country.

Methods: Nursing homes were recruited through the national expertise network for patients with severe acquired brain injury, regional brain injury teams and by searching the Internet. Patient characteristics were collected through digital questionnaires. Inappropriate sexual behaviour was assessed with the St. Andrews Sexual Behaviour Assessment, concurrent challenging behaviours with the NeuroPsychiatric Inventory-Nursing Home Version and the Cohen-Mansfield Agitation Inventory, cognition with the Mini-Mental State Examination and activities of daily living with the Disability Rating Scale. Psychotropic drug use was retrieved from the electronic prescription system. Associations between determinants and inappropriate sexual behaviour were examined using multilevel multivariate linear regression model analyses. Data collection started in June 2017 and ended in April 2019.

Results: Of the 118 included patients, 38.1% had one or more inappropriate sexual behaviours. Verbal comments (30.1%) and non-contact behaviour (24.8%) were the most prevalent types of inappropriate sexual behaviour. Less severe behaviours were more common than more severe behaviours. The most frequent concurrent challenging behaviours were agitation, aggression and hyperactivity. Physical aggression was associated with more inappropriate sexual behaviour. Being married and pain were associated with less inappropriate sexual behaviour.

Conclusion: Inappropriate sexual behaviour is prevalent in patients with acquired brain injury ≤ 65 years of age residing in nursing homes.

Impact: Inappropriate sexual behaviour may have impact not only on the patients themselves but also on nursing staff. Insight into the magnitude, severity, course and

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concurrent challenging behaviours, sexuality and quality of life could give direction to the kind of interventions and education that is needed. The ultimate goal is to develop appropriate care for this vulnerable group of patients, specifically psychosocial interventions and appropriate use of psychotropic drugs.

KEYWORDS

acquired brain injury, challenging behaviours, inappropriate sexual behaviour, long-term care, nurses/midwives/nursing, nursing home, prevalence

1 | INTRODUCTION

Little is known about challenging behaviours, especially inappropriate sexual behaviour (ISB) in patients ≤ 65 years of age with severe acquired brain injury (ABI) residing in nursing homes. In our recent systematic review, we found six studies about challenging behaviours in patients below the age of 65 years with ABI in long-term care (Kohnen et al., 2018, 2020). As part of the Chronic Acquired Brain Injury Netherlands (CABINET) study, we did a survey of 118 patients ≤ 65 years of age from 12 nursing homes (Kohnen et al., 2019, 2020). We found that the most common challenging behaviours were agitation, verbal and physical aggression and irritability (Kohnen et al., 2020). The prevalence rates of verbal and physical sexual advances as assessed with the Cohen-Mansfield Agitation Index were 10.3% and 4.7%.

1.1 | Background

ISB is defined as a verbal or physical act of an explicit, or perceived, sexual nature, which is unacceptable within the social context in which it is carried out (Johnson et al., 2006; Stubbs, 2011). ISB includes behaviours such as making obscene gestures, touching body parts of others, non-consensual hugging, exposing one's own body parts, disrobing and public masturbation (Philo et al., 1996). Due to memory problems, patients may forget what appropriate and inappropriate behaviour is (Lawrie & Jillings, 2004). In traumatic brain injury (TBI) which is a subgroup of ABI, changes in behaviour may be caused by lack of control such as disinhibition, impulsivity, irritability and aggression in TBI (Azouvi et al., 2017).

Patients with severe ABI who are too impaired to live at home are commonly admitted to long-term care facilities (Kohnen et al., 2020). ISB can place an immense strain on relationships with close relatives, friends, and professional caregivers, but ISB in ABI is a relatively neglected area within the literature (Johnson et al., 2006). ISB can cause anxiety, distress and embarrassment in caregivers and often disrupts the continuity of care (Alagiakrishnan et al., 2005; De Giorgi & Series, 2016; Wallace & Safer, 2009). A study among people with dementia showed that the most common ISB was inappropriate touching of the opposite gender, especially the home-care workers (Alagiakrishnan et al., 2005).

Challenging behaviours, such as ISB, may prompt prescription of psychotropic drugs like antipsychotics but these drugs may have adverse effects on cognition (Hammond et al., 2015; Stanislav, 1997). Hormonal treatment for ISB, controversial especially because of social stigma associated with 'chemical castration', has side effects as well, specifically osteoporosis, oedema, weight change and mood changes (Black et al., 2005; De Giorgi & Series, 2016). According to a systematic review, a non-pharmacological intervention may be behaviour modification, for example, explaining patients the unacceptable nature of their behaviours and distraction with social activities (Torrise et al., 2017). The same review also states that changing the attitudes of nursing home staff toward sexual behaviour by providing educational programmes can add to the quality of life of patients. The need for normal sexual expression should be emphasized while preventing ISBs because unmet needs may be a cause of ISB (Cipriani et al., 2016; Torrise et al., 2017; Wallace & Safer, 2009). Sexuality is a human need that is often neglected among long-term care residents and a satisfying sexual life significantly contributes to quality of life as reported in people with chronic diseases or permanent handicaps (Incrocci & Gianotten, 2008; Turner et al., 2015; Wallace & Safer, 2009). Given the importance of good sexual functioning for quality of life, the high prevalence of sexual problems following TBI implies that sexuality after TBI is a particularly important area to address (Turner et al., 2015).

Studies focusing on ISB in ABI are scarce and mainly performed in community-dwelling populations (Kelly et al., 2008; Knight et al., 2008; Sabaz et al., 2014; Simpson et al., 2013). Great differences in prevalence rates of ISB ranging from 3.6% to 27.9% were reported (Kelly et al., 2008; Sabaz et al., 2014; Simpson et al., 2013). The most common ISBs were sexual talk, non-genital touching and exhibitionism. Concurrent challenging behaviours in 43 of 45 community patients with TBI and ISB were mainly inappropriate social behaviour, verbal aggression, physical aggression and lack of initiation (Simpson et al., 2013). ISBs are related to more functional disability, younger age, male gender, higher levels of challenging behaviours and more comorbid mental health issues (Simpson et al., 2013; Turner et al., 2015). Identifying relevant determinants of ISB is important because challenging behaviours, such as ISB, hinder the provision of quality care (Kivunja et al., 2018). Insight into the determinants of ISB could give direction to the kind of appropriate interventions that is needed, for example, the treatment of concurrent challenging behaviours or fulfilling sexual needs (Kohnen et al., 2019). However, the prevalence

and correlates of ISB in people residing in nursing homes with ABI for many years and the different types of ISB are unknown.

