Validation of a checklist used when searching for possible causes of Behavioural and Psychological Symptoms of Dementia (BPSD) - a study based on the Swedish BPSD registry.

Validering av checklista för tänkbara orsaker till Beteendemässiga och Psykiska Symptom vid Demens (BPSD) – en studie baserad på svenska BPSD-registret.

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Abstract

Background: Swedish healthcare professionals use a special checklist to evaluate possible causes of Behavioural and Psychological Symptoms of Dementia (BPSD). The checklist includes items such as vital parameters and whether basic human needs are met concerning nutrition, sleep, social interactions etc. BPSD frequency and severity can be assessed in the nursing home setting using the Neuropsychiatric Inventory-Nursing Home Version (NPI-NH).

Objective: To evaluate the utility of the checklist, when considering possible causes of BPSD among Swedish nursing home residents.

Methods: BPSD in Swedish nursing home residents (n = 19 553) were evaluated using NPI-NH and the BPSD checklist. NPI-NH domain scores were compared depending on if checklist items were satisfactory or unsatisfactory. Subjects with clinically significant BPSD (NPI-NH domain score > 4) were also studied separately, in relation to the checklist.

Results: When unsatisfactory, most checklist items were associated with significantly higher NPI-NH domain scores. Different from other items, unsatisfactory sleep and social interactions, were associated with several different forms of clinically significant BPSD.

Conclusion: Among Swedish nursing home residents, the checklist seems to be of clinical utility when evaluating possible cause of BPSD. Sleep and social interactions are two check-

list items of special interest, as both are associated with several different forms of clinically significant BPSD. These results might be of interest when writing future versions of the Swedish BPSD checklist, or when developing other BPSD assessment systems.

Populärvetenskaplig sammanfattning

Vid demenssjukdomar utvecklas med tiden ofta symptom och beteenden som innebär en sänkt livskvalitet för den drabbade, och som är svåra att hantera för närstående och vårdpersonal. Dessa går under begreppet Beteendemässiga och Psykiska Symptom vid Demens (BPSD). Till BPSD räknas t ex psykotiska symptom (t ex hallucinationer), men också onaturlig upprymdhet, ilska eller ledsnad. Sömnstörningar och ett planlöst vandrande är andra exempel på BPSD. BPSD är mycket vanligt förekommande, särskilt i ett senare skede av demenssjukdomen.

I svenska BPSD-registret samlas information om hur mycket BPSD personer med demens har, och i vilken form den visar sig (hallucinationer, ilska etc.). Allvarlighetsgraden av BPSD utvärderas av vårdpersonalen med hjälp av mätinstrumentet *Neuropsychiatric Inventory-Nursing Home Version* (NPI-NH). De flesta som är registrerade i BPSD-registret är personer med demens på särskilda boenden. När vårdpersonalen uppmärksammar BPSD hos en person, är det också viktigt att systematiskt utvärdera tänkbara orsaker. Till hjälp används en checklista, där det bl a kontrolleras om personen får sina behov tillgodosedda vad gäller matintag, sömn, social samvaro etc. Man kontrollerar även om det finns något som tyder på kroppslig sjukdom (lågt blodtryck, feber etc.). Det övergripande syftet med BPSD-registret är att det ska fungera som ett arbetsverktyg för vårdpersonal i syfte att sätta in rätt åtgärder och därmed minska BPSD och öka personens livskvalitet.

Anledningen till att man valt just ovan nämnda punkter i checklistan är den kliniska erfarenheten att dessa kan ge upphov till BPSD. Checklistan har dock aldrig utvärderats vetenskap-

ligt, vilket är syftet med denna studie.

Data från 19 553 personer med en demensdiagnos, alla på särskilt boende, ingick i studien. Data angående allvarlighetsgrad av BPSD (uppmätt med NPI-NH) och checkliste-data inhämtades från BPSD-registret. Beräkningar gjordes därefter i syfte att utvärdera checklistan som instrument för att hitta orsaker till BPSD.

Vårt viktigaste fynd är att avvikelser i checklistan generellt sett är kopplade till ökade värden på NPI-NH (ökad BPSD). Detta är statistiskt signifikant. Värt att nämna är att det inte finns några enkla samband mellan ett visst BPSD (t ex onaturlig ilska) och en viss punkt på checklistan (t ex otillräckligt med sömn). Detta tyder på att orsakerna till BPSD är komplexa, och det är viktigt att angripa problemet från flera olika håll.

Två punkter på checklistan – huruvida personen får tillräckligt med sömn och om det finns daglig positiv social samvaro med andra – visade sig vara särskilt intressanta. Avvikelser här var i högre grad än andra punkter förknippade med olika former av BPSD som innebär ett signifikant lidande (engelsk term ’clinically significant’). Det finns många aspekter på både social samvaro och sömn och kanske skulle checklistan kunna förbättras i framtiden genom att dessa preciserades mer noggrant. Det skulle kunna göra det lättare att mer exakt beskriva vad problemet är och sätta in rätt åtgärd.

Av deltagarna visade sig 93.3% ha BPSD, och 65.9% ha BPSD i den grad att det orsakade signifikant lidande. De tre vanligaste BPSD som orsakade signifikant lidande var agitation/

aggression (28.2%), irritabilitet (24.5%) och 28.0% för motorisk rastlöshet (t ex planlöst vandrande). Den höga förekomsten av BPSD är i linje med tidigare forskning.

Sammanfattningsvis visar denna studie på att checklistans punkter är associerade med en rad olika former av BPSD. Den är därför ett värdefullt instrument för vårdpersonalen vid utvärdering av tänkbara orsaker till BPSD. Resultaten från denna studie skulle kunna användas som stöd vid utformandet av framtida versioner av checklistan. Det slutgiltiga målet med all forskning på BPSD, denna studie inkluderad, är att förbättra livskvaliteten för den drabbade och närstående.

Abbreviations

AD, Alzheimer's Disease.

BEHAVE-AD, Behavioral Pathology in Alzheimer's Disease Rating Scale.

BEHAVE-AD-FW, BEHAVE-AD Frequency-Weighted Severity Scale.

BPSD, Behavioural and Psychological Symptoms of Dementia.

