Received: 17 September 2024 | Revised: 20 December 2024 | Accepted: 20 January 2025

DOI: 10.1002/trc2.70057

Alzheimer's & Dementia
Translational Research & Clinical Interventions

RESEARCH ARTICLE

Person-centered care at population scale: The Swedish registry for behavioral and psychological symptoms of dementia

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Funding information
Swedish Municipalities and Regions; Swedish Innovation Agency (Vinnova), Grant/Award Number: 2021-02680; Innovative Health Initiative Joint Undertaking (IHI JU), Grant/Award Number: 101112145; Regions and Municipalities of Sweden (SKR); European Union's Horizon Europe research and innovation programme

Abstract

INTRODUCTION: Behavioral and psychological symptoms of dementia (BPSD) are a common driver of suffering and high care needs. We describe the Swedish BPSD registry, founded in 2010 to develop an evidence base for quality improvement in the care of patients with BPSD. Further, we illustrate the potential of the registry by evaluating how individual BPSD affects mortality.

METHODS: The registry provides a framework for documenting the occurrence of BPSD, formulating individual care plans, and following up outcomes. Symptoms are recorded by the nursing home version of the neuropsychiatric inventory (NPI), and data are entered by trained staff, mainly at institutional care facilities.

RESULTS: Enrollment in the registry totaled 114,869 patients with dementia and a mean age of 84 years. Patients were followed until death (median overall survival 2.2 years) or loss to follow-up (median time under observation 4.2 years in patients remaining alive). Common symptoms included agitation/aggression, aberrant motor behavior, and irritability. Mortality increased with NPI severity and use of neuroleptics but decreased in patients receiving cholinesterase inhibitors or memantine.

DISCUSSION: The scale, completeness, and duration of the registry, together with the possibility of linking to other data sources, offer great potential for data-driven research.

KEYWORDS
behavioral and psychological symptoms of dementia, mortality, quality registry

Highlights

- The Swedish BPSD Registry, founded in 2010, has followed over 114,000 patients collecting data on symptoms, care plans, interventions and outcomes.
- The registry provides a framework for providing and evaluating person-centered care for patients with BPSD, and represents an unparalleled data source for research into BPSD and its management.

- Mortality increased in patients with more severe BPSD symptoms and for those treated with neuroleptics, but decreased in patients receiving cholinesterase inhibitors or mematine.

1 | BACKGROUND

Major neurocognitive (dementia) disorders are primarily characterized by a progressive decline across various cognitive domains, including memory, language, and executive functions, leading to impairment and loss of autonomy in activities of daily living (ADL). Alongside cognitive and functional impairment, behavioral and psychological symptoms of dementia (BPSD), including disturbances in perception, content of thoughts, and behavior and mood are also frequent.[1] BPSD play a significant role in contributing to functional impairment and care needs,[1] an increase in caregiver burden,[2] and the need to transition to institutional care.[3] The spectrum of BPSD encompasses a wide array of different symptoms and behavioral changes, ranging from psychotic manifestations, depression, and anxiety to sleep disturbances, irritability, agitation, changes in eating patterns, aberrant motor behavior, apathy, and euphoria.[1] Ninety percent of persons with major neurocognitive disorders experience one or more BPSD throughout the disease course.[4,5] The etiology and pathogenesis of BPSD are intricate, involving various direct factors and indirect mediators. Different brain alterations, comorbidities, and medication can intersect with psychological factors like personal life history and personality, as well as social aspects, such as support networks and living arrangements.[1]

Progressive neurocognitive disorders can lead to an inability to communicate wishes and needs to the surrounding world. This difficulty often results in various means to express oneself and frequently gives rise to a diverse array of behavioral and psychiatric symptoms.[6,7] Different cognitive disorders engage different brain areas and functions, leading to varying behavioral and psychiatric symptoms.[1,8] In Alzheimer's disease (AD), memory deficiency is a possible background to delusions and agitation, as well as anxiety and irritability. In dementia with Lewy bodies (DLB), visual hallucinations are already part of the core criteria, while in frontotemporal dementia (FTD), there is a behavioral variant and vascular pathology is often present, with frontal influence increasing the occurrence of behavioral and psychological symptoms.[9]

Psychotropic medication is frequently used to mitigate BPSD[10–12]; however, it is linked to numerous side effects, including an elevated risk of mortality for neuroleptics.[11–13] Therefore, systematic and strategic interventions aimed at reducing the frequency or intensity of BPSD are important to prevent subjecting individuals to potential adverse effects associated with pharmacological interventions. Non-pharmacological treatments are recommended as a first-line strategy in numerous guidelines[14–16]; however, it should be noted that there are few head-to-head comparisons of drug treatments and non-pharmacological management strategies, and there may be systematic differences in symptom severity between studies.[17]

Person-centered care (PCC) has been applied to manage BPSD, aiming to improve health outcomes and quality of life. While PCC lacks a universal definition,[18] it emphasizes recognizing all patients' individual strengths and active participation in their care. A recent systematic literature review identified 35 studies of non-pharmacological, person-centered interventions, including music therapy, reminiscence therapy, and multisensory stimulation.[19] The estimated mean standardized effect size on BPSD was moderate (−0.52), varying by intervention type and targeted symptom. However, evidence to guide customization of non-pharmacological treatments to individual symptoms and patient characteristics remains insufficient.[20] Generating such evidence through conventional randomized controlled trials alone will be difficult. Large-scale registries capturing patients with BPSD, documenting their symptoms, and interventions longitudinally offer complementary real-world data. This study delineates 13 years of experience with establishing and operating the Swedish BPSD registry, utilizing collected data to investigate long-term mortality outcomes in relation to BPSD.

2 | METHODS

The Swedish BPSD registry was initiated as a local quality development project and was nominated as a National Quality Registry in 2010, whose aim is to improve the quality of care for patients with dementia and ensure a common standard of care across Sweden. It was founded in alignment with the recommendations of non-pharmacological intervention for the management of BPSD from the Swedish national guidelines for dementia care by the National Board of Health and Welfare, published in 2010 and revised in 2017.[14] The registry received wider uptake through the government initiative "Better Care for Frail Elders" (2010 to 2014).

