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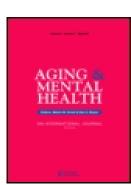
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Natural course of neuropsychiatric symptoms in nursing home patients with mental-physical multimorbidity in the first eight months after admission

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ABSTRACT

Objective: Aging societies will bring an increase in the number of long-term care patients with mental-physical multimorbidity (MPM). This paper aimed to describe the natural course of neuropsychiatric symptoms (NPS) in patients with MPM in the first 8 months after admission to a geronto-psychiatric nursing home (GP-NH) unit.

Methods: Longitudinal cohort study among 63 patients with MPM no dementia living in 17 GP-NH units across the Netherlands. Data collection consisted of chart review, semi-structured interviews, and brief neuropsychological testing, among which our primary outcome measure the Neuropsychiatric Inventory (NPI). Descriptive and bivariate analyses were conducted.

Results: Our study showed a significant increase of the NPI total score (from 25.3 to 29.3, p = 0.045), and the total scores of a NPI hyperactivity cluster (from 9.7 to 11.8, p = 0.039), and a NPI mood/apathy cluster (from 7.7 to 10.1, p = 0.008). Just over 95% had any clinically relevant symptom at baseline and/or six months later, of which irritability was the most prevalent and persistent symptom and the symptom with the highest incidence. Hyperactivity was the most prevalent and persistent symptom cluster. Also, depression had a high persistence.

Conclusions: Our results indicate the omnipresence of NPS of which most were found to be persistent. Therefore, we recommend to explore opportunities to reduce NPS in NH patients with MPM, such as creating a therapeutic milieu, educating the staff, and evaluating patient's psychotropic drug use.

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Cohort study: geriatric psychiatry; long-term care; multimorbidity; neuropsychiatric symptoms: nursing homes; psychotropic drug use

Introduction

A nursing home (NH) is a facility with a domestic-styled environment that provides 24-hour care for persons who require assistance with activities of daily living and who often have complex health needs due to physical as well as psychosocial vulnerability (Sanford et al., 2015).

Nowadays, NHs are faced with a growing number of patients with mental-physical multimorbidity (MPM). On the one hand, this is caused by the increasing number of elderly people with MPM that results from the rising number of elderly people in our society and MPM being common in older people (Schram et al., 2008; Singh, 2010). On the other hand, in recent decades the total number of psychiatric hospital beds has decreased dramatically (Novella, 2010). Since then, NHs have partly taken over the traditional asylum function of psychiatric hospitals (Bartels, Miles, Dums, & Levine, 2003).

Long-term care (LTC) patients with MPM constitute a heterogeneous group. Compared to other LTC patients, patients with MPM are more likely to be younger, male and unmarried and more often have cognitive impairment no dementia and neuropsychiatric symptoms (NPS) (van den Brink, Gerritsen, Voshaar, & Koopmans, et al., 2013). Recent studies in Dutch NHs confirmed these results and also showed that clinically relevant NPS were highly prevalent in MPM patients with and without dementia as well as chronic psychiatric and physical disorders and associated medication use (Collet, de Vugt, Verhey, Engelen, & Schols, 2018; van den Brink, Gerritsen, de Valk, Oude Voshaar, & Koopmans, 2017).

In the Netherlands, many NHs focus on specializing their care to specific patient groups, among others those with MPM. Most of these NHs house patients with MPM on separate units, so-called geronto-psychiatric nursing home (GP-NH) units, in contrast with among others psycho-geriatric (dementia special care) and somatic units. The care needs of NH patients with MPM differ from the traditional patients in nursing homes having primarily dementia and/or physical multimorbidity (van den Brink, Gerritsen, Oude Voshaar, & Koopmans, 2014; van den Brink et al., 2018; Wieczorowska-Tobis et al., 2016). In this way, Dutch nursing homes aim to provide the most appropriate care-environment, knowing that care that is not tailored to the needs and preferences of a patient can have a negative influence on NPS (Bakker et al., 2014; Slade, Leese, Cahill, Thornicroft, & Kuipers, 2005; White et al., 1997). However,

research on how these patients fare after admission to a GP-NH unit is lacking.