CERAD, The Consortium to Establish a Registry for Alzheimer's Disease.

DSD, Delirium Superimposed on Dementia.

NPI, Neuropsychiatric Inventory.

NPI-NH, Neuropsychiatric Inventory-Nursing Home Version.

Introduction

Behavioural and Psychological Symptoms of Dementia (BPSD)

Those afflicted by Alzheimer's disease (AD) and other dementias suffer immensely and the burden of care is significant. As the disease progresses, it is complicated by behavioral and psychological symptoms which decrease the patient's quality of life, and are difficult for healthcare providers to manage. These symptoms are collectively referred to as 'BPSD' (Behavioural and Psychological Symptoms of Dementia (1). BPSD symptoms may arise regardless of the type of dementia and is a common cause of hospital and nursing home admissions (1). BPSD have been described in patients since the days of Alois Alzheimer, but it was not until the 1990s that scientific studies on BPSD were starting to be published. This may reflect a growing interest in this group of elderly, chronically ill individuals, and how they are viewed (1).

BPSD are highly prevalent, both in the outpatient population (2, 3) and in inpatient settings (4-6). In the inpatient setting, Margallo-Lanna et al. (5) have reported depression and delusions to be most common in mild or moderate dementia, while aberrant motor behaviour was highly prevalent in subjects with late-stage dementia. In a study of nursing home residents, Brodaty et al. (4) observed psychotic symptoms in 60%, depressed mood in 42% and activity disturbances or aggression in 82% of subjects. Overall, different forms of BPSD are reported in the inpatient setting at a rate of 90% or more (4, 5).

Rating scales of BPSD

Through the years, many different rating scales have been used to evaluate the degree of BPSD, each differing in symptoms included and how they are quantified. The Consortium to Establish a Registry for Alzheimer's Disease (CERAD) rating scale (7) was developed for patients with AD and includes both symptoms such as apathy, agitation, delusions, and problematic behaviors such as wandering and repetitive questioning. The CERAD rating scale is based on frequency of symptoms, and does not take severity into account. It is based on an interview with an informant who has observed the patient.

Another frequently used scale is the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) (8). The scale was specifically created to evaluate BPSD prevalent in AD, and that are responsive to pharmacological and non-pharmacological intervention. The original BEHAVE-AD does not take frequency of symptoms into account, whereas the newer BEHAVE-AD Frequency-Weighted Severity Scale (BEHAVE-AD-FW) does. Both versions are informant-based. BEHAVE-AD assessments have been used in various clinical trials, with one important result being the efficacy and relative safety of treatment with anti-psychotic medication such as risperidone for certain types of BPSD (8).

The Neuropsychiatric Inventory (NPI) and the modified Neuropsychiatric Inventory-Nursing Home Version (NPI-NH) (9) differ from previously mentioned rating scales as it encompasses a wider variety of symptoms and behaviors, present not only in AD, but in other forms of dementia as well. Psychotic symptoms are included such as delusions and hallucinations, and affective symptoms (agitation, depression, anxiety, apathy, irritability, euphoria). Included are also disinhibition, aberrant motor behavior, night time behavior disturbances, and appetite and eating abnormalities. In the NPI, every type of symptom is scored by frequency and severity,

and a sum is calculated by multiplying frequency *x* severity scores. As Reisberg et al. (8) point out, the NPI differs from the often used BEHAVE-AD in that symptoms such as delusions are not differentiated but treated as a category. This gives a quick estimation of the type of symptoms being present. However, the management of a symptom such as delusions may differ substantially depending on how it presents. Another possible weakness of the NPI is the use of screening questions for different symptoms. Theoretically, BPSD could go unnoticed if the screening question fails to capture symptoms apparent to the observer only when given a more detailed description. Relevant to the present study, the NPI-NH has been validated for the assessment of BPSD among Scandinavian (Norwegian) nursing home residents (10, 11).

Treatment recommendations

Swedish national recommendations have been published on the treatment of BPSD (12, 13). According to the recommendations, symptomatic pharmacological treatment of BPSD should only be commenced after the exclusion of somatic illness as an underlying cause, and the cessation of medication having a negative effect on the central nervous system. In addition, optimization should be made concerning basic needs such as nutrition, sleep, social activity etc. Psycho education of the patient and caregivers also plays a central role in the treatment recommendations. Only after these steps, is it advisable to treat symptoms such as agitation, irritability or psychotic features pharmacologically, and primarily short term if possible. Avoiding the use of neuroleptics decreases the risk of stroke, metabolic disease and total mortality (13). It should also be noted that pharmacological treatment of BPSD in general only has a modest effect (13).

Studying non-pharmacological intervention of BPSD scientifically is difficult. Randomization is hard, since the effect on the intervention group may generalize to the control group, if both groups live in the same nursing home. The high number of participants lost before follow-up due to death, also acts as a confounder (14). Examples of non-pharmacological interventions on BPSD include music therapy, reminiscence, touch therapy and the use of validation (12).

BPSD often can present itself in a chronic, subacute or acute manner. When the onset of symptoms in a patient with dementia is acute, the clinician should always consider somatic illness and delirium superimposed on dementia (DSD) as a possible cause. Differentiating between DSD and dementia with associated BPSD can be very challenging due to their shared features. For example, both Lewy body dementia and DSD can present with hallucinations and fluctuations in cognitive abilities (15). Nevertheless, diagnostic precision is vital, as case reports such as that of Takita et al. (16) illustrate, since delirium demands very quick intervention.

The Swedish BPSD registry

The Swedish national BPSD registry has been in use since year 2010, and is organized by the Memory Clinic, Skåne University Hospital, Malmo, Sweden (registry holder Lennart Minthon) (17). The primary purpose of the registry is to provide healthcare professionals with information that can be used to improve the care of subjects presenting with BPSD. BPSD frequency and severity are evaluated using the NPI-NH. This scale was chosen due to the ease of administration, and the fact that it encompasses a wide variety of BPSD symptoms and not only those typically observed in AD.