The registry provides a structured and systematic approach for healthcare professionals to assess BPSD in patients with neurocognitive disorders, involving relatives when possible. This person-centered analysis identifies and trigger factors, informing multiprofessional interventions. Follow-up evaluations validate chosen interventions and facilitate care improvement at individual, care provider, and health system levels.

2.1 | Workflow of BPSD registry

The BPSD registry covers dementia care units and nursing homes across Sweden. Certified educators trained by the registry staff provide local training to enroll patients. With 800 certified educators,

RESEARCH IN CONTEXT

1. **Systematic review**: Most guidelines recommend non-pharmacological management as first-line treatment for BPSD. A recent systematic literature review identified 35 studies of person-centered interventions in BPSD, such as music therapy, multisensory stimulation, and reminiscence therapy. The efficacy of these interventions is highly variable across studies.
2. **Interpretation**: The Swedish BPSD registry demonstrates the feasibility and value of delivering patient-centered care at a population scale. It provides a structured framework for identifying precipitating factors, developing personalized care plans and interventions, and following up their effect. The data enable comparisons between different care facilities and regions, allowing identification of best practices and areas for improvement, contributing to enhancing the overall quality of care for individuals with BPSD.
3. **Future directions**: More knowledge is needed on how to individualize the management of BPSD. The Swedish BPSD registry provides a uniquely large database for research into the occurrence of BPSD, their pharmacological and non-pharmacological management, and outcomes related to them.

over 50,000 multiprofessional team members in all 290 municipalities in Sweden have been trained. The registry methodology requires assessment by at least two different professional disciplines, including assistant nurses, nurses, occupational therapists, physiotherapists, physicians, and managers, before data input registration.

2.2 | Data collection process

The BPSD registry enrolls subjects with dementia, diagnosed in routine care, regardless of symptoms or etiological diagnosis. Most residents participating in care units enrolled. Trained staff familiar with the patient conducts baseline and follow-up assessments as needed, typically every 6 months, though annual assessments are recommended by Swedish guidelines.[14] Data are collected at care facilities or by municipal home-care teams and entered into an online electronic data capture system.

2.3 | Data collected in BPSD registry

The registry captures basic demographics, care setting, and mortality data from official records. Neurocognitive diagnoses (according to the International Classification of Diseases, ICD-10)[21] and drug prescriptions are obtained from medical records. Current medication with a focus on psychotropic drugs is inventoried at baseline and updated as needed. At each registration, the Neuropsychiatric Inventory—Nursing Home version (NPI-NH)[22] captures the frequency and severity of 12 symptoms: delusions, hallucinations, agitation/aggression, depression, apathy, elation/euphoria, anxiety, disinhibition, irritability, aberrant motor behavior, sleep and nighttime behavior changes, and appetite and eating abnormalities. Further, a structured checklist is used to identify potential trigger factors and ensures that potential issues related to pain, sleep disturbances, oral health, food and drink intake, or elimination problems in the patient have been considered. Finally, a plan for care and psychosocial interventions is recorded in the registry as free-text descriptions of the planned interventions. Further details and the registration template are available in Supplementary Materials.

2.4 | Statistical analysis

This study is based on data from the Swedish BPSD registry and covers all individuals in the registry aged 40 or older from its inception in November 2010 until December 31, 2023. Descriptive statistics are presented with mean, range, median, and interquartile range (IQR). Confidence intervals (CI) were calculated by ± 1.96 standard errors for approximately normally distributed variables. For NPI scores, as these are typically non-normally distributed, we applied a cutoff score of >3 points to denote significant symptoms within each domain.[23] Mortality was described using the Kaplan–Meier product limit estimator,[24] while factors affecting mortality were analyzed using a Cox proportional hazards regression model stratified by sex and age group.[25] Significant BPSD at baseline were included as binary indicators for each domain. Patients were censored if still alive at 12 months after baseline. Schoenfeld residuals were plotted to examine the validity of the proportional hazards assumption.

2.5 | Research ethics considerations

The study was approved by the Swedish Ethical Review Authority and conducted in accordance with the Helsinki Declaration.[26] For further details, see Supplementary Materials.

3 | RESULTS

Table 1 describes the total patient population captured by the BPSD registry. From the start of the registry in 2010 until the end of 2023, a total of 114,869 patients (63% women) were included in the registry. The mean (median) age at inclusion into the registry was 83.6 (85) years, with a range of 40 to 111 years. Most participants (88.5%) were in permanent institutional care at the time of inclusion. Total NPI-NH scores at baseline ranged from 0 to 144, with mean and median of 21 and 15 points, respectively. Females were slightly older at baseline than

TABLE 1 Description of study population.