Studies investigating the course of NPS and associated determinants have mainly focused on people with dementia. These studies, that were conducted in various settings, showed that an increase of NPS was associated with a decline in cognitive functioning, and with the use of psychotropic drugs and the level of NPS at baseline (Aalten, de Vugt, Jaspers, Jolles, & Verhey, 2005; Brodaty, Connors, Xu, Woodward, & Ames, 2015; Selbaek, Engedal, Benth, & Bergh, 2014; Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010). In a study in patients with young-onset dementia, high levels of unmet needs and higher education were associated with an increase of NPS over time (Bakker et al., 2014).

Also in patients with MPM no dementia, NPS are a substantial challenge for their carers (van den Brink et al., 2017). Knowledge about the prevalence and course of NPS in these patients is important for being able to plan and realize adequate care in a supportive environment, to arrange the necessary staff education, and to inform patients and their families about prognosis and treatment approaches.

Therefore, the aim of this study is to describe the change in NPS over the first eight months of institutionalization at a GP-NH unit and associations with change in NPS between two measurements in this period. Since changes in psychotropic drug use (PDU) could have an impact on NPS, we also describe PDU and its changes.

Methods

The MAPPING study (patients with both Mental And Physical Problems residing In Dutch NursinG homes) is a cohort study with a follow up of six months. The design of the MAPPING study has been described extensively elsewhere (van den Brink et al., 2017) but will be summarized below.

Participants

Participants were recruited from 17 Dutch NHs with a geronto-psychiatric unit. The study population consisted of NH patients, newly admitted to one of these units, with somatic illness and persistent psychiatric disorders or severe behavioural problems. Patients were included if (1) they needed both physical and psychiatric care, as shown in the medical history, and (2) the psychiatric or behavioural problems had been present for 2 years or longer without prospect of substantial recovery. Exclusion criteria were: (1) dementia, (2) inability to give informed consent, (3) a mental or physical illness too severe for reliable data collection, and (4) refusal to participate. The physician of the GP-NH unit applied the in- and exclusion criteria and determined whether a patient was eligible for participating in the study. If so, written informed consent was requested from the patient.

Ethical considerations

Formal approval according to the Medical Research Involving Human Subjects Act was not necessary, as established by the local Medical Ethics Review Committee 'CMO

Regio Arnhem-Nijmegen', that has reviewed the study protocol (number 2011/171). NH management boards gave permission for the study, which was conducted in accordance with the Declaration of Helsinki and the Code of Conduct for Health Research (2004) as well as the rules applicable in the Netherlands.

Data collection

Data collection took place between April 2012 and July 2015 and was carried out by the researcher (AvdB) and a research assistant (MdV). Both are certified elderly care physicians (Koopmans, Pellegrom, & van der Geer, 2017). Beforehand they were trained in administering the assessment instruments.

NH patients and licensed nurses specifically assigned to individual patients for care management purposes were interviewed twice: six to nine weeks after admission of the patient (T0) and six months (plus/minus 3 weeks) later (T1).

Data collection consisted of chart review, semi-structured interviews, (brief) neuropsychological testing, and self-report questionnaires. Medical and demographic data were collected from the patients' medical Demographic characteristics were the patient's age, sex, ethnicity, marital status, level of education and residence prior to admission to the nursing home.

Data on psychotropic drug use on the day of assessment were retrieved from pharmacy files. Drugs were clas-Therapeutic Chemical sified the Anatomical usina classification (Nordic Councel on Medicines 1990. Guidelines for ATC Classification. WHO collaborating Center for Drugs Statistic Methodology) and grouped into antipsychotics, anxiolytics, hypnotics, antidepressants, anti-epileptics, and other psychotropic drugs. Prescriptions for incidental use were not involved.

Primary outcome: neuropsychiatric symptoms

NPS were assessed with the Neuropsychiatric Inventory Nursing Home version (NPI-NH). The NPI-NH is a modified version of the Neuropsychiatric Inventory (Cummings et al., 1994) originally designed to measure psychiatric symptoms in geriatric patients with dementia. The NH version was developed for use by professional caregivers within institutions and was found to be valid and reliable when administered by trained nursing staff (Wood et al., 2000). The NPI-NH can also be used to screen for neuropsychiatric symptoms in an elderly neuropsychiatric population (Lange, Hopp, & Kang, 2004). The NPI-NH has been translated and validated in the Dutch setting (Kat et al., 2002).