2 | THE STUDY

2.1 | Aims

The aims of this study are to establish the prevalence of (1) ISB, (2) the concurrent challenging behaviours and (3) the determinants of ISB among patients with severe ABI residing in Dutch nursing homes.

2.2 | Design

The CABINET study is a cross-sectional, observational study among people with chronic ABI ≤ 65 years in Dutch nursing homes (Kohnen et al., 2019, 2020).

2.3 | Participants

2.3.1 | Recruitment nursing homes

Recruited nursing homes have been visited by the first author and the research assistant for conducting the data collection between June 2017 and April 2019 as published in this journal (Kohnen et al., 2019, 2020). Professional care in the Netherlands is provided in more than 480 long-term care organizations spread throughout the country ("CBS [Statistics Netherlands]," 2016). To enhance logistical efficiency, nursing homes with ABI special care units for at least 10 patients with ABI were identified, contacted and recruited through (1) the national expertise network for patients with severe ABI (EENnacoma, 2017), (2) the regional brain injury teams (3) and the websites of nursing homes. In the Netherlands, 17 regional brain injury teams throughout the country provide information and advice about ABI to patients, family members and professional caregivers (Hersenletselteams [Brain Injury Teams]; Kohnen et al., 2019; Kohnen et al., 2020). Nursing homes that have participated in previous prevalence studies of our research group were contacted and recruited as well (van Erp et al., 2015; Kohnen et al., 2013, 2020; Lavrijsen et al., 2005). Nursing homes with ABI special care units were contacted if their websites did not mention the size of their special care units (Kohnen et al., 2020).

2.3.2 | Residents

An e-mail was sent to the treating physicians of the identified nursing homes to inform them about the study and to ask them to systematically screen all residents ≤ 65 years of age in the chronic stage of ABI for inclusion (Kohnen et al., 2019, 2020). Inclusion criteria were as follows: (1) nursing home admission because of ABI, (2) in

the chronic phase of non-progressive, stabile forms of ABI, such as TBI, stroke and anoxia, (3) age from 18 up to and including 65 years of age and (4) residing in the nursing home for at least 4 weeks at the time of inclusion. The exclusion criteria were as follows: (1) nursing home admission other than ABI, (2) progressive forms of ABI, such as multiple sclerosis, Parkinson's and Huntington's disease, (3) admitted for rehabilitation, temporary admission or having outreaching nursing home care, (4) prolonged disorders of consciousness like unresponsive wakefulness syndrome and minimally conscious state and (5) being terminally ill at the time of inclusion defined as a life expectancy of less than 3 months.

2.4 | Data collection

The professional caregivers involved in the daily care of the residents observed symptoms during a 2-week period before assessment (Kohnen et al., 2019, 2020). After this period, these professional caregivers were asked to fill in assessment instruments, St. Andrews Sexual Behaviour Assessment (SASBA), the Cohen Mansfield Agitation Inventory (CMAI) and the Disability Rating Scale (DRS) through a web-based digital system (see below). Professional caregivers were also visited by the first author or the research assistant for a structured interview administering the Neuropsychiatric Inventory-Nursing Home Version (NPI-NH). The treating physicians were asked to digitally register patient characteristics. Nursing home staff and the treating physicians were contacted by telephone if questionnaires were not returned, or if data they had provided were inconsistent, such as a date of injury that predates the date of birth.

2.4.1 | Patient characteristics

The collected patient characteristics were gender, age, marital status, level of education, cause of ABI, age of onset ABI, duration of ABI, duration of nursing home admission, psychiatric history, pain, constipation, spasms and the presence of psychotropic drug use (Kohnen et al., 2019, 2020).

2.4.2 | Inappropriate sexual behaviour

ISB was assessed by the Dutch version of the SASBA (Bartelet et al., 2014; Knight et al., 2008; Kohnen et al., 2019). The assessment instrument consists of four sexual behaviour categories, verbal comments (e.g. description of female breasts), non-contact (e.g. making obscene gestures), exposure (e.g. intentionally exposing genitals) and touching others (e.g. lifting skirts), with each four severity levels ranging from mild (e.g. blowing kisses or staring at another person's breasts) to severe (e.g. masturbating with genitals being clearly exposed in a public setting) (Bartelet et al., 2014; Kohnen et al., 2019). Each item is rated on a 6-point Likert scale: never; happened once; happened less than once a month; happened less than once a week;

happened every week or happened several times a week. The total score of the scale ranges from 0 to 80, a higher score represents more severe ISB. The original SASBA was designed to establish inappropriate sexual behaviour in progressive and acquired neurological impairment and has strong construct and content validity with a mean rating of 4.79, and good inter-rater and test-retest reliability (Kappa 0.41–0.94) (Knight et al., 2008; Kohnen et al., 2019).

2.4.3 | Concurrent neuropsychiatric symptoms

The Dutch version of the Neuropsychiatric Inventory-Nursing Home Version (NPI-NH) was used to assess challenging behaviours (Cummings, 1997; Cummings et al., 1994; Kohnen et al., 2019, 2020). The NPI-NH is a structured interview administered to the patients' professional caregiver including 12 challenging behaviours: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, night-time disturbances and appetite/eating change. The frequency (F) and the severity (S) of each symptom are rated on a 4- and 3-point Likert scale. A score can be calculated for each symptom by multiplying the frequency and the severity (FxS scores) resulting in values ranging from 0 to 12. A challenging behaviour is considered clinically relevant when the FxS score for an item is 4 or more. We grouped challenging behaviours based on a study in nursing home patients with mental and physical multimorbidity in which challenging behaviours were clustered after performing a factor analysis (Kohnen et al., 2020; van den Brink et al., 2018). Irritability, agitation and disinhibition were grouped in a cluster 'hyperactivity', depression, apathy and anxiety in 'mood/apathy', and delusions and hallucinations in 'psychosis'. The nursing home version, developed for use by professional caregivers within institutions, has been translated into Dutch and found valid and reliable for trained nursing home staff (Kat et al., 2002; Kohnen et al., 2019; Wood et al., 2000). The NPI has been used in several studies on TBI and stroke and is considered suitable for assessing challenging behaviours in ABI (Castano Monsalve et al., 2012; Castellanos-Pinedo et al., 2011; Ciurli et al., 2011; Kohnen et al., 2019).