	Female	Male	All
Total number of patients			
N	72,870	41,999	114,869
Age			
Mean	84.62	81.75	83.57
Median	86	83	85
Range	41 to 109	40 to 111	40 to 111
Interquartile range	80 to 90	77 to 88	79 to 89
Age group			
40 to 65	995 (1.37%)	1154 (2.75%)	2149 (1.87%)
65 to 74	5816 (7.98%)	6165 (14.68%)	11,981 (10.43%)
75 to 84	25,414 (34.88%)	17,701 (42.15%)	43,115 (37.53%)
85 to 94	36,121 (49.57%)	15,888 (37.83%)	52,009 (45.28%)
95+	4524 (6.21%)	1091 (2.6%)	5615 (4.89%)
Diagnosis			
Alzheimer's disease	25,579 (35.1%)	12,633 (30.08%)	38,212 (33.27%)
Vascular dementia	11,490 (15.77%)	7713 (18.36%)	19,203 (16.72%)
Mixed dementia	5576 (7.65%)	3262 (7.77%)	8838 (7.69%)
Dementia with Lewy bodies	834 (1.14%)	1124 (2.68%)	1958 (1.7%)
Frontotemporal dementia	902 (1.24%)	833 (1.98%)	1735 (1.51%)
Dementia in Parkinson's disease	723 (0.99%)	1126 (2.68%)	1849 (1.61%)
Other dementia	5371 (7.37%)	3670 (8.74%)	9041 (7.87%)
Unspecified dementia	8993 (12.34%)	4421 (10.53%)	13,414 (11.68%)
Unknown	13,402 (18.39%)	7217 (17.18%)	20,619 (17.95%)
Care setting			
Daycare	910 (1.25%)	802 (1.91%)	1712 (1.49%)
Dementia team	1438 (1.97%)	857 (2.04%)	2295 (2%)
Home health care	3384 (4.64%)	1668 (3.97%)	5052 (4.4%)
Short-term care	1837 (2.52%)	1848 (4.4%)	3685 (3.21%)
Acute hospital care	152 (0.21%)	140 (0.33%)	292 (0.25%)
Institutional care	50,138 (68.8%)	27,903 (66.44%)	78,041 (67.94%)
Dementia-specific institutional care	14,886 (20.43%)	8701 (20.72%)	23,587 (20.53%)
Other	125 (0.17%)	80 (0.19%)	205 (0.18%)
NPI total score			
Mean	21.07	21.86	21.36
Range	0 to 144	0 to 144	0 to 144
Median	15	16	15
Interquartile range	5 to 31	5 to 32	5 to 32
Drug usage			
Analgesics	11,192 (15.36%)	4521 (10.76%)	15,713 (13.68%)
Antiepileptics	4167 (5.72%)	2944 (7.01%)	7111 (6.19%)
Neuroleptics	11,450 (15.71%)	7889 (18.78%)	19,339 (16.84%)
Anxiolytics	13,463 (18.48%)	6712 (15.98%)	20,175 (17.56%)
Hypnotics	5149 (7.07%)	4281 (10.19%)	9430 (8.21%)
Antidepressants	32,520 (44.63%)	16,576 (39.47%)	49,096 (42.74%)
Cholinesterase inhibitors	14,222 (19.52%)	8017 (19.09%)	22,239 (19.36%)
Other anti-dementia drugs	13,431 (18.43%)	8582 (20.43%)	22,013 (19.16%)

Abbreviation: NPI, neuropsychiatric inventory.

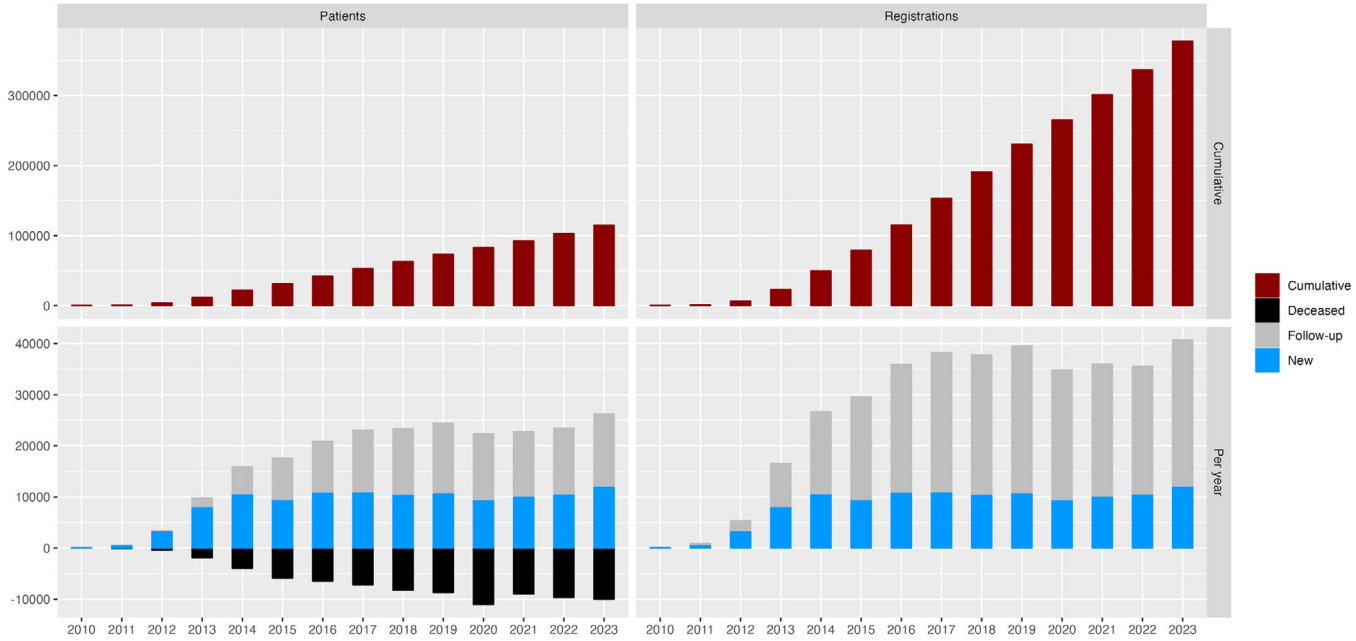

FIGURE 1 Number of patients and registrations in BPSD registry. BPSD, behavioral and psychological symptoms of dementia.

males and had a slightly higher proportion of AD diagnoses, while males had a higher proportion of vascular dementia and Parkinson's disease (PD) dementia diagnosis.

Tables S1 and S2 shows detailed patient characteristics by care setting and diagnosis, respectively. Total NPI-NH scores were highest for patients in the acute hospital care setting (mean 33 points) and lowest in the daycare setting (mean 6 points). There were no notable differences in mean total NPI-NH scores at baseline across diagnostic groups.

Figure 1 shows the number of patients and registrations by year in the registry. The left panes show numbers of unique patients, and the right panes show the number of registrations per year. Top panes are cumulative, while bottom panes show the numbers of patients/registrations within each year. The number of patients active in the registry each year is stabilized between 20,000 and 25,000, while the annual number of registrations is about 35,000.

Figure S1 shows the distribution of enrolled patients over all the 290 Swedish municipalities, as a share of the number of inhabitants in the municipality aged 65 or older. This includes all registered patients since the inception of the registry; thus, many of these individuals are deceased, which explains the high share of individuals enrolled (over 20% in some municipalities). The registry has coverage over most geographic regions across the country; only one municipality out of 290 had no registered patients. The median number of enrollees was 54.7 per 1000 inhabitants aged 65+, and 90% of municipalities have registered more than 24 patients per 1000 inhabitants.