The NPI-NH includes 12 neuropsychiatric symptoms. The frequency (F) and severity (S) of a particular symptom are rated on a four- (1-4) and a three-point (1-3) Likert scale, respectively. A separate score can be calculated for each symptom by multiplying the frequency and severity scores (F x S score), resulting in values ranging from zero to 12 for each symptom. The total NPI score is the summed symptom score and ranges from zero to 144.

We grouped NPI-NH items in neuropsychiatric clusters after performing a factor analysis (Supplementary data, Table 1). Factors with eigenvalues >1 were extracted and orthogonally rotated (varimax). Factors loading ≥0.4 were

Table 1. Characteristics of the patient sample (N = 71).

Characteristic	% (n)
Age, y ^a	69.3 (SD 10.5)
Sex (% female)	56.3% (40)
Country of origin	
The Netherlands	94.4% (67)
Marital status	
Unmarried	32.4% (23)
Married	19.7% (14)
Divorced	21.1% (15)
Widow(er)	26.8% (19)
Level of education ^b	
Low	31.4% (22)
Medium	55.7% (39)
High	12.9% (9)
Residence prior to admission to the GP-NH unit	
Psychiatric hospital	46.5% (33)
Nursing home	23.9% (17)
Care home	14.1% (10)
Home	7.0% (5)
Other	8.5% (6)
Number of chronic medical disorders ^a	6.8 (SD 2.7)
Number of chronic psychiatric disorders ^a	2.2 (SD 0.9)

aMean, SD.

considered to be relevant. This analysis showed a 4-factor solution that explained 38.0% of the variance in the data. The first factor (14.4% of the total variance) represents a cluster "hyperactivity" and has high loadings on irritability, agitation, and disinhibition. The second factor (12.0% of the total variance) represents a "mood/apathy" cluster and consists of depression, apathy, and anxiety. The third factor (6.0% of the total variance) represents a "psychosis" cluster and includes delusions and hallucinations. The fourth factor (5.5% of the total variance) solely consists of the item "euphoria".

Potential determinants of neuropsychiatric symptoms

Cognition was assessed with the Standardized Mini Mental State Examination (S-MMSE) (Folstein, Folstein, & McHugh, 1975; Molloy, Alemayehu, & Roberts, 1991) and the Frontal Assessment Battery (FAB) (Dubois, Slachevsky, Litvan, & Pillon, 2000). The FAB evaluates the following executive functions: conceptualization, mental flexibility, motor programming, sensitivity to interferences, inhibitory control, and environmental autonomy. The score ranges from 0 to 18, with higher scores indicating better frontal functioning.

Care needs were assessed with the Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000). The CANE covers 24 areas targeting physical, psychological, social, and environmental needs. Each item can be assessed as 0 = no need (no problem), 1 = met need (the care provided can be considered as appropriate and potentially of benefit), and 2 = unmet need (the interviewee experiences a significant care need requiring intervention or assessment, for which currently no or the wrong kind of help is received). The CANE is applicable in elderly patients with different levels of cognitive functioning (Reynolds et al., 2000; van der Roest, Meiland, van Hout, Jonker, & Droes, 2008).

Analysis

In accordance with previous studies, neuropsychiatric symptoms with a FxS score >4 on the NPI-NH were considered clinically relevant (Cravello, Palmer, de Girolamo, Caltagirone, & Spalletta, 2011; Lyketsos et al., 2002).

For describing the characteristics of the patient sample, categorical variables were summarized as percentages and continuous variables as means (Standard Deviation) or medians (InterQuartile Range). Comparison of outcomes at TO and T1 was performed with Student's t-tests for paired samples for normally distributed variables, and with Wilcoxon Signed Ranks tests if variables were not normally distributed. Effect sizes (Cohen's d) were calculated by dividing the difference between means by the standard deviation at baseline. In accordance with Cohen's widely used rule-of-thumb regarding effect sizes, we consider d=0.2 as a small, d=0.5 as a medium, and d=0.8 as a large effect size (Cohen, 1992).