In the Swedish BPSD registry, a checklist is used to check for different causes of BPSD, that could be adjusted. Basic needs concerning nutrition, sleep, social life etc. are included, as well as vital parameters, pain assessment and blood glucose. Also, the healthcare professional checks if a structured medical evaluation by a physician has been made. After the assessment of BPSD (using the NPI-NH) and potential causes according to the checklist have been ruled out, the healthcare professional decides on an intervention which may lessen the BPSD. After implementation, the above steps are repeated, evaluating the chosen intervention and if it is necessary to take further action.

The BPSD checklist contains simple items (vital parameters, blood glucose etc.) screening for acute somatic illness. Other items are more complex. These include the structured medical evaluation by a physician (recommended by the Swedish National Board of Health and Welfare (13)), and if the person has enough daily meaningful social interactions. BPSD checklist items were initially chosen based on the clinical experiences of healthcare professionals experienced in dementia. While the BPSD checklist has been in use for many years, it has never been validated scientifically. As has been discussed, BPSD is highly prevalent (especially in the inpatient setting) and an important cause of decrease in patient's quality of life and increased burden of care. It is therefore important to evaluate an instrument such as the BPSD checklist, as this may lead to future improvements in dementia care. A focus on different causes of BPSD is also warranted, considering the lack of research on the subject.

The primary aim of this study is to evaluate the checklist in its current form as a working tool used by Swedish healthcare professionals to screen for possible causes of BPSD. In the present study we will also explore possible improvements of the checklist and its items. A

special focus will be on BPSD that is severe and frequent enough to be of clinical significance. Prevalence of different forms of BPSD will be explored and compared with previous research.

Methods

The present study is cross-sectional with a focus on BPSD in Swedish nursing home residents. Subject data was included from the Swedish BPSD registry between year 2010 and 2015 (n = 28 215). Only subjects with a physician's diagnosis of dementia were included (n = 21 851). After the exclusion of subjects not living in a nursing home (n = 2298), 19 553 individuals remained.

In healthcare facilities which take part in the Swedish BPSD registry, all residents with a diagnosis of dementia (which may or may not be confirmed by a physician) are registered. At least one healthcare professional at every healthcare facility has attended a two-day course, in order to assure correct use of the BPSD registry.

BPSD severity and frequency were evaluated using the NPI-NH (9) by a healthcare professional with experience in dementia (a nurse or an auxiliary nurse). The NPI-NH contains 12 domains (see figure 1), each rated by frequency (1 – 4 points) and severity (1 – 3 points). The domain score is calculated by multiplying the frequency and severity scores. A NPI-NH total score, all domains, is calculated by adding all domain scores. NPI domain scores are interpreted as being 'clinically significant' if above 4. This threshold is based on previous research

(2, 18) and although somewhat arbitrary, makes dichotomization and group comparisons possible. The NPI-NH has been validated in a Scandinavian (Norweigan) nursing home setting (10) and unpublished data also indicate high validity and inter-rater reliability of the translated Swedish version of the NPI-NH (19).

Possible causes of BPSD are evaluated using the BPSD checklist by a nurse or an auxiliary nurse. Checklist items are scored in a binary fashion, either being satisfactory or unsatisfactory. These include daily food and fluids intake and if the person gets enough sleep. Also, urine and faeces are evaluated for abnormalities. Furthermore, it is assessed whether sight and hearing (with or without aid) is satisfactory, along with social interactions. Social interactions are only recorded as satisfactory if there are daily meaningful social interactions. It is left to the rater of the NPI-NH to interpret the word ’meaningful’. Body temperature, pulse rate, blood pressure, respiratory rate, and blood glucose levels are rated as normal or abnormal. Finally, it is noted whether a structured physician’s evaluation of present medication, possibly causing BPSD, has been made. Presence of pain is also an item used in the checklist. However, the pain checklist item will have been studied separately and is therefore not included in the present study. Checklist items have not been validated previously.

Statistics

Statistical analyses are made using IBM SPSS Statistics v. 23. Descriptive statistics are used for quantitative presentation of the data.

NPI-NH total score, all domains, are compared depending on the number of unsatisfactory checklist items. This is done in order to check for possible additive effects on NPI-NH total

score, all domains, of the different checklist items. More advanced calculations checking for additive effects of checklist items are outside the scope of this study.

In order to assess the clinical utility of the checklist, mean NPI-NH domain scores are compared based on satisfactory or unsatisfactory answers to the checklist items. Also, the relationships between checklist items and clinically significant or insignificant NPI-NH domain scores are assessed using Pearson Chi Square, with Yates Continuity Correction due to expected cell count less than 5 in some of the cases.

Nonparametric statistics are used since NPI scores are unlikely to be normally distributed, and domain score values are non-continuous (20). Since nonparametric data is used, group differences are compared using Mann-Whitney U-test and differences between multiple groups are evaluated using Kruskal-Wallis.

Statistical significance is set to $p < 0.05$.

Ethics

The Swedish BPSD registry contains personal information about subjects presenting with BPSD and is used by healthcare professionals as a working tool to try to lessen symptoms. According to Swedish law on national registries, the subject has the right to object to data registration, and may at any time request deletion of data already registered. Due to cognitive impairment, subjects may not have the ability to make these decisions, and he or she may therefore use a legal representative. Every time data from the Swedish BPSD registry is used

for scientific purposes, an evaluation is made to make sure that this does not do harm to the person in any way (offentlighets- och sekretesslagen). The use of coded BPSD registry data for research purposes, such as in the present study, have also been approved by an ethics committee. Following all these rules allows for scientific study of BPSD (which has the possibility to improve future care of persons presenting with BPSD), while at the same time protecting the person's integrity. Possible consequences of participation in the BPSD registry short- and long-term should be explained to the person, and also the fact that information may be used in future studies, in ways that at present cannot be described in detail.

All information given to the person should be as easy to understand as possible, and adjusted to his or her cognitive abilities. This can be a challenging task considering the complex nature of the data used in the registry. Transparency is vital though, since it is only on the information given to the person that he or she understands, that he or she can use to make an informed decision whether to participate or not participate in the BPSD registry.

Results

Demographic data and subjects by dementia diagnosis is shown in table 1.