In Figure 2 we show the share of patients at baseline who report significant symptoms (NPI score >3) on each of the NPI domains, by diagnosis. The most common symptoms include agitation/aggression, aberrant motor behavior, and irritability, which are included as criteria in the recently updated International Psychogeriatric Association (IPA) definition of *agitation in cognitive disorders*.[27] This is noteworthy as it corresponds to the licensed indication of the first US Food and Drug Administration-approved drug for treatment of BPSD. There were some expected variations by diagnosis; for example, hallucinations were more common in DLB patients, while aberrant motor behavior was the dominant issue in PD dementia. FTD patients in addition showed high levels of disinhibition, irritability, and agitation/aggression.

The total number of registrations per individual patient over the entire period of observation ranges from 1 to 56, with a mean (median) of 3.29 (2). More details are presented in Figure S2. A total of 72,749 patients (66%) had at least two registrations, allowing for longitudinal assessment. The effective median observation time in the registry was 7 months. Nineteen percent of patients were still being followed in the registry when data were obtained for this study (administrative censoring), 52% had died within a year of the last assessment, and 29% were lost to follow-up (1 year elapsed without assessment). Among patients who remain alive, the mean time until loss to follow-up was 4.2 years.

The main reason for discontinued follow-up was death. In total 83,499 of the enrolled patients were deceased at the time of data extraction for this study. The median overall survival (time until death for any cause) was 22.0 months (95% CI 21.7 to 22.3 months) for men, 28.3 months (95% CI 28.0–28.6 months) for women. Kaplan–Meier survival curves are presented in Figure S3. We analyzed the association with mortality for NPI-NH symptoms and drug utilization with a Cox regression model stratified by age and sex, and the results are presented in Figure 3. For most NPI-NH domains, significant symptoms (score of 3 points or more) were associated with increased mortality risk; in the case of hallucinations, agitation/aggression, apathy, and appetite/eating disturbances the risk increase was significantly over 10%. Euphoria was associated with significantly lower

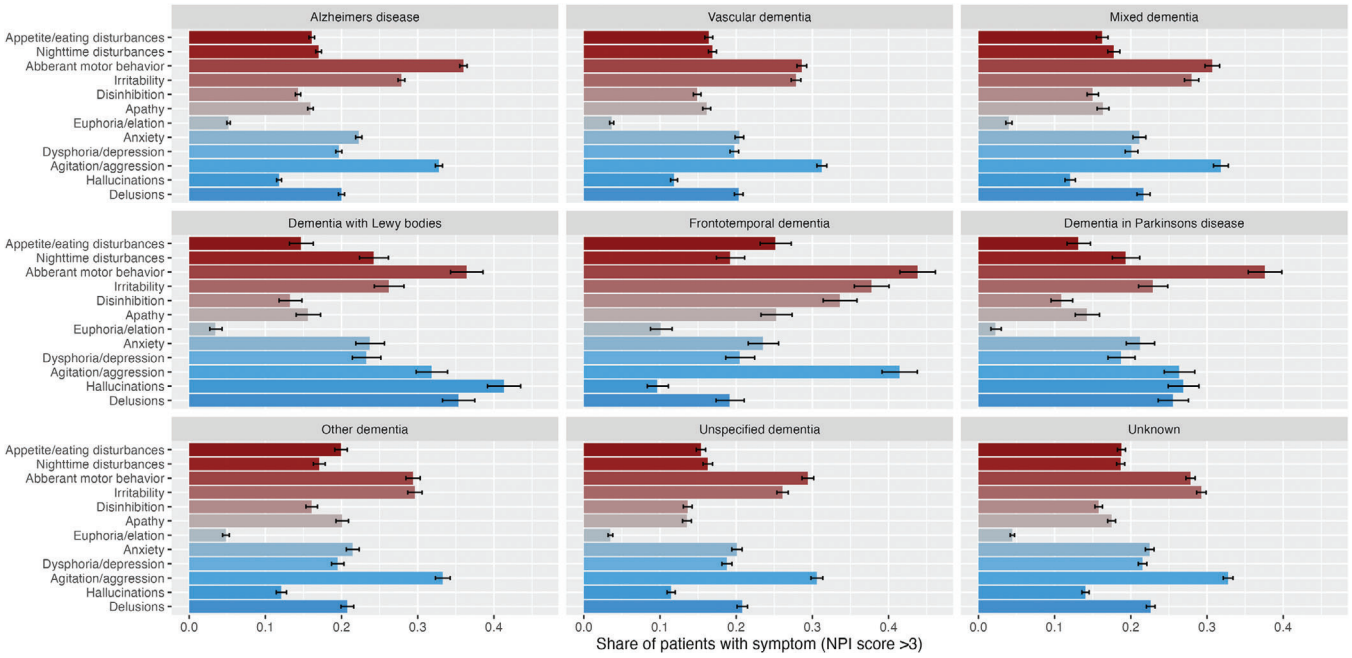

FIGURE 2 Occurrence of BPSD at baseline. BPSD, behavioral and psychological symptoms of dementia.