The frequency distributions of neuropsychiatric symptoms and the identified symptom clusters were calculated.

We calculated the following frequency parameters for all patients with complete follow-up: point prevalence (the proportion of patients with a specific symptom at each assessment), cumulative prevalence (the percentage of patients where the symptom was present on at least one of the two assessments), incidence (the proportion of patients who had a specific symptom at the second assessment but had no symptoms in the first assessment), and persistence (the proportion of patients who had a symptom at both of the assessments).

Bivariate analyses (Pearson correlations, analysis of variance, t-tests) were used to investigate associations between change in the difference score of the NPI total score, the NPI cluster hyperactivity, and the NPI cluster mood/apathy and several possible determinants as based on the literature (age, sex, level of education, cognitive functioning, and the number of unmet needs).

Statistical analysis was carried out using SPSS version 22.

Results

Between March 1 2012 and December 31 2014, 180 patients were admitted to the participating GP-NH units. Of these, 109 patients (mean age 70.1 (SD = 12.1) 39.4% females (n = 43)) could not be included in the study due to dementia and/or inability to give informed consent (n=43), a physical illness too severe for reliable data collection (n=6), an expected duration of stay of less than 6 months (n = 21), or no chronic MPM (n = 11). Twentyeight patients (mean age 71.4 (SD = 9.2) 42.9% females (n = 12)) met all the criteria for inclusion, but gave no informed consent or this could not be obtained in time, leaving 71 patients to be included. For 8 of them, no data could be collected at T1 because of death (n = 5), relocation (n=2) and withdrawal from the study (n=1). So, for 63 patients data were collected at both T0 and T1.

Demographic and clinical characteristics

The patient sample consisted of slightly more women than men, with a mean age of almost 70 years (Table 1). Almost half of them stayed in a psychiatric hospital before being admitted to the GP-NH unit.

Neuropsychiatric symptoms

The mean total NPI FxS score increased from 25.3 (SD = 17.5) at T0 to 29.3 (SD = 16.5) at T1 (t = -2.044)

^b1 missing.



Table 2. Frequency parameters of clinically relevant NPS (FxS \geq 4) in patients with complete follow-up (N=63) on individual items and identified clusters; prevalence rates on total group level; incidence and persistence on subgroup level.

	Point Prevalence	Point Prevalence at	Cumulative		
	at baseline	baseline $+$ 6 months	Prevalence	Incidence ^a	Persistence ^b
Individual neuropsychiatric sym	nptoms:				
Delusions	33.3% (21)	25.4% (16)	39.7% (25)	9.5% (4)	57.1% (12)
Hallucinations	11.1% (7)	11.1% (7)	17.5% (11)	7.1% (4)	42.9% (3)
Agitation	47.6% (30)	50.8% (32)	68.3% (43)	39.4% (13)	63.3% (19)
Depression	30.2% (19)	47.6% (30)	52.4% (33)	31.8% (14)	84.2% (16)
Anxiety	25.4% (16)	39.7% (25)	50.8% (32)	34.0% (16)	56.3% (9)
Euphoria	6.3% (4)	4.8% (3)	7.9% (5)	1.7% (1)	50.0% (2)
Apathy	33.3% (21)	39.7% (25)	50.8% (32)	26.2% (11)	66.7% (14)
Disinhibition	23.8% (15)	33.3% (21)	42.9% (27)	25.0% (12)	60.0% (9)
Irritability	52.4% (33)	65.1% (41)	71.4% (45)	40.0% (12)	87.9% (29)
Aberrant motor behavior	9.5% (6)	7.9% (5)	14.3% (9)	5.3% (3)	33.3% (2)
Night time disturbances	11.1% (7)	12.7% (8)	19.0% (12)	8.9% (5)	42.9% (3)
Eating changes	28.6% (18)	22.2% (14)	34.9% (22)	8.9% (4)	55.6% (10)
Neuropsychiatric symptom clus	ters:				
Hyperactivity	61.9% (39)	73.0% (46)	81.0% (51)	50.0% (12)	87.2% (34)
Mood/apathy	57.1% (36)	66.7% (42)	79.4% (50)	51.9% (14)	77.8% (28)
Psychosis	34.9% (22)	28.6% (18)	42.9% (27)	12.2% (5)	59.1% (13)
Other neuropsychiatric sympto	m counts:				
Any symptom	87.3% (55)	87.3% (55)	95.2% (60)	62.5% (5)	90.9% (50)
More than 3 symptoms	42.9% (27)	54.0% (34)	63.5% (40)	36.1% (13)	77.8% (21)

