

ANNE VAN DEN BRINK

Nursing home residents with mental and physical multimorbidity

Characteristics, neuropsychiatric symptoms and needs

Colofon

Nursing home residents with mental and physical multimorbidity

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CHAPTER 1

General introduction

Residents with mental-physical multimorbidity in Dutch nursing homes

As stated by the International Association of Gerontology and Geriatrics and the American Medical Directors Association, a nursing home (NH) is a facility with a domestic-styled environment that provides 24-hour functional support and care for persons who require assistance with activities of daily living and who often have complex health needs and increased vulnerability.¹

In the Netherlands, most of the frail elderly people stay at home for as long as possible, even if problems arise. NHs only admit people with severe and complex health care problems who, in addition to 24-hour surveillance, also need multidisciplinary care. This trend is likely to continue in the coming years, as a result of which the complexity of care in NHs will increase further. Dutch NHs employ multidisciplinary teams which generally include nursing staff, an elderly care physician, a psychologist, a physical therapist, an occupational therapist, a speech therapist, and a recreational therapist. The Netherlands is the only country in the world that recognizes elderly care physicians as an official medical specialty. Medical doctors have to follow a 3-year national training program to be certified as an elderly care physician.²

In 2017, Dutch NHs had a capacity for long-term care (LTC) of approximately 92.000 beds and provided LTC and services to more than 117.000 persons.³ The mean age of NH residents is 85 years and 72% is female.⁴

Admission to a NH is suitable if a person's care needs exceed the possibilities for support within his or her psychosocial context. Usually this is the result of an accumulation of diseases and disabilities. Not so much the number of disorders, but their nature and resulting limitations in daily functioning, appear to determine the need for 24-hour care in an inpatient setting. In this respect the co-occurrence of medical and psychiatric illnesses (mental-physical multimorbidity) needs special attention.⁵

Multimorbidity is the co-existence of several medical conditions at the same time in one person.⁶ Reported prevalence-rates of multimorbidity vary widely across studies, from around 20-30% in the general population to 55 to 98% when only older persons were included.⁷⁻¹⁰ The prevalence of multimorbidity in the elderly population is much higher than the prevalence of the most common diseases among the elderly such as heart failure or dementia.¹¹

Multimorbidity has negative consequences for patients' physical and mental well-being,^{12,13} quality of life,¹⁴⁻¹⁷ and mortality.^{17,18} It also has negative consequences for health care utilisation, e.g. doctor visit frequency, length of hospital stay, referral and (re) admission rates, and costs.¹⁷⁻²¹

Mental-physical multimorbidity (MPM) is common in older people. Nevertheless, surprisingly little is known about one of their most vulnerable groups: chronic psychiatric patients with additional physical care needs requiring residential LTC. Traditionally, these patients were institutionalized in psychiatric hospitals for the rest of their lives. However, since the 1950s, deinstitutionalization has dominated mental healthcare reforms in most industrialized countries. As a result, the total number of psychiatric hospital beds has decreased dramatically. Since then, LTC facilities have partly taken over the traditional asylum function of psychiatric hospitals.²² Another vulnerable group of patients with MPM that resides in LTC facilities consists of older patients with primarily physical multimorbidity that is accompanied by neuropsychiatric symptoms forming part of a physical disease, a relapse of existing psychiatric conditions triggered by physical problems, or a late-onset psychiatric disorder.²³ This group is also expected to increase over the upcoming years, due to a greying society and increased prevalence of physical diseases with aging.

In addition to providing general geriatric care, in the Netherlands many NHs also develop specialized care programs for specific patient groups, like those with MPM. Most of these NHs house patients with MPM in separate units, so-called geronto-psychiatric nursing home (GP-NH) units, in contrast with for instance dementia special care units and somatic units. This choice is often based on the experience that patients with MPM differ from the traditional patients in NHs having primarily dementia and/or physical multimorbidity. To date, however, this experience cannot be substantiated with the results of scientific research. Such research is necessary to develop an appropriate care program, including the associated preconditions, and to solve bottlenecks in laws, regulations and funding. For example, since the introduction of the Long-term Care Act in 2015, patients with MPM in whom a psychiatric disorder is the dominant basis for the need for residential LTC, are no longer eligible for admission to Dutch NHs.²⁴⁻²⁶ However, patients with MPM have physical care needs by definition and therefore, other LTC facilities are less suitable to provide care to these patients. As a result, MPM patients may fall through the cracks.

To prevent this, more insight in the characteristics and needs of patients with MPM should be obtained, in order to make better informed decisions about the accessibility of various health care settings for these patients.

Aim of this thesis and research questions

The **MAPPING** study (a study in residents with **m**ental and **p**hysical **p**roblems residing in Dutch **n**ursing homes) aims to increase the knowledge about the characteristics and care needs of these residents and to gain insight into the patient-related factors affecting changes in neuropsychiatric symptoms after admission to a GP-NH unit. Such knowledge is a prerequisite for ultimately being able to develop a standard of care that is appropriate for NH residents with MPM.

The following research questions were specifically formulated for this thesis:

- 1 What are the characteristics and care needs of NH residents with MPM?
- 2 What changes have occurred eight months after admission in resident behaviour and what is the influence of various patient-related factors on these changes?

Outline of this thesis

Chapter 2 offers a conceptual perspective on why residents with MPM should be considered a separate group of NH residents with specific needs. It contains a number of suggestions regarding preconditions for GP-NH units, that allow residents to benefit from specialized care.

Chapter 3 provides a systematic review of the literature on prevalence, characteristics and care needs of residents with MPM living in long-term care facilities.

The study design and methods of the MAPPING study are described in **chapter 4**.

The empirical results of the study are described in chapters 5 through 7 of this thesis. **Chapter 5** explores the characteristics, behaviour, and care dependency of residents with MPM without dementia, living in GP-NH units, stratified by those referred from mental healthcare services and other healthcare services. **Chapter 6** focuses on (un)met care needs of these residents both from the residents' and nursing staff's perspectives and on the differences between their opinions. Determinants of unmet needs are also presented.

Chapter 7 describes the natural course of neuropsychiatric symptoms of residents with MPM in the first eight months after admission to a GP-NH unit and associations with change in neuropsychiatric symptoms between two measurements in this period.

Finally, in **chapter 8** the main findings and conclusions are summarized and discussed. Also, the relevance of the present study for clinical practice and health care policy is addressed. This chapter ends with suggestions for future research and a general conclusion.

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Patients with mental-physical multimorbidity: do not let them fall by the wayside

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Introduction

Although exact figures are lacking, many studies show that mental-physical multimorbidity is common in older people.¹ Particularly older patients with a chronic disease often have psychiatric disorders.² Conversely, medical comorbidity is common in psychiatric patients, especially cardiovascular, pulmonary and neurological disorders and diabetes.³

Patients with mental-physical multimorbidity can benefit from integrated mental and physical health care and a variety of care models has been introduced accordingly.⁴ For instance, in primary care there is a growing interest in collaborative care programs, in which primary care providers, care managers and psychiatric consultants work together to provide care and monitor the patients.⁵⁻⁷ In secondary care, integrated care for older patients with mental-physical multimorbidity is available on geriatric wards and psychiatric medical units of general, academic and psychiatric hospitals. Despite this, a group of patients is at risk of falling between two stools, namely chronic psychiatric patients who need long-term residential care because of additional physical disorders.

An example of this type of patients is a 63-years old woman with depression, panic attacks and a mixed personality disorder with dependent and histrionic features, and concomitant multiple sclerosis. She lived alone and received intensive home care, because of immobility and full dependency in activities of daily living due to the progressive neurological deficits. After the relative who cared for her died, she often phoned the home care organization for help. The home care organization was not able to provide what she requested.

Another example is a man, aged 72-years, with psychotic depression, tardive dyskinesia and serious diabetes insipidus. Psychiatric hospitalization was necessary because of severe symptoms of psychotic depression, including nihilistic delusions, suicidality and delirium caused by dehydration as a result of the diabetes insipidus. After rehydration and intensive psychiatric treatment, the patient stabilized. However, extensive care remained necessary, both to prevent dehydration as well as to prevent recurrence of a severe depressive episode. Because of these care needs and the high burden his wife experienced, discharge back home was impossible.

Previously, such patients would likely have stayed in psychiatric hospitals for the rest of their lives. However, since the 1950⁵, deinstitutionalization has dominated mental healthcare reforms in most industrialized countries. As a result, the total number of

psychiatric hospital beds has decreased dramatically. Since then, long-term care (LTC) facilities have partly taken over the traditional asylum function of psychiatric hospitals.^{8,9} Initially, there was a trend of so-called transinstitutionalization: a part of the former psychiatric inmates moved to LTC facilities.^{10,11} In addition, since the 1990^s a trend of reinstitutionalization of people with long-term and more complex mental health needs and those with a forensic-psychiatric history is going on, resulting in increased numbers of forensic beds, places in prisons, and also in community based nursing and residential care homes.¹²⁻¹⁴ This reinstitutionalization has occurred largely unnoticed by policy makers, and systematic research into its reasons, costs, and effects is lacking almost completely.¹⁴⁻¹⁶ Given the differences in national health care systems, this has resulted in a wide range of LTC facilities for heterogeneous groups of residents with mental illnesses.^{1,17,18} However, it has been doubted whether these LTC facilities address the mental health needs of these residents adequately.¹⁹

In the Netherlands, nursing homes have a long tradition of housing patients in units which provide specific care to a particular group of residents, needing multiprofessional care that cannot be offered by home care or in assisted living facilities.²⁰ Individual treatment is based on personal needs and wishes of each resident within an appropriate social living environment. In order to achieve all this, a unique organization of nursing home care has been developed. Dutch nursing homes employ not only nursing staff, but also their own medical, paramedical, and psychosocial staff, including a specially trained physician.²¹ This so called elderly care physician (ECP) has completed a 3-year full-time training program, that makes him or her a medical practitioner who has specialized as a primary care expert in geriatric medicine and qualified as a basic specialist with expertise in geriatric medicine.²²

Some traditional nursing homes are evolving towards centres for specialized care, among others for older people with mental-physical multimorbidity.²³ The care needs of these patients differ from those of nursing home residents with dementia or with only physical conditions.²⁴ Therefore, we think these residents will benefit from living in specialized units, so-called geronto-psychiatric nursing home units. Below we will discuss the preconditions for these units.

Preconditions

Competences of the multidisciplinary team

Geronto-psychiatric nursing home units have to be run by a specialized multidisciplinary team that consists of at least an ECP (or other physician with similar expertise), a

psychologist and a nurse specialist. It is their job to assess, treat and support residents but also to coach the nursing staff. It is difficult to interpret signs, symptoms and care needs of residents with mental-physical multimorbidity. Psychiatric diseases and personality disorders affect the way patients present their physical symptoms and needs.²⁵ Alternatively, symptoms caused by a physical condition, such as decreased responsiveness and lack of energy, can also be interpreted as symptoms of a psychiatric disorder, for example depression.²⁶⁻²⁸ Besides, guidelines mostly focus on a single disease whereby the issues arising from multimorbidity are neglected.

Therefore, all members of the specialized multidisciplinary team must have appropriate skills to identify signs of mental and physical disruptions at an early stage. They must have broad knowledge about medical and psychiatric conditions and their mutual influence and should be able to apply this knowledge in the diagnostic and therapeutic process. Additionally, to complement the predominantly physical care professionals should be trained in counselling strategies and recognize the influence of their own personal characteristics when interacting with these residents to prevent iatrogenic countertransference dynamics.

Collaboration

Unfortunately, the availability and quality of mental health services in nursing homes is perceived as a bottleneck in many countries.^{4,19,24,29} Even if a specialized multidisciplinary team is available for residents of a geronto-psychiatric nursing home unit, this team has to collaborate with medical and mental health care specialists in order to provide optimal care to these residents. On the one hand, it is important to arrange routine presence of qualified mental health clinicians for ongoing consultation and follow-up during episodes of acute illness, for management of maintenance treatment and for programmatic consultation to the facility and its staff.³⁰ On the other hand, clear agreements are required about referral of residents for diagnostic investigation and for therapy that cannot be carried out in the nursing home. Staff members should thus know the limits of their professional competence and refer residents timely if that is indicated.

Supportive environment

A supportive environment includes physical design concepts as well as the social environment and organizational setting. This environment can strengthen or undermine mental health.^{31,32} The literature on supportive environments for nursing home residents with mental health problems focuses on residents with dementia. The resulting design principles^{33,34} may not be appropriate for achieving a supportive environment specifically tailored to the needs of residents with mental-physical multimorbidity.

Interestingly, there is a risk that nursing homes, from their proficiency in caring for residents with dementia, provide an environment that is too supportive for residents with mental-physical multimorbidity. Based on the experience of inpatient mental health, it seems to be appropriate for residents of a geronto-psychiatric nursing home unit, to create a therapeutic milieu 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).^{35,36} In addition, there must be daytime activities adjusted to the wishes and capabilities of these residents of whom several are relatively young.¹

A unit for specialized care should consist of private rooms, where residents can store their property and where their privacy is ensured, and of rooms for social, labour-oriented and therapeutic activities. There must be multiple rooms, so the size of the group and the amount of stimuli can be varied. Safety and oversight have to be guaranteed.

Recommendations

Nursing homes can play an important role in caring for patients with severe mental-physical multimorbidity if these will evolve towards specialized care centres, which have fulfilled the preconditions described above. We conclude with some recommendations:

- 1 To fulfil these preconditions optimally, regulatory and funding barriers need to be overcome;²⁴ reimbursement policies should at least enable: consultation, the provision of psychotherapies, staff education and evaluation of the therapeutic milieu.^{37,38}
- 2 “Good practices” of care for residents with mental-physical multimorbidity should move towards “best practices” with best evidence-based care. For this purpose, guidelines tailored to the specific characteristics and care needs of these residents, should be developed.
- 3 The above described preconditions generate the following research agenda: it is essential to investigate the care needs of these residents, most effective therapies and care models and the required knowledge and skills of the members of the multidisciplinary team. Furthermore, the assessment of psychiatric and physical symptoms in patients with mental-physical multimorbidity is complicated. For the use in this group, we recommend clinimetric evaluation of potentially useful screening and diagnostic instruments designed for other patient groups. Where necessary, new instruments should be developed. Finally, research is needed for a better insight into

all aspects of the supportive environment that maintain and enhance quality of life of nursing home residents with mental-physical multimorbidity without dementia.

- 4 There are considerable differences in long-term residential care arrangements between countries. Precisely because of the different experiences, we can learn from each other. Hence, the International Psychogeriatric Association (IPA) has established the Long-term Care Shared Interest Forum (SIF). Main objectives of SIF are to gather cross-national input when optimizing mental health care in LTC facilities and to support and strengthen mental health services in the LTC sector. Therefore, we recommend international collaboration as in the SIF, both for the development of guidelines as for carrying out the research agenda. (http://www.ipa-online.net/ipaonline4/main/programs/sif/sif_ltc.html).

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**Residents with mental-physical
multimorbidity living in long-term
care facilities: prevalence
and characteristics**

A systematic review

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Abstract

Background

Aging societies will be confronted with increased numbers of long-term care residents with multimorbidity of physical and mental disorders other than dementia. Knowledge about the prevalence rates, medical and psychosocial characteristics and care needs of this particular group of residents is mandatory for providing high-quality and evidence-based care. The purpose of this paper is to review the literature regarding these features.

Methods

A systematic literature search was conducted in PubMed, EMBASE, PsycINFO and CINAHL from January 1, 1988 to August 16, 2011. Two reviewers independently assessed eligibility of studies on pre-established inclusion criteria as well as methodological quality using standardized checklists.

Results

Seventeen articles were included. Only one small study describes multimorbidity of a wide range of chronic psychiatric and somatic conditions in LTC residents and suggests that physical-mental multimorbidity is rather rule than exception. All other studies show prevalence rates of comorbid physical and mental illnesses (range 0.5% - 84.9%), roughly in line with reported prevalence rates among community-dwelling older people. LTC residents with mental-physical multimorbidity were younger than other LTC residents and had more cognitive impairment no dementia and problem behaviours. Care needs of these residents were not described.

Conclusion

Although exact figures are lacking, mental-physical multimorbidity is common in LTC residents. Given the specific characteristics of the pertaining residents, more knowledge of their specific care needs is essential. The first step now should be to perform research on symptoms and behaviour, which seem more informative than diagnostic labels as well as care needs of LTC residents with mental-physical multimorbidity.

Key words long-term care, neuropsychiatric symptoms, medical comorbidity, residential facilities

Introduction

The world's population is aging. Ten-year projections suggest that the annual net increase of the number of people over the age of 65 will be about 23 million.¹ Because the prevalence of many health problems increases with age, this demographic trend will also lead to a rising prevalence of multimorbidity in the upcoming years, and probably also to an increased need for long-term care (LTC).^{2,3}

Multimorbidity is defined as the simultaneous occurrence of several medical conditions in the same person.⁴ Reported prevalence-rates of multimorbidity vary widely across studies, from around 20% to 30% in the general population to 55% to 98% when only older persons were included.⁵ The prevalence of multimorbidity in the elderly population is much higher than the prevalence of the most common diseases of the elderly such as heart failure and dementia.⁶ Still, the number of studies on multimorbidity is much smaller than those on individual chronic diseases.⁷ Moreover, research on multimorbidity mainly focuses on either somatic or psychiatric multimorbidity. Furthermore, multimorbidity by itself does not predict the need for LTC, but its consequences with respect to disability and dependency.⁸ Given that psychosocial and mental health problems are strongly associated with a higher level of dependency,⁹ mental-physical multimorbidity requires special attention.^{10,11} Yet, the few studies that do investigate mental-physical multimorbidity¹² typically focus on the association between one somatic or one psychiatric index disease and one or a restricted set of comorbid conditions.¹³⁻¹⁷ Undeniably, the clustering of general somatic and psychiatric morbidity is hardly studied,^{18,19} although Lobo-Escolar *et al.* (2008) found it to be prevalent (20%) in elderly people over 55 years of age living in the community. LTC facilities will accommodate an even higher proportion of individuals with comorbid mental and physical illnesses compared to the community.¹⁰

In order to improve the cost-effectiveness of mental health care, a trend has been observed to reduce the number of psychiatric hospital beds for both short-stay and long-stay wards in many Western countries.²⁰ Consequently, the traditional asylum function of psychiatric hospitals for older adults with severe mental illness who require assistance with physical health care is largely taken over by nursing homes.²¹

Between 60% and 90% of nursing home residents have a mental condition, including dementia.²²⁻²⁴ A recent systematic review reported a median prevalence rate of 58% for dementia, 10% for major depressive disorder, and 29% for depressive symptoms.²⁴ Data on other psychiatric disorders are scarce, but suggest relatively high prevalence rates of anxiety problems (range 3.5% for anxiety or panic disorder to 29.7% for clinically relevant anxiety symptoms), substance use disorders (SUDs) (range 0.9% – 18%), schizophrenia (range 5.9% – 9.8%), and bipolar disorder (3%).

Two recent studies in the United States using three different data sources^{25,26} concluded that the prevalence rate of a primary diagnosis of mental illness excluding dementia in nursing home residents varied from 4.4% in Medicaid claims to 7% in the National Nursing Home Survey (NNHS). Taking secondary mental illness diagnoses into account, prevalence rates increased to 7% in Medicaid claims, 33.1% in the NNHS, and 46% in the Minimum Data Set (MDS)²⁷ of the Resident Assessment Instrument.²⁵ Using a sample of all “first-time” nursing home admissions from the MDS in 2005, Fullerton *et al.* (2009) found that 24% had a mental illness as defined by schizophrenia, bipolar disorder, depression or anxiety disorder.