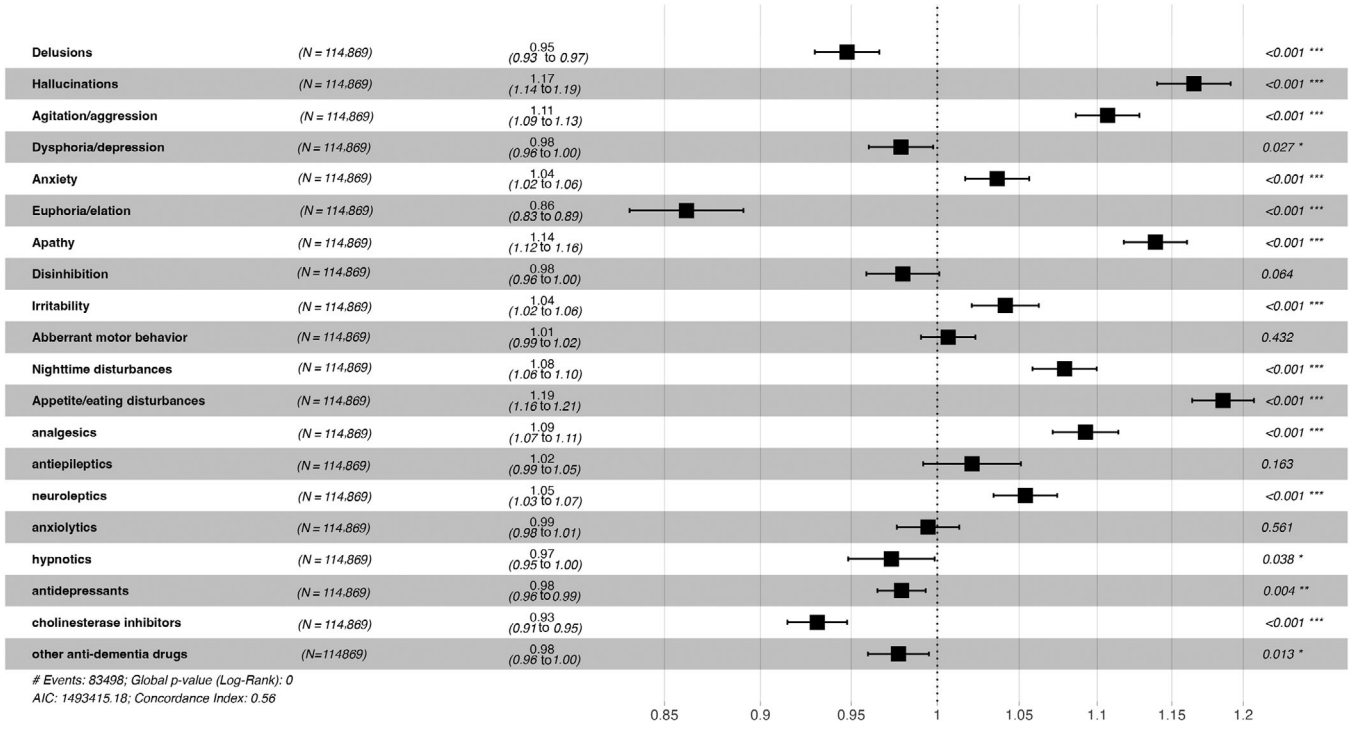

FIGURE 3 Hazard ratios, Cox model of overall survival.

mortality risk (−22%). The use of neuroleptics or analgesics was associated with increased mortality. Patients using cholinesterase inhibitors or memantine showed lower mortality risk (−16% and −11%, respectively). No substantial differences were seen when analyzing data for males and females separately (Figures S4 and S5) or when including interaction terms between neuroleptic use and BPSD. Figure S6 shows plotted Schoenfeld residuals that were approximately linear over time across covariates, indicating that the proportional hazards assumption was met.

In Figure 4, we present the mean NPI-NH score by study visit and NPI-NH domain, subdivided by the score at baseline. Study visits are plotted at the mean number of months since the baseline for each study

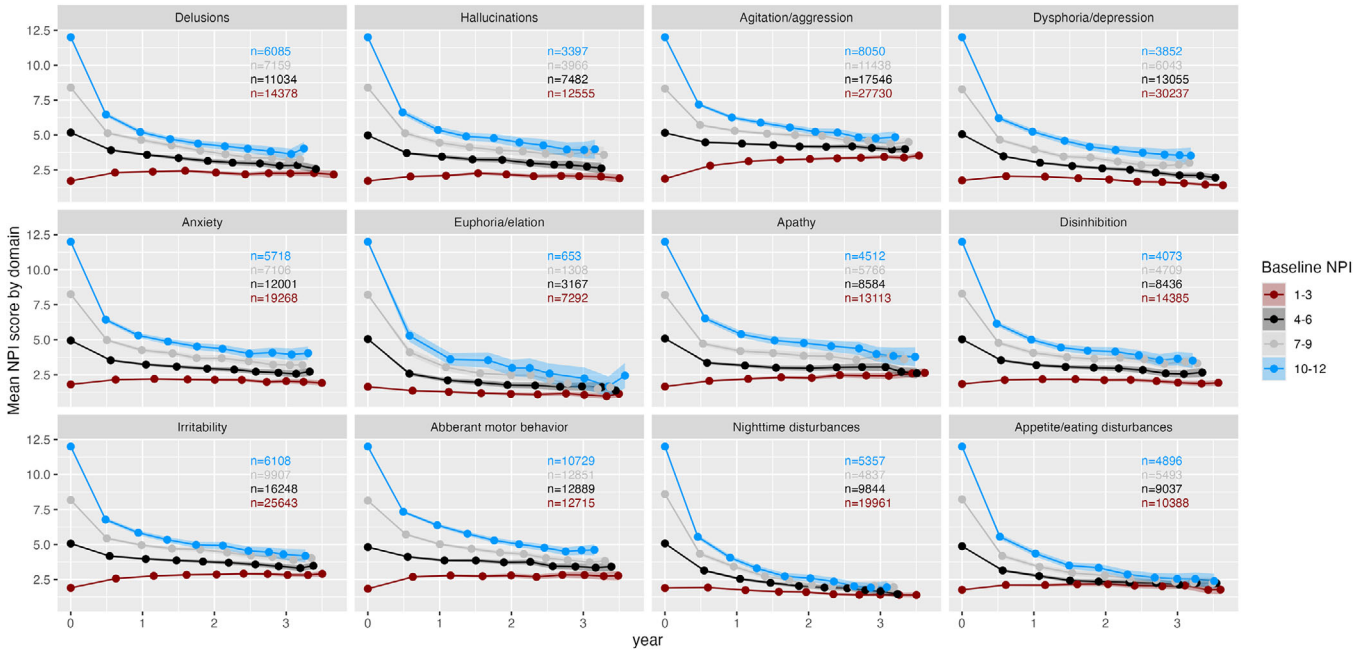

FIGURE 4 Mean NPI score by domain and visit. NPI, neuropsychiatric inventory.

visit, and 95% confidence bands are shown. Each graph includes only patients scoring above zero at baseline on that NPI-NH domain. Across domains there was rapid improvement over the first few visits, most notably in patients with high baseline NPI-NH scores, which likely indicates a regression toward the mean. The time between assessments tends to be somewhat shorter for patients with more severe symptoms than patients with less severe symptoms.