We used the Dutch version of the Cohen-Mansfield Agitation Inventory (CMAI) to assess agitation and aggression (Cohen-Mansfield, 1986; Kohnen et al., 2019, 2020). This instrument assesses 29 agitated or aggressive behaviours which are scored on a 7-point frequency scale: 1 = never; 2 = <once a week; 3 = 1–2 times a week; 4 = several times a week; 5 = 1–2 times a day; 6 = several times a day and 7 = several times per hour. Individual behaviours were considered as clinically relevant when the behaviours appeared at least once a week or more (frequency score of 3 or more) (Kohnen et al., 2019, 2020; Zuidema, Derksen, et al., 2007). The individual behaviours were grouped based on a study in institutionalized patients with dementia in the clusters 'physically aggressive', 'physically nonaggressive' and 'verbally agitated' (Kohnen et al., 2019, 2020; Zuidema, de Jonghe, et al., 2007). The CMAI has been validated in the assessment of behavioural disorders in elderly nursing

home patients (Cohen-Mansfield, 1986; Kohnen et al., 2019; Miller et al., 1995). A Dutch translation is available and has been validated in elderly patients admitted to a psychiatric hospital (de Jonghe & Kat, 1996; Kohnen et al., 2019). As far as we know, this is the first time that the CMAI is used in ABI (Kohnen et al., 2019).

2.4.4 | Disability

The Dutch version of the Disability Rating Scale (DRS) was used to assess ADL disabilities (Eilander et al., 2007; Kohnen et al., 2019, 2020). The DRS consists of eight sections: eye opening, communication ability, motor response, feeding, toileting, grooming, level of functioning and employability. Each item is rated on a 4-, 5- or 6-point Likert scale. The total DRS score ranges between 0 and 29, a higher score representing a higher level of disability. The DRS was originally developed and tested in severe head trauma patients (Kohnen et al., 2019, 2020; Rappaport et al., 1982). It has been recommended as one of the most appropriate instruments to assess long-term outcomes in severe brain damage and has been translated into Dutch, adapted to be filled out by a proxy of the patient (Bullock et al., 2002; Eilander et al., 2007; Kohnen et al., 2019).

2.4.5 | Cognition

The Mini-Mental State Examination (MMSE) was used to assess cognitive functioning in general (Folstein et al., 1975; Kohnen et al., 2019, 2020). The MMSE includes 11 questions and measures orientation, attention, concentration, memory, language and constructive capacity. The total score ranges from 0 to 30, a lower score represents lower cognitive functioning. There is an inverse relationship between cognitive performance and age and the median MMSE score is higher in people with longer duration of education (Crum et al., 1993; Kohnen et al., 2020). Scores below 27, a cut off that has been recommended in people with higher educational levels, indicated cognitive impairment (Eagles et al., 2019; Kohnen et al., 2020; O'Bryant et al., 2008). The MMSE has been used in TBI studies, and Turkish study validated the use of a Turkish version of the MMSE in ABI concluding that the MMSE can be used as a cognitive screening tool in this group (Elhan et al., 2005; de Guise et al., 2011, 2013; Kohnen et al., 2019).

2.4.6 | Psychotropic drug use

The names, dosages, continuous and/or incidental usage and prescription indications of PDU were retrieved from the electronic prescription system (Kohnen et al., 2019, 2020). PDU was categorized using the Anatomical Chemical classification (ATC) system in anti-convulsants, antidepressants, antipsychotics, anxiolytics and hypnotics (WHO Collaborating Centre for Drug Statistics Methodology, 2018). The treating physicians were asked to register the indications

for PDU to determine if patients actually received psychotropic drugs because of challenging behaviours.

2.5 | Ethical considerations

This study (case number 2017-3143) was presented for medical ethics review at the regional Committee on Research Involving Human Subjects (CMO) region Arnhem-Nijmegen, the Netherlands (Kohnen et al., 2019). The committee concluded that our study did not require ethical approval because it did not involve scientific research according to the criteria of the Dutch Medical Research Involving Human Subjects Act (WMO) and could be conducted without review by the CMO. The research project was performed according to the principles of the Declaration of Helsinki (Kohnen et al., 2019; World Medical Association, 2013). Patients were only included after written informed consent was provided by themselves or by the legal representative if the patient was not mentally competent. All data were collected anonymously with the use of unique patient codes.

2.6 | Statistical analysis

Descriptive analyses were performed to describe the patient characteristics (Kohnen et al., 2020). Mean and standard deviation (SD) or median and interquartile ranges for continuous variables and frequencies for categorical characteristics were determined. The frequency of ISB was categorized in 'absent', 'less than once a week or less' and 'approximately once a week and more'. The Wilson score interval was used to calculate 95% confidence intervals (CIs) for the prevalence of challenging behaviours.

We studied the association between the SASBA total score and the four ISB types with patient characteristics and co-occurrent challenging behaviours as explanatory variables (Kohnen et al., 2020). The patient characteristics were gender, age, marital status, level of education, cause of ABI, age of onset ABI, duration of ABI, duration of nursing home admission, psychiatric history, pain, constipation, spasms, disability, cognition and the presence of PDU. Co-occurrent challenging behaviours were the cluster scores of the NPI-NH and CMAI. All outcome variables were used as continuous variables. The patient characteristics age, age of onset ABI, duration of ABI, duration of nursing home admission, disability and cognition were used as continuous variables. Marital status was dichotomized in 'not married' and 'married', level of education in 'none/low' and 'secondary/high' and cause of ABI in 'TBI' and 'Non-TBI'. The other characteristics were dichotomized in 'present' and 'absent'. Because of the hierarchical structure of our study, patients nested within nursing homes, we performed multilevel mixed-model analyses in which patients were only included if data of the outcomes and/or determinants were available. We used a model with a random intercept and all other variables were fixed. Only determinants with at least 30 events in the subgroups were included in the analysis. A number of 30 representative participants from the population of interest have

been suggested as a reasonable minimum recommendation for a study where the purpose is explorative analysis (Johanson & Brooks, 2010; Kohnen et al., 2020). All determinants with a $p < .20$, which is often used to limit the possibility of losing determinants, from the univariate linear regression analysis were included in multilevel multivariate linear analyses to determine their unique effect on ISB (Heymans et al., 2011; Kohnen et al., 2020). We removed the least significant determinants stepwise until only statistically significant determinants remained. Significance was defined as $p < .05$ based on two-sided testing (Kohnen et al., 2020).