Data on BPSD prevalence is presented in table 2 and illustrated in figure 1. BPSD was present (NPI-NH total score, all domains > 0) in 93.3% of subjects, and 65.9% of subjects had clini-

cally significant BPSD (NPI-NH domain score > 4 on one or more NPI-NH domains). Clinically significant euphoria was only reported in 4.5% of subjects. Euphoria excluded, the percentage of clinically significant BPSD in the subjects ranged from 10.9% for hallucinations to 28.2% for agitation/aggression. The percentage of BPSD present (NPI-NH total score, all domains > 0), that was also clinically significant ranged from 32% for euphoria to 62% for aberrant motor behavior.

Checklist items were satisfactory at a high degree, ranging from 82.1% for structured medical evaluation, to 98% for body temperature (see table 3).

NPI-NH total score, all domains increased in a stepwise fashion, according to how many checklist items that were unsatisfactory (see table 4). These group differences in NPI-NH total scores, all domains, were statistically significant ($H(4) = 1622$, $p < 0.001$) (see figure 2). Significance of group differences (data not shown) was also confirmed using ad hoc Mann-Whitney U-tests, comparing groups two by two in ascending order, according to the number of unsatisfactory checklist items. Differences in NPI domain scores, depending on number of unsatisfactory checklist items, were also assessed for each NPI-NH domain individually. Kruskall-Wallis testing (data not shown) showed highly statistically significant group differences ($p < 0.001$) for all domains.

Most items in the checklist had significantly different mean NPI-NH domain scores depending on if the item was satisfactory or unsatisfactory (see table 5A-5C). Notable exceptions were body temperature and if a structured medical evaluation had been done. For these two

items many group differences in mean NPI-NH domain scores were insignificant. Similarly, in regards to NPI-NH total scores, all domains, differences were significant for all checklist items except body temperature and structured medical evaluation (see table 5A-5C).

Mean NPI-NH domain scores were, as expected, higher in almost all cases when a checklist item was unsatisfactory compared to when satisfactory (see table 5A-5C). Exceptions were abnormal urine (lower score on 'appetite and eating change'), impaired hearing (lower score on 'euphoria'), abnormal blood glucose level (lower score on 'aberrant motor behavior') and structured medical evaluation which, when not done, was associated with lower scores on 'delusions', 'hallucinations', 'agitation/aggression', 'apathy' and 'irritability'.

Finally, worth noting is the fact that when sleep and social interactions were unsatisfactory, mean NPI-NH domain scores were not only higher but also clinically significant for several domains (see table 5A-5C, highlighted in gray). This was not seen as clearly with other items in the checklist.

Focusing on relationships between checklist items and clinically significant or insignificant NPI-NH domain scores (see table 6A-6C), most items were, when unsatisfactory, associated with clinically significant NPI-NH scores on many or most domains. Notable exceptions to this were body temperature and structured medical evaluation.

Discussion

This study has for the first time scientifically evaluated a checklist used in Swedish nursing homes and other healthcare settings, for the evaluation of possible causes of BPSD. There is no previous research on checklists used to screen for causes of BPSD. Our results suggest this

checklist to be of high clinical utility, differentiating between BPSD of clinical significance and milder forms of BPSD. Possible improvements in future versions of the checklist are discussed below.

A high percentage of this study population of subjects with dementia living in nursing homes, presented with BPSD. This is in accordance with previous research (4, 5). The three most common clinically significant BPSD were agitation/aggression (28.2%), irritability (24.5%), and aberrant motor behavior (28%). High prevalence of activity disturbances and aggression in nursing home residents has been reported previously (4). One might ask, if there could be a tendency to under-report other symptoms than these, that are not as burdensome and hard to handle for healthcare professionals. However, also more easily handled symptoms such as apathy were reported at a high degree in our study population. A large proportion of the BPSD reported in this study are clinically significant, indicating an obvious need to try to find possible causes of the BPSD, in order to improve the quality of life of the patient.

As in previous research (3, 21), euphoria is reported in only a small percentage of the population, possibly reflecting the fact that this symptom is not a core part of AD or other common dementias.

Concerning checklist results, the frequency of satisfactory checklist answers are high, ranging from 81.1% (structured medical evaluation has been done) to 98 % (body temperature is normal). Also, 33.6% of subjects do not have a single item on the checklist that is unsatisfactory. These are positive findings, considering that this study population consists of older subjects, with probable late-stage dementia and a high degree of comorbidities.

As the checklist is used as a working tool by healthcare professionals, it would be ideal and make interventions very straight-forward if certain checklist items could be linked to specific types of BPSD. However, it is clear from our results that the relationships between checklist items and BPSD are much more complex. Checklist items (body temperature and structured medical evaluation excluded) are linked to a wide variety of BPSD, stressing the fact that BPSD is a complex construct and one should not expect to find simple cause and effect-relationships. This is further demonstrated by the fact that for every additional checklist item that is unsatisfactory, the mean NPI-NH total score, all domains is increasing, possibly indicating an additive effect on BPSD frequency and severity between different checklist items.

Overall, the checklist items seem to be of high clinical relevance since they discriminate between milder BPSD and clinically significant BPSD, on many or most of the NPI-NH items. Exceptions are again body temperature and structured medical evaluation. This is very interesting since structured medical evaluation by a physician has been emphasized in the management of BSPD by the Swedish National Board of Health and Welfare (13).The reasoning is that this might avoid unnecessary polypharmacy and other inappropriate medication use (common in patients with dementia (22)) which may affect cognition or behavior negatively. One example of inappropriate medication is the overuse of benzodiazepines and anticholinergics (23). While, for the above mentioned reasons, it cannot be denied that a structured medical evaluation is vital in certain cases, looking at this group of Swedish nursing home residents, whether a performed structured medical evaluation have been made or not does not seem to be a very important factor in clinically significant BPSD.

Concerning checklist item ‘body temperature’, there are no significant mean differences in NPI-NH domain scores between subjects with normal or abnormal answers. Also, mean differences are small (data not shown). Thus, one might consider removing item ‘body temperature’ in future versions of the checklist, since it does not seem to be a major cause of BPSD in this study population. If the aim is to keep the checklist short and easy to administer, another item (or rather sub item) that could be excluded is ‘unstable blood glucose’, since this is only reported for 0.015% (n = 3) of subjects.