The interpretation of the above-mentioned prevalence rates and consequences for LTC health care planning depends on the relative importance of three components within a society, that is, (1) the informal system, (2) the community-based system, and (3) the institutional system.⁸ In other words, from which component a patient will receive LTC depends not only on his level of functioning and the complexity of the services he or she needs, but also on a host of sociocultural factors, such as the structure and organization of the health care system, the health insurance system by both the government and the private sector, the availability and type of housing, the structure of families and the preferences of elderly people and their caregivers.²⁸ Nevertheless, potential decisions on these components should be driven by prevalence as well as care needs of this patient group.

In order to disentangle some of this heterogeneity, we aimed to perform a systematic review on the mental-physical multimorbidity of residents in LTC facilities.

The specific aims of the present literature review are to study:

- 1 the prevalence of mental-physical multimorbidity in middle-aged and elderly LTC residents without dementia,
- 2 the characteristics and care needs of these residents, and
- 3 the determinants of mental disorders in physical disorders or vice versa.

Methods

Identification of relevant literature

A systematic search was conducted in PubMed, EMBASE, PsycINFO and CINAHL in order to identify literature on the mental-physical multimorbidity of residents in LTC facilities. For the search MeSH (PubMed) and Thesaurus (EMBASE, PsycINFO and CINAHL) terms and free text words were used. Search terms included (“residential facilities” or “assisted living facilities” or “group homes” or “homes for the aged” or “nursing homes” or “long-

term care facilit*" or "supervised residential setting*" or "residential aged care facilit*" or "elderly care facilit*") combined with ("comorbidity" or "multimorbidity") or (("mental*" or "psychiatr*") and ("somatic*" or "physical*" or "general medical")). Articles with the keywords "dementia", "mental retardation" or "acute" were excluded from the search. Furthermore, the search was limited to residents in the age of 45 years and older and to English and Dutch publications from January 1, 1988 to August 16, 2011. The start date for the search was chosen because of the policy changes in the LTC in the United States by the introduction of the Omnibus Reconciliation Act of 1987 (OBRA 87). In addition, a search of the listed references in the reviewed papers was performed.

Selection of the literature

The first author (AvdB) screened all titles and abstracts on their potential to meet the inclusion criteria as described below. The second author (DG) checked all references published in the years 2009-2011 on the same potential. As the results were fully consistent with the results of the first author, titles and abstracts published before 2009 were screened by the first author only. Full text of the references remaining after the first screening was studied on the inclusion criteria by both authors. Disagreements were discussed until consensus was reached. Finally, the reference list of included articles was manually screened to identify any relevant references that had not yet been included.

Studies were included in the review if they:

- 1 included original data on LTC residents aged 45 years and older,
- 2 comprised a substantive description of both chronic medical and psychiatric problems (not dementia or mental retardation), and
- 3 contained at least one of the following outcomes:
 - prevalence rates of mental-physical comorbidity,
 - characteristics and/or care needs of LTC residents with mental-physical comorbidity,
 - or
 - determinants of mental disorders in physical disorders or vice versa.

In order to determine whether mental-physical multimorbidity was investigated, a description of specific mental and physical diseases in the studies was a prerequisite. Studies in which multimorbidity was only numerically measured (for instance with the Charlson Comorbidity Index or the Cumulative Illness Rating Scale) were excluded.

Data extraction

Information was collected on country and year of publication, study design, setting, sample size, mean age of patient population, method and period of data gathering,

and statistical analysis (Table 1-3). For the purpose of this review, data about prevalence of mental-physical comorbidity (Table 4 and 5) and associations between mental and physical conditions (Table 3) were included in the results tables. Data were extracted by one author (AvdB) and reviewed by the other authors.

Appraisal of the methodological quality

Gold standards to evaluate internal and external validity of observational research do not exist.²⁹ For the appraisal of the selected studies, two checklists with criteria for methodological quality were used.

Prevalence studies were rated using the criteria adapted by Pitfield *et al.* from Boyle's guidelines.^{30,31} Each paper was rated, with up to one point being given if a criterion was fulfilled and a total score was calculated (Appendix 1).

The same method was used for the non-prevalence studies, applying a checklist for etiological research as described by Van der Windt *et al.*³² (Appendix 2).

Two authors (AvdB and DG) rated the studies blind to each other's assessments. Disagreement between reviewers was resolved by discussion.

Results

Identification and selection of the literature

The electronic search generated a list of 1747 references. All references were imported into a bibliographic management software program to detect duplicates.

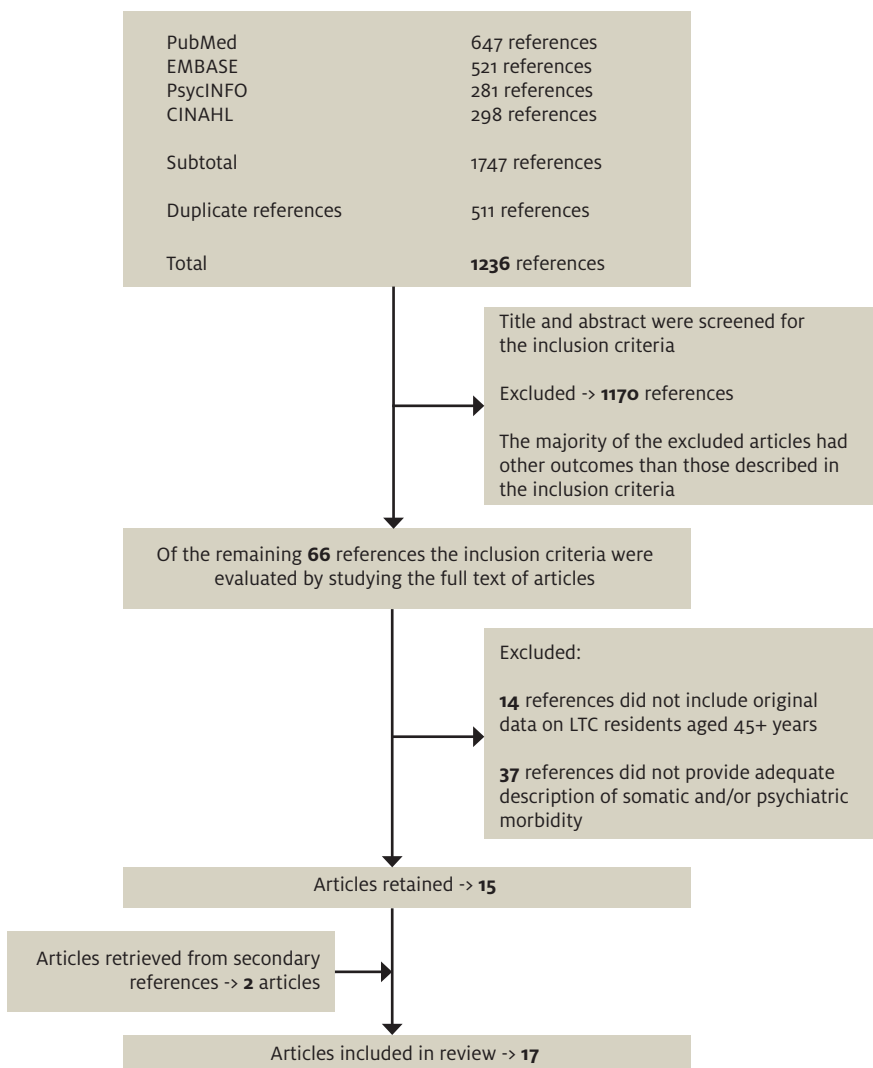
After removing duplicates, a list of 1236 references remained. From this list 1170 references were excluded because title and abstract made clear that, without any doubt, the articles did not meet one or more of the inclusion criteria. The vast majority of the articles that have been excluded had other outcomes than those described in the inclusion criteria.

The initial screening resulted in a list of 66 references of which the full texts were studied. Regarding 7 articles (11%) either the first or the second author was in doubt about the need to exclude the article. After consensus discussion, 51 articles were excluded because of failure to meet one or more inclusion criteria. Although both publications of Buchanan *et al.* (2002, 2003) were conducted on the same source population, they

were not considered duplicates as analyses were performed on two different subsamples (patients with multiple sclerosis (MS) and with human immunodeficiency virus (HIV), respectively).^{33,34} Comparably, Jang *et al.* (2006, 2007) examined different sets of determinants of the association between depression and physical illness within the same study population, without duplication of quantitative data.^{35,36}

Two articles were retrieved from secondary references. Finally, 17 articles were retained for analysis in this review (Flowchart: see Figure 1).

Figure 1 | Flowchart



Twelve prevalence studies were identified. Six of those were based on national nursing home databases in the United States.^{26,33,34,37-39} Six describe prevalence rates in selected subpopulations: three in residential facilities in Italy,⁴⁰⁻⁴² one in a nursing home in Sweden,⁴³ one in a nursing home in the United States,⁴⁴ and one in a Dutch nursing home.⁴⁵ Further, five observational studies were included: one in Norwegian nursing homes,⁴⁶ two in assisted living facilities in the United States^{35,36} and two in Dutch nursing homes.^{47,48}

Methodological quality

The percentage of agreement between the first and the second author in the scores on the checklists was 83.4%; regarding the score on 24 input fields discussion was needed to achieve consensus.

As shown in Appendix 1 (sum scores are displayed in Table 1 and 2), four of the prevalence studies, based on national databases, are of good methodological quality.^{26,37-39} Whether the studies of Buchanan *et al.* (2002, 2003) are of similar methodological quality is not clear, because in these studies the question “Was the whole population approached” could not be answered.

Of the prevalence studies in selected subpopulations, one is of moderate quality,⁴¹ and five studies^{40,42-45} are of poor methodological quality. These studies were not primarily designed as prevalence studies but as descriptive studies. Hence, especially external validity is compromised.

As shown in Appendix 2 (sum scores are displayed in Table 3) the other five studies^{35,36,46-48} are of similar moderate methodological quality. The most important flaw of all these studies is that determinants and outcomes were not assessed independently from each other.

Prevalence rates of mental-physical co- and multimorbidity

Of the 12 prevalence studies, only one study⁴³ describes multimorbidity in LTC residents not starting from an index disease or a group of index diseases. Akner (2009) identified a total of 275 separate chronic health conditions in a sample of 70 nursing home residents. The residents had a mean of 17 different chronic health problems. The most prevalent chronic health conditions were neuropsychiatric, cardiovascular and gastrointestinal conditions.

In 4 studies, the prevalence of comorbid depression in LTC residents with a somatic index disease was investigated.^{33,34,39,44} This prevalence varied from 20.7% in residents with HIV to 36% in residents with MS.

The other 7 studies describe the prevalence of comorbidity in LTC residents with a psychiatric disorder.^{26,33,34,37-39,44} Several differences in the prevalence of mental and medical comorbidities were found, depending on the primary psychiatric disorder, age, and residential setting. Prevalence ranged from 0.5% (any psychiatric illness + psoriasis) to 84.9% (anxiety disorder + cardiovascular disorder) (Tables 4 and 5).

Table 1 | Characteristics of included prevalence studies based on national databases

Reference	Design	Setting and Sample	Methods and period of data gathering	Methods of data analysis	Quality score (max 8)
#1. Aschbrenner et al. (2011) USA	Retrospective cohort study	Nursing homes Mean age: SMI < 65: 51.12 (SD=9.81) SMI > 65: 75.59 (SD=7.24) Non-SMI < 65: 54.33 (SD=8.85) Non-SMI > 65: 80.94 (SD=7.74)	Using data from the national nursing home Minimum Data Set (MDS) clinical and functional assessment; 2005	Descriptive statistics; Comparison of proportions	7.5
#2. Lemke and Schaefer (2010) USA	Cross-sectional study	N=1,094,560 VA Nursing homes Mean age: SUD: 70.0 (SD=8.5) Non-SUD: 75.1 (SD=8.2)	Using data from the VA National Patient Care Database; Patient Assessment Instrument October 1999 – September 2000	Descriptive statistics; Chi-square analyses; t-tests; Bonferroni correction; Logistic regression analyses	6.5
#3. Fullerton et al. (2009) USA	Longitudinal study (dynamic population) and cross-sectional study	N=27,002 Nursing homes Mean age: 80.9 Longitudinal study: N=7364,470 Cross-sectional study: N=996,311	Using data from the national nursing home Minimum Data Set (MDS) resident assessment instrument Longitudinal: 1999 – 2005 Cross-sectional: 2005	Descriptive statistics; Chi-square test;	7.5
#4. Travis et al. (2004) USA	Cross-sectional study	Nursing homes Mean age: 72.8 (SD=13.6) N=548,572	Using data from the national nursing home Minimum Data Set (MDS) 2002	Descriptive statistics, using the statistical software package SAS	7.5
#5. Buchanan et al. (2003) USA	Cross-sectional study	Nursing homes Mean age: MS-D: 55.9 (SD=13.6) MS-D: 58.4 (SD=14.0)	Using data from the national nursing home Minimum Data Set (MDS) 23 June 1998 – 31 December 2000	Descriptive statistics, using the statistical software package SAS; Two sample tests for comparisons of proportion and for continuous variables were used; Two-way contingency table chi-squared test	3.5
#6. Buchanan et al. (2002) USA	Cross-sectional study	N=14,009 Nursing homes Mean age: HIV-D: 48.0 (SD=15.1) HIV-D: 45.9 (SD=11.4) N=5114	Using data from the national nursing home Minimum Data Set (MDS) 23 June 1998 – 31 December 2000	Descriptive statistics, using the statistical software package SAS; Two sample tests for comparisons of proportion and for continuous variables were used; Two-way contingency table chi-squared test	3.5

SMI = Serious Mental Illness; MDS = Minimum Data Set; SUD = Substance Use Disorder; SAS = Statistical Analysis Software

Table 2 | Characteristics of included prevalence studies in selected subpopulations

Reference	Design	Setting and Sample	Methods and period of data gathering	Methods of data analysis	Quality score (max 8)
#7. Akner (2009) Sweden	Cross-sectional study	Nursing homes Mean age: 85.0 (SD=7.0) N=70 NH residents in stable clinical condition	Clinical examination (history and physical examination); Mini-mental state examination, Katz score; Review of the medical records; Serum chemical analysis (serum creatinine)	Descriptive statistics using the statistical software package SAS; t-test	2.5
#8. Placentino et al. (2009) Italy	Cross-sectional study	Residential facilities Mean age: 47.7 (SD=14.7) N=426 psychiatric patients	2001 - 2002 Structured Clinical Interview for DSM-IV, Brief Psychiatric Rating Scale, Global Assessment of Functioning Scale, Disability Assessment Schedule; Review of the medical records; physical examination, blood and serum chemical analyses, ECG	Descriptive statistics using the statistical software package SPSS; One-way ANOVA; Bonferroni test; Pearson and Spearman correlations	2.5
#9. De Girolamo et al. (2005) Italy	Cross-sectional study	Residential facilities Mean age: males: 48.6 females: 50.9 N=2962 severely mentally ill patients	22 month Standardized interviews; Review of the medical records; The Health of Nation Outcome Scale, the Global Assessment of Functioning, the Physical Health Index	Descriptive statistics, using the statistical software package SPSS; X2 test with Yates' correction; t-tests; One-way ANOVA; Bonferroni method; Multiple logistic regression analysis.	4.5
#10. Schepers et al. (2000) The Netherlands	Case series	Nursing homes Mean age: 53 (SD=8,9) N=77 patients with Korsakoff's syndrome	Review of the medical records 01-01-1984 – 01-01-1998	Descriptive statistics, using the statistical software package SPSS; Kaplan-Meier method	2.5
#11. Trilling et al. (1998) USA	Cross-sectional study	Nursing homes N=804	Review of the medical records Unknown	Descriptive statistics; Pearson X2 statistic	2.5
#12. Mukherjee et al. (1996) Italy	Cross-sectional study	Long-term care facility Mean age: Sch+DM: 62.4 (SD=5.5) Sch-DM: 60.7 (SD=7.4) N=95 patients with schizophrenia	Review of the medical records Unknown	Descriptive statistics; X2 Mann-Witney U test	2.5

NH = Nursing Home; ECG = Electrocardiogram; ANOVA = Analysis of Variance; Sch = Schizophrenia; DM = Diabetes Mellitus

Table 3 | Characteristics of included other observational studies

Reference	Design	Setting and Sample	Methods and period of data gathering	Methods of data analysis	Quality score (max 8)	Main Results
#13. Barca et al. (2009) Norway	Cross-sectional study	Nursing homes Age: <80: N=167 80-84: N=234 85-89: N=246 >89: N=255 N=902	Neuropsychiatric Inventory nursing home version, Cornell Scale for Depression in Dementia, Clinical Dementia Rating scale, Physical Self-Maintenance scale; Review of the medical records November 2004 – January 2005	Univariate analyses using the statistical software package SPSS; Spearman's rho; Mann-Whitney U-test; Kruskal Wallis test; Linear regression analyses	5.5	In the adjusted analysis, depression according to the Cornell total score was associated with worse medical health (strongest) and worse cognitive impairment, but not with worse functional impairment. The mood subscale score was associated with worse medical health (strongest), pulmonary diseases, being unmarried and female gender, but not with worse cognitive impairment. The non-mood subscale score was correlated with cognitive impairment (strongest), worse medical health, younger age, digestive diseases and not having suffered from stroke.
#14. Jang et al. (2007) USA	Cross-sectional study (Survey)	Assisted living facilities Mean age: 82.8 (SD=9.41) N=150	Structured questionnaire, including the Geriatric Depression Scale (15 items), 5 items from the SF-36, a checklist of comorbid medical conditions, a 17 items composite measure to assess functional status, and control variables (age, gender, marital status and cognition (Short Portable Mental Status Questionnaire)) Summer 2004	Descriptive statistics; Bivariate correlations; Multivariate analyses (collinearity diagnostics were conducted with the Variance Inflation Factor); Regression analyses; Sobel test	4	In bivariate analysis, both chronic conditions and functional disability were positively associated with depressive symptoms. In a multivariate model, only functional disability was identified as a significant risk factor for depressive symptoms. But the analyses showed that the initially significant associations between health-related variables and depressive symptoms either became non-significant or decreased when health perceptions were controlled.
#15. Jang et al. (2006) USA	Cross-sectional study (Survey)	Assisted living facilities Mean age: 82.8 (SD=9.41) N=150	Structured questionnaire, including the Geriatric Depression Scale (15 items), 5 items from the SF-36, a checklist of comorbid medical conditions, a 17 items composite measure to assess functional status, and control variables (age, gender, marital status and cognition (Short Portable Mental Status Questionnaire)) Summer 2004	Descriptive statistics; Bivariate correlations; Hierarchical regression analyses	4	Higher levels of depressive symptoms were observed among older residents with greater level of functional disability, poorer self-rated health, lower sense of mastery, less religiosity, and less positive attitude towards aging. In addition, the linkages between physical and mental health were modified by psychosocial resources. For older residents with more positive beliefs and attitudes (a higher sense of mastery, greater religiosity, and more positive attitudes toward aging), the adverse effects of functional disability or poorer self-rated health on depressive symptoms were attenuated. Psychosocial resources have a protective role against physical health constraints.