According to literature, the prevalence rate of challenging behaviours in nursing homes is approximately 35% (Kohnen et al., 2019, 2020; McMillan & Laurie, 2004). We assumed that 50% of the patients would meet the inclusion criteria and that the response rate would be 50%. Through the national expertise network for patients with severe ABI, the regional brain injury teams and the nursing homes themselves, the number of patients residing on ABI special care units for at least 10 patients ($n = 937$) was estimated. The expected population thus would approximately be 230 patients with ABI. A rule of thumb for a continuous outcome is that one determinant can be studied for every 10 patients (Heymans et al., 2011; Kohnen et al., 2019, 2020; Peduzzi et al., 1996). With an estimated challenging behaviours prevalence rate of 35%, the number of patients with challenging behaviours would be 80 in a study population of 230 patients (Kohnen et al., 2019, 2020). The number of determinants that could be studied would then be eight. Statistical analyses were performed using SPSS 25.0 (IBM SPSS Statistics, IBM Corporation) (Kohnen et al., 2020).

2.7 | Validity, reliability and rigour

The psychometric properties of the used instruments have been described above.

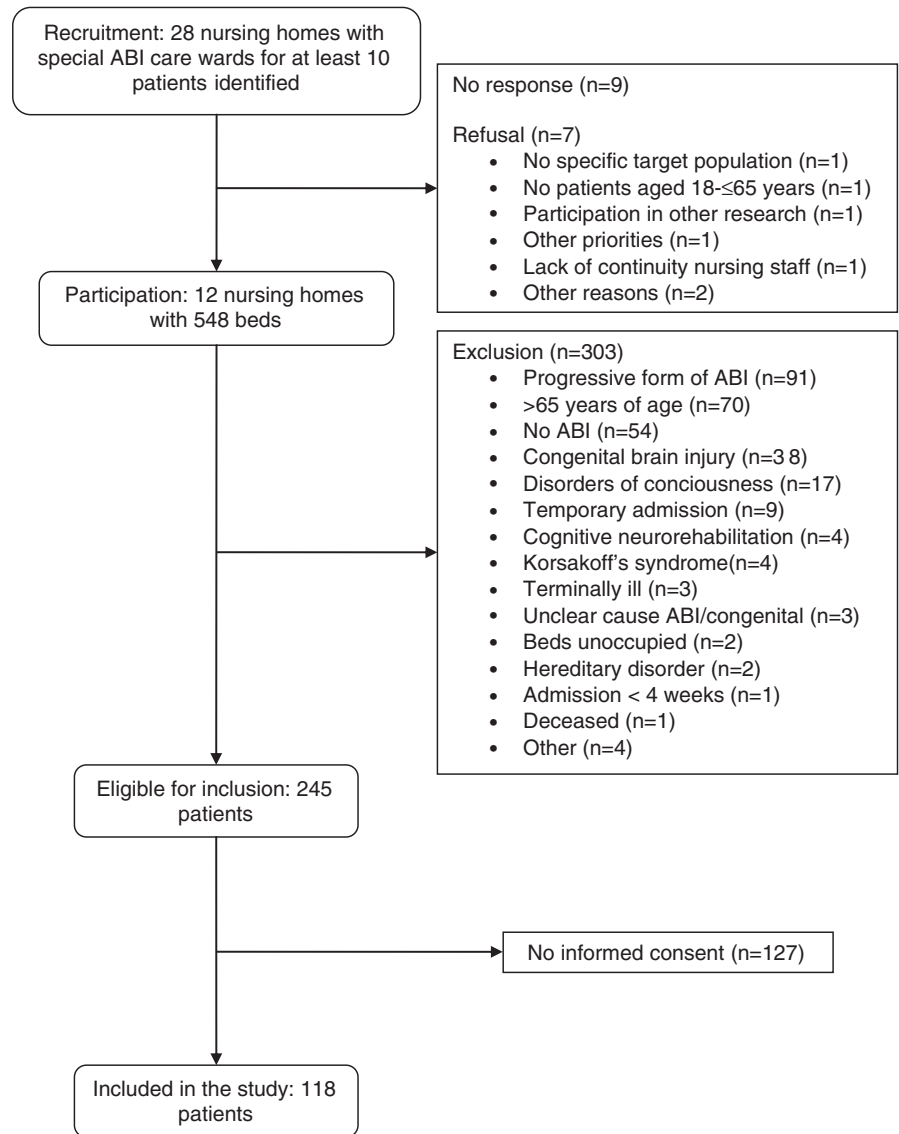
3 | RESULTS

Of the identified 28 nursing homes with ABI special care units with at least 10 patients, 12 nursing homes (42.9%) participated (Figure 1) (Kohnen et al., 2020). In these nursing homes, a total of 245 of 548 patients were eligible for inclusion and informed consent was obtained in 118 patients of these 245 (48.2%). Patient characteristics and PDU were available for 117 patients, from whom duration of ABI was missing in two patients and duration of nursing home admission in one patient. Data of the SASBA were available for 113 patients, the CMAI and MMSE for 107 patients and DRS for 110 patients.

3.1 | Characteristics of the patients

Male/female ratio was approximately 2:1 (Table 1) (Kohnen et al., 2020). Cognitive impairment (MMSE <27) was present in 72.9% of

FIGURE 1 Flow chart of the patient inclusion



the patients. The median DRS score was 8.5 with an interquartile range of 8, which represents moderately severe disabilities. The severity ranged from partial to extremely severely disabled. With regard to the MMSE, eight patients were aphasic and 18 patients had physical disabilities impeding them to perform actions such as taking and folding a piece of paper, writing and drawing.

3.2 | Prevalence and frequency of ISB

One or more ISBs were present in 38.1% of the patients. Patients most commonly displayed one or more types of verbal comments (30.1% of patients; 95% CI 22.0%–39.6%), followed by non-contact behaviour 24.8% (95% CI 17.4%–34.0%), touching others 16.8% (95% CI 10.7%–25.3%) and exposure 7.1% (95% CI 3.3%–13.9%). Intimate personal comments of mild severity were most common with a prevalence rate of 25.7% followed by non-contact behaviour, such as blowing kisses, staring at another person's groin, or making

obscene gestures (18.6%) and the description of another person's groin or female breasts (17.7%) (Table 2).