Looking at mean NPI-NH domain scores based on checklist items, and significances of between-group differences., one can discern a pattern where subjects with unsatisfactory ’enough sleep’ or ’social interactions’ – contrary to other checklist items - seem to present with *several* BPSD symptoms that are clinically significant, compared to when checklist items are satisfactory. In a cross-sectional study like this, it is hard to say anything about cause and effect, but it may very well be the case that sleep and social interactions are more important than other factors as underlying causes of BPSD. Future studies should explore this in more detail. Both ’enough sleep’ and ’social interactions’ are complex items and it might be necessary in future versions of the checklist to be more specific in order to pinpoint what exactly might be causing the BPSD observed. For example ‘social interactions’ could be broken down into smaller components; ”Are meaningful social interactions happening many times per day?”, “Are there some days *without* meaningful social interactions”?, ”Are social interactions validating?” etc.

Body temperature, pulse, blood pressure, respiratory rate and blood glucose levels do not

seem to be as useful as other items when differentiating between mild and clinically significant BPSD. Group differences for various BPSD symptoms are often not significant for these items. These factors all have in common that they more often come into play in patients with acute deterioration of BPSD (i.e. delirium). A possible hypothesis for the lack of significant correlations is that the BPSD seen in this material is of a more chronic or subacute nature, and therefore markers of acute somatic illness are not as useful. Still, it cannot be denied that these items are important for a subset of individuals, alerting the healthcare professional to acute illness demanding quick intervention. Unfortunately, more detailed analysis of BPSD, based on acute or chronic presentation, is not possible since data on how long the person has presented with BPSD is not available.

The strength of this study is the very high number of participants (n = 19 553) and unreported variable data generally less than 3%. This gives statistical power to the results in this study. The broad inclusion criteria used in this study can both be viewed as a strength and a weakness. No specific conclusions concerning various diseases of dementia can be drawn, since a large percentage of subjects had an unspecified (23.7%) type of dementia. On the other hand, the inclusion criteria used herein allowed for study of BPSD in a broader context, and this is in line with how the term BPSD was first defined; behavioral and psychological symptoms of dementia which the person may present with regardless of dementia etiology.

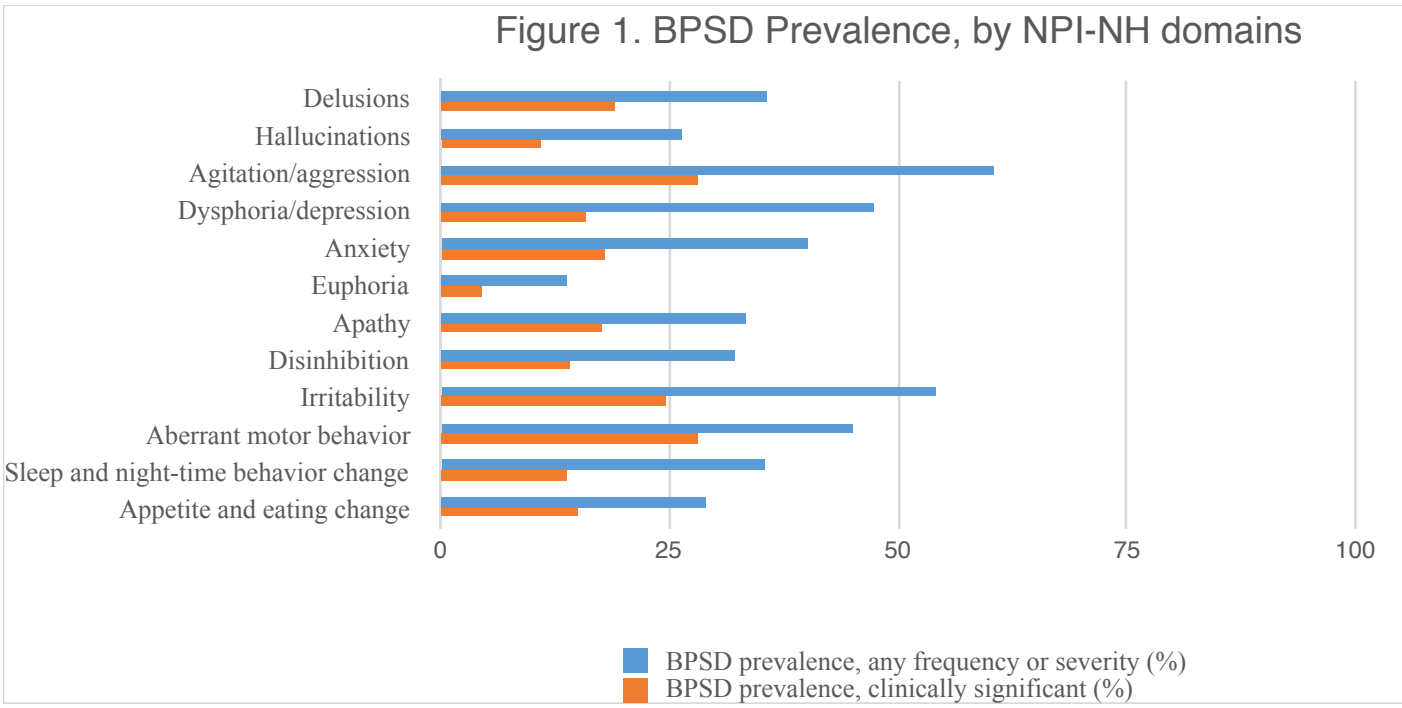
This study is cross-sectional, and future interventional studies would have to be made, in order to evaluate the checklist in detail. We make the assumption that unsatisfactory checklist items (eg. ‘not enough sleep’) is causing BPSD, however, BPSD symptoms such as agitation

may in itself be a cause of sleep disturbances. Also, different variables may interplay in a more complex manner, not possible to describe using only correlational analyses such as in the present study.