We analyzed trigger factors for patients with a NPI-NH score of 8 or higher on each of the NPI domains (results presented in Figure S7). Pain was the most cited trigger factor across most symptoms, with the exception of nighttime disturbances (sleep-related issues most common trigger) and appetite/eating disturbances (food related issues most common trigger).

Further, we evaluated the relationship between the objective of the care actions (the result that is aimed to achieve) and the symptom (NPI-NH domain), which is the target of the care action (results in Figure S8). The most common care objective is affirmation/security, followed by sensory stimulation and social activity. Increasing physical activity was a common objective for patients with dysphoria/depression, nighttime disturbances, or aberrant motor behavior. Meeting basic needs was the most important objective in appetite/eating disturbances.

4 | DISCUSSION

4.1 | Experiences with BPSD registry

The Swedish BPSD registry demonstrates the feasibility of PCC at the population scale, allowing for consistently monitoring care quality and outcomes. Over 114,000 patients have received PCC through the registry, contributing to the largest database on BPSD occurrence, treatments, and outcomes.

Continuous development through user dialogue has enhanced data visualization at the individual care practice level, aiding in management and staff allocation. The registry publishes an annual report on a range of quality indicators, encompassing the prevalence of BPSD, care interventions for the management of BPSD, collaboration with multiprofessional teams, pain management, and the use of specific pharmaceuticals. Care providers and decision makers utilize the data to formulate, implement, and monitor guidelines and other regulatory measures as required at the national, regional, and local levels. Participating care units are able to access their data at any time and compare their results with other care units and with national averages. Since December 2022, there has also existed an integrated tool to improve daily workflow to manage and prevent BPSD. Staff can easily initiate a project aiming to, for example, raise the number of registrations made by a multiprofessional team at the care unit. A care unit that has implemented the BPSD registry has a more person-centered approach, which allows individuals even with advanced dementia to feel more validated and be met on their own terms, which can lead to greater well-being in the given situation. In this way, the method may also prevent the occurrence of BPSD over time. The registry's method has spread throughout the municipalities to regional health care and private care providers. The expanded uptake of the registry over time is a testament to the perceived value for care providers in participating in the registry, at the level of the individual care provider and the organizational level. Experience with the registry indicates that staff appreciate that more of their time is spent on meaningful activities, as well as having a shared language to discuss symptoms and goals with the interventions. Staff and next of kin report better quality of life as well as enhanced occupational safety.

4.2 | Effects of BPSD on mortality

There have been few large-scale studies on the effects of individual BPSD on mortality. An earlier analysis of the BPSD registry using data only from 2010 to 2013 found that mortality increased with BPSD severity, with a relative risk (RR) of 1.71, $p < .001$, for patients with NPI scores of 9 to 12 on >1 item.[28] The increase in mortality was driven by agitation, hallucinations, and eating disturbances, while patients with euphoria had lower mortality (RR 0.93, $p < .001$). A recent Japanese study found an association between BPSD and mortality in males, but not in females.[29] Our study confirms the association between BPSD and mortality and found this association in males as well as females. The effect on mortality varied by individual symptoms, warranting further analysis including the assessment of treatment interactions. The mortality analysis only examined the association between BPSD at baseline and mortality during the subsequent 12 months. Incorporating longer follow-up and longitudinal data on BPSD and treatments in the analysis may introduce time-dependent confounding, and addressing this issue is beyond the scope of the present study.

4.3 | Limitations

There are opportunities for further developing the scope of data captured by the registry. There is currently no automatic transfer of data from medical records, so manual data entry is required, which limits the amount of information collected. Importantly, the registry currently does not contain information on disease staging in terms of cognitive function or ADL abilities. These outcomes are captured in a different quality register (SveDem), and in principle, the same information should not be collected in multiple quality registers. It is possible to merge data from registers and from electronic medical records, partly overcoming this limitation; however, future development of the registy infrastructure should consider obtaining detailed disease staging information in terms of cognition and functioning for all participants.

Diagnosis is made according to routine clinical practice, so there is no centralized harmonization of diagnostic criteria, and the use of biomarkers to confirm etiological diagnosis varies. Furthermore, the registry does not directly capture biomarker information, though again this can be linked from other data sources.

The NPI is a commonly used scale for capturing BPSD and has been recommended for clinical use as well as research.[30] The NPI and NPI-NH) scales are flexible and easy to administer. Since the interview questions are formulated, the administration is not dependent on the clinical experience of the administrator which suits the purpose and spread of the Swedish BPSD registry to care units all over Sweden. Another advantage is that apathy and depression, which can influence other symptoms, are measured separately.

However, for research, there are some obstacles despite reasonable psychometric attributes such as validity and reliability, which require further investigation.[31] Since scores are calculated by multiplying severity and frequency, the resulting values are non-continuous and not normally distributed, which must be considered statistically. Dedicated scales for specific symptoms such as the geriatric depression scale,[32] Apathy Evaluation Scale,[33] and Cohen-Mansfield Agitation Inventory[34] may provide greater resolution and sensitivity to change. Alternatives to the NPI, including the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) and the Neurobehavioral Rating Scale (NRS), have shown similar performance in detecting symptoms and response to treatment,[35] while the Revised Memory and Behavior Problems Checklist (RMBPC) may be better correlated with caregiver outcomes.[36] A future direction of research would be to complement these scales that rely on caregiver reports with objective measurements from home monitoring platforms.[37]

As this is a naturalistic study, factors such as time of inclusion of patients into the registry and the frequency and timing of assessments are not governed by research protocol but will be influenced by patient-related factors as well as factors associated with the care unit and staff. There is no random assignment of care interventions, which limits the potential for drawing conclusions about the causal effects of care interventions. Further, as participants were not randomly selected, and BPSD are not systematically documented outside the registry, it is difficult to ascertain potential selection biases in patient inclusion or the representativity of the study sample of the overall population of patients with BPSD. Caution is warranted when using registry data to estimate the occurrence of BPSD in the overall population of persons living with dementia.

Detailed information on interventions to manage BPSD are captured in free-text descriptions, which will require further processing and evaluation and were not included in the present study. Regarding triggers for BPSD, it should be noted that the collected information is based on the opinion of care staff regarding potential causal factors. Pain is recognized as one of the most common triggers. Few studies have been conducted on non-pharmacological interventions for pain, although a recent review indicates that such interventions are effective in individuals with dementia[38] and help reduce BPSD.[39] However, triggers of BPSD are an important and complex issue in themselves, which we intend to address further in upcoming studies.