Of the patients with ISB ($n = 43$), intimate personal comments of mild severity were most commonly displayed approximately once a week or more (27.9%) followed by descriptions of another person's groin or female breasts (25.6%), non-contact behaviour, such as blowing kisses, staring at another person's groin or making obscene gestures (20.9%) and comments of sexual nature, clearly not person directed (18.6%) (Table 3).

3.3 | Concurrent challenging behaviours

The most concurrent challenging behaviours were verbally agitated behaviour with a frequency of 66.7%, physically aggressive and non-aggressive behaviour of both 61.1% and hyperactivity of 65.1%. Disinhibition was present in 39.5% of the patients. The prevalence rates of verbal and physical sexual advances as

TABLE 1 Characteristics of the patients with ABI in nursing homes

Characteristics	Participants (n = 117)
Age (years)	(n = 117)
Median (IQR; range) ^a	54.2 (12.9; 24.1–65.7)
Gender (n (%))	(n = 117)
Male	79 (67.5%)
Female	38 (32.5%)
Marital status (n (%))	(n = 117)
Single	64 (54.7%)
Married	31 (26.5%)
Divorced	19 (16.2%)
Widow	3 (2.6%)
Level of education (n (%))	(n = 117)
No education completed	4 (3.4%)
Primary education	5 (4.3%)
Secondary education	64 (54.7%)
Higher professional education	10 (8.5%)
University education	7 (6.0%)
Other	3 (2.6%)
Unknown	24 (20.5%)
Cause of ABI (n (%))	(n = 117)
Traumatic	42 (35.9%)
Non-traumatic	
Stroke	52 (44.4%)
Anoxia	9 (7.7%)
Post brain tumour	5 (4.3%)
Other	9 (7.7%)
Age of onset ABI	(n = 115)
Median (IQR; range) ^a	44.1 (19.3; 8–61)
Duration of ABI (years)	(n = 115)
Median (IQR; range) ^a	8.3 (14.4; 0.6–45.6)
Duration nursing home admission (years)	(n = 116)
Median (IQR; range) ^a	5.2 (7.1; 0.1–32.6)
Place of residence before admission (n (%))	(n = 117)
Rehabilitation centre	33 (28.2%)
Another nursing home	21 (17.9%)
Mental health institution	17 (14.5%)
Hospital	12 (10.3%)
Rehabilitation unit in nursing home	10 (8.5%)
Other	14 (12.1%)
Unknown	10 (8.5%)
Psychiatric history before ABI (n (%))	(n = 117)
No history	87 (74.4%)
Substance abuse	14 (12.0%)
Mood disorder	12 (10.3%)
Personality disorder	6 (5.1%)
Suicide attempt	3 (2.6%)

(Continues)

TABLE 1 (Continued)

Characteristics	Participants (n = 117)
Other	10 (8.5%)
Comorbidity/complications (n (%))	(n = 117)
Pain	34 (29.1%)
Spasms	23 (19.7%)
Constipation	10 (8.5%)
Delirium	1 (0.9%)
MMSE	(n = 107)
Median (IQR; range) ^a	22 (12; 0–30)
Cognitive impairment (MMSE <27)	78 (72.9%)
DRS	(n = 110)
Median (IQR; range) ^a	8.50 (8; 3–26)
Psychotropic drugs (n (%))	(n = 117)
Anticonvulsants	11 (9.4%)
Antidepressants	33 (28.2%)
Antipsychotics	29 (24.8%)
Anxiolytics	28 (23.9%)
Hypnotics	20 (17.1%)

^aNon-normal distribution.

assessed by the CMAI were 27.8% and 11.1% in residents with ISB, respectively (Table 4).

3.4 | Determinants associated with ISB

Constipation and spasms were excluded from the analyses because of less than 30 events (Kohnen et al., 2020). The number of determinants that could be included in the different multilevel multivariate linear analyses ranged from four to eight.

Being married was associated with less ISB, specifically non-contact, such as blowing kisses and touching own genitals, with a lower score -1.39 (95% CI $-2.50, -0.29$) compared to being unmarried. Pain was associated with a lower SASBA total score of -3.27 (95% CI $-6.27, -0.28$) and non-contact ISB (-1.16 ; 95% CI $-2.23, -0.08$). Secondary/high education was also associated with less ISB, namely exposure, such as exposing own genitals or masturbating in a public setting, with a lower score of -0.48 (95% CI $-0.92, -0.04$) compared to none/low education. Physically aggressive behaviour was associated with a higher SASBA total score (0.48; 95% CI 0.22–0.73) (Table 5).

4 | DISCUSSION

This is the first study that extensively investigated challenging behaviour, specifically ISB, in patients with ABI ≤ 65 years of age in nursing homes (Kohnen et al., 2020). We found a prevalence rate of ISB of 38.1% and the most common ISBs were verbal comments and non-contact behaviour. The most frequent concurrent challenging

behaviours were verbally agitated, physically aggressive and physically nonaggressive behaviour and hyperactivity. Being married and the presence of pain were associated with less non-contact ISBs and the level of education with less exposure ISBs. Patients with physically aggressive behaviour were more likely to display ISB in general.

Although ISB in ABI has been studied in other settings, comparison is difficult because of difference in study populations, specifically ABI versus TBI and nursing home versus community, and the use of a different assessment instrument, specifically the Overt Behaviour Scale (OBS) (Kelly et al., 2008; Sabaz et al., 2014; Simpson et al., 2013). The OBS has been developed to assess nine categories of challenging behaviours, including ISB, in people with ABI in community settings but the use of the OBS beyond those settings is still to be determined (Kelly et al., 2006; Knight et al., 2008). While the OBS does include some ISB, the range of behaviours is likely to underestimate the extent of ISB (Knight et al., 2008). ISB was found in all causes of ABI with prevalence rates ranging from 6.7% to 47.1% between the aetiologies (Kelly et al., 2008). Studies conducted in the community which only included patients with TBI found much lower prevalence rates of ISB compared to patients with ABI in the community (Kelly et al., 2008; Sabaz et al., 2014; Simpson et al., 2013). We found, however, more ISB in general compared to the previously mentioned studies which may be explained by the concentration of patients with ABI and ISB on ABI special care units in nursing homes (Kelly et al., 2008; Sabaz et al., 2014; Simpson et al., 2013). Another explanation might be the inclusion of different aetiologies of ABI implicated by a study in the community which reported the highest prevalence rate of ISB and included TBI, cerebrovascular accident, alcohol-related brain injury, hypoxia, tumour and a category 'other' as causes of ABI (Kelly et al., 2008). Our prevalence rates of