Conclusions

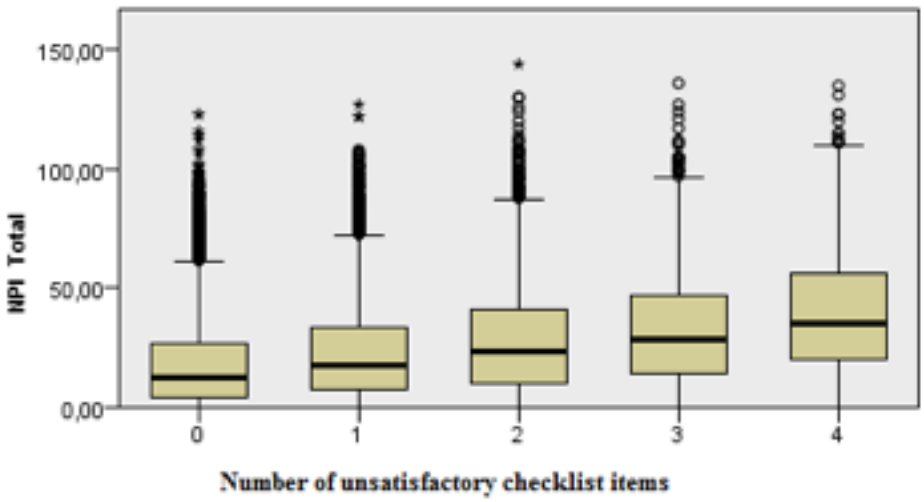
In this study of Swedish nursing home residents, we have reported a high prevalence of BPSD. When evaluating BPSD causes, the registry checklist described in this study seems to be of clinical utility as most of the items can be linked to different forms of clinical BPSD. Different from other checklist items, social interactions and sleep seem be linked to a wider variety of clinically significant BPSD. As these two items are complex, the checklist might be improved by breaking these items down into subunits, thereby making it easier to identify the problem, and to choose the correct intervention. The results of this study may be used to improve future care of persons with dementia in Swedish nursing homes.

Figure legends



BPSD prevalence, by NPI-NH domains, all subjects. NPI-NH; Neuropsychiatric Inventory-Nursing Home Version; Clinically significant BPSD, NPI-NH domain score > 4.

Figure 2. NPI-NH total score, all domains, depending on number of unsatisfactory checklist items.



NPI-NH total score, all domains, depending on number of unsatisfactory checklist items. Numbers on X-axis indicate the number of unsatisfactory checklist items (‘4’ indicates 4 or more unsatisfactory checklist items). Outliers are marked separately, outside of box plots.

Table 1. Demograhics and subjects by dementia diagnosis.

Demographics:	*n* = 19 553
Gender (% males)	33.4%
Age, years ± std dev	83.32 ± 7.64
Subjects by dementia diagnosis:	
Alzheimer's disease	40.9%
Vascular dementia	18.9%
Mixed dementia	10.7%
Lewy body dementia	1.7%
Parkinsons's disease dementia	1.7%
Frontotemporal dementia	2.3%
Dementia, Not Otherwise Specified (NOS)	23.7%

Demographics and subjects by dementia diagnosis. std dev, standard deviation.

Table 2. BPSD prevalence by NPI-NH domains

	BPSD present (%)	Clinically significant BPSD (%)	BPSD present that is clinically significant (%)
Delusions	35,6%	19,1%	54%
Hallucinations	26,3%	10,9%	41%
Agitation/aggression	60,5%	28,2%	47%
Dysphoria/depression	47,4%	15,8%	33%
Anxiety	40,1%	18%	45%
Euphoria	13,9%	4,5%	32%
Apathy	33,4%	17,6%	53%
Disinhibition	32,3%	14%	43%
Irritability	54,1%	24,5%	45%
Aberrant motor behavior	44,9%	28%	62%
Sleep and night-time behavior change	35,5%	13,8%	39%
Appetite and eating change	28,9%	15%	52%
All categories	93.3%	65.9%	-

BPSD prevalence by NPI-NH domains, all subjects. NPI-NH; Neuropsychiatric Inventory-Nursing Home Version; BPSD present (%), NPI-NH domain score > 0; Clinically significant BPSD (%), NPI-NH domain score > 4.

Table 3. Descriptive data on checklist items.

Checklist item:	Satisfactory (%) *n* = 19 553	Unsatisfactory (%) *n* = 19 553	Unreported (%) *n* = 19 553
Nutrition (food)	86.2%	12.4 %	1.3 %
Nutrition (fluids)	88.9%	9.7 %	1.3%
Enough sleep	84.2%	14.4%	1.4%
Normal urine	93.1%	5.5%	1.4%
Normal faeces	88.3%	10.3%	1.4%
Sight	82.1%	15.5%	1.3%
Hearing	82.6%	16.1%	1.3%
Social interactions	91.1%	7.5%	1.4%
Body temperature	98%	0.2%	1.8%
Pulse	96.3%	1.7%	2.0%
Blood pressure	90.1%	7.7%	2.1%
- hypertensive	-	3.6%	-
- hypotensive	-	3.1%	-
- orthostatic hypotension	-	1.0%	-
Respiratory rate	94.6%	3.5%	1.8%
Blood glucose level	93.6%	4.3%	2.1%
- hyperglycemic	-	3.9%	-
- hypoglycemic	-	0.3%	-
- unstable	-	0.015%	-
Structured medical evaluation	81.1%	17.0%	2.0%

Descriptive data on checklist items.

Table 4. NPI-NH total score, all domains depending on number of unsatisfactory checklist items.

	N (%)	Mean NPI-NH total score, all domains (std dev)
0 checklist items unsatisfactory	6564 (33.6%)	18.04 (18.53)
1 checklist items unsatisfactory	5817 (29.7%)	22.49 (20.45)
2 checklist items unsatisfactory	3484 (17.8%)	27.73 (22.63)
3 checklist items unsatisfactory	1761 (9.0%)	32.79 (24.27)
4 or more checklist items unsatisfactory	1397 (7.1%)	39.64 (25.68)
Checklist items unreported	530 (2.7%)	-

NPI-NH total score, all domains depending on number of unsatisfactory checklist items. NPI-NH, Neuropsychiatric Inventory-Nursing Home Version; std dev, standard deviation.

Table 5A. Mean NPI-NH domain scores based on checklist items, and significances of between-group differences.