Table 3 | Continued

Reference	Design	Setting and Sample	Methods and period of data gathering	Methods of data analysis	Quality score (max 8)	Main Results
#16. Jongeneelis et al. (2004) The Netherlands	Cross-sectional study	Nursing homes Mean age: 79.4 (SD=8.3) N=333	Face-to-face interview, including the Geriatric Depression Scale, the Schedule of Clinical Assessment in Neuropsychiatry, the Mini-Mental State Examination, Nottingham Health Profile (items concerning pain), Sickness Impact Profile (items concerning ADL), Loneliness Scale, Social Support List Interaction version, the Dutch Quality of Life scale. November 1999 – May 2001	Descriptive statistics; Bivariate analysis; Calculation of the odds ratios, with their 95% CI; Stepwise multivariate logistic regression analysis	4.5	Significant risk indicators for major depression: pain, functional limitations, visual impairment, stroke, loneliness, lack of social support, negative life events and perceived inadequacy of care. For sub-clinical depression the same risk indicators were found, with the exception of lack of social support.
#17. Cuijpers and Van Lammeren (1999) The Netherlands	Cross-sectional study	Residential facilities Mean age: 84.5 N=424	Pre-test data from an intervention study; Information from the staff (interview); Mini-Mental State Examination, Geriatric Depression Scale, the Medical Outcomes Study Short Form-20 (mental health subscale and pain subscale), seven items measuring limitations in instrumental activities of daily living, Questionnaire Recent Life Events, Social Support List Interaction version Unknown	Descriptive statistics; t-tests; ANOVA; Linear multiple regression analyses;	4.5	In the analysis of variance, the level of depressive symptoms did not differ significantly for the illnesses investigated in this study (lung disease, cardiac disease, peripheral atherosclerosis, diabetes mellitus, stroke, rheumatoid arthritis, cancer). This study found strong support for the significance of other risk factors for depression: earlier depression, life events, lack of social support, pain, and functional impairment. Possibly, the absence of a strong link between depressive symptomatology and chronic illness was because inhabitants of residential homes all had major physical, psychological or social limitations, which prevented them from living independently. If impairment was considerable and people could not live independently, then it could be hypothesized that the illness did not add very much to the risk of getting depressed, so other risk factors may become more important in this context.

Table 4 | Results of included prevalence studies based on national databases

#1 Aschbrenner	#2 Lemke	#3 Fullerton
SMI < 65 (N=13,730)	SUD (N=4,849)	Schizophrenia (N=5,404)
+ Diabetes: 29.90%	+ Diabetes : 31.1%	+ Diabetes: 31.5%
+ Obesity: 40.96%	+ CHF: 26.7%	+ Endocrine, excluding diabetes: 10.6%
+ CHF: 7.30%	+ Cerebrovascular disease: 35.4%	+ Cardiovascular: 55.5%
+ AHD: 3.30%	+ Neurological disorders: 21.2%	+ Musculoskeletal: 22.0%
+ Stroke: 6.43%	+ COPD: 55.0%	+ Neurological, excluding dementia: 11.2%
+ PD: 1.66%	+ Gastro-intestinal disorders: 64.7%	+ Pulmonary: 26.0%
+ COPD: 18.00%	+ Renal failure/nephritis: 14.7%	+ Sensory: 5.2%
	+ AIDS/HIV/hepatitis : 7.2%	+ Other: 29.3%
	+ Skin/subcutaneous infection: 23.2%	
SMI > 65 (N=13,913)	+ SMI: 30.2%	Bipolar disorder (N=5,299)
+ Diabetes: 28.48%	+ Depressive disorders: 43.6%	+ Diabetes: 28.0%
+ Obesity: 24.70%	+ PTSD: 10.8%	+ Endocrine, excluding diabetes: 15.9%
+ CHF: 13.81%	+ Verbal disruption: 7.5%	+ Cardiovascular: 56.1%
+ AHD: 9.19%	+ Injury: 55.3%	+ Musculoskeletal: 26.4%
+ Stroke: 10.29%		+ Neurological, excluding dementia: 10.3%
+ PD: 5.92%	Non-SUD (N=22,153)	+ Pulmonary: 25.5%
+ COPD: 21.98%	+ Diabetes : 41.2%	+ Sensory: 5.2%
	+ CHF: 34.0%	+ Other: 32.4%
Non-SMI < 65	+ Cerebrovascular disease: 41.2%	
(N=110,050)	+ Neurological disorders: 26.3%	Depression (N=154,262)
+ Diabetes: 37.72%	+ COPD: 41.4%	+ Diabetes: 30.3%
+ Obesity: 38.66%	+ Gastro-intestinal disorders: 53.1%	+ Endocrine, excluding diabetes: 12.1%
+ CHF: 11.58%	+ Renal failure/nephritis: 17.9%	+ Cardiovascular: 64.3%
+ AHD: 6.33%	+ AIDS/HIV/hepatitis : 2.1%	+ Musculoskeletal: 30.6%
+ Stroke: 14.08%	+ Skin/subcutaneous infection: 25.8%	+ Neurological, excluding dementia: 15.6%
+ PD: 0.94%	+ SMI: 19.1%	+ Pulmonary: 25.2%
+ COPD: 15.57%	+ Depressive disorders: 31.7%	+ Sensory: 7.3%
	+ PTSD: 5.0%	+ Other: 34.4%
Non-SMI > 65	+ Verbal disruption: 6.2%	
(N=956,867)	+ Injury: 44.3%	Anxiety disorder (N=22,513)
+ Diabetes: 27.26%		+ Diabetes: 24.9%
+ Obesity: 20.67%		+ Endocrine, excluding diabetes: 18.8%
+ CHF: 19.71%		+ Cardiovascular: 84.9%
+ AHD: 12.01%		+ Musculoskeletal: 48.1%
+ Stroke: 13.15%		+ Neurological, excluding dementia: 11.2%
+ PD: 2.54%		+ Pulmonary: 31.6%
+ COPD: 17.87%		+ Sensory: 12.7%
		+ Other: 60.3%
		Neither mental illness nor dementia (N=625,874)
		+ Diabetes: 28.4%
		+ Endocrine, excluding diabetes: 8.2%
		+ Cardiovascular: 58.7%
		+ Musculoskeletal: 26.4%
		+ Neurological, excluding dementia: 13.2%
		+ Pulmonary: 19.9%
		+ Sensory: 5.9%
		+ Other: 28.1%

#4 Travis	#5 Buchanan	#6 Buchanan
Diabetes (N=144,969) + depression: 30%	MS + depression : 36% MS without depression : 64%	HIV + depression: 20.7% HIV without depression: 79.3%
Non-Diabetes (N=403,603) + depression : 27.5%	MS + depression (36% of N=14,009) + Verbally abusive: 7.5% + Socially disruptive behaviour: 7.4% + Resists care: 13.3% + Delusions: 4.9% + Hallucinations: 4.6% + Anxiety disorder: 15.8% MS without depression: (64% of N= 14,009) + Verbally abusive: 4.6% + Socially disruptive behaviour: 5.0% + Resists care: 9.1% + Delusions: 1.1% + Hallucinations: 0.8% + Anxiety disorder: 3.6%	HIV + depression (20.7% of N=5114) + Delusions: 11.0% + Hallucinations: 9.8% + Anxiety disorder: 20.0% HIV without depression: (79.3% of N=5114) + Delusions: 1.9% + Hallucinations: 1.4% + Anxiety disorder: 2.9%

SMI: serious mental illness
PD: Parkinson's disease
CHF: congestive heart failure
AHD: arteriosclerotic heart disease
SUD: substance use disorder
PTSD: post traumatic stress disorder
MS: multiple sclerosis
HIV: human immunodeficiency virus

Table 5 | Results of included prevalence studies on selected subpopulations

#7 Akner	#8 Placentino	#9 De Girolamo	#10 Schepers	#11 Trilling	#12 Mukherjee
A total of 275 separate chronic health problems were identified.	Primary (psychiatric) diagnosis: Schizophrenia/psychotic disorders: 41.8%	Primary (psychiatric) diagnosis: Schizophrenic disorders: 68.2%	Comorbidity at admission: Neurological: 52/77	Hypertension: + Psychosis: 4.5%	Schizophrenia + diabetes: 15.8%
Average number of different health problems: 16.8 (SD=5.3, range 6-33).	Affective disorders: 35.4%	Bipolar disorders: 4.1%	Gastrointestinal: 25/77	+ Depression: 23.9%	< 50 years: 0%
Most frequent (≥50%): Neuropsychiatric: 100%	Personality disorders: 14.1%	Mental retardation and organic brain disorders (incl. dementia): 13.1%	Cardio-vascular: 20/77	+ Other mental disease: 8.2%	50-59 years: 12.9%
Cognitive impairment: 66%	Substance use disorders: 3.5%	Substance or alcohol abuse: 0.8%	Skeleton –muscular: 17/77		60-69 years: 18.9%
Brain ischemia: 53%	Mental disability: 3.1%	Other disorders (e.g. unipolar depression, anxiety disorders, eating disorders, other psychiatric disorders): 6.7%	Psychiatric: 15/77	Normotension: + Psychosis: 1.8%	70-74 years: 16.7%
Sleeping problems: 46%	Obsessive-compulsive disorders: 2.1%		Skin: 10/77	+ Depression: 14.0%	
Depression: 39%	Psychiatric comorbidity: 33.3%		Respiratory: 9/77	+ Other mental disease: 4.5%	
Anxiety disorders: 39%	Personality disorders: 42.9%		Chronic disorders diagnosed during admission: Psychiatric: 21/77		
Psychotic state: 26%	Substance use disorders: 39.4%		Cardio-vascular: 15/77		
Cardio-vascular: 78%	Affective disorders: 8.5%		Neurological: 13/77		
Gastrointestinal: 86%	Anxiety disorders: 7.1%	Moderate and severe physical disabilities: Cardiovascular: 7.5%	Gastrointestinal: 9/77		
Renal-urinary: 86%	Eating disorders: 2.1%	Respiratory: 5.2%	Endocrine: 8/77		
Endocrine-metabolism: 54%	Comorbid physical conditions: Cardio-vascular: 30%	Digestive: 5.0%			
Skeleton: 60%	Endocrine-nutrition-metabolic: 28.5%	Urogenital: 4.5%			
Pain: 73%	Gastrointestinal: 18.4%	Motor: 8.0%			
Eyes-vision: 64%	Respiratory: 7.5%	Central nervous system: 5.9%			
	Neurological: 7%	Endocrine-metabolic: 7.1%			
	Hematologic: 2.2%	Infective (incl. HIV+): 1.9%.			
	Physical injury: 1.8%				
	Sensory disorders: 1.5%				
	Immune disorders: 1%				
	Renal-urinary: 0.9%				
	Neoplasm: 0.7%				
	Psoriasis: 0.5%				

Characteristics and care needs of residents with both mental and physical disorders

Characteristics of LTC residents with mental-physical multimorbidity were embedded in the text of the studies rather than the primary focus of research. Therefore, for the second research question, relevant information is presented here as a narrative description.

Aschbrenner *et al.* (2011) found that newly admitted nursing home residents with serious mental illness (SMI) were younger and more likely to become long-stay residents than those admitted with other conditions. Newly admitted residents with SMI had higher rates of psychiatric histories and psychiatric medication use, but lower rates of dependence in transfer and less need for assistance with activities of daily living (ADLs).

Lemke and Schaefer (2010) found that, compared with other residents, the residents with SUDs were more likely to be younger, male, African-American, unmarried, and have a low income. SUD residents were more independent in ADLs. They were more likely to engage in verbal disruption but not in other problem behaviours such as aggression.

Fullerton *et al.* (2009) found that, compared with those who neither had mental illness nor dementia, residents with mental illness were in general younger and white (except for those with schizophrenia). Those admitted with schizophrenia or an anxiety disorder were less educated. Residents with schizophrenia or bipolar disorder were less likely to be married, had lower ADL scores and had higher levels of cognitive impairment than those with depression, anxiety disorder or neither mental illness nor dementia.

Placentino *et al.* (2009) and de Girolamo *et al.* (2005) reported that the majority of mentally ill residents in Italian LTC facilities was male, middle-aged (40-64 years) and had never been married.

Buchanan *et al.* (2002) found that HIV patients with depression were more likely to be older, female and white than other residents with HIV. HIV residents with depression were approximately twice as likely as other residents with HIV to have a history of mental health conditions; also they were more likely to have unsettled relationships, such as conflicts with staff, family, or friends, unstable health conditions, to be at the end stage of disease, and to have other diseases and infections.

In his other study Buchanan *et al.* (2003) found that MS patients with depression were more likely to be younger and female than other residents with MS; they were more likely to have a history of mental health conditions, and to have unsettled relationships. Both groups of MS residents had high levels of physical disability, although MS residents with

depression tended to be slightly less disabled, were more likely to experience daily pain and to have the diseases common to residents with MS.

None of the studies included in this review had examined care needs of residents with both mental and physical disorders.

Associations between mental and physical disorders

Of the 5 studies that investigated associations between mental and physical disorders, all concern associations between depression and medical conditions or health-related variables (Table 3).

In these studies, the following risk factors for depression were found: pain,^{47, 48} stroke,⁴⁸ number of chronic conditions,^{46, 35} functional impairment,^{35, 47, 48} negative life events,^{47, 48} and negative health perceptions.³⁶

Discussion

Main findings

This is the first systematic review of the literature describing older adults with multimorbidity of both physical and mental illnesses other than dementia, living in LTC facilities.

Prevalence rates

We found only one study⁴³ on multimorbidity focusing on the whole range of chronic physical and mental morbidity affecting older persons in a LTC facility. In this study among 70 LTC residents in Norway, nearly all patients were suffering from mental-physical multimorbidity. Because this study was conducted in a relatively small population, results are not generalizable. Therefore, the prevalence of multimorbidity of a wide range of chronic psychiatric and somatic conditions in a residential LTC population remains unclear.

All other studies included in this review show prevalence rates of comorbid physical and mental illnesses. These rates range from 0.5% (any psychiatric illness + psoriasis) to 84.9% (anxiety disorder + cardiovascular disorder). Depression appears to be the most studied psychiatric disorder. The prevalence of comorbid depression in LTC residents with a physical illness ranges from 20.7% to 36%.

These prevalence rates roughly correspond to the prevalence of mental-physical comorbidity in community-dwelling elderly.^{14,49-51} This means that the diseases in itself may not be the decisive factor for admission to a LTC facility. LTC residents probably have more severe symptoms and impairments than home-living elderly with the same diseases. Therefore it is of great importance that research on multimorbidity focuses not only on diagnoses but also on the ensuing symptoms, impairments, and care needs.

Characteristics and care needs

The findings here show that LTC residents with mental-physical multimorbidity are more likely to be younger, male, and unmarried than other LTC residents. Also, these residents more often have problem behaviour and cognitive impairment no dementia, whereas results regarding the need for assistance with ADLs are inconclusive. These differences in characteristics indirectly point to different care needs for LTC residents with and without mental-physical multimorbidity. Therefore, it is remarkable that there is no published research into the care needs of residents with mental-physical multimorbidity. This seriously hampers political decision-making on the strategies for future LTC delivery. In economic terms, Say's law will work, i.e. people will ask for the care that is made available by the system. From a patient's perspective, it should be vice versa; the health care system should provide the care that is asked for by patients, based on their individual needs.

Associations between mental and physical disorders

Studies into associations between physical and mental disorders other than depression were not found. This is regrettable because these psychiatric disorders are common in the population of LTC residents without dementia,²⁴ and will only further increase by political trends to minimize the traditional asylum function of psychiatric hospitals.

More knowledge about associations and risk factors can contribute to improving the diagnostic process and to preventing or reducing complications due to specific (co) morbidity.

Methodological considerations

A limitation of any systematic review is the potential omission of relevant articles.

In this review, only studies with a substantive description of both chronic medical and psychiatric conditions were involved. Studies on multimorbidity only recording the number of diseases were excluded because in these studies it is not clear whether they

concern purely somatic multimorbidity or mental-physical multimorbidity. Furthermore, dementia was excluded a priori in the search strategy. Studies on dementia, however, might have secondary objectives relevant for the present review.

The study methods used in the selected studies vary and have some limitations.

Two studies were entirely or largely performed in VA nursing homes,^{38,44} whereas these have a special resident population. Most notably, VA nursing home residents are predominantly men, in contrast with the population of community nursing homes.³⁸

In 5 studies data from the MDS were used.^{26,33,34,37,39} The MDS is an important measurement tool used in the USA by the Centers for Medicare and Medicaid Services and the state health regulators. MDS data are collected on all nursing facility residents in the Medicare and Medicaid certified facilities and are used for two main purposes: to determine the appropriate daily case-mix nursing facility reimbursement rate for Medicare and Medicaid payment, and to create the MDS quality indicators.⁵² These purposes lead to unintended incentives for providers to both under or over report the presence of mental illness in the MDS.⁵³ This is why the use of the MDS to quantify prevalence and incidence rates of mental illness in nursing homes has drawbacks. Furthermore, the MDS depends on accurate recording of information by assessment nurses, including diagnoses. Studies have generally confirmed the reliability and validity of the MDS data,⁵⁴ but we have to keep in mind that the recorded diagnosis is not a validated method for assigning a diagnosis.²⁶

As a prevalence study, 5 of the 6 studies in selected subpopulations^{40,42-45} have a moderate methodological quality because of limitations in sampling and analysis. In these studies, no probability sampling was used, which implies that the results may not be representative for all LTC residents with the studied comorbidities.

In the 5 studies in which associations between mental and physical disorders were investigated,^{35,36,46-48} a methodological limitation is the fact that the determinants (risk factors) and the outcome (depression) are not measured independently from each other. Thus, no firm conclusions can be drawn about the strength of the associations, although these are necessary for health care planning and addressing patients' care needs.

Another difficulty within the context of health care planning and addressing patients' care needs is the diversity of LTC residents with mental-physical multimorbidity without dementia. This is supported by the heterogeneity of the study populations that, despite the strict inclusion criteria, were included in this review.

An important reason for this diversity relates to differences between countries regarding the structure and the organization of the health care system. The functions of LTC facilities in the different health care systems are not uniform.²⁸ For instance, in the USA the downsizing and closure of state hospitals has resulted in transinstitutionalization into nursing homes of many older persons with severe and persistent mental illness, especially those with severe psychiatric symptoms, cognitive deficits, functional and physical impairment, aggressive behaviours, and a lack of social support.^{10,55} As another example, during the process of deinstitutionalization the mental hospitals in Italy were replaced by small residential care facilities with an average number of places of 12.5. Two-thirds of the residents have a diagnosis of schizophrenia.⁵⁶ Finally, in the Netherlands residential facilities were developed alongside the mental hospital. Yet, this has not led to a substantial decrease in the total number of available hospital beds compared to other European countries.⁵⁷ Nevertheless, also in the Netherlands the number of nursing home residents with mental illness other than dementia is rising, partly as a result of changed policy towards both mental health care and long-term care for the elderly. International studies with similar designs across settings would reveal unique data.

Implications

Despite differences in LTC facilities, in all of them changes in the characteristics of their residents have occurred: an increasing number of them have both physical and mental problems.²⁶ This creates problems for maintaining the quality of care. LTC facilities for physically disabled elderly are not sufficiently staffed and funded to provide mental health care which conversely holds for physical care in mental health care facilities.