TABLE 2 The occurrence of ISB in patients with ABI in nursing homes grouped by frequency (n = 113)

Behaviours	Verbal comments	Non-contact	Exposure	Touching others
Frequency type 1 (n (%), CI)				
Once	2 (1.8%, 0.3%–6.9%)	-	1 (0.9%, 0.1%–5.5%)	1 (0.9%, 0.1%–5.5%)
Less than once a month	7 (6.2%, 2.7%–12.8%)	5 (4.4%, 1.6%–10.5%)	1 (0.9%, 0.1%–5.5%)	4 (3.5%, 1.1%–9.4%)
Less than once a week	8 (7.1%, 3.3%–13.9%)	7 (6.2%, 2.7%–12.8%)	-	-
Approximately once a week	3 (2.7%, 0.7%–8.1%)	5 (4.4%, 1.6%–10.5%)	1 (0.9%, 0.1%–5.5%)	2 (1.8%, 0.3%–6.9%)
Multiple times a week	9 (8.0%, 3.9%–15.0%)	4 (3.5%, 1.1%–9.4%)	1 (0.9%, 0.1%–5.5%)	5 (4.4%, 1.6%–10.5%)
Total	29 (25.7%, 18.1%–34.9%)	21 (18.6%, 12.1%–27.2%)	4 (3.5%, 1.1%–9.4%)	12 (10.6%, 5.9%–18.2%)
Frequency type 2 (n (%), CI)				
Once	-	-	-	-
Less than once a month	3 (2.7%, 0.7%–8.1%)	3 (2.7%, 0.7%–8.1%)	1 (0.9%, 0.1%–5.5%)	2 (1.8%, 0.3%–6.9%)
Less than once a week	1 (0.9%, 0.1%–5.5%)	3 (2.7%, 0.7%–8.1%)	-	2 (1.8%, 0.3%–6.9%)
Approximately once a week	-	1 (0.9%, 0.1%–5.5%)	-	1 (0.9%, 0.1%–5.5%)
Multiple times a week	8 (7.1%, 3.3%–13.9%)	5 (4.4%, 1.6%–10.5%)	-	3 (2.7%, 0.7%–8.1%)
Total	12 (10.6%, 5.9%–18.2%)	12 (10.6%, 5.9%–18.2%)	1 (0.9%, 0.1%–5.5%)	8 (7.1%, 3.3%–13.9%)
Frequency type 3 (n (%), CI)				
Once	2 (1.8%, 0.3%–6.9%)	-	-	-
Less than once a month	5 (4.4%, 1.6%–10.5%)	4 (3.5%, 1.1%–9.4%)	1 (0.9%, 0.1%–5.5%)	4 (3.5%, 1.1%–9.4%)
Less than once a week	2 (1.8%, 0.3%–6.9%)	1 (0.9%, 0.1%–5.5%)	-	-
Approximately once a week	6 (5.3%, 2.2%–11.7%)	1 (0.9%, 0.1%–5.5%)	1 (0.9%, 0.1%–5.5%)	4 (3.5%, 1.1%–9.4%)
Multiple times a week	5 (4.4%, 1.6%–10.5%)	1 (0.9%, 0.1%–5.5%)	1 (0.9%, 0.1%–5.5%)	1 (0.9%, 0.1%–5.5%)
Total	20 (17.7%, 11.4%–26.3%)	7 (6.2%, 2.7%–12.8%)	3 (2.7%, 0.7%–8.1%)	9 (8.0%, 3.9%–15.0%)
Frequency type 4 (n (%), CI)				
Once	-	-	-	-
Less than once a month	3 (2.7%, 0.7%–8.1%)	-	-	2 (1.8%, 0.3%–6.9%)
Less than once a week	-	1 (0.9%, 0.1%–5.5%)	-	1 (0.9%, 0.1%–5.5%)
Approximately once a week	1 (0.9%, 0.1%–5.5%)	-	-	2 (1.8%, 0.3%–6.9%)
Multiple times a week	4 (3.5%, 1.1%–9.4%)	1 (0.9%, 0.1%–5.5%)	1 (0.9%, 0.1%–5.5%)	1 (0.9%, 0.1%–5.5%)
Total	8 (7.1%, 3.3%–13.9%)	2 (1.8%, 0.3%–6.9%)	1 (0.9%, 0.1%–5.5%)	6 (5.3%, 2.2%–11.7%)

Verbal comments: type 1 = intimate personal comments of mild severity; type 2 = comments of sexual nature, clearly not person directed; type 3 = descriptions of another person's groin or female breasts; type 4 = explicit accounts of sexual intent or activity. Non-contact: type 1 = blowing kisses, kissing self or staring at another person's groin, female breasts or buttocks, or makes obscene gesture; type 2 = touches own groin, female breasts or buttocks over or under clothes (no exposure); type 3 = masturbates in a non-shared setting where staff are present; type 4 = masturbates without genitals being exposed in a public setting. Exposure: type 1 = appears unaware that is exposing genitals, female breasts or buttocks; type 2 = wearing no clothes in a public setting, clearly not person directed; type 3 = intentionally exposes genitals, female breasts or buttocks to another; type 4 = masturbates with genitals being clearly exposed in a public setting. Touching others: type 1 = touches for a prolonged period or strokes another person – does not include groin, female breasts or buttocks; type 2 = kissing another person; type 3 = lifting skirts, pinching or touching buttocks, sitting on other's knees; type 4 = touching other's groin, female breasts or rubbing own genitals or female's breasts against another person.

the different types of ISB and concurrent challenging behaviours, however, were generally lower compared to the studies in the community (Kelly et al., 2008; Simpson et al., 2013). One of the studies showed that less severe behaviours were more common than more severe behaviours which is in line with our results (Kelly et al., 2008).

Like Simpson et al., we found a positive association between increasing disabilities and ISB (Simpson et al., 2013). Having more disabilities may be related to more severe brain injury which can affect sexual behaviour through injury of particularly the brain's frontal and temporal lobes with disinhibition and impulsivity as a result (Lawrie & Jillings, 2004). We also found that physical aggression and

hyperactivity were associated with ISB. This reflects the behavioural changes in ABI due to lack of control with the resulting disinhibition and impulsivity, the higher levels of challenging behaviours and comorbid mental health issues found in patients with ABI and ISB (Azouvi et al., 2017; Lawrie & Jillings, 2004; Simpson et al., 2013).