^aThe ratio of residents with clinically relevant NPS at follow-up to residents without clinically relevant NPS at baseline.

Table 3. Bivariate relationships between potential determinants and the NPI FxS difference score.

	FxS difference score NPI total (T0-T1)		FxS difference score NPI hyperactivity (T0-T1)		FxS difference score NPI mood/apathy (T0-T1)	
	Pearson's r	Sig (2-tailed)	Pearson's r	Sig (2-tailed)	Spearman's rho	Sig (2-tailed)
Age	0.151	0.239	0.131	0.307	-0.069	0.589
MMSE score	-0.023	0.861	-0.040	0.759	-0.063	0.627
FAB score	-0.165	0.209	-0.287	0.026	0.018	0.890
Number of unmet needs	0.010	0.938	0.091	0.477	0.029	0.823
	Student's t	Sig (2-tailed)	Student's t	Sig (2-tailed)	Student's t	Sig (2-tailed)
Sex	0.027 ANOVA <i>F</i>	0.979 Sig (2-tailed)	−0.852 ANOVA <i>F</i>	0.398 Sig (2-tailed)	−0.193 ANOVA <i>F</i>	0.848 Sig (2-tailed)
Level of education	2.583	0.084	0.298	0.743	2.424	0.097

df = 62, p = 0.045, Cohen's d = -0.23). The mean FxS score increased from 9.7 (SD = 8.7) at T0 to 11.8 (SD = 9.0) at T1 in the cluster hyperactivity (Z = -2.065, p = 0.039, Cohen's d = -0.24), and from 7.7 (SD = 7.7) at T0 to 10.1 (SD = 9.4) at T1 in the cluster mood/apathy (Z = -2.651, p = 0.008, Cohen's d = -0.31).

As Table 2 shows, overall NPS were very frequent: 87.3% (n=55) of the patients had at least one clinically relevant symptom and 42.9% (n = 27) had more than 3 symptoms simultaneously at T0. At T1, 87.3% (n = 55) and 54.0% (n=34) had at least one and four symptoms respectively. Just over 95% had any symptom at T0 and/or T1, of which irritability was the most prevalent and persistent symptom and the symptom with the highest incidence. Depression was also notable for its high persistence. Hyperactivity was the most prevalent and persistent symptom cluster.

A lower FAB score at baseline was related to a more positive difference score on hyperactivity (less frequency x severity at T1 than at T0) (Table 3). Other significant relationships were not found.

Psychotropic drug use

Patients used a mean number of 2.5 (SD = 1.5) psychotropic drugs at T0 and 2.4 (SD = 1.5) at T1. The proportion of patients using a particular class of psychotropic drugs is shown in Table 4.

Table 4. Proportion of patients using psychotropic drugs (N = 63).

	T0	T1
Mean number of psychotropic drugs ^a	2.5 (SD 1.5)	2.4 (SD 1.5)
Antipsychotics	58.7% (37)	58.7% (37)
Anxiolytics	31.7% (20)	36.5% (23)
Hypnotics	22.2% (14)	20.6% (13)
Antidepressants	57.1% (36)	52.4% (33)
Antiepileptics ^b	31.7% (20)	30.2% (19)
Anti-dementia drugs	3.2% (2)	1.6% (1)
Drugs used in addictive disorders	1.6% (1)	1.6% (1)
Psychotropics (total)	88.9% (56)	87.3% (55)

^aMean, SD.