It is clear that changes in the characteristics of residents require adjustments in the informal, the community-based, and the institutional LTC system. Unfortunately, the current research findings do not answer the question which adjustments are preferred, because no information was found about care needs. Nevertheless, several authors underscore the importance of a comprehensive assessment to identify specific clinical and care needs.^{42, 43} Based on these needs, individually targeted treatment plans for each resident could be formulated and pursued, with special attention for mental health needs, advance care planning, and, if possible, discharge planning.^{33,34,38,39,41-43} Results of de Girolamo *et al.* (2005), Fullerton *et al.* (2009), Lemke and Schaefer (2010), and Aschbrenner *et al.* (2011), suggest that a number of nursing home residents with mental illness may have the functional capacity to live in the community if these patients could participate in appropriate rehabilitation programs during their stay in the nursing home and if there would be a strong local mental health infrastructure to deliver suitable support.

Conclusion

So far, little research has been conducted on multimorbidity focusing on the whole range of chronic physical and mental morbidity affecting older persons in LTC facilities, although it is common in LTC residents. Given the specific characteristics of the pertaining residents, more knowledge of their specific care needs is essential to improve the quality of care for these residents.

Possibly, there is not much difference in the need for LTC among older psychiatric patients with somatic comorbidity and elderly patients with a somatic disorder and psychiatric comorbidity. More than the diagnoses, symptoms and behaviour are responsible for the limitations in functioning and therefore for the content of the care needs. The split between mental and physical healthcare is probably not desirable for both groups of patients. They are most likely best served by one LTC facility in which care for residents with physical disorders, residents with psychiatric disorders, and residents with mental-physical multimorbidity, merge into each other in a hybrid manner. As such radical decisions must be based on empirical findings, the first step now should be to perform research on symptoms, impairments, behaviour and care needs of LTC residents with mental-physical multimorbidity.

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Appendix 1 | Methodological quality of included prevalence studies (Boyle, 1998)

	#1	#2	#3	#4	#5	#6	#7	#8	#9	#10	#11	#12
1 Was the target population defined clearly?	1	1	1	1	1	1	0.5	0.5	1	1	1	0.5
2 Was probability sampling used to identify potential respondents (or the whole population approached)?	1	1	1	1	?	?	0	0	1	0	0	0
3 Did characteristics of respondents match the target population?	1	0.5	1	1	?	?	?	?	?	?	0	?
4 Were the data collection methods standardized?	1	1	1	1	1	1	1	1	1	1	1	1
5 Were the survey instruments reliable?	1	1	1	1	1	1	0.5	0.5	0.5	?	0	0.5
6 Were the survey instruments valid?	0.5	?	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5
7 Were special features of the sampling design accounted for in the analysis, through appropriate weighting of the data, or the whole population approached?	1	1	1	1	?	?	0	?	?	0	0	0
8 Do the reports include confidence intervals for statistical estimates or was the whole population approached?	1	1	1	1	?	?	0	0	0.5	0	0	0
Quality score	7.5	6.5	7.5	7.5	3.5	3.5	2.5	2.5	4.5	2.5	2.5	2.5

1: Yes 0.5: Partly 0: No ?: Unknown

Appendix 2 | Methodological quality of included other observational studies (van der Windt *et al.*, 2000)

	#13	#14	#15	#16	#17
1 Are valid selection criteria used in the composition of the study population?	1	0.5	0.5	1	1
2 Is the response to the first measurement at least 80%?	0.5	?	?	0	0
3 Are the determinants determined with a valid and reliable method?	1	0.5	0.5	1	0.5
4 Is the exposure to the determinant assessed independently of knowledge about the outcome?	0	0	0	0	0
5 Is the outcome determined with a valid and reliable method?	1	1	1	1	1
6 Is the outcome assessed independently of knowledge about the determinants?	0	0	0	0	0
7 Is in the analysis adjusted for potential confounders?	1	1	1	1	1
8 Are there sufficient participants included in the study?	1	1	1	0.5	1
Quality score	5.5	4	4	4.5	4.5

1: Yes 0.5: Partly 0: No ?: Unknown





CHAPTER 4

Design of the MAPPING study

Introduction

The MAPPING study was set up to investigate characteristics and care needs of nursing home (NH) residents with mental-physical multimorbidity (MPM), and change in neuropsychiatric symptoms after admission to a geronto-psychiatric nursing home (GP-NH) unit.

Initially, the MAPPING study was designed as a cohort study of residents with MPM who were newly admitted to a GP-NH unit. All participants participated in a baseline assessment within 8 weeks of admission and a second time after 6 months. Since the admission rate of new residents on the participating units proceeded less rapidly than expected, a second group of participants was included consisting of residents who had been residing for at least 6 months on the GP-NH unit. For this group, the same inclusion criteria were applied, but only a single measurement was performed. By combining this group and the follow-up measurement of the primary sample, we increased the power of the cross-sectional study on the characteristics and care needs of residents with MPM.

Participants

Participants were recruited from Dutch NHs. Eligible NHs were those with a GP-NH unit which was explicitly mentioned on their website. To enhance external validity, no further selection criteria for NHs were applied and we contacted NHs spread across the country. This resulted in 43 potential participating organizations. Fifteen organizations, of which two with GP units in two different NH locations, responded positively, so 17 GP-NH units participated.

Residents 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 too severe mental or physical illness for reliable data collection, and (4) refusal to participate.

Procedures

The physician of the GP-NH unit determined in the first 2 weeks after a resident's admission whether he or she was eligible for participating in the study. If so, the physician requested written informed consent from the resident. If the resident did not meet the inclusion criteria or did meet one or more of the exclusion criteria, the physician listed age and sex of the resident and reason(s) for exclusion.

Six to ten weeks after admission of the resident and six months later (plus/min 3 weeks), several assessment instruments were administered to participating residents and licensed nurses who are specifically assigned to individual residents for care management purposes. Two questionnaires were completed by a relative. For this, separate consent were requested.

Data were collected between April 2012 and September 2015 by well-trained elderly care physicians with knowledge about and experience with residents with MPM. Acknowledging the frailty of the population, most of the assessment instruments were administered in face-to-face interviews. Medical and demographic data were collected from residents' medical files.

All collected data were related to the residents.

Table 1 summarizes all variables collected and their method of assessment.

Table 1 | Assessed resident characteristics

Variable	Assessment Instrument	Method
Demographics		Chart review
Chronic medical disorders	Classification: ICD-10	Chart review
Chronic psychiatric disorders	Classification: ICD-10	Chart review
Current psychiatric problems	Mini-SCAN	Resident interview
Drug use	Classification: ATC	Review of the medication file
Agitation / aggression	CMAI	Nurse interview
Anxiety	HADS-A	Resident interview
Apathy	AES-10	Nurse interview
Care dependency	CDS	Nurse interview
Cognition	5-MMSE	Test
	FAB	Test
Depression	GDS-15	Resident interview
Needs	CANE	Resident interview
Neuropsychiatric symptoms	NPI-NH	Nurse interview
Personality traits	HAP	Written questionnaire relative
	GPS	Written questionnaire relative
Quality of life	3 items from TOPICS-MDS	Resident interview
Social well-being	SWON	Nurse interview
	RISE	Nurse interview
Subjective perception of health status	5 items from RAND-36	Resident interview

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 (<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>) and the Code of Conduct for Health Research.¹

Measures

Primary outcome measures

Neuropsychiatric symptoms were assessed with the Neuropsychiatric Inventory Nursing Home version (NPI-NH). The NPI-NH is a modified version of the original Neuropsychiatric Inventory² designed to measure psychiatric symptoms in geriatric patients with dementia. The nursing home version was developed for use by professional caregivers within institutions and appeared to be valid and reliable for trained nursing staff.³ The NPI-NH has been translated into Dutch⁴ and can also be used as a screen for neuropsychiatric symptoms in an older population with neurological and/or psychiatric disorders (e.g. Parkinson's disease, bipolar disorder, schizophrenia, major depression).⁵

The NPI-NH includes 12 neuropsychiatric symptoms: delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, night-time disturbances, and appetite/eating changes. In each domain, a screening question is used to establish the presence or absence of the symptom cluster for the patient. If the response is positive, both the frequency (F) and the severity (S) of the 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. Furthermore, distress of the health care professional, due to these neuropsychiatric symptoms, can be determined.

Agitation and aggression were further assessed with the Cohen Mansfield Agitation Inventory (CMAI).⁶ This instrument is designed to assess 29 agitated or aggressive behaviours and has been extensively used for assessment purposes in nursing homes.

The original CMAI was validated by Miller.⁷ It is the only instrument specifically addressing agitation or aggression, which has been translated into Dutch.⁸ The frequency of each symptom is rated on a seven-point scale (1-7) ranging from 'never' to 'several times an hour'.

(Un)met needs were assessed with the Dutch version of the Camberwell Assessment of Needs in the Elderly (CANE).⁹ This instrument has been based on the structural model of the Camberwell Assessment of Need.¹⁰

The CANE is a semi-structured interview consisting of 24 areas that cover social, physical, psychological and environmental needs. The interview starts with an open question concerning a specific area, followed by questions regarding the help and (in)formal support that the patient receives in that particular area, as well as the amount of help and support that is needed. Satisfaction with the amount and quality of the received help and support was also assessed. The answers are used to rate a need as 'no need', 'met need' or 'unmet need'.

The CANE was shown to have very good validity and reliability.⁹ The Dutch version of the CANE has been tested and demonstrated acceptable construct and criterion validity and test-retest reliability.¹¹

Secondary outcome measures

Drug use was listed and coded according to the Anatomical Therapeutic Chemical (ATC) classification system (www.whocc.no). This pharmaceutical coding system divides drugs into different groups according to the organ or system on which they act and/or their chemical, pharmacological and therapeutic characteristics.

Chronic diseases were identified from the medical history and the physical examination at admission as written down in the medical record and registered in a list of 56 diagnosis groups of chronic diseases based on ICD-10 (International Statistical Classification of Diseases and Related Health Problems, 10th Revision¹²) codes.

Chronic psychiatric disorders were identified from the medical history as listed in the medical record.

Current psychiatric disorders were assessed according to DSM-IV-TR criteria¹³ with the computerized version of a short clinical interview for psychiatric diagnosis: the mini-SCAN.¹⁴ The mini-SCAN was developed under the auspices of the World Health Organization Advisory Committee as a more practical and shorter version of the

Schedules for Clinical Assessment in Neuropsychiatry (SCAN).¹⁵ The SCAN is a semi-structured psychiatric interview using the technique of cross-examination. This technique entails in-depth exploration of the symptoms in terms of severity, frequency and interference, until the interviewer is convinced that the criteria for the symptom are or aren't met. The interviewer has to ensure that sufficient information is gathered through cross-examination before the rating is given and should probe further, using his or her own questions when needed. The mini-SCAN has been described as a valid diagnostic instrument that can be used for clinical studies.¹⁴

Cognition was assessed with the Standardized Mini Mental State Examination (S-MMSE)¹⁶ and with the Frontal Assessment Battery.¹⁷

The MMSE¹⁸ is a widely used measure to screen for cognitive impairment and to document cognitive functioning changes over time.¹⁹ Eleven items assess orientation in time and place, attention and concentration, language, constructional ability and immediate and delayed recall memory. Scoring consists of a sum of correct responses, resulting in a continuous scale from 0 to 30 points.

Reliability and construct validity have been found to be satisfactory. Measures of criterion validity have shown high levels of sensitivity for moderate-to-severe cognitive impairment and lower levels for mild degrees of impairment. The MMSE scores have been found to be affected by age, education and cultural background.²⁰

Molloy *et al.* (1991) have developed a standardized version of the MMSE with explicit detailed guidelines for its administration and scoring. The S-MMSE has been shown to have a better interrater and intrarater reliability than the MMSE.²¹

The MMSE is more specific and sensitive in detecting cognitive deficits related to language and memory than frontal executive dysfunction. For this purpose, the Frontal Assessment Battery (FAB) was administered. The FAB consists of 6 subtests, each exploring one of the following functions related to the frontal lobes: conceptualization, mental flexibility, motor programming, sensitivity to interferences, inhibitory control, and environmental autonomy. For each subtest, 3 points can be achieved. The interrater reliability, internal consistency, and concurrent validity have been considered as good.¹⁷

Depressive symptom severity was assessed with the 15-item version of the Geriatric Depression Scale (GDS-15).²²

The original GDS²³ is a questionnaire with 30 dichotomous items, specifically developed for the elderly. Although the GDS-30 was designed for older people, some of the items

are not well applicable to elderly nursing home residents. Since its introduction, several shortened versions of the GDS-30 have been constructed. The GDS-15, for example, was constructed for use in physically ill patients and those with dementia, in order to improve its reliability and validity. The GDS-15 has appropriate properties for use as a screening tool²⁴⁻²⁶ and also for use as an instrument for repeated measurements in longitudinal research.^{27,28}

The GDS-8 is an even shorter version, in which the items that are not suitable for nursing home residents have been deleted. The 8-item GDS version has shown similar internal consistency and even better sensitivity and specificity estimates than the GDS-15.²⁹ In our study, the GDS-8 was derived from the GDS-15.

Anxiety symptoms were assessed with the anxiety section of the Hospital Anxiety and Depression Scale (HADS-A).³⁰ The Hospital Anxiety and Depression Scale (HADS) is a questionnaire comprising 14 items with a four-point Likert-scale: 7 items for anxiety (HADS-A) and 7 items for depression (HADS-D). The items on anxiety cover mainly generalized anxiety and panic attacks.

The HADS was found to perform well in assessing the symptom severity and caseness of anxiety disorders and depression³¹ in both somatic and psychiatric patients;³² the basic psychometric properties of the HADS were considered as quite good to very good.^{32,33}

Apathy was assessed with the abbreviated Apathy Evaluation Scale (AES-10).³⁴ The original Apathy Evaluation Scale (AES-18) was developed to characterize and quantify apathy in individuals aged 55 and older.³⁵ Lueken *et al.* (2007) refined the AES for the nursing home population by eliminating 8 items that either had no specificity owing to the mainly externally driven context in nursing homes, or were difficult to measure in residents with severe cognitive deficits. The AES-10 is an observational scale and consists of 10 items. Each item gives an example of apathetic behaviour. The items can be rated from 1 (not at all characteristic) to 4 (very characteristic).

The AES-10 performed well on different psychometric properties and correlated strongly with the original AES-18; it can be used to distinguish apathy and non-apathy, in residents with and without dementia.³⁶

Care dependency was assessed with the Care Dependency Scale (CDS).³⁷ The CDS consists of 15 items on basic functional care demands that are scored on a 5 point Likert scale; the total score ranges from 15 (completely dependent on care) to 75 (almost independent of care). The NH version of the CDS was found to be reliable and valid for use in both physically disabled nursing home residents and those with dementia.³⁸

Personality traits were assessed with the Dutch informant personality questionnaire (the HAP)³⁹ and with the Gerontological Personality disorders Scale (GPS).⁴⁰

The HAP was especially developed for clinical practitioners in Dutch nursing homes who need a tool using informant information in order to assess 10 premorbid personality traits of older adults (i.e. socially avoidant behaviour, uncertain behaviour, vulnerability in interpersonal relationships, somatizing behaviour, disorderly behaviour, rigid behaviour, perfectionist behaviour, antagonistic behaviour, self-satisfied behaviour, unpredictable and impulsive behaviour). The HAP has 62 age-neutral items, which have to be assessed by the informant as 'yes', 'more or less', or 'no'. The psychometric properties of the HAP, applied in nursing home and elderly psychiatric patient populations, were described as generally reasonable to excellent.⁴¹

The GPS is a screening instrument for personality disorders, based on the general diagnostic criteria of the DSM-IV-TR.⁽¹³⁾ It consists of two versions (one for patients and one for informants), each with seven items concerning habitual behaviour (HAB) and nine items concerning biographical information (BIO). The sensitivity and specificity of the 16 items in the patient version were defined as reasonable.⁴² If the resident did not agree with sending the HAP to an informant or if there was no suitable informant, the score on the GPS could provide some information about the possibility of the presence of a personality disorder.

Subjective perception of health status was assessed with the corresponding items of the RAND-36.⁴³ The RAND-36 is a multi-dimensional instrument to capture general health. The Dutch version of the RAND-36 was shown to be reliable, valid and sensitive.⁴⁴

Quality of life was assessed with 3 questions about the perceived quality of life and with two questionnaires about social well-being.

The questions about the perceived quality of life were taken from the TOPICS-MDS, the minimum data set of the Dutch 'National Care for the Elderly Programme'.⁴⁵ Commissioned by the Ministry of Health, Welfare and Sport, this programme aims to improve care and support for elderly people with complex care needs (<https://www.beteroud.nl/topics-mds-database-vragenlijst.html>).

The following questions were asked:

- 1 How is your quality of life in general? (excellent, very good, good, reasonable, poor);
- 2 Which report mark would you give your life at this moment? (a number between 0 and 10);
- 3 How is your quality of life in general, in comparison to one year ago? (much better, slightly better, about the same, slightly worse, much worse).

The two questionnaires about social well-being concern the Social Well-being Of Nursing home residents-scale (SWON)⁴⁶ and the Revised Index for Social Engagement (RISE).⁴⁷

The SWON is an observational measurement scale for social well-being in nursing home residents, assessing both the social behaviour of the resident towards others and the social behaviour of others towards the resident. The SWON consists of nine items and has been found to have satisfactory psychometric properties, including interrater reliability and test-retest reliability.⁴⁶

The RISE is the revised version of the Index for Social Engagement (ISE)⁴⁸, an observational scale that measures positive features of long-term care residents' social behaviour through six dichotomous items. In comparison with the ISE, the RISE is an improved index by including additional dimensions of social engagement. The RISE has also been shown to have higher interrater item reliability and scale reliability in residents with moderate to severe cognitive impairment.⁴⁷

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**Characteristics and health
conditions of a group of nursing
home patients with mental-
physical multimorbidity**

The MAPPING study

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Abstract

Background

Long-term care facilities have partly taken over the traditional asylum function of psychiatric hospitals and house an increasing group of patients with mental-physical multimorbidity (MPM). Little is known about the characteristics, behaviour and care dependency of these patients. This paper aims to describe these aspects.

Methods

Explorative, descriptive study among patients with MPM without dementia (n=142), living in 17 geronto-psychiatric nursing home (NH) units across the Netherlands, stratified by those referred from mental healthcare services (MHS) and other healthcare services (OHS). Data collection consisted of chart review, semi-structured interviews, (brief) neuropsychological testing, and self-report questionnaires. Patients referred from MHS (n=58) and from OHS (n=84) were compared by descriptive statistics.

Results

Despite exclusion of patients with dementia, the majority of participants had cognitive impairment. Prevalence and severity of frontal impairment were high, as well as the number of patients with clinically relevant neuropsychiatric symptoms. MHS patients were younger, had more chronic psychiatric disorders and more often used antipsychotics. Neuropsychiatric symptoms, domains of care dependency, physical conditions and concomitant medication use differed not significantly between the subgroups.

Conclusions

Both groups of patients with MPM showed heterogeneity in various aspects but differed not significantly regarding the consequences of their multimorbidity. In a variety of characteristics, this group seems to be different from other NH patient groups, which requires extra knowledge and skills of the staff. To uncover which knowledge and skills are necessary, the next step should be to investigate the specific care needs of NH patients with MPM without dementia.