4.1 | Strengths and limitations

Strengths of this study are that ISBs in general, and the different types in particular, have been studied extensively using an

TABLE 3 The frequency of ISB in the patients with ABI and ISB (n = 43)

Behaviours	Verbal comments	Non-contact	Exposure	Touching others
Frequency type 1				
Absent	14 (32.6%)	22 (51.2%)	39 (90.7%)	31 (72.1%)
Less than once a week or less	17 (39.5%)	12 (27.9%)	2 (4.7%)	5 (11.6%)
Approximately once a week or more	12 (27.9%)	9 (20.9%)	2 (4.7%)	7 (16.3%)
Frequency type 2				
Absent	31 (72.1%)	31 (72.1%)	42 (97.7%)	35 (81.4%)
Less than once a week or less	4 (9.3%)	6 (14.0%)	1 (2.3%)	4 (9.3%)
Approximately once a week or more	8 (18.6%)	6 (14.0%)	-	4 (9.3%)
Frequency type 3				
Absent	23 (53.5%)	36 (83.7%)	40 (93.0%)	34 (79.1%)
Less than once a week or less	9 (20.9%)	5 (11.6%)	1 (2.3%)	4 (9.3%)
Approximately once a week or more	11 (25.6%)	2 (4.7%)	2 (4.7%)	5 (11.6%)
Frequency type 4				
Absent	35 (81.4%)	41 (95.3%)	42 (97.7%)	37 (86.0%)
Less than once a week or less	3 (7.0%)	1 (2.3%)	-	3 (7.0%)
Approximately once a week or more	5 (11.6%)	1 (2.3%)	1 (2.3%)	3 (7.0%)

Verbal comments: type 1 = intimate personal comments of mild severity; type 2 = comments of sexual nature, clearly not person directed; type 3 = descriptions of another person's groin or female breasts; type 4 = explicit accounts of sexual intent or activity. Non-contact: type 1 = blowing kisses, kissing self or staring at another person's groin, female breasts or buttocks, or makes obscene gesture; type 2 = touches own groin, female breasts or buttocks over or under clothes (no exposure); type 3 = masturbates in a non-shared setting where staff are present; type 4 = masturbates without genitals being exposed in a public setting. Exposure: type 1 = appears unaware that is exposing genitals, female breasts or buttocks; type 2 = wearing no clothes in a public setting, clearly not person directed; type 3 = intentionally exposes genitals, female breasts or buttocks to another; type 4 = masturbates with genitals being clearly exposed in a public setting. Touching others: type 1 = touches for a prolonged period or strokes another person—does not include groin, female breasts or buttocks; type 2 = kissing another person; type 3 = lifting skirts, pinching or touching buttocks, sitting on other's knees; type 4 = touching other's groin, female breasts, or rubbing own genitals or female's breasts against another person.

assessment instrument for the first time in a substantial number of nursing homes spread throughout a country, the use of strict inclusion and exclusion criteria and a high response rate of nurses and treating physicians within the participating nursing homes (Kohnen et al., 2020). However, there are some considerations about the used assessment instruments and possible limitations to address. In the same study population, we conducted a prevalence study of different types of challenging behaviours using the NPI-NH and the CMAI. The CMAI includes two small items about ISB, specifically verbal and physical sexual advances (Cohen-Mansfield, 1986). We found prevalence rates of 10.3% and 4.7% of verbal and physical sexual advances in our previous study (Kohnen et al., 2020). The prevalence rates of these types of ISB are lower compared to this study. Given the importance and relevance of ISB, we also studied

ISB in depth with the SASBA. We found that the number of patients with concurrent verbal and physical sexual advances was lower as well. This could be explained by using cut-off scores for clinical relevance in the CMAI, and the use of the SASBA which assesses ISB in more detail.

A limitation is the low response rate of patients and nursing homes (Kohnen et al., 2020). The low rate of informed consent may be due to not speaking the Dutch language leading to selection bias. The reason for the low participation rate of nursing homes was mainly unknown due to non-response of nursing homes. In a small number of cases, reasons were the absence of patients with ABI with regard to age and inclusion criteria, lack of continuity in nursing staff, already involved in other studies or having other priorities. These reasons were reported by the nursing homes during recruitment.

TABLE 4 The prevalence rates of clinically relevant concurrent challenging behaviours among patients with ABI and ISB (n = 43) in nursing homes

Neuropsychiatric symptoms	Frequency (n (%))	CI (%)
NPI-NH (n = 43)		
Delusions	3 (7.0%)	1.8%–20.1%
Hallucinations	-	-
Agitation/aggression	19 (44.2%)	29.4%–60.0%
Dysphoria/depression	6 (14.0%)	5.8%–28.6%
Anxiety	6 (14.0%)	5.8%–28.6%
Euphoria/elation	5 (11.6%)	4.4%–25.9%
Apathy/indifference	10 (23.3%)	12.3%–39.0%
Disinhibition	17 (39.5%)	25.4%–55.6%
Irritability/lability	12 (27.9%)	15.8%–43.9%
Aberrant motor behaviour	11 (25.6%)	14.0%–41.5%
Night-time behaviour disturbances	5 (11.6%)	4.4%–25.9%
Appetite/eating disturbances	15 (34.9%)	21.5%–51.0%
Hyperactivity	28 (65.1%)	49.0%–78.6%
Mood/apathy	16 (37.2%)	23.4%–53.3%
Psychosis	3 (7.0%)	1.8%–20.1%
CMAI (n = 36)		
Pacing	9 (25.0%)	12.7%–42.5%
Inappropriate robbing/disrobing	1 (2.8%)	0.2%–16.2%
Spitting	4 (11.1%)	3.6%–27.0%
Cursing or verbal aggression	12 (33.3%)	19.1%–51.1%
Constant request for attention	14 (38.9%)	23.6%–56.5%
Repetitious sentences/questions	17 (47.2%)	30.8%–64.3%
Hitting	2 (5.6%)	1.0%–20.0%
Kicking	2 (5.6%)	1.0%–20.0%
Grabbing	8 (22.2%)	10.7%–39.6%
Pushing	3 (8.3%)	2.2%–23.6%
Throwing things	4 (11.1%)	3.6%–27.0%
Making strange noises	9 (25.0%)	12.7%–42.5%
Screaming	9 (25.0%)	12.7%–42.5%
Biting	1 (2.8%)	0.2%–16.2%
Scratching	3 (8.3%)	2.2%–23.6%
Get to different place	5 (13.9%)	5.2%–30.3%
Intentional falling	-	-
Complaining	11 (30.6%)	16.9%–48.3%
Negativism	9 (25.0%)	12.7%–42.5%
Eating inappropriate substances	1 (2.8%)	0.2%–16.2%
Hurting oneself or others	2 (5.6%)	1.0%–20.0%
Handling things inappropriately	3 (8.3%)	2.2%–23.6%