	Nutrition (food)	Nutrition (fluids)	Enough sleep	Urine	Faeces
Delusions	2.00/2.53 ***	2.03 / 2.36 *	1.84/3.40 ***	2.04 /2.54 ***	2.02 / 2.46 ***
Hallucinations	1.26/1.73 ***	1.28 / 1.75 ***	1.16/2.24 ***	1.30 / 1.69 ***	1.27 / 1.73 ***
Agitation/aggression	3.05/4.30 ***	3.11 / 4.10 ***	2.96/4.68 ***	3.16 /4.03 ***	3.12 / 3.99 ***
Dysphoria/depression	1.87/2.84 ***	1.92 / 2.67 ***	1.82 /2.97 ***	1.96 /2.46 ***	1.93 / 2.54 ***
Anxiety	2.03/2.88 ***	2.07 /2.08 ***	1.85 /3.80 ***	2.10 / 2.81 ***	2.07 / 2.76 ***
Euphoria	0.54/0.60 **	0.55 /0.59 **	0.51 /0.80 ***	**n.s.**	0.54 / 0.68 ***
Apathy	1.74 / 3.37 ***	1.77 /3.60 ***	1.91/2.17 ***	1.90 /2.81 ***	1.84 / 2.88 ***
Disinhibition	1.57 / 2.27 ***	1.63 /1.95 **	1.51 /2.53 ***	1.63 /2.06 ***	1.60 / 2.17 ***
Irritability	2.66 /3.69 ***	2.71 / 3.46 ***	2.55 / 4.17 ***	2.75 /3.37 ***	2.71 / 3.42 ***
Aberrant motor behavior	2.98 /3.59 **	2.99 /3.72 ***	2.63 / 5.54 ***	3.03 /3.63 ***	3.01 / 3.15 ***
Sleep and night-time behavior change	1.68 / 2.15 ***	1.71 / 1.95 **	0.85 / 6.94 ***	1.68 /2.62 ***	1.69 / 2.13 ***
Appetite and eating change	1.04 / 6.55 ***	1.41 /4.71 ***	1.61 / 2.42 ***	1.68 /2.60 ***	1.60 / 2.85***
NPI-NH total score, all domains	22.36 / 36.37 ***	23.10 / 33.50 ***	21.14 / 41.52 ***	23.71 / 31.05 ***	23.32 / 30.99 ***

Mean NPI-NH domain scores based on checklist items, and significances of between-group differences. Means for subjects with satisfactory checklist item answers are reported first, thereafter means for subjects with unsatisfactory checklist item answers. Mann-Whitney U-test significances reported in asterisks. Items where unsatisfactory checklist item answer have mean NPI-NH domain scores above 4 (clinically significant BPSD) are highlighted in gray. NPI-NH, Neuropsychiatric Inventory-Nursing Home Version; n.s., not significant; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 5B (continued). Mean NPI-NH domain scores based on checklist items, and significances of between-group differences.

	Sight	Hearing	Social interactions	Body temperature	Pulse
Delusions	1.97 / 2.54 ***	1.99 / 2.44 ***	1.99 / 2.97 ***	**n.s.**	2.05/2.74 **
Hallucinations	1.18 / 2.05 ***	1.28 / 1.55 ***	1.25 / 2.16 ***	**n.s.**	**n.s.**
Agitation/aggression	3.14 / 3.56 ***	**n.s.**	3.06 / 5.02 ***	**n.s.**	**n.s.**
Dysphoria/depression	1.94 / 2.24 ***	**n.s.**	1.88 / 3.34 ***	**n.s.**	1.98/2.65 **
Anxiety	2.05 / 2.59 ***	**n.s.**	2.04 / 3.36 ***	**n.s.**	2.12/3.12 ***
Euphoria	0.54 / 0.59 *	0.57 / 0.48 *	0.53 / 0.76 ***	**n.s.**	**n.s.**
Apathy	1.87 / 2.35 ***	**n.s.**	1.76 / 4.29 ***	**n.s.**	1.93/2.52 **
Disinhibition	**n.s.**	**n.s.**	1.55 / 2.95 ***	**n.s.**	1.65/2.19 *
Irritability	2.72 / 3.12 ***	**n.s.**	2.64 / 4.52 ***	**n.s.**	2.77/3.36 *
Aberrant motor behavior	2.99 / 3.41 ***	**n.s.**	2.97 / 4.08 ***	**n.s.**	**n.s.**
Sleep and night-time behavior change	1.65 / 2.15 ***	1.68 / 2.00 ***	1.68 / 2.48 ***	**n.s.**	1.72/2.56 ***
Appetite and eating change	1.69 / 1.94 ***	1.70 / 1.90 ***	1.63 / 3.01 ***	**n.s.**	1.72/2.29 *
NPI-NH total score, all domains	23.31 / 28.20 ***	23.84 / 25.57 ***	22.92 / 38.77 ***	**n.s.**	23.97 / 30.26***

Mean NPI-NH domain scores based on checklist items, and significances of between-group differences. Means for subjects with satisfactory checklist item answers are reported first, thereafter means for subjects with unsatisfactory checklist item answers. Mann-Whitney U-test significances reported in asterisks. Items where unsatisfactory checklist item answer have mean NPI-NH domain scores above 4 (clinically significant BPSD) are highlighted in gray. NPI-NH, Neuropsychiatric Inventory-Nursing Home Version; n.s., not significant; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 5C (continued). Mean NPI-NH domain scores based on checklist items, and significances of between-group differences.