Key words mental-physical multimorbidity, geriatric psychiatry, long-term care, nursing home

Introduction

Nursing homes (NHs) provide some of the highest levels of care to patients having a wide array of physical or mental disorders who do not need to be in a hospital but cannot be cared for at home.

In the Netherlands, NHs house their patients in units that provide specific care to a particular group, for example, in dementia special care units or units for physically frail elderly.¹ In this latter unit type, more and more patients also have mental and/or behavioural problems in addition to their physical morbidity. This concerns older patients with primarily physical disorders that are accompanied by neuropsychiatric symptoms forming part of a physical disease, a relapse of existing psychiatric conditions triggered by physical problems, or physically frail patients with a late-onset psychiatric disorder.²

The fact that their number increases in NHs is understandable. For decades, the number of elderly people in our society has been rising. This trend has gained momentum since 2010, because from that year on baby boomers have been reaching the age of 65 years. Since mental-physical multimorbidity (MPM) is common in older people,³ the number of elderly people with MPM is also increasing rapidly, which leads to more patients being admitted to a NH because of their need for 24/7 multiprofessional care. In the Netherlands, they usually are referred to a NH by healthcare services, such as district nursing, general practices, hospitals, rehabilitation clinics, and other long-term care facilities.

Next to the graying society, a second trend is responsible for the growing number of patients with MPM referred to LTC facilities. Since the 1950s, deinstitutionalization has dominated mental healthcare reforms in most industrialized countries. As a result, the total number of psychiatric hospital beds has decreased dramatically.⁴ Since then, LTC facilities have partly taken over the traditional asylum function of psychiatric hospitals.⁵ Nowadays, approximately one-fourth of newly admitted NH patients has a mental illness such as schizophrenia, bipolar disorder, depression, or anxiety disorder.² These patients are mainly referred to a NH by mental healthcare services.

In the Netherlands, some traditional NHs are evolving toward centres for specialized care, among others for patients with MPM. Most of these centres have decided to house the two etiologically different groups of NH patients with MPM together on separate units, so-called geronto-psychiatric nursing home (GP-NH) units, because daily practice shows that the care needs of NH patients with MPM differ from the traditional patients in NHs having dementia and/or physical multimorbidity.⁶ This is supported by the few studies about patients with MPM in LTC facilities.⁷ These suggest that LTC patients with MPM are

more likely to be younger, male, and unmarried than other LTC patients. Also, they more often have challenging behaviour and cognitive impairment no dementia. However, in the literature a clear overview of the characteristics of long-term care patients with MPM is lacking entirely.³

In order to create care that is appropriate for the needs of patients with MPM and that contributes to optimizing their well-being, more knowledge about this patient group is therefore the necessary first step. Accordingly, the primary aim of this study is to describe the demographics, physical and psychiatric morbidity, medication use, and care dependency of patients with MPM without dementia residing in GP-NH units. Because in these units care is provided for both patients with physical multimorbidity complicated with psychiatric conditions and for psychiatric patients with physical multimorbidity, the secondary aim is to describe whether the characteristics differ for these two groups.

Methods

The **MAPPING** study (a study in patients with **mental and physical problems** residing in Dutch **nursing homes**) is an explorative, descriptive, cohort study.

Participants

Participants were recruited in Dutch NHs. Eligible NHs were those with a GP-NH unit. To enhance external validity, we contacted NHs spread across the country that explicitly mentioned on their websites that they have a GP-NH unit. This resulted in 43 potential participating organizations. Fifteen organizations, of which two with GP units in two different NHs, responded positively, so seventeen GP-NH units participated. No further selection criteria for NHs were applied.

The MAPPING study includes two groups of participants. The first group consists of patients who were newly admitted to a GP-NH unit. In this group two measurements were performed: at baseline and a follow-up after six months. Since the admission rate of new patients on the participating GP-NH units proceeded less rapidly than expected, a second group of participants was added to enlarge the power of the study. This group consists of already residing patients on the GP-NH unit who met all the inclusion criteria. In this group a single measurement was performed. The patient characteristics in both groups were found not to differ significantly from each other in respect to age, sex, marital status, level of education, and cognitive functioning.

Patients were included if (1) they needed both physical and psychiatric care, as shown in the medical history, (2) the psychiatric or behavioural problems had been present for 2 years or longer without prospect of substantial recovery and (3) they stayed for at least 6 months on the GP-NH unit. Exclusion criteria were: (1) dementia, (2) inability to give informed consent, (3) a too severe mental or physical illness for reliable data collection, and (4) refusal to participate. The physician of the GP-NH unit determined whether a patient met all these criteria; if so, written informed consent was requested from the patient by the physician.

In this paper, we present a cross-sectional overview of the data collected from all participants. Of the group of newly admitted patients data of the follow-up measurement were used in order to rule out confounding by temporary distress due to admission on the GP-NH unit at the time of the baseline measurement.

Data collection and assessments

Data collection took place between April 2012 and September 2015 and was carried out by the researcher (AvdB) and a research assistant (MdV). Both are certified elderly care physicians, a medical specialty in nursing home and primary care geriatric medicine in the Netherlands.⁸ Beforehand they were trained in administering the assessment instruments. 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 file. Registered were: age, gender, ethnicity, marital status, level of education, residence prior to admission to the NH, and all known chronic conditions. These conditions were classified in a list of 56 diagnosis groups of chronic diseases based on ICD-10 codes (International Statistical Classification of Diseases and Related Health Problems, 10th Revision). Medication use was retrieved from pharmacy files. Drugs were classified using the Anatomical Therapeutic Chemical classification (ATC).

In addition to the registration of chronic psychiatric disorders by chart-review, *current psychiatric disorders* were assessed with the mini-SCAN,⁹ a semi-structured diagnostic interview. The mini-SCAN is a shortened and computerized version of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN),¹⁰ developed under the auspices of the World Health Organization Advisory Committee. The mini-SCAN covers a wide range of Axis I disorders. Severity, frequency and interferences of individual psychiatric symptoms and signs are explored bottom-up, i.e. the rater must decide whether a symptom/sign is present, whereafter a computerized algorithm enables psychiatric diagnoses to be made. The mini-SCAN has good diagnostic properties for current psychiatric disorders.⁹

Cognition was assessed with the Standardized Mini Mental State Examination (S-MMSE)¹¹ and the Frontal Assessment Battery (FAB).¹² The MMSE¹³ is a widely used measure to screen for cognitive impairment. Scoring consists of a sum of correct responses on 11 items, resulting in a continuous scale from 0 to 30 points. The standardized version with explicit detailed guidelines for its administration and scoring was applied. The S-MMSE has been shown to have a better interrater and intrarater reliability than the MMSE.¹¹ The MMSE is more specific and sensitive in detecting cognitive deficits related to language and memory rather than frontal executive dysfunction.¹⁴ For this purpose, the FAB is administered. This test consists of 6 subtests, each exploring one of the following functions related to the frontal lobes: conceptualization, mental flexibility, motor programming, sensitivity to interferences, inhibitory control, and environmental autonomy. For each subtest, 3 points can be achieved, which are summed into a score ranging from 0-18. The interrater reliability, internal consistency, and concurrent validity were found to be good.¹²

Neuropsychiatric symptoms and agitation were assessed with the Neuropsychiatric Inventory Nursing Home version (NPI-NH) and the Cohen Mansfield Agitation Inventory (CMAI) respectively. The NPI-NH is a modified version of the original Neuropsychiatric Inventory¹⁵ designed to measure psychiatric symptoms in geriatric patients with dementia. The nursing home version was developed for use by professional caregivers within institutions and was found to be valid and reliable for trained nursing staff.¹⁶ The NPI-NH can also be used as a screen for neuropsychiatric symptoms in an elderly neuropsychiatric population.¹⁷ 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. The CMAI is designed¹⁸ and validated¹⁹ to assess 29 agitated behaviours and has been extensively used for assessment purposes in NHs. The frequency of each symptom is rated on a seven-point scale (1-7) ranging from 'never' to 'several times an hour'. Total score ranges from 29 to 203.

Care dependency was assessed with the Care Dependency Scale (CDS).²⁰ The CDS consists of 15 items on basic functional care demands that are scored on a 5 point Likert scale; the total score ranges from 15 (completely dependent on care) to 75 (almost independent of care). The NH version of the CDS was found to be reliable and valid for use in both physically disabled NH patients and those with dementia.²¹

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 (<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>) and the Code of Conduct for Health Research.²²

Analysis

In accordance with previous studies, MMSE-scores were categorized into no (≥ 24), mild (21-23) and moderate (≤ 20) cognitive impairment.^{23,24} The presence of frontal impairment was defined as FAB-score ≤ 12 .²⁵ Neuropsychiatric symptoms with a F x S score > 3 on the NPI-NH were considered clinically relevant.²⁶ Relevant agitation measured with the CMAI was defined as behaviour occurring at least once a week (frequency score > 2).²⁷

The data were analyzed for the entire group and, in order to describe whether characteristics differ for the two etiologically different groups, also stratified by the referring health services (mental healthcare services (MHS) or other healthcare services (OHS)).

Categorical variables were summarized as percentages (number); continuous variables were summarized as means (Standard Deviation; minimum-maximum) or medians (InterQuartile Range). Comparison of patients referred from MHS and patients referred from OHS, was performed by cross tabulation with χ^2 tests for nominal variables, with Student's t-tests for independent samples in the case of normally distributed continuous variables, and with Mann-Whitney U tests for independent samples if continuous variables were not normally distributed. Although correcting for multiple comparisons may increase the risk of type II error, we did not correct for multiple testing, because our study was explorative. Instead, we have chosen to present all individual p-values combined with the descriptives. Statistical analysis was carried out using SPSS version 22.0.o.1.

Results

One hundred seventy patients were eligible for enrollment into the study. Twenty-eight of them (man: 57,1% (n=16), mean age: 71,4 years (SD= 9.3)) did not agree to participate. One hundred forty two patients provided informed consent and data of these patients were collected.

Patient characteristics

The patient characteristics are presented in Table 1, showing slightly more women than men, with a mean age of 70 years. Residents referred from MHS (n=58) were younger than those who were referred from OHS (n=84) ($t = -2.93$, $df = 140$, $p = .004$). The majority of the included patients had no partner. Nearly half of the patients had cognitive impairment ($MMSE \leq 23$) and almost 70% had frontal impairment ($FAB \leq 12$).

Table 1 | Patient Characteristics

	Total (n=142)	Referral from mental health- care services (n=58)	Referral from other health- care services (n=84) ^a	p-value
Age, y ^{b,c}	69.9 (11.5; 36-92)	66.6 (10.8; 36-86)	72.2 (11.5; 45-92)	0.004
Sex (% female) ^{d,e}	56.3% (80)	51.7% (30)	59.5% (50)	0.392
Native country ^{d,e}				0.122
The Netherlands	95.1% (135)	91.4% (53)	97.6% (82)	
Marital status ^{d,e}				0.221
Unmarried	26.8% (38)	31.0% (18)	23.8% (20)	
Married	15.5% (22)	17.2% (10)	14.3% (12)	
Divorced	27.5% (39)	31.0% (18)	25.0% (21)	
Widow(er)	30.3% (43)	20.7% (12)	36.9% (31)	
Level of education ^{d,e,f}				0.509
Low	34.3% (48)	39.7% (23)	30.5% (25)	
Medium	53.6% (75)	50.0% (29)	56.1% (46)	
High	12.1% (17)	10.3% (6)	13.4 (11)	
S-MMSE ^{g,h,i}	24 (20-27)	24.5 (19.8-27)	24 (20-27)	0.979
				0.123
Patients with:				
No cognitive impairment ($MMSE \geq 24$)	52.6% (72)	51.7% (30)	53.2% (42)	
Mild cognitive impairment ($MMSE 21-23$)	16.8% (23)	10.3% (6)	21.5% (17)	
Moderate cognitive impairment ($MMSE \leq 20$)	30.7% (42)	37.9% (22)	25.3% (20)	
FAB ^{b,c,j}	9.7 (4.4; 1-18)	10.0 (4.3; 2-18)	9.4 (4.5; 1-18)	0.419
Patients with frontal impairment ($FAB \leq 12$) ^{d,e}	69.6% (94)	66.7% (38)	71.8% (56)	0.572

^a Nursing home (26.1%; n=37), Residential home (11.3%; n=16), Independently at home (14.1%; n=20), Other (7.7%; n=11)

^b Mean (SD; min-max) ; ^c Student's t-test ; ^d % (n) ; ^e χ^2 -test ; ^f Missing data n=2 ; ^g Median (IQR) ; ⁱ Missing data n=5 ;

^j Missing data n=7

Physical conditions and associated use of medication

The median number of chronic physical conditions was 7 (IQR=5-9) (Table 2). More than three quarters of the patients had one or more diseases of the circulatory system. Diseases of the digestive system were present in 66.2% of all patients, followed by endocrine, nutritional and metabolic diseases in 58.2%. Both the mean number and the type of chronic physical conditions did not differ significantly between the two categories of patients.

Patients used a median number of 7 (IQR=4-9) types of medicines plus 1 (IQR=0-2) for pro re nata use. Almost everyone (99.3%) used drugs from the category 'alimentary tract and metabolism' with the following top-3: vitamins and mineral supplements (88.7%), laxatives (72.5%) and proton-pump inhibitors (62.7%). Of the patients 67.6% used analgesics, of which 35.2% on a daily basis. Drugs for the purpose of disorders of the cardiovascular system were used in 59.9%. Medication use for physical conditions did not differ significantly between both patient groups.

Psychiatric conditions and associated use of medication

The mean number of chronic psychiatric conditions as registered in the medical record was 2.2 (SD 0.9; range 1-5) (Table 3). Patients referred from MHS had less organic mental disorders than other patients (27.6% versus 50.0%; $\chi^2 = 7.13$, $df = 1$, $p = .009$), but more often mood disorders (60.3% versus 44.0%; $\chi^2 = 3.65$, $df = 1$, $p = .062$), anxiety disorders (39.7% versus 25.0%; $\chi^2 = 3.45$, $df = 1$, $p = .068$), and schizophrenia and other psychotic disorders (37.9% versus 11.9%; $\chi^2 = 13.31$, $df = 1$, $p < .001$). The median number of current psychiatric diagnoses (not including disorders of personality and behaviour) was 2 (IQR=1-2).

The mean number of psychotropic drugs that patients used, was 2.3 (SD=1.5; range 0-6); patients referred from MHS used more than those referred from OHS (2.8 versus 1.9; $t = 3.16$, $df = 140$, $p = .002$). The largest difference in percentage of psychotropic drug use regarded antipsychotics: 75.9% versus 32.1% ($\chi^2 = 24.83$, $df = 1$, $p < .001$). About half of all patients used an antidepressant. More than one third used anxiolytics and another 20% had a prescription for pro re nata use of an anxiolytic.

Table 2 | Physical conditions and associated use of medication

	Total (n=142)	Referral from mental health- care services (n=58)	Referral from other health- care services (n=84) ^a	p-value
Number of chronic physical conditions ^{b,c}	7 (5-9)	7 (5.8-8.3)	7 (5-9.8)	0.451
Patients with a certain physical condition ^{d,e}				
Diseases of the circulatory system	78.9% (112)	77.6% (45)	79.8% (67)	0.835
Diseases of the digestive system	66.2% (94)	62.1% (36)	69.0% (58)	0.471
Endocrine, nutritional and metabolic diseases	58.5% (83)	62.1% (36)	56.0% (47)	0.493
Diseases of the musculoskeletal system	54.2% (77)	58.6% (34)	51.2% (43)	0.397
Diseases of the nervous system	52.8% (75)	58.6% (34)	48.8% (41)	0.305
Diseases of the genitourinary system	52.8% (75)	55.2% (32)	51.2% (43)	0.733
Injury and other consequences of external causes	31.0% (44)	36.2% (21)	27.4% (23)	0.275
Diseases of the respiratory system	28.9% (41)	32.8% (19)	26.2% (22)	0.453
Diseases of the eye and adnexa	21.8% (31)	15.5% (9)	26.2% (22)	0.152
Diseases of the skin and subcutaneous tissue	21.1% (30)	24.1% (14)	19.0% (16)	0.532
Diseases of the ear and mastoid process	17.6% (25)	15.5% (9)	19.0% (16)	0.658
Neoplasm	14.8% (21)	10.3% (6)	17.9% (15)	0.240
Diseases of the blood and blood-forming organs	13.4% (19)	19.0% (11)	9.5% (8)	0.134
Other	6.3% (9)	8.6% (5)	4.8% (4)	0.487
Infectious and parasitic diseases	3.5% (5)	3.4% (2)	3.6% (3)	1.000
Number of medications associated with physical conditions ^{b,c}	8 (5-11)	8 (4-11)	8 (5-11)	0.455
Scheduled	7 (4-9)	7 (3-10)	7 (4-9)	0.827
Pro Re Nata	1 (0-2) ^f	1 (0-2)	1 (0-2)	0.123

^a Nursing home (26.1%; n=37), Residential home (11.3%; n=16), Independently at home (14.1%; n=20), Other (7.7%; n=11) ; ^b Median (IQR) ; ^c Mann-Whitney U test ; ^d % (n) ; ^e χ^2 -test ; ^f Analgetics: 0.42 Laxatives: 0.41 Other: 0.37 (sympaticomimetics, nitrovasodilators, antidiabetics, ophtamologicals)

Table 3 | Psychiatric disorders and associated use of medication

	Total (n=142)	Referral from mental health- care services (n=58)	Referral from other health- care services (n=84) ^a	p-value
Medical records:				
Number of chronic psychiatric disorders ^{b,c}	2.2 (0.9; 1-5)	2.4 (1.0; 1-5)	2.1 (0.9; 1-4)	0.027
Patients with a certain psychiatric disorder ^{d,e} :				
Organic mental disorder	40.8% (58)	27.6% (16)	50.0% (42)	0.009
Substance use	16.9% (24)	25.9% (15)	10.7% (9)	0.023
Schizophrenia and other psychotic disorders	22.5% (32)	37.9% (22)	11.9% (10)	0.000
Mood disorders	50.7% (72)	60.3% (35)	44.0% (37)	0.062
Anxiety disorders	31.0% (44)	39.7% (23)	25.0% (21)	0.068
Disorders of personality and behaviour	43.7% (62)	41.4% (24)	45.2% (38)	0.731
Other	12.7% (18)	6.9% (4)	16.7% (14)	0.123
Mini-SCAN based diagnoses:				
Number of current psychiatric disorders ^{f,g}	2 (1-2)	2 (1-2)	1 (1-2)	0.048
Patients with a certain psychiatric disorder ^{d,e} :				
Organic mental disorder	57.7% (82)	56.9% (33)	58.3% (49)	0.865
Substance use	4.9% (7)	6.9% (4)	3.6% (3)	0.444
Schizophrenia and other psychotic disorders	21.8% (31)	24.1% (14)	20.2% (17)	0.680
Mood disorders	45.1% (65)	51.7% (30)	40.5% (35)	0.230
Anxiety disorders	23.9% (34)	32.8% (19)	17.9% (15)	0.047
Other	8.5% (12)	5.2% (3)	10.7% (9)	0.360
Number of psychotropics ^{b,c}	2.3 (1.5; 0-6)	2.8 (1.5; 0-6)	1.9 (1.4; 0-6)	0.002
Patients with medication prescriptions in the category below ^{d,e} :				
Antidepressants	50.7% (72)	53.4% (31)	48.8% (41)	0.612
Antipsychotics	50.0% (71)	75.9% (44)	32.1% (27)	0.000
Anxiolytics	37.3% (53) ^h	44.8% (26)	32.1% (27)	0.120
Antiepileptics	30.3% (43) ⁱ	34.5% (20)	27.4% (23)	0.458
Hypnotics	21.8% (31) ^j	20.7% (12)	22.6% (19)	1.000
Anti-dementia drugs	1.4% (2)	1.7% (1)	1.2% (1)	1.000
Drugs used in addictive disorders	1.4% (2)	1.7% (1)	1.2% (1)	1.000
Patients without psychotropics	12.0% (17)	10.3% (6)	13.1% (11)	0.794

^a Nursing home (26.1%; n=37), Residential home (11.3%; n=16), Independently at home (14.1%; n=20), Other (7.7%; n=11); ^b Mean (SD; min-max); ^c Student's t-test; ^d % (n); ^e χ^2 -test; ^f Median (IQR); ^g Mann-Whitney U test;

^h Another 20.4% (n=29) has a prescription for pro re nata use of an anxiolytic; ⁱ Of these 43 patients 44.2% (n=19) have been diagnosed with epilepsy; ^j Another 8.5% (n=12) has a prescription for pro re nata use of a hypnotic

Behaviour and care dependency

The mean total NPI-NH FxS score was 28.0 (SD=16.2) (Table 4). 90.1% had clinically relevant neuropsychiatric symptoms. A majority of the patients (85.9%) had multiple clinically relevant symptoms (median=4; IQR=2-5). 'Irritability', 'agitation' and 'depression' were the most prevalent neuropsychiatric symptoms with rates of 63.4%, 50.0% and 45.8% respectively. Prevalence rates of all neuropsychiatric symptoms did not differ significantly between the two patient groups.