(Continues)

TABLE 4 (Continued)

Neuropsychiatric symptoms	Frequency (n (%))	CI (%)
Hiding things	8 (22.2%)	10.7%–39.6%
Hoarding things	8 (22.2%)	10.7%–39.6%
Tearing things	2 (5.6%)	1.0%–20.0%
Performing repetitious mannerisms	9 (25.0%)	12.7%–42.5%
Verbal sexual advances	10 (27.8%)	14.8%–45.4%
Physical sexual advances	4 (11.1%)	3.6%–27.0%
General restlessness	15 (41.7%)	26.0%–59.1%
Physically aggressive behaviour	22 (61.1%)	43.5%–76.4%
Physically nonaggressive behaviour	22 (61.1%)	43.5%–76.4%
Verbally agitated behaviour	24 (66.7%)	49.0%–80.9%

The low sample size and small number of nursing homes might limit the generalizability of the findings. Another limitation is that there was no even distribution of patients between the participating nursing homes. Almost a quarter of the patients were recruited from one nursing home. Indirect assessment by professional caregivers is a possible limitation as well due to subjective interpretation of appropriateness and sexual intent behind an act (Johnson et al., 2006). There also may be discomfort in reporting and addressing ISB, which may have led to an underestimation of the prevalence. Use of extensive language in the MMSE might lead to unreliable results in aphasic patients and patients who do not speak the Dutch language (Kohnen et al., 2019; Tombaugh & McIntyre, 1992). Eight patients were aphasic and the MMSE was not administrable in five of these patients (Kohnen et al., 2020). These five patients were excluded from the analysis with regard to the MMSE. Physical disabilities in patients with ABI, such as paralysis, might have led to an underestimation of their cognitive abilities because of not being able to perform actions such as taking and folding a piece of paper, writing and drawing. Eighteen patients in our study who had physical disabilities were not able to perform these actions.

4.2 | Recommendations

We recommend more cross-sectional and longitudinal studies about ISB and concurrent challenging behaviours in ABI with greater sample sizes to enhance the generalizability of findings and to determine their course. Direct assessment of frequency and description of ISB by observation, possibly using video recordings, is recommended. We also recommend conducting assessing the presence of ISB and quality of life in relation to sexual expression. Furthermore, we advise to conduct qualitative research to determine the impact of ISB on professional caregivers working for this population of patients. Provision of quality care may be enhanced, for example, by giving nursing

TABLE 5 The results (coefficient and confidence intervals) from the multilevel multivariate linear regression analysis of the SASBA

Explanatory variables ^a	SASBA ^b				
	Verbal comments	Non-contact	Exposure	Touching others	Total score
Patient characteristics					
Marital status (married)	-	-1.39 (-2.50, -0.29)	-	-	-
Level of education (secondary/high)	-	-	-0.48 (-0.92, -0.04)	-	-
Presence of pain	-	-1.16 (-2.23, -0.08)	-	-	-3.27 (-6.27, -0.28)
DRS ^c	-	0.12 (0.02, 0.21)	-	-	-
CMAI ^d					
Physically aggressive	0.17 (0.04, 0.30)	-	-	0.15 (0.06, 0.25)	0.48 (0.22, 0.73)
NPI-NH ^e					
Hyperactivity	-	-	0.04 (0.01, 0.06)	-	-

^aNon-significant results were omitted.

^bSt. Andrews Sexual Behaviour Assessment.

^cDisability Rating Scale.

^dCohen Mansfield Agitation Inventory.

^eNeuropsychiatric Inventory-Nursing Home Version.

home staff, who are responsible for the daily care of patients with ABI, the tools to improve handling ISB through educational programmes (Kohnen et al., 2019). Research could give direction to the kind of education that is needed. In an educational and supportive environment, nursing staff may, for example, be provided with opportunities to discuss ISB, explore their own sexual attitudes and gain knowledge about the sexual needs of their patients with the provision of feedback from a nursing educator (Wallace & Safer, 2009). From other settings and populations, it is known that individualized behavioural interventions have been highly effective to decrease ISB despite the fact that none of the interventions were identical and a single overarching treatment to address ISB was not identified (Clay et al., 2018). More research about the use of these behavioural interventions in nursing home populations of patients with severe ABI is recommended. This will also enlarge the awareness of ISB and enhance the development of individualized interventions for ISB in an effective and respectful manner.

5 | CONCLUSION

ISB is prevalent in patients with ABI ≤65 years of age residing many years in nursing homes. This may have impact not only on the patients themselves but also on nursing staff. It is therefore important to shed more light on ISB, with regard to magnitude, severity, course and concurrent challenging behaviours, sexuality and quality of life. Insight into the magnitude and severity of these issues could give direction to the kind of interventions and education that is needed. The ultimate goal is to develop appropriate care for this vulnerable group of patients, specifically psychosocial interventions and appropriate use of psychotropic drugs.

ACKNOWLEDGEMENTS

We would like to thank all the organizations, professional caregivers, physicians, patients and their relatives who generously agreed to participate in this project. The researchers of this study would like to acknowledge in particular B. Meuwese and L. de Haan of Vivent for initiating and facilitating this project. The researchers would also like to acknowledge O. Smals for her contribution in the design of the study and S. Kruijer for her help with the data collection during an academic traineeship.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR'S CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE): (i) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; and (ii) drafting in the article or revising it critically for important intellectual content.

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.14817>.

DATA AVAILABILITY STATEMENT

Data available on request from the authors.

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How to cite this article: Kohnen RF, Lavrijsen J, Akkermans R, Gerritsen D, Koopmans R. The prevalence and determinants of inappropriate sexual behaviour in people with acquired brain injury in nursing homes. *J Adv Nurs*. 2021;77:3058–3072. <https://doi.org/10.1111/jan.14817>

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