4.4 | Potential of BPSD registry for data-driven research

The BPSD registry has great potential as a resource for data-driven research. The scale, data completeness, and long duration of the registry is unparalleled. Structured health outcomes data combined with detailed free-text descriptions of care interventions captures a wealth of information about the symptomatology of BPSD, measures taken in routine care to manage these symptoms and the resulting health outcomes. Modern methods for natural language processing offer opportunities for further structuring and extracting information from the available free-text fields.[40] This may enable analyses to determine optimal care strategies tailored to individual patient characteristics, trigger factors, and symptom profiles.

The potential of the registry is further enhanced by the possibility of linking with other available data sources at national and regional levels.[8] Each person in Sweden has a unique identifying number, which enables linkage across all registries and healthcare databases. The BPSD registry can be linked with the Swedish registry for cognitive/dementia disorders (SveDem), which captures longitudinal information on cognitive function, ADL assessment, diagnostic procedures, and other factors. A previous record linkage study based on data until 2016 found that about 30% of patients in the BPSD registry are also present in SveDem, and 20% of patients in SveDem are captured by the BPSD registry.[8] The data have also been linked to the National Patient Registry, which contains information on all healthcare encounters in inpatient care and specialist outpatient care. Other relevant data sources include the prescription pharmaceutical registry (enabling analysis of the effect of drug therapy on BPSD) and the registry for elderly care and functional impairment.

5 | CONCLUSIONS

The Swedish BPSD registry provides a view into the final stages in the disease course of dementia disorders, with specific focus on the role of behavioral disturbances, psychological symptoms, and their management. It offers unparalleled insights into the management of BPSD in routine care as well as long-term outcomes. BPSD appear to improve over time; however, this may also be the result of "regression to the mean," and further analysis is warranted. The analysis presented here is the largest study to date on the association between BPSD and mortality. We confirm previous findings that BPSD are associated with increased mortality risk and that treatment with certain classes of pharmaceuticals such as neuroleptics is associated with increased mortality. We also confirm reduced mortality in cholinesterase inhibitor users, in line with previous studies based on Swedish registry data.[41,42]

ACKNOWLEDGMENTS

The BPSD registry is funded by the Swedish Municipalities and Regions. The study was supported by research grants from the Swedish Innovation Agency (Vinnova). This project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No 101112145. The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, EFPIA, Europa Bío, MedTech Europe, and Vaccines Europe. The authors would like to acknowledge the invaluable contributions of the staff of the BPSD registry: Håkan Minthon, Maggie Andersson, Carina Törnkvist, and Karin Sjölin. Further, Sofia Schuss conducted an early analysis of the BPSD registry data on which this paper is based. In memory of Lennart Minthon, founder of the BPSD registry, who sadly passed away in 2023. The BPSD registry is funded by the Regions and Municipalities of Sweden (SKR).

CONFLICT OF INTEREST STATEMENT

All authors are members of the steering group for the Swedish BPSD registry. L.J. has received research funding and consultancy fees unrelated to this work from Novo Nordisk A/S, H. Lundbeck A/S, and Eli Lilly. M.W. has received consultancy fees unrelated to this work from Bioarctic AB, Biogen Sweden AB, Eisai AB, and Roche Diagnostics AB. E.L. has received consultancy fees unrelated to this work from Bioarctic AB. K.N. has received consultancy fees unrelated to this work from Bioarctic AB and Biogen Sweden AB. Author disclosures are available in the Supporting Information.

CONSENT STATEMENT

The Swedish BPSD registry is a quality registry operating under routine care conditions, so informed consent was not required by participants. The study was approved by the Swedish Ethics Review Authority.

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REFERENCES

1. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. *Front Neurol*. 2012;3:73.
2. Feast A, Moniz-Cook E, Stoner C, Charlesworth G, Orrell M. A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *Int Psychogeriatr*. 2016;28(11):1761-1774.
3. Toot S, Swinson T, Devine M, Challis D, Orrell M. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatr*. 2017;29(2):195-208.
4. Lyketsos CG, Steinberg M, Tschanz JT, Norton MC, Steffens DC, Breitner JCS. Mental and behavioral disturbances in dementia: findings from the cache county study on memory in aging. *Am J Psychiatry*. 2000;157(5):708-714.
5. Zuidema SU, Derksen E, Verhey FRJ, Koopmans RTCM. Prevalence of neuropsychiatric symptoms in a large sample of Dutch nursing home patients with dementia. *Int J Geriatr Psychiatry*. 2007;22(7):632-638.
6. Hancock GA, Woods B, Challis D, Orrell M. The needs of older people with dementia in residential care. *Int J Geriatr Psychiatry*. 2006;21(1):43-49.
7. Cohen-Mansfield J, Dakheel-Ali M, Marx MS, Thein K, Regier NG. Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry Res*. 2015;228(1):59-64.
8. Schwertner E, Pereira JB, Xu H, et al. Behavioral and psychological symptoms of dementia in different dementia disorders: a large-scale study of 10,000 individuals. *J Alzheimers Dis*. 2022;87(3):1307-1318.
9. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. (5th ed.). 2022.
10. Gustafsson M, Sandman P-O, Karlsson S, Gustafson Y, Lövheim H. Association between behavioral and psychological symptoms and psychotropic drug use among old people with cognitive impairment living in geriatric care settings. *Int Psychogeriatr*. 2013;25(9):1415-1423.
11. Schneider LS, Dagerman KS, Insel P. Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *J Am Med Assoc*. 2005;294(15):1934-1943.
12. Schwertner E, Secnik J, Garcia-Ptacek S, et al. Antipsychotic treatment associated with increased mortality risk in patients with dementia. A registry-based observational cohort study. *J Am Med Dir Assoc*. 2019;20(3):323-329.
13. Gill SS, Bronskill SE, Normand S-LT, et al. Antipsychotic drug use and mortality in older adults with dementia. *Ann Intern Med*. 2007;146(11):775-786.