Agitated behaviour as assessed with the CMAI was present in 85.9% of the patients and 76.0% had multiple agitated behaviours (median=4; IQR=2-5). The most prevalent symptoms were 'complaining' and 'negativism', which both occurred more in OHS than in MHS patients (complaining: 65.5% versus 37.9%, $\chi^2 = 10.49$, $df = 1$, $p = .001$; negativism: 63.1% versus 39.7%, $\chi^2 = 7.58$, $df = 1$, $p = .006$). Other frequently occurring symptoms were 'constant request for attention' and 'general restlessness' with prevalence rates of 43.7% and 40.8% respectively, and 'cursing or verbal aggression' and 'repetitious sentences/questions' with prevalence rates of 33.8% and 31.7% respectively. Prevalence rates of these symptoms did not differ significantly between the two patient groups.

The mean total CDS score was 48.5 (SD=10.2) which corresponds to 'partially care dependent' (Dijkstra *et al.*, 2012). The care dependency varied considerably between patients, reflected by a broad range of the CDS sum score (22-70). The top-3 items on which patients showed the highest level of dependency in the MHS group was (1) avoidance of danger, (2) contact with others, and (3) daily activities, and in the OHS group (1) hygiene, (2) getting (un)dressed, and (3) mobility. Of the mean CDS-scores on the 7 items with the highest level of dependency, only 'getting (un)dressed' showed a significant difference between both patient categories ($t = 3.52$, $df = 140$, $p = .001$).

Table 4 | Behaviour and Care Dependency

	Total (n=142)	Referral from mental healthcare services (n=58)	Referral from other healthcare services (n=84) ^a	p-value
NPI				
Total NPI score ^{b,c}	26 (16-39.3)	30 (15.8-40.3)	25.5 (16-34.8)	0.535
Patients with a certain symptom ^{d,e} :				
Irritability	63.4% (90)	55.2% (32)	69.0% (58)	0.112
Agitation	50.0% (71)	41.4% (24)	56.0% (47)	0.124
Depression	45.8% (65)	39.7% (23)	50.0% (42)	0.236
Anxiety	38.7% (55)	41.4% (24)	36.9% (31)	0.604
Disinhibition	36.6% (52)	31.0% (18)	40.5% (34)	0.290
Apathy	33.8% (48)	41.4% (24)	28.6% (24)	0.149
Delusions	26.1% (37)	32.8% (19)	21.4% (18)	0.173
Eating change	22.5% (32)	34.5% (20)	14.3% (12)	0.007
Night time disturbances	16.9% (24)	13.8% (8)	19.0% (16)	0.498
Hallucinations	9.2% (13)	10.3% (6)	8.3% (7)	0.770
Euphoria	8.5% (12)	12.1% (7)	6.0% (5)	0.229
Aberrant motor behavior	8.5% (12)	8.6% (5)	8.3% (7)	1.000
CMAI				
Total CMAI score ^{b,c}	41 (35.8-50.3)	40.5 (33.8-47.3)	42 (36-54)	0.170
Patients with a certain behaviour ^{d,e} :				
Complaining	54.2% (77)	37.9% (22)	65.5% (55)	0.001
Negativism	53.5% (76)	39.7% (23)	63.1% (53)	0.006
Constant request for attention	43.7% (62)	39.7% (23)	46.4% (39)	0.492
General restlessness	40.8% (58)	39.7% (23)	41.7% (35)	0.863
Cursing or verbal aggression	33.8% (48)	27.6% (16)	38.1% (32)	0.211
Repetitious sentences/questions	31.7% (45)	34.5% (20)	29.8% (25)	0.585
Making strange noises	14.8% (21)	17.2% (10)	13.1% (11)	0.631
CDS				
Total CDS score ^{f,g}	48.5 (10.2; 22-70)	50.3 (10.0; 22-69)	47.2 (10.2; 27-70)	0.074
Mean item score (SD) of the 7 items with the highest level of dependency ^{h,g} :				
Avoidance of danger	2.70 (1.0)	2.53 (1.0)	2.81 (1.1)	0.121
Hygiene	2.77 (1.1)	2.98 (1.1)	2.62 (1.0)	0.042
Contact with others	2.79 (1.0)	2.64 (1.0)	2.89 (0.9)	0.117
Daily activities	2.82 (1.1)	2.79 (1.2)	2.85 (1.1)	0.784
Mobility	2.89 (1.1)	3.14 (1.2)	2.73 (1.0)	0.025
Getting (un)dressed	2.95 (1.4)	3.41 (1.2)	2.63 (1.3)	0.001
Recreational activities	2.95 (1.1)	3.05 (1.1)	2.88 (1.1)	0.368

^a Nursing home (26.1%; n=37), Residential home (11.3%; n=16), Independently at home (14.1%; n=20), Other (7.7%; n=11); ^b Median (IQR); ^c Mann-Whitney U test; ^d % (n); ^e χ^2 -test; ^f Mean (SD; min-max); ^g Student' t-test; ^h Mean (SD)

Discussion

To our knowledge, this is the first study that reports characteristics of NH patients with MPM. Despite exclusion of patients with dementia, the majority had cognitive impairment. Particularly the prevalence and severity of frontal impairment were high, as well as the number of patients with clinically relevant neuropsychiatric symptoms. Comparison of those referred from mental healthcare services (MHS) and other healthcare services (OHS) showed that the MHS group was younger, had more chronic psychiatric disorders and more antipsychotic drug use than the OHS group. Nonetheless, neuropsychiatric symptoms as well as items of care dependency did not significantly differ between both groups, except complaining and the need for help with getting (un)dressed, which occurred more in the OHS group. Median number and distribution of physical conditions and concomitant medication use also did not differ significantly between the both subgroups.

Overall, MHS patients had more psychiatric disorders, driven by psychotic disorders, substance use disorders, mood disorders, and anxiety disorders (the latter two differences not statistically significant). Nonetheless, organic disorders were more prevalent in the OHS patients. These differences suggest that MHS patients were primarily referred because of severe mental illness and/or personality disorders, while OHS patients for organic mental disorders and/or personality disorders.

These observed differences were less pronounced if current psychiatric disorders according to the mini-SCAN were considered. The higher prevalence rates of organic mental disorder in both patient groups and psychotic disorders among OHS patients identified by the mini-SCAN compared to the medical records point to under-diagnosing and/or under-reporting of these disorders in routine daily practice. The lower prevalence rates for current substance use, mood, and anxiety disorders in both groups, are probably associated with environmental factors, such as no supply of alcohol in a NH and the continued presence of staff. Regrettably, the decline in prevalence rates of mood and anxiety disorders is relatively small. Probably, this can be explained by one of the inclusion criteria: psychiatric or behavioural problems existing for 2 years or longer without prospect of substantial recovery. Because of therapy resistance these patients could be referred to the NH with the aim to guide them in coping with their limitations. Interestingly, although we are dealing with two etiologically different subgroups, these differ not much regarding behaviour and care dependency.

The fact that we hardly found statistically significant differences between both groups, particularly in cognition, neuropsychiatric symptoms and care dependency, can be regarded as a basis for housing the two subgroups together and developing care

standards for the entire group of NH patients with MPM. Our findings indicate that not the diagnoses, but symptoms and behaviour are responsible for the limitations in functioning and therefore for the content of the care needs.

As Seitz *et al.* (2010) reported in their systematic review, there are gaps in the existing literature in psychiatric disorders in LTC. Therefore, we were not able to compare our findings with similar studies. Because of the experience in practice that characteristics and care needs of NH patients with MPM differ from those of traditional NH patients, we discuss our results in the light of those from studies in NH patients with dementia and with only physical disorders.

The cognitive functions as measured with the MMSE (i.e. memory, orientation, language and concentration) were less impaired in our study population (median MMSE score: 24 (IQR=20-27)) than in patients on units for physically frail patients in Dutch NHs. In the AGED study, for instance, the mean score of the MMSE at baseline was 21.9 (SD=3,8) and only 36.9% of the patients had no cognitive dysfunction (MMSE score \geq 24).²³ In the Act in case of Depression (AiD) study, the mean score of the MMSE at baseline was 19.5 (SD=5.5).²⁸ On the other hand, executive functions as measured by the FAB (mean FAB score: 9.7 (SD=4.4)) were comparable to patients with dementia: Boban *et al.* (2012) found mean total FAB scores of 11.5 (SD=3.0) in patients with Alzheimer disease, 9.7 (SD=2.8) in patients with subcortical vascular cognitive impairment, and 9.7 (SD=3.9) in patients with fronto-temporal lobar degeneration.²⁹ Possibly, the combination of (neuro)psychiatric disorders and frontal cognitive impairment increases the need for hospitalization, resulting in high prevalence rates of impaired executive functioning in NH patients with MPM.

The total NPI-NH score in our study (median 26; IQR=16-39.3) was lower than found in geriatric psychiatry inpatients (mean 32.6 (SD=19.5)³⁰ and mean 31.5 (SD=25.5)³¹), but higher than in patients with dementia (mean 14.6 (SD=13.6)³²). In comparison with chronic NH patients with stroke, in our study more patients had agitation (50.0% versus 29.6%), delusions (26.1% - 9.9%) and hallucinations (9.2% versus 3.6%), and less had depression (45.8% versus 52.6%);³³ compared with NH patients with dementia, more MPM patients had depression (45.8% versus 20%) and less had aberrant motor behaviour (8.5% versus 29%).²⁷

Care dependency in patients in our study was comparable with physically frail NH patients (mean total score CDS 48.5 (SD=10.2) versus 51.7 (SD=15.9)²¹) but lower than in NH patients with dementia (37.2 (SD=17.1)²⁰) The results indicated that the domains with the highest levels of care dependency are different in NH patients with MPM, in those with only physical disorders and in those with dementia.^{20,21} 'Avoidance of danger',

'hygiene' and 'contact with others' are uppermost in domains of care dependency in patients with MPM, 'getting (un)dressed', 'hygiene' and 'mobility' in somatic NH patients, and 'learning ability', 'daily activities' and 'recreational activities' in NH patients with dementia. Interacting with patients who need physical care but who also have problems with estimating danger and initiating or maintaining social contact, requires specific skills of the nursing staff such as mediating and counseling abilities.

In this study, an extensive range of data was collected. Since the interviews were conducted by two elderly care physicians who are familiar with this patient group, the data are of good quality and there are only few missing data. However, some limitations must be mentioned. First of all, study participants were recruited from specialized geronto-psychiatric 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 modest 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 a (GP-NH) unit. Nevertheless, different profiles in GP-NH units could have influenced the severity of neuropsychiatric symptoms and care dependency of participants and also have limited the generalizability. Furthermore, despite the use of inclusion criteria, patients with severe symptoms may be underrepresented in our study population because the physician of the unit was responsible for judging whether a patient was able to participate in the study. Finally, albeit our sample is likely to be representative for patients with MPM admitted in Dutch NHs, the sample size is modest and representativeness for other countries remains unknown. Nonetheless, our data provide important information on the characteristics of NH patients with MPM.

Conclusion and recommendations

In order to create care and services that are appropriate for the specific needs of patients with MPM, we studied the characteristics of two groups of NH patients with MPM without dementia, one group referred from mental healthcare services and another group referred from other healthcare services. These groups were heterogeneous in many characteristics such as their physical and psychiatric multimorbidity, but differed not significantly regarding the consequences of these diseases for behaviour and care dependency. Because these consequences are decisive for the daily care, it seems appropriate to accommodate and support patients of both patients groups together once care has become more indispensable than cure.

Our study indicates that NH patients with MPM without dementia differ from NH patients with dementia and those with only physical illnesses in particular regarding age, cognitive functioning, challenging behaviour and domains of care dependency. Interacting with patients with this specific characteristics, probably requires extra knowledge and skills of the staff. To uncover which knowledge and skills are necessary, the next step should be to investigate the specific care needs of NH-patients with MPM without dementia; this is essential in order to improve the quality of care for these patients.

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**What do nursing home
residents with mental-physical
multimorbidity need and who
actually knows this?
A cross-sectional cohort study**

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Abstract

Objective

Aging societies will bring an increase in the number of long-term care residents with mental-physical multimorbidity. To optimize care for these residents, it is important to study their care needs, since unmet needs lower quality of life. To date, knowledge about care needs of residents with mental-physical multimorbidity is limited. The aim of this study was to explore (un)met care needs of residents with mental-physical multimorbidity and determinants of unmet needs.

Methods

Cross-sectional cohort study among 141 residents with mental-physical multimorbidity without dementia living in 17 geronto-psychiatric nursing home units across the Netherlands. Data collection consisted of chart review, semi-structured interviews, (brief) neuropsychological testing, and self-report questionnaires. The Camberwell Assessment of Need for the Elderly (CANE) was used to rate (un)met care needs from residents' and nursing staff's perceptions. Descriptive and multivariate regression analyses were conducted.

Results

Residents reported a mean number of 11.89 needs (SD 2.88) of which 24.2% ($n = 2.88$, SD 2.48) were unmet. Nursing staff indicated a mean number of 14.73 needs (SD 2.32) of which 10.8% ($n = 1.59$, SD 1.61) were unmet. According to the residents, most unmet needs were found in the social domain as opposed to the psychological domain as reported by the nursing staff. Different opinions between resident and nursing staff about unmet needs was most common in the areas accommodation, company, and daytime activities. Further, nearly half of the residents indicated 'no need' regarding behaviour while the nursing staff supposed that the resident did require some kind of support. Depression, anxiety and less care dependency were the most important determinants of unmet needs.

Conclusions

Systematic assessment of care needs showed differences between the perspectives of resident and nursing staff. These should be the starting point of a dialogue between them about needs, wishes and expectations regarding care. This dialogue can subsequently lead to the most optimal individually tailored care plan. To achieve this, nurses with effective communication and negotiation skills, are indispensable.

Key words cohort study, geriatric psychiatry, long-term care, multimorbidity, needs assessment, nursing homes, nursing staff

Introduction

Mental-physical multimorbidity is common in older people. Of this group, the number that is dependent on residential long-term care is increasing. Approximately one-fourth of newly admitted nursing home residents has a mental illness such as schizophrenia, bipolar disorder, depression, or anxiety disorder.¹ These residents differ from other resident groups residing in nursing homes. They are younger, have more chronic psychiatric disorders, more severe frontal impairment, and more clinically relevant neuropsychiatric symptoms.² As a result, it is very likely that residents with mental-physical multimorbidity will have specific care needs. Therefore, in some nursing homes so-called geronto-psychiatric units have been set up for residents with mental-physical multimorbidity.

As in all residential care facilities, person-centeredness should be the basis of care in these units, because this contributes to a better quality of life.³⁻⁵ Taking into account a resident's need is one of the key elements in providing person-centered care, which implies that the resident's needs should be clear.

Yet, although several studies have focused on care needs in populations of patients with varying mental illnesses, including dementia,⁶⁻⁸ there are no publications concerning care needs of nursing home residents with mental-physical multimorbidity without dementia.⁹

Perceived needs can be subdivided into met and unmet needs.¹⁰ A met need refers to a situation in which individuals have had difficulties in a particular area, but these are being adequately taken care of. An unmet need exists when the individual believes that he or she does not receive the right care or the appropriate level of care. The presence of unmet needs is a strong predictor of less favourable health perceptions and a lower quality of life.¹¹ Research shows that unmet needs lead to more behavioural problems and an increased caregiver burden,¹² both of which adversely affect quality of life,¹² and increase the risk of institutionalization.¹³

Studies in older patients found various determinants of unmet needs. A higher number of unmet needs was associated with more severe psychiatric symptoms,^{11,14,15} less social participation,⁷ and a lower number of medications.¹⁶ Inconsistent and even opposite results have been found with respect to age,¹⁷⁻¹⁹ sex,¹¹ education,^{16,18} level of functional dependency,^{11,16,18} and cognitive functioning.^{16,19} In studies of younger psychiatric patients, personality disorder was found to be independently associated with more (un)met needs,^{20,21} but no studies have examined these associations in elderly patients. However, based on our clinical experience, we also expect associations between personality traits and unmet care needs.

In addition to resident-related determinants, barriers in the organization and delivery of healthcare may contribute to unmet needs. In their conceptual framework for identifying unmet health care needs, Diwan and Moriarty described five potential barriers: availability, accessibility, affordability, acceptability of interventions, and recognition of need / knowledge of interventions.²²

Residents and nursing staff form their opinions on care needs from their own frames of reference. Previous research in which care needs were assessed both from the perspective of the resident as well as from that of the professional shows that they differ significantly in their view on the presence of needs and the extent to which these are fulfilled.^{7,23,24} Disagreement between residents and staff on needs may influence therapy compliance²⁵ and hence the experience of the quality of treatment.²³ This may be challenging, especially if the resident is convinced that he has no care need but the staff believes he has one, or if the resident has an unmet care need that is not perceived as such by the staff.

To achieve an individually tailored approach, knowledge about the needs of residents with mental-physical multimorbidity living in nursing homes is required. Therefore, the aim of this study is to gain insight into (1) the residents' and nursing staff's view of (un)met care needs of residents with mental-physical multimorbidity without dementia living in geronto-psychiatric nursing home units, (2) the differences between these views, and (3) determinants of unmet needs experienced by the resident.

Methods

The **MAPPING** study (a study in residents with **mental and physical problems** residing in Dutch **nursing homes**) is a cohort study. The design of the MAPPING study has been described extensively,² but will be summarized below.