In addition to the results shown in Table 4, we found that 90.5% (n = 57) used at least one psychotropic drug at T0 and/or T1. In total, it concerned 167 prescriptions. Twothirds of the prescriptions (66.5%, n = 111) were exactly the same at T0 and T1. In 19.2% (n = 32) of the patients a new psychotropic drug was prescribed and/or the dose was increased, and in 14.4% (n = 24) a prescription was discontinued and/or the dose was decreased. Starting (n = 9) and stopping (n=6) a prescription was most common with benzodiazepines (n = 45). In 19.6% (n = 10) of the antipsychotic prescriptions (n = 51) the dose was higher at T1 than at T0.

Discussion

This first study on the natural course in NPS in nursing home patients with MPM no dementia in the first 8 months

^bThe ratio of residents with clinically relevant NPS at follow-up to residents with clinically relevant NPS at baseline.

^bPatients with epilepsy n = 10; patients with neuropathic pain n = 1.

after admission to a GP-NH unit, showed a significant increase of the NPI FxS score concerning the total score of the 12 NPI items, the total score of the hyperactivity cluster, and the total score of the mood/apathy cluster.

Overall NPS were very frequent. Just over 95% had any clinically relevant symptom at T0 and/or T1, of which irritability was the most prevalent and persistent symptom and the symptom with the highest incidence. Hyperactivity was the most prevalent and persistent symptom cluster. Also, depression had a high persistence.

Firstly, we compared our follow-up results with the results of the NH patients with MPM (with and without dementia) in the cross sectional SpeCIMeN study, the only study that is fairly akin to our study in terms of study population and assessment instruments (Collet et al., 2018). Similar symptoms appeared to be most prevalent, although the prevalence rates were higher in our study. Our study extends these findings by having longitudinal results. Unfortunately, there are no longitudinal studies of NH patients with MPM. Longitudinal studies in NH patients with dementia (Bergh, Engedal, Røen, & Selbaek, 2011; Selbaek et al., 2014; Wetzels et al., 2010), showed similar NPS that occurred most frequently, with our prevalence rates generally being slightly higher at both measurements. In our study, as well as in two of the dementia studies, irritability was the most prevalent NPS and increased between the baseline and first follow-up assessment. In all studies, one of the hyperactivity symptoms had the highest incidence and persistence. The dementia studies, by contrast, showed considerably higher prevalence, incidence, and persistence rates for aberrant motor behaviour than our study.

Although patients with MPM have different clinical characteristics than patients with dementia, the high prevalence rate of hyperactivity symptoms stands out in both groups. These are symptoms that have been shown to contribute to admission to a nursing home in people with dementia (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). This probably also applies to patients with MPM no dementia, because these symptoms cause a great burden for (informal) caregivers, regardless of the underlying diagnosis.

We also found depression was highly persistent. This is not surprising because 'having a chronic psychiatric or behavioural problem' was one of the inclusion criteria.

Finally, we found a slight increase in the total FxS score of the NPI, which was mainly caused by the increased FxS scores of the hyperactivity- and mood/apathy-items. This finding is not in line with the results of a recent systematic literature review of studies investigating the course of NPS in NH patients with dementia showing that NPS were stable or decreased after admission to NH (Selbaek, Engedal, & Bergh, 2013).

Although the change we found was statistically significant, the effect size was small and the mean increase of 4 points was less than previous studies have indicated as clinically meaningful (18-22 points in acute geriatric neuropsychiatric inpatients (Iverson, Hopp, DeWolfe, & Solomons, 2002), 11 points in nursing home patients with dementia (Zuidema et al., 2011), and 9 points in outpatients with dementia (Kaufer, Cummings, & Christine, 1996)). Hence, the clinical relevance of the change found in NPI total score may be limited.

In aiming to explain our findings, the found increase in the prevalence rates of most NPS as well as in the total FxS score, was probably not considerably influenced by changes in PDU, since most prescriptions remained unchanged at follow up.

Alternatively, the results may partially be explained by the design of the study. Acknowledging that admission to a GP-NH itself is an intervention aimed to improve functioning, the baseline should be conducted prior to admission as usually done in pre-post designs (Thiese, 2014). In the MAPPING study, the assessment at baseline was performed 6-8 weeks after admission. This may have led to an underestimation of decreases in NPS, as the largest improvement of psychological symptoms usually happen within the first weeks after an intervention is administered (in this case: the admission to a GP-NH unit). Based on our clinical experience, we think that many patients have responded positively to the new social contacts and activities, and the personal attention they have received from the staff that was aiming to draw up an individual care plan. So, most improvement might have occurred before the first assessment.