14. The National Board of Health and Welfare. *Nationella riktlinjer för vård och omsorg vid demenssjukdom. (National guidelines for dementia care)*. Sweden. 2017.
15. Kales HC, Gitlin LN, Lyketsos CG. Management of neuropsychiatric symptoms of dementia in clinical settings: recommendations from a multidisciplinary expert panel. *J Am Geriatr Soc*. 2014;62(4):762-769.
16. Ma H, Lu X, Zhou A, et al. Clinical practice guidelines for the management of behavioral and psychological symptoms of dementia: a systematic review with AGREE II. *Front Neurol*. 2022;13:799723.
17. Dyer SM, Harrison SL, Laver K, Whitehead C, Crotty M. An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *Int Psychogeriatr*. 2018;30(3):295-309.
18. Byrne AL, Baldwin A, Harvey C. Whose centre is it anyway? defining person-centred care in nursing: an integrative review. *PLoS One*. 2020;15(3):e0229923.
19. Lee KH, Lee JY, Kim B. Person-centered care in persons living with dementia: a systematic review and meta-analysis. *Gerontologist*. 2022;62(4):e253-e264.
20. Yin Z, Li Y, Bao Q, et al. Comparative efficacy of multiple non-pharmacological interventions for behavioural and psychological symptoms of dementia: a network meta-analysis of randomised controlled trials. *Int J Ment Health Nurs*. 2024;33(3):487-504.
21. Organization, World Health. *The ICD-10 Classification of Mental and Behavioural Disorders*. World Health Organization; 1993.
22. Wood S, Cummings JL, Hsu M-A, et al. The use of the neuropsychiatric inventory in nursing home residents. Characterization and measurement. *Am J Geriatr Psychiatry*. 2000;8(1):75-83.
23. Lyketsos CG, Lopez O, Jones B, Fitzpatrick AL, Breitner J, DeKosky S. Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: results from the cardiovascular health study. *J Am Med Assoc*. 2002;288(12):1475-1483.
24. Kaplan EL, Meier P. Nonparametric estimation from incomplete observations. *J Amer Statist Assoc*. 1958;53(282):457-481.
25. Cox DR. Regression models and life tables. *J R Stat Soc*. 1972;34(34):187-220.
26. World Medical, Association. World medical association declaration of Helsinki: ethical principles for medical research involving human subjects. *J Am Med Assoc*. 2013;310(20):2191-2194.
27. Sano M, Cummings J, Auer S, et al. Agitation in cognitive disorders: progress in the international psychogeriatric association consensus clinical and research definition. *Int Psychogeriatr*. 2024;36(4):238-250.
28. Bränsvik V, Granvik E, Minthon L, Nordström P, Nägga K. Mortality in patients with behavioural and psychological symptoms of dementia: a registry-based study. *Aging Ment Health*. 2021;25(6):1101-1109.
29. Noguchi T, Nakagawa T, Sugimoto T, et al. Behavioral and psychological symptoms of dementia and mortality risk among people with cognitive impairment: an 8-year longitudinal study from the NCGG-STORIES. *J Epidemiol*. 2024;34(11):543-552.
30. Jeon Y-H, Sansoni J, Low L-F, et al. Recommended measures for the assessment of behavioral disturbances associated with dementia. *Am J Geriatr Psychiatry*. 2011;19(5):403-415.
31. Lai CK. The merits and problems of neuropsychiatric inventory as an assessment tool in people with dementia and other neurological disorders. *Clin Interv Aging*. 2014;9:1051-1061.
32. Yesavage JA, Brink TL, Rose TL, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *J Psychiatr Res*. 1982;17(1):37-49.
33. Marin RS, Biedrzycki RC, Firinciogullari S. Reliability and validity of the Apathy Evaluation Scale. *Psychiatry Res*. 1991;38(2):143-162.
34. Cohen-Mansfield J, Marx MS, Rosenthal AS. A description of agitation in a nursing home. *J Gerontol*. 1989;44(3):M77-84.
35. Ismail Z, Emeremni CA, Houck PR, et al. A comparison of the E-BEHAVE-AD, NBRS, and NPI in quantifying clinical improvement in the treatment of agitation and psychosis associated with dementia. *Am J Geriatr Psychiatry*. 2013;21(1):78-87.
36. Jackson MA, Fauth EB, Geiser C. Comparing the neuropsychiatric inventory and the revised memory and behavior problems checklist for associations with caregiver burden and depressive symptoms. *Int Psychogeriatr*. 2014;26(6):1021-1031.
37. Yuan H, Yang T, Xie Q, Lledos G, Chou W-H, Yu W. Modeling and mobile home monitoring of behavioral and psychological symptoms of dementia (BPSD). *BMC Psychiatry*. 2024;24(1):197.
38. Bao Z, Landers M. Non-pharmacological interventions for pain management in patients with dementia: a mixed-methods systematic review. *J Clin Nurs*. 2022;31(7-8):1030-1040.
39. Gillis K, van Diermen L, Lahaye H, et al. Effect of need-based care on behavioural and psychological symptoms in residents with dementia and formal caregivers' distress in nursing homes: a three-arm cluster randomized controlled trial. *Eur Geriatr Med*. 2023;14(5):1083-1096.
40. Falissard L, Morgand C, Ghosn W, Imbaud C, Bounebache K, Rey G. Neural translation and automated recognition of ICD-10 medical entities from natural language: model development and performance assessment. *JMIR Med Inform*. 2022;10(4):e26353.
41. Shahim B, Xu H, Haugaa K, et al. Cholinesterase inhibitors are associated with reduced mortality in patients with Alzheimer's disease and previous myocardial infarction. *Eur Heart J Cardiovasc Pharmacother*. 2024;10(2):128-136.
42. Xu H, Garcia-Ptacek S, Jönsson L, Wimo A, Nordström P, Eriksdotter M. Long-term effects of cholinesterase inhibitors on cognitive decline and mortality. *Neurology*. 2021;96(17): e2220-e2230.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Jönsson L, Wibom M, Londos E, Nägga K. Person-centered care at population scale: The Swedish registry for behavioral and psychological symptoms of dementia. *Alzheimer's Dement*. 2025;11:e70057. https://doi.org/10.1002/trc2.70057