Participants

Participants were recruited from 17 Dutch nursing homes with a geronto-psychiatric unit.

The MAPPING study included two groups of participants. The first group consisted of residents who were newly admitted to a geronto-psychiatric nursing home unit. In this group two measurements were performed: a baseline measurement and a follow-up after 6 months. Since the admission rate of new residents on the participating units proceeded less rapidly than expected, a second group of participants was included to enlarge the power of the study. This group consisted of residents who had been residing for at least

6 months on the geronto-psychiatric nursing home unit and who met all the inclusion criteria. In this group a single measurement was performed. The resident characteristics in both groups were found not to differ significantly from each other in respect of age, sex, marital status, level of education, and cognitive functioning.²

Residents 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 too severe mental or physical illness for reliable data collection, and (4) refusal to participate. The physician of the geronto-psychiatric nursing home unit determined whether a resident was eligible for participating in the study. If so, written informed consent was requested from the resident.

In this paper, we present a cross-sectional overview of the data collected from all participants. For the group of newly admitted residents data of the follow-up measurement were used.

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). Nursing home management boards gave permission for the study, which was conducted in accordance with the Declaration of Helsinki (<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>) and the Code of Conduct for Health Research²⁶ as well as the rules applicable in the Netherlands.

Data collection

Data collection took place between April 2012 and September 2015 and was carried out by the researcher (Anne van den Brink) and a research assistant (Miranda de Valk). Both are certified elderly care physicians, a medical specialty in nursing home and primary geriatric care in the Netherlands.²⁷ Beforehand they were trained in administering the assessment instruments. Data collection consisted of chart review, semi-structured interviews, (brief) neuropsychological testing, and self-report questionnaires.

Medical and demographic data were collected from the residents' medical file. Demographic characteristics were the resident's age, sex, ethnicity, marital status, level

of education and residence prior to admission to the nursing home. All known chronic conditions were classified in a list of 56 diagnosis groups of chronic diseases based on ICD-10 codes (International Statistical Classification of Diseases and Related Health Problems, 10th Revision).²⁸

Primary outcome: (un)met needs

Care needs were assessed with the Camberwell Assessment of Need for the Elderly (CANE)²⁹ by interviewing both the resident and a licensed practical nurse who knew the resident well. The CANE is designed as a comprehensive instrument for measuring a broad range of needs of older people with mental health problems. It 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 problem requiring intervention or assessment, for which currently no assistance or the wrong kind of help is received). The validity and reliability of the original scale are good²⁹ and acceptable for the Dutch version.³⁰ The CANE is applicable in elderly patients with different levels of cognitive functioning.^{29,30}

Determinants of unmet needs

Cognition was assessed with the Standardized Mini Mental State Examination (S-MMSE)³¹ and the Frontal Assessment Battery (FAB).³² The MMSE³³ is a widely used assessment instrument for screening cognitive impairment. Scoring consists of a sum of correct responses on 11 items, resulting in a continuous scale from 0 to 30 points. The standardized version with explicit detailed guidelines for its administration and scoring was applied. The S-MMSE has been shown to have a better interrater and intrarater reliability than the MMSE.³⁴ The MMSE is more specific and sensitive in detecting cognitive deficits related to language and memory than in detecting deficits in frontal executive functions.³⁵ For this purpose, the FAB is administered. This test consists of 6 subtests, each exploring one of the following functions related to the frontal lobes: conceptualization, mental flexibility, motor programming, sensitivity to interferences, inhibitory control, and environmental autonomy. For each subtest, 3 points can be achieved, which add up to a score ranging from 0 to 18. The interrater reliability, internal consistency, and concurrent validity were found to be good.³²

Social participation was assessed with the Revised Index for Social Engagement (RISE). The RISE is the revised version of the Index for Social Engagement (ISE),³⁶ an observational scale that measures positive features of long-term care residents' social behaviour through six dichotomous items. In comparison with the ISE, the RISE is an

improved index by including additional dimensions of social engagement. The RISE has also been shown to have higher interrater item reliability and scale reliability in residents with moderate to severe cognitive impairment.³⁷

Care dependency was assessed with the Care Dependency Scale (CDS).³⁸ The CDS consists of 15 items on basic functional care demands that are scored on a 5-point Likert scale; the total score ranges from 15 (completely dependent on care) to 75 (almost independent of care). The nursing home version of the CDS was found to be reliable and valid for use in both physically disabled nursing home residents and those with dementia.³⁹

Depression was assessed with the 8-item version of the Geriatric Depression Scale (GDS-8).

The original GDS⁴⁰ is a questionnaire with 30 dichotomous items, specifically developed for the elderly. Although the GDS-30 was designed for older people, some of the items are not well received by elderly nursing home residents. Since its introduction, several shortened versions of the GDS-30 have been constructed. The GDS-8 is a shorter version, in which the items that are not suitable for nursing home residents have been deleted. It shows good psychometric properties.⁴¹

Anxiety was assessed with the anxiety section of the Hospital Anxiety and Depression Scale (HADS-A). The Hospital Anxiety and Depression Scale (HADS)⁴² is a questionnaire comprising 14 items with a four-point Likert-scale: 7 items for anxiety (HADS-A) and 7 items for depression (HADS-D) during the past week. The items on anxiety cover mainly generalized anxiety and panic attacks.

The HADS was found to perform well in assessing the symptom severity and caseness of anxiety disorders and depression⁴³ in both somatic and psychiatric patients;⁴⁴ the basic psychometric properties of the HADS were considered as quite good to very good.^{44,45}

Personality traits were assessed with the Dutch informant personality questionnaire (the HAP).

The HAP⁴⁶ is especially developed for clinical practitioners in Dutch nursing homes who need a tool using informant information in order to assess 10 premorbid personality traits of older adults (i.e. socially avoidant behaviour, uncertain behaviour, vulnerability in interpersonal relationships, somatizing behaviour, disorderly behaviour, rigid behaviour, perfectionist behaviour, antagonistic behaviour, self-satisfied behaviour, unpredictable and impulsive behaviour). The HAP has 62 age-neutral items, which have to be assessed by the informant as 'yes', 'more or less', or 'no'. The psychometric properties of the HAP,

applied in nursing home and elderly psychiatric patient populations, are described as generally reasonable to excellent.⁴⁷

Analysis

The CANE item 'benefits' (getting all the money that the patient is entitled to) was excluded from the analyses because this information was usually not known to residents and the nursing staff. It is valid to leave out items, because individual CANE items have been separately evaluated on content validity and reliability.^{29,30}

Consistent with previous studies, we assumed cognitive impairment if the MMSE-score was ≤ 23 .^{48,49} The MMSE was considered as 'missing' if 8 or more tasks were not carried out.

The presence of frontal impairment was defined as a FAB-score ≤ 12 .⁵⁰ The FAB was regarded as 'missing' if more than half of the tasks were not carried out.

Missing answers on the HAP questionnaire were applied in accordance with the manual,⁴⁶ and the 10 HAP scales were corrected for positive and negative rating trends. Finally, based on the standard tables for nursing home residents as described in this manual, we have dichotomized the personality traits in present or not present. If a score was classed as high or very high in the standard table, we rated the personality trait as present.

In order to describe the characteristics of the resident sample, categorical variables were summarized as percentages (number) and continuous variables were summarized as means (Standard Deviation; minimum-maximum) or medians (InterQuartile Range). The frequency distributions of met and unmet needs in the different areas of the CANE were calculated. Comparisons between the mean total numbers of (unmet) needs as reported by the resident and nursing staff were conducted using the paired samples t-test.

Bivariate analyses (Pearson correlations, analysis of variance, t-tests) were used to investigate relationships between the total number of unmet needs and the potential determinants as based on the literature: age, sex, level of education, number of medications, number of chronic conditions, social participation, care dependency, depression, anxiety, and cognitive functioning.

Subsequently, variables that were statistically significant at a $p < 0.25$ level in the bivariate analyses were included in the multivariate regression model.⁵¹ A backward stepwise regression was carried out by removing the least significant variables one at a time until all contributed significantly ($p < 0.05$).⁵² Regression diagnostics were performed to investigate any violation of the assumptions of normality, linearity, multicollinearity and homoskedasticity. Any missing scales were excluded pair-wise.

A complete HAP-questionnaire was available in 75.2% (n = 106) of the study population. Refusal of consent by the resident to send the HAP-questionnaire to a relative or the lack of relatives were the most important reasons for missing HAP-questionnaires. This may create selection bias. Therefore, we did not include personality traits in the main model. Instead, we conducted a sensitivity analysis in order to study the impact of personality traits on the total number of unmet needs in the subgroup of 106 residents. The bivariate analyses for this sensitivity analysis were carried out with Mann-Whitney U tests. The regression analysis has been carried out in the same manner as described above, this time by also including personality traits that appeared to be statistically significant at a $p < 0.25$ level in the bivariate analyses. Statistical analysis was carried out using SPSS version 22.

Table 1 | Characteristics of the resident sample (N=141)

Characteristic	% (n)
Age, y ^a	69.9 (11.5; 36-92)
Sex (% female)	56.0% (79)
Country of origin	
The Netherlands	95.0% (134)
Marital status	
Unmarried	27.0% (38)
Married	15.6% (22)
Divorced	27.7% (39)
Widow(er)	29.8% (42)
Level of education ^b	
Low	33.8% (47)
Medium	54.0% (75)
High	12.2% (17)
Residence prior to admission to the geronto-psychiatric NH-unit	
Psychiatric hospital	41.1% (58)
Nursing home	26.6% (37)
Care home	11.3% (16)
Home	13.5% (19)
Other	7.8% (11)
Length of stay (months) ^a	8.6 (29.2; 3-137)
Number of chronic medical disorders ^a	7.4 (3.0; 2-18)
Number of chronic psychiatric disorders ^a	2.2 (0.9; 1-5)
MMSE ^{c,d}	24 (20-27)
FAB ^{a,e}	9.7 (4.4; 1-18)

^a Mean (SD; min-max) ; ^b Missing data n=2 ; ^c Median (IQR) ; ^d Missing data n=5 ; ^e Missing data n=6

Results

One hundred and forty-two residents were included and data of these residents were collected. One resident (female, 71 years) had to be excluded because of her refusal to submit to the CANE.

TABLE 2 | Ratings of (un)met needs in 23 individual CANE areas, according to resident and nursing staff (N=141)

Needs domains	Resident: met needs, % (n)	Nursing staff: met needs, % (n)	Resident: unmet needs, % (n)	Nursing staff: unmet needs, % (n)
Environmental				
Accommodation	62,4% (88)	85,1% (120)	37,6% (53)	14,9% (21)
Household activities	90,8% (128)	98,6% (139)	2,1% (3)	1,4% (2)
Food	81,6% (115)	94,3% (133)	10,6% (15)	5,7% (8)
Money	88,7% (125)	95,0% (134)	2,1% (3)	2,1% (3)
Caring for others	2,8% (4)	2,1% (3)	0,7% (1)	0% (0)
Physical				
Physical health	62,4% (88)	73,8% (104)	22,0% (31)	18,4% (26)
Medication	87,9% (124)	95,7% (135)	5,7% (8)	4,3% (6)
Eyesight/hearing	17,7% (25)	25, % (36) ^a	21,3% (30)	5,7% (8) ^a
Mobility	67,4% (95)	78,7% (111)	16,3% (23)	7,8% (11)
Self-care	79,4% (112)	92,9% (131)	2,1% (3)	2,1% (3)
Continence	36,9% (52)	56,7% (80)	9,9% (14)	6,4% (9)
Psychological				
Psychological distress	30,5% (43)	56,7% (80)	26,2% (37)	14,9% (21)
Memory	22,7% (32)	51,1% (72)	5,7% (8)	2,1% (3)
Behavior	17,1% (24) ^a	58,9% (83)	10,0% (14) ^a	15,6% (22)
Alcohol	2,8% (4)	17,7% (25)	0,7% (1)	1,4% (2)
Deliberate self-harm	5,7% (8)	5,7% (8) ^a	4,3% (6)	0% (0) ^a
Accidental self-harm	8,5% (12)	46,1% (65)	2,8% (4)	6,4% (9)
Psychotic symptoms	20,9% (29) ^b	34,8% (49)	9,4% (13) ^b	6,4% (9)
Social				
Company	26,2% (37)	55,7% (78) ^a	36,9% (52)	18,6% (26) ^a
Intimate relationships	1,4% (2)	5,2% (7) ^c	17,7% (25)	10,4% (14) ^c
Daytime activities	44,7% (63)	79,4% (112)	24,8% (35)	12,8% (18)
Information	21,4% (30) ^a	42,4% (59) ^b	12,1% (17) ^a	2,9% (4) ^b
Abuse/neglect	15,8% (22) ^b	53,2% (75)	7,2% (10) ^b	0,7% (1)

^a missing data n=1 ; ^b missing data n=2 ; ^c missing data n=6

Demographic and clinical characteristics

The resident characteristics are presented in Table 1, showing slightly more women than men, with a mean age of 70 years. Almost all participants were born in the Netherlands. The majority of the residents included had no partner. The average number of chronic conditions was 9.6 (SD 3.1, range 3-20). The median score of the MMSE was 24 (IQR 20-27) and the mean score of the FAB was 9.7 (SD 4.4, range 1-18).

Care needs

Residents reported a mean number of 11.89 needs (SD 2.88, range 1-18) of which 24.2% (mean number = 2.88, SD 2.48, range 0-11) were unmet. The nursing staff reported a mean number of 14.73 resident needs (SD 2.32, range 7-20) of which 10.8% (mean number = 1.59, SD 1.61, range 0-9) were unmet.

Residents rated a significantly lower number of needs ($t = -10.76$, $CI = -3.36$ - -2.32 , $p = 0.001$) than nurses did. Moreover, the number of unmet needs from the resident's perspective was significantly higher than when rated by the nursing staff ($t = 6.72$, $CI = 0.90$ - 1.65 , $p = 0.001$).

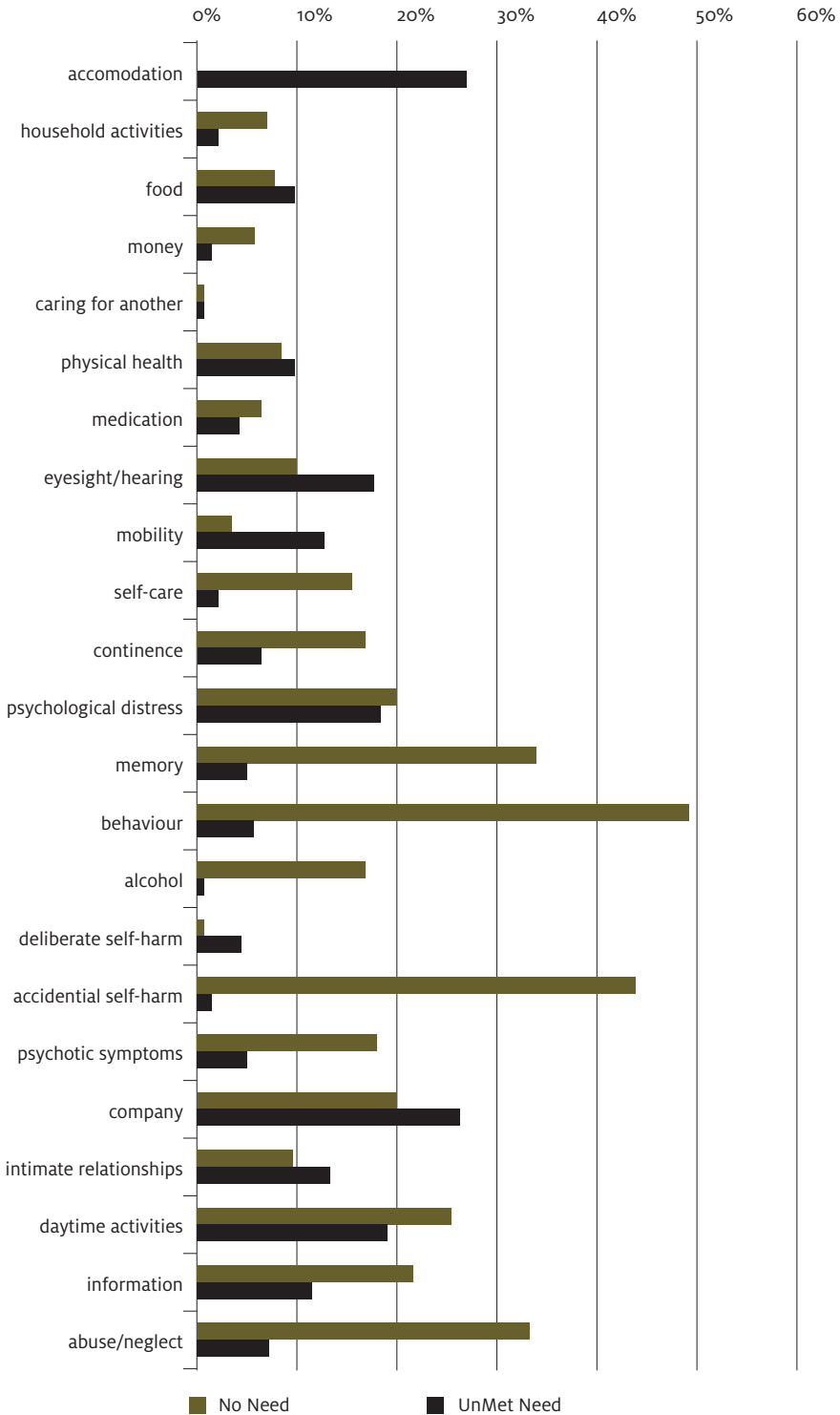
With regard to individual needs (Table 2), 'household activities', 'money', 'medication', 'food', and 'self-care' were the most frequently rated met needs, both by residents and nursing staff. The most frequently reported unmet needs rated by both residents and nursing staff were 'accommodation', 'company', 'physical health', and 'psychological distress'. Additionally, 'daytime activities' and 'eyesight/hearing' were frequently rated as an unmet need by residents as was 'behaviour' by nursing staff.

Differences in scores on needs between residents and nursing staff

The median number of domains in which residents reported 'no need' whereas the nursing staff rated a care need, was 3 (IQR 2-5). In only 1.6% ($n = 2$) of the cases residents and nursing staff had the same scores regarding 'no need'. The median number of domains in which the resident rated 'unmet need' and the nursing staff did otherwise, was 2 (IQR 1-3). In 19.5% of the cases ($n = 24$) residents and nursing staff had no different scores regarding 'unmet needs'.

Figure 1 shows per needs domain the proportion of residents that had different scores than the nursing staff on 'no need' and 'unmet need'. Nearly half of the residents (49.3%, $n = 69$) reported that they had no care need regarding 'behaviour' while the nursing staff's scores indicated that the resident did require some kind of care. In 84.1% ($n = 58$) of these cases, the nursing staff rated 'behaviour' as a met need, in 15.9% ($n = 11$) as an

Figure 1 | % of patients with another view on the care need than the nursing staff



unmet need. In the same way, the scores on needs of resident and nursing staff differed frequently in the needs areas 'accidental self-harm' (44.0%, n = 62), 'memory' (34.0%, n = 48), and 'abuse/neglect' (33.3%, n = 47). In the vast majority of these cases, the nursing staff rated the care need as a met need (88.7% (n = 55), 97.9% (n = 47) and 97.9% (n = 46) respectively). Residents' unmet care needs were most often not assessed as such by the nursing staff on the areas 'accommodation' (27.0%, n = 38), 'company' (26.4%, n = 37), and 'daytime activities' (19.1%, n = 27). These care needs were reported by the nursing staff as met needs in 100% (n = 38), 70.3% (n = 26) and 88.9% (n = 24) respectively.