	Blood pressure	Respiratory rate	Blood glucose level	Structured medical evaluation
Delusions	2.03/2.44 ***	**n.s.**	**n.s.**	2.08/1.98 **
Hallucinations	1.30/1.58 **	**n.s.**	**n.s.**	1.34/1.22 ***
Agitation/aggression	**n.s.**	**n.s.**	**n.s.**	3.22/3.12 **
Dysphoria/depression	1.96/2.30***	1.97/2.39 ***	1.98/2.30 *	**n.s.**
Anxiety	2.10/2.49***	2.10/2.99 ***	**n.s.**	**n.s.**
Euphoria	**n.s.**	**n.s.**	**n.s.**	**n.s.**
Apathy	**n.s.**	1.93/2.46 ***	1.93/2.24**	1.97/1.82 ***
Disinhibition	1.64/1.91*	1.65/1.99 *	1.65/1.97*	**n.s.**
Irritability	2.76/3.05**	2.77/3.23 ***	2.76/3.25***	2.80/2.71 *
Aberrant motor behavior	**n.s.**	**n.s.**	3.07/2.68**	**n.s.**
Sleep and night-time behavior change	1.71/1.98**	1.71/2.25 ***	1.72/2.09***	**n.s.**
Appetite and eating change	1.70/2.07**	1.70/2.54 ***	1.71/2.20***	**n.s.**
NPI total score, all domains	23.83 / 26.94***	23.93 / 28.07 ***	23.99 / 26.42**	**n.s.**

Mean NPI-NH domain scores based on checklist items, and significances of between-group differences. Means for subjects with satisfactory checklist item answers are reported first, thereafter means for subjects with unsatisfactory checklist item answers. Mann-Whitney U-test significances reported in asterisks. Items where unsatisfactory checklist item answer have mean NPI-NH domain scores above 4 (clinically significant BPSD) are highlighted in gray. NPI-NH, Neuropsychiatric Inventory-Nursing Home Version; n.s., not significant; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 6A. Relationships between checklist items and clinically significant or insignificant NPI-NH domain scores.

	Nutrition (food)	Nutrition (fluids)	Enough sleep	Urine	Faeces
Delusions	36.16***	8.79**	424.45***	17.88***	21.33***
Hallucinations	46.28***	29.87***	265.39***	13.35***	37.91***
Agitation/aggression	165.39***	73.71***	401.38***	38.29***	54.51***
Dysphoria/depression	141.26***	75.80***	272.33***	22.29***	45.47***
Anxiety	111.03***	65.88***	602.89***	28.77***	55.43***
Euphoria	**n.s.**	**n.s.**	40.06***	**n.s.**	9.22**
Apathy	354.09***	352.30***	13.44***	62.71***	121.28***
Disinhibition	74.33***	11.16***	201.07***	13.13***	39.24***
Irritability	122.92***	62.37***	374.89***	21.23***	51.85***
Aberrant motor behavior	30.69***	34.46***	936.19***	20.33***	20.48***
Sleep and night-time behavior change	43.84***	15.05***	6816.45***	63.53***	24.02***
Appetite and eating change	4852.53***	1343.34***	101.67***	56.07***	175.14***

Relationships between checklist items and clinically significant or insignificant NPI-NH domain scores. Checklist items are satisfactory or unsatisfactory. NPI-NH domain scores are dichotomized, being either clinically significant (NPI-NH domain score > 4) or clinically insignificant (NPI-NH domain score < 4).
Pearson Chi Square with Yates Continuity correction is used. Continuity correction values are reported. NPI-NH, Neuropsychiatric Inventory-Nursing Home Version; n.s., not significant; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 6B (continued). Relationships between checklist items and clinically significant or insignificant NPI-NH domain scores.

	Sight	Hearing	Social interactions	Body temperature	Pulse
Delusions	49.91***	28.28***	75.41***	**n.s.**	14.88***
Hallucinations	152.18***	22.96***	89.02***	**n.s.**	**n.s.**
Agitation/aggression	15.91***	7.14**	258.17***	**n.s.**	6.63**
Dysphoria/depression	13.91***	**n.s.**	212.83***	**n.s.**	13.39***
Anxiety	53.74***	6.85**	155.85***	**n.s.**	11.61***
Euphoria	**n.s.**	**n.s.**	16.15***	**n.s.**	**n.s.**
Apathy	27.89***	**n.s.**	521.68***	**n.s.**	7.63**
Disinhibition	**n.s.**	**n.s.**	221.67***	**n.s.**	10.96***
Irritability	27.92***	**n.s.**	250.44***	**n.s.**	**n.s.**
Aberrant motor behavior	19.55***	**n.s.**	66.44***	**n.s.**	4.10*
Sleep and night-time behavior change	50.76***	16.24***	65.14***	**n.s.**	17.09***
Appetite and eating change	6.78**	5.58*	180.36***	4.17*	3.93*

Relationships between checklist items and clinically significant or insignificant NPI-NH domain scores. Checklist items are satisfactory or unsatisfactory. NPI-NH domain scores are dichotomized, being either clinically significant (NPI-NH domain score > 4) or clinically insignificant (NPI-NH domain score < 4).
Pearson Chi Square with Yates Continuity correction is used. Continuity correction values are reported. NPI-NH, Neuropsychiatric Inventory-Nursing Home Version; n.s., not significant; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 6C (continued). Relationships between checklist items and clinically significant or insignificant NPI-NH domain scores.

	Blood pressure	Respiratory rate	Blood glucose level	Structured medical evaluation
Delusions	16.18***	**n.s.**	**n.s.**	**n.s.**
Hallucinations	10.39***	**n.s.**	**n.s.**	**n.s.**
Agitation/aggression	5.58*	**n.s.**	7.00**	**n.s.**
Dysphoria/depression	10.29***	4.78*	9.66**	**n.s.**
Anxiety	8.29**	26.06***	**n.s.**	**n.s.**
Euphoria	**n.s.**	**n.s.**	**n.s.**	4.84*
Apathy	**n.s.**	11.70**	6.56**	**n.s.**
Disinhibition	10.94***	5.80*	6.71**	6.19*
Irritability	6.86**	5.85*	14.99***	**n.s.**
Aberrant motor behavior	**n.s.**	**n.s.**	6.44**	**n.s.**
Sleep and night-time behavior change	6.00*	13.56***	11.45***	**n.s.**
Appetite and eating change	7.80**	21.90***	8.81**	**n.s.**

Relationships between checklist items and clinically significant or insignificant NPI-NH domain scores. Checklist items are satisfactory or unsatisfactory. NPI-NH domain scores are dichotomized, being either clinically significant (NPI-NH domain score > 4) or clinically insignificant (NPI-NH domain score < 4).
Pearson Chi Square with Yates Continuity correction is used. Continuity correction values are reported. NPI-NH, Neuropsychiatric Inventory-Nursing Home Version; n.s., not significant; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

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