Nevertheless, we must not close our eyes to the possibility that our findings also could indicate a non-optimal care setting for the studied patient group. Possibly, the supportive environment of a GP-NH unit does not sufficiently match the needs of patients with MPM. There is a risk that NHs, from their proficiency in caring for residents with dementia, provide an environment that is too supportive for patients with MPM. Based on the experience of inpatient mental health, it seems to be appropriate to create a more therapeutic milieu on GP-NH units (van den Brink et al., 2014). In addition, daytime activities may not be sufficiently adapted to the wishes and capabilities of these patients of whom several are relatively young (van den Brink, Gerritsen, Oude Voshaar, & Koopmans, 2013). Finally, there is also the possibility that the expertise of the staff may be insufficient to optimally meet the complex care needs of patients with MPM (van den Brink et al., 2018).

Strengths and limitations

In this study, the NPI questionnaires were completed in the form of structured interviews. Since the interviews were conducted by two elderly-care physicians who were familiar with this patient group and their professional careers, the data are of high quality and there were few missing data.

However, some limitations must be mentioned.

Firstly, in our study, behavioural problems were operationalized as NPS. NPS were assessed with the NPI-NH which is a validated measure instrument in our study population (Lange et al., 2004). However, the NPI relies on information from a licensed nurse who has observed the patient over the past four weeks. The correct unravelling of behaviour in symptoms is a difficult task for the nursing staff for which they may not have been adequately trained. Furthermore, the results may be influenced by the attitude of the nurse. Moreover, the broad perspective on behaviour is narrowed down to a symptom approach when studying behavioural problems by assessing NPS with the NPI. This could be considered as potentially inaccurate and misleading (Caspi, 2013; Macaulay, 2018).



Secondly, the sample size and the heterogeneity of the study population, due to diversity in the composition of the multimorbidity per individual, have limited the possibility to find out determinants of NPS. In addition, this study included only one follow-up assessment after 6 months. Participants' NPS may have fluctuated in this period rather than being persistent or consequently deteriorating.

Finally, study participants were recruited from specialized GP units in several Dutch NHs. These units have varying criteria for admission depending on, for example, the qualitative and quantitative composition of the multidisciplinary team and cooperation agreements with mental and other healthcare services. As the MAPPING study is an explorative, descriptive study with a small sample size, we did not investigate the effect of these criteria on the composition of the study population. We tried to reduce this impact by using inclusion criteria at the individual patient level and not at the level of the unit. Nevertheless, different profiles in GP-NH units could have influenced the severity of NPS.

Despite these limitations, we believe that the findings in this first explorative and descriptive longitudinal study showed valuable results for clinical practice which require and justify further research.

Conclusion and recommendations

In conclusion, our results indicate the omnipresence of NPS of which most were found to be persistent.

Future studies with larger samples and longer follow-up periods in which more assessments are performed, are necessary to not only gain a better insight in the course of NPS and its determinants but also to assess the effect of interventions. After all, it remains a purpose of LTC to reduce patients' NPS and several opportunities for this may exist.

First of all a therapeutic milieu could be created including the following practices: containment (meeting the basic needs and providing physical care and safety to the people within the environment), support (giving kindness as the basis for a structure that fosters predictability and control), structure (having a predictable organization of roles and responsibilities as well as setting limits when necessary), involvement (practices in which the resident engages in the social environment) and validation (affirming a resident's individuality) (Gunderson, 1978; Mahoney, Palyo, Napier, & Giordano, 2009).

Secondly, a specialized multidisciplinary team could be composed of which all members have appropriate knowledge and skills to identify signs of mental and physical disruptions at an early stage. If there is a lack of knowledge and/or skills, staff education is indispensable.

Finally, it could be worthwhile to investigate whether thought-out changes in PDU cause reduction in NPS.

Disclosure statement

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