Associations between the total number of unmet needs and resident characteristics

The total number of unmet needs showed a significant positive association with depression ($r = 0.55$, $CI = 0.41-0.68$, $p < 0.001$) and anxiety ($r = 0.60$, $CI = 0.46-0.72$, $p < 0.001$) and a significant negative association with social participation ($r = -0.22$, $CI = -0.38- -0.08$, $p = 0.008$) and the care dependency scale ($r = -0.21$, $CI = -0.35- -0.06$, $p = 0.012$) (Table 3a), the latter meaning that more unmet needs were related to higher care dependency. Also sex was significantly associated with the total number of unmet needs: men showed less unmet needs than women ($t = -2.12$, $CI = -0.64- -0.06$, $p = 0.036$).

TABLE 3a | Bivariate relationships between potential determinants and total number of unmet needs

	Pearson's r (95% CI)	Sig (2-tailed)	N
Age	-0.014 (-0.183 – 0.151)	0.870	141
Number of medications	0.033 (-0.119 – 0.193)	0.700	141
Number of chronic conditions	0.154 (-0.026 – 0.327)	0.069	141
Social Participation (RISE)	-0.224 (-0.384 – -0.076)	0.008	141
Care Dependency (CDS) ^a	-0.212 (-0.350 – -0.055)	0.012	141
Cognitive functioning (MMSE)	-0.016 (-0.191 – 0.173)	0.852	136
Cognitive functioning (FAB)	0.024 (-0.144 – 0.199)	0.778	135
Depression (GDS-8)	0.551 (0.407 – 0.681)	< 0.001	141
Anxiety (HADS-a)	0.595 (0.457 – 0.718)	< 0.001	141
	Student's t (95% CI)		
Gender	-2.119 (-1.643 – -0.057)	0.036	141
	ANOVA F		
Level of education	0.254	0.776	139

^a higher score means less care dependency

These variables were entered, along with the number of chronic conditions ($r = 0.15$, $CI = -0.03-0.33$, $p = 0.069$ (not significant, but $p < 0.25$)), into a linear regression model. We found that three variables remained statistically significant in the multiple regression analysis: depression, anxiety, and care dependency, which explained 47.5% of the variance in the total number of unmet needs ($R^2 = 0.48$, $df = 3$, $F = 41.31$, $p < 0.001$) (Table 3b).

Table 3b | Multiple linear regression 6 predictors (method: backward stepwise)

	B	Std. Error	Beta	t	Sig
Constant	2.386	0.796		2.997	0.003
GDS-8	0.347	0.069	0.351	5.060	0.000
HADS-a	0.233	0.039	0.421	6.049	0.000
CDS	-0.036	0.015	-0.147	-2.360	0.020
<i>R Square</i>	0.475				
<i>Adjusted R Square</i>	0.463				
<i>Std Error of the Estimate</i>	1.817				
<i>F</i>	41.305				
<i>Sig</i>	0.000				

Sensitivity analysis:

The prevalence of ten premorbid, maladaptive personality traits ranged between 14.0% (perfectionist behaviour) and 31.2% (disorderly behaviour) (Table 3c). When personality traits were included in the analyses as independent variables (Table 3d), the regression analysis showed that three variables (depression, anxiety and the personality trait 'uncertain behaviour') were associated with the total number of unmet needs. This model explains 50.5% of the variance in the total number of unmet needs ($R^2 = 0.51$, $df = 3$, $F = 35.75$, $p < 0.001$).

Table 3c | Bivariate relationships between personality traits and total number of unmet needs

	Personality trait was present % (n/N)	Mann-Whitney U test Z-value	Sig (2-tailed)
Socially avoidant behaviour	22.6% (24/106)	-0.585	0.558
Uncertain behaviour	24.8% (27/109)	-1.534	0.125
Vulnerability in interpersonal relationships	26.9% (29/109)	-0.559	0.576
Somatizing behaviour	21.3% (23/108)	-0.374	0.708
Disorderly behaviour	31.2% (34/109)	-2.180	0.029
Rigid behaviour	18.5% (20/108)	-1.330	0.183
Perfectionist behaviour	14.0% (15/107)	-0.226	0.821
Antagonistic behaviour	21.1% (23/109)	-0.972	0.331
Self-satisfied behaviour	25.7% (28/109)	-0.569	0.569
Unpredictable and impulsive behaviour	29.4% (32/109)	-1.099	0.272

Table 3d | Multiple linear regression 9 predictors (method: backward stepwise)

	B	Std. Error	Beta	t	Sig
Constant	0.975	0.307		3.170	0.002
GDS-8	0.363	0.076	0.368	4.772	0.000
HADS-a	0.225	0.043	0.407	5.255	0.000
HAP-uncertain	-1.312	0.396	-0.229	-3.313	0.001
<i>R Square</i>	0.505				
<i>Adjusted R Square</i>	0.491				
<i>Std Error of the Estimate</i>	1.769				
<i>F</i>	35.747				
<i>Sig</i>	0.000				

Discussion

To our knowledge, this is the first study to examine the prevalence of met and unmet needs of nursing home residents with mental-physical multimorbidity without dementia from the residents' and nursing staff's perspectives while also focusing on the differences between their opinions.

We found that residents rated a lower total number of needs, but a higher number of unmet needs than the nursing staff. The highest numbers of met care needs were reported in the physical and environmental domains. According to the residents, most unmet needs pertained to the social domain. The nursing staff reported most unmet needs in the psychological domain. Discrepancy between residents and nursing staff about unmet needs was most common in the areas accommodation, company, and daytime activities. Nearly half of the residents indicated 'no need' regarding behaviour while the nursing staff supposed that the resident did require some kind of support. Depression, anxiety and care dependency were the most important determinants of residents' unmet needs.

Lasalvia *et al.* (2000) described two main approaches to needs assessment: a normative model, based on the judgment of an expert, and a negotiated model, assuming that needs are not a fixed concept that can be objectively measured, but are best viewed as a dynamic and relative concept that can be influenced by a range of contextual factors and on which there is no single correct perspective.²¹ Given the negotiated model, it is not surprising that the visions of residents and nursing staff are different. They form their opinions based on different frames of reference.

Our study shows that the average number of needs reported by the nursing staff was higher than in the residents' opinion, but the proportion of unmet needs was higher

in the residents' view. This is in agreement with other studies among long-term care residents.^{24,53} On the one hand, residents may underestimate their needs for several reasons, such as (1) desire for independence,⁵⁴ (2) lack of knowledge of health care services,⁵⁵ (3) cognitive problems such as lack of insight²³ or (4) current neuropsychiatric symptoms (e.g. positive bias due to a manic episode).⁷ On the other hand, the nursing staff may report more care needs on the basis of professional training and background.⁵⁶ Yet, there is also the risk that they provide more care than necessary. Additionally, the nursing staff may underestimate the unmet needs, because of (1) lack of knowledge or skills to identify unmet needs in this particular group of residents^{24,57} or (2) a need to feel effective in the jobs they do.²⁴

The resident's perspective on needs must be central to the process of planning and providing care,⁵⁸ but adding interventions initiated on the basis of the nursing staff's expertise can be valuable, since the expert professional may have a more informed opinion about the probable outcome than the resident.⁵⁹ Nurses play an important role in bridging the different perspectives. In long-term care facilities, this should be done by a team of workers with different education levels and competences. Nurse assistants, licensed practical nurses and vocationally trained registered nurses, collect data about residents and implement components of residents' care plans. To this end, they should be able to employ different skills and personal qualities, such as effective communication and negotiation skills, empathy, compassion, and humor.⁶⁰⁻⁶² In addition, baccalaureate-educated registered nurses and/or advanced nurse practitioners are needed because they have the clinical assessment and care management expertise that facilitates integration and synthesis of data to accomplish quality care.^{61,63,64} They also have a role as supervisor of other nursing personnel.^{60, 65, 66} They can facilitate them in influencing resident outcomes through their leadership and coaching skills, such as team-building, collaboration, negotiation, empowering others, shared decision making, and conflict management.⁶⁶⁻⁶⁸

Our finding that company (C) and daytime activities (DA) were frequently reported as unmet needs in the view of residents, is of great importance. It would be expected that these care needs were met as professional support for these needs is part of the basic care. However, the ratio of unmet needs to the total number of needs in these areas was comparable with community-dwelling elderly people (i.e. C: 58.4% and DA: 35.7% (our study), C: 46.9% and DA: 42.2%,¹⁵ C: 55.6% and DA: 27.8%⁷).

Possibly, lack of resources in the field of elderly care plays a role. Rationing of care and shortage of personnel could reduce the time nursing staff spend together with nursing home residents and can also reduce the time for supporting nursing home residents in performing activities of daily living. Furthermore, the nursing staff might have a stronger focus on physical care than on social support.⁶⁹

In the areas company (C) and daytime activities (DA) the nursing staff did not perceive residents' unmet needs as such in 26.4% (C) and 19.1% (DA). In addition, we found that almost all residents had a different opinion than the nursing staff regarding 'no need'. Differences were mainly reported in the areas behaviour, accidental self-harm, memory, and abuse/neglect. Possibly, a resident's impaired insight in his situation due to the mental-physical multimorbidity may play a role. Our results suggest that the support offered does not meet individual wishes and preferences.

Our finding that depression and anxiety were the determinants that were most strongly associated with the number of unmet needs, is in accordance with the studies of Hancock *et al.* (2006) and Houtjes *et al.* (2010). Unfortunately, these three studies do not allow us to conclude on a causal relationship between these variables. It is likely that depression and anxiety will affect the residents' receptiveness for and perception of meeting needs, resulting in more unmet needs. On the other hand, unmet needs can contribute to the onset or increase of depression and anxiety.

In addition, our results could indicate that the different frames of reference of residents and staff might have played a role. From their professional background, nurses usually are focused on outcomes (i.e. depression, anxiety, behavioural issues, care dependency), whereas residents may "translate" such outcomes into external circumstances that can cause them and experience needs in these areas (e.g. lack of company and/or daytime activities, and dissatisfaction about the accommodation).

Although personality problems are associated with the presence of unmet needs in younger psychiatric patients,^{20,70} in our sample hardly any association between personality traits and unmet care needs was found. In the multivariate model, only uncertain behaviour was associated with unmet care needs pointing to more uncertain behaviour resulting in less unmet care needs. Several explanations can be put forward for this counterintuitive finding. Firstly, inpatient care is specifically suitable for meeting the needs of patients with dependent personality styles because of provision of a safe environment and the continued presence of trusted carers.⁷¹ Secondly, maladaptive personality traits primarily result in interpersonal dysfunctioning, which put a significant burden on their relationship with family and close friends. In long-term care facilities, new relationships can be build. Especially professional carers (primarily nurses) may be much better in containing this behaviour as well as correcting deviant behaviour more empathically and consistently. Finally, the association between personality traits and care needs may partially be masked by the presence of multimorbidity as the HAP measures premorbid personality traits. For example, premorbid rigid or perfectionist personality traits can be masked by impulsivity due to frontal brain damage and premorbid impulsive or disorderly behaviour can be masked by apathy due to physical multimorbidity.

Although this latter explanation is less likely (in view of our multivariate analyses), it can only be fully rejected in much larger studies powered for testing multiple interaction effects.

Strengths and limitations

Since the interviews were conducted by two elderly-care physicians who were familiar with this resident group and their professional carers, the data are of high quality and there were few missing data. Care needs were assessed both from the residents' and nursing staff's perspective. Residents generally spoke candidly about their views on needs, since the interviewers had no professional relationship with them nor with nursing staff members.

However, some limitations must be mentioned. First, the cross-sectional design limits causal interpretation. Second, as the CANE has been developed for geriatric psychiatry, not all items are equally applicable for the nursing home setting, e.g. benefits. Moreover, some showed floor- or ceiling effects, e.g. caring for another or household activities. Finally, albeit our sample is likely to be representative for residents with mental-physical multimorbidity admitted to Dutch nursing homes, the sample size is modest and representativeness for other countries remains unknown. Nonetheless, our data provide important new insights on the met and unmet care needs of nursing home residents with mental-physical multimorbidity.

Conclusion and recommendations

Systematic assessment of care needs showed differences between the perspectives of resident and nursing staff. These differences should not be the subject of a discussion on who knows what is best for the resident. They are all valuable for individualized care. Nursing staff must be aware of these different perspectives, which should be the starting point of the dialogue between resident and nursing staff about needs, wishes and expectations regarding care. In order to draw up an individually tailored care plan, based on a well-conducted dialogue, nurses with effective communication and negotiation skills are indispensable. The gap between residents' and nurses' views on needs must be interpreted in daily practice and bridged appropriately. Therefore, the nursing staff should have a broad knowledge of medical and psychiatric conditions and their mutual influence and should be able to apply this knowledge in their work. In order to discuss and implement interventions that are acceptable to both the resident and the caregivers, the nursing staff must show leadership and coaching skills, such as skills to collaborate, to ensure shared decision making and to empower others. We recommend strengthening the nursing staff in long-term care facilities by regularly training these skills.

Additionally, we recommend systematic screening for depression and anxiety, since these may be critical factors in the process of reducing unmet needs. Nevertheless, the relationship may have another direction, which brings us to another recommendation, namely that future studies on determinants of (un)met care needs should be conducted with longitudinal designs. Longitudinal data are necessary to clarify the causality and direction of the association between various variables and (un)met needs.

Finally, our study has shown that the CANE was feasible for use in a research setting as a needs assessment tool that can yield important new information. However, we recommend the development of a nursing home version of the CANE that is useful in the systematic assessment of needs in elderly nursing home residents in daily practice.

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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.

Key words 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.¹

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.^{2,3} On the other hand, in recent decades the total number of psychiatric hospital beds has decreased dramatically.⁴ Since then, NHs have partly taken over the traditional asylum function of psychiatric hospitals.⁵

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).⁶ 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.^{7,8}

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.⁹⁻¹¹ 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.¹²⁻¹⁴ 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.¹⁵⁻¹⁸ 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.¹²

Also in patients with MPM no dementia, NPS are a substantial challenge for their carers.⁸ 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 **m**ental and **p**hysical **p**roblems residing **i**n Dutch **n**ursing homes) is a cohort study with a follow up of six months. The design of the MAPPING study has been described extensively elsewhere⁸ 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 (<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>) and the Code of Conduct for Health Research¹⁹ 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.²⁰ 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 file. 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 classified using the Anatomical Therapeutic Chemical classification²¹ 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 Inventory²² 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.²³ The NPI-NH can also be used to screen for neuropsychiatric symptoms in an elderly neuropsychiatric population.²⁴ The NPI-NH has been translated and validated in the Dutch setting.²⁵

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 0 - 144.

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

rotated (varimax). Factors loading ≥ 0.4 were 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)^{26,27} and the Frontal Assessment Battery (FAB).²⁸ 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).²⁹ 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.^{29,30}

Analysis

In accordance with previous studies, neuropsychiatric symptoms with a FxS score ≥ 4 on the NPI-NH were considered clinically relevant.^{31,32}

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 T₀ 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.³³

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). Twenty-eight 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.

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 geronto-psychiatric nursing home 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)

^a Mean, SD

^b 1 missing

Neuropsychiatric symptoms

The mean total NPI FxS score increased from 25.3 (SD = 17.5) at To to 29.3 (SD = 16.5) at T1 ($t = -2.044$, $df = 62$, $p = 0.045$, Cohen's $d = -0.23$). The mean FxS score increased from 9.7 (SD = 8.7) at To 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 To to 10.1 (SD = 9.4) at T1 in the cluster mood/apathy ($Z = -2.651$, $p = 0.008$, Cohen's $d = -0.31$).

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 at baseline	Point Prevalence at baseline + 6 months	Cumulative Prevalence	Incidence ^a	Persistence ^b
<i>Individual neuropsychiatric symptoms:</i>					
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 behaviour	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)
<i>Neuropsychiatric symptom clusters:</i>					
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)
<i>Other neuropsychiatric symptom counts:</i>					
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)

^a The ratio of residents with clinically relevant NPS at follow-up to residents without clinically relevant NPS at baseline

^b The ratio of residents with clinically relevant NPS at follow-up to residents with clinically relevant NPS at baseline

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 To. 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 To 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 To) (Table 3). Other significant relationships were not found.

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

	FxS difference score NPI total (To-T1)		FxS difference score NPI hyperactivity (To-T1)		FxS difference score NPI mood/apathy (To-T1)	
	Pear- son's r	Sig (2-tailed)	Pear- son's r	Sig (2-tailed)	Spear- man'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	0,979	-0,852	0,398	-0,193	0,848
	ANOVA F	Sig (2-tailed)	ANOVA F	Sig (2-tailed)	ANOVA F	Sig (2-tailed)
Level of education	2,583	0,084	0,298	0,743	2,424	0,097

Psychotropic drug use

Patients used a mean number of 2.5 (SD = 1.5) psychotropic drugs at To 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)

	To	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)

^a Mean, SD

^b Patients with epilepsy n=10; patients with neuropathic pain n=1

In addition to the results shown in Table 4, we found that 90.5% (n = 57) used at least one psychotropic drug at To and/or T1. In total, it concerned 167 prescriptions. Two-thirds of the prescriptions (66.5%, n = 111) were exactly the same at To 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 To.

Discussion

This first study on the natural course in NPS in nursing home patients with MPM no dementia in the first 8 months 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 To 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.⁷ 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,^{16,17,34} 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.³⁵ 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.³⁶

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,³⁷ 11 points in nursing home patients with dementia³⁸, and 9 points in outpatients with dementia³⁹). 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.⁴⁰ In the MAPPING study, the assessment at baseline was performed 6 to 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.⁹ In addition, daytime activities may not be sufficiently adapted to the wishes and capabilities of these patients of whom several are relatively young.⁶ 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.¹¹

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 carers, 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.²⁴ 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.^{41,42}

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).^{43,44}

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.

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CHAPTER 8

General discussion

This thesis is about nursing home (NH) residents with mental-physical multimorbidity (MPM) without dementia. It focuses on their characteristics and care needs. Furthermore, attention is paid to the patient-related factors affecting changes in neuropsychiatric symptoms after admission to a geronto-psychiatric nursing home (GP-NH) unit.

In this chapter, first of all an overview of the main findings is provided and these are discussed against the background of the recent literature. Next, several methodological considerations are addressed. Finally, implications and recommendations for clinical practice, education, and future research are provided.

Main findings

The systematic review of the literature showed:

- That scarcely any studies have been published focusing on the whole range of mental and physical multimorbidity affecting older residents in long-term care (LTC) facilities, and that there is no published research about the care needs of these residents;
- That these residents were more likely to be younger, male and unmarried than other LTC residents and that they had more severe cognitive impairment and challenging behaviour.

The MAPPING study found:

- That GP-NH units in the Netherlands house a heterogeneous group of residents with MPM regarding various aspects, such as age, physical and psychiatric conditions, neuropsychiatric symptoms and care dependency;
- That, despite exclusion of residents with dementia, the majority of residents with MPM had cognitive impairment. Particularly the prevalence and severity of frontal impairment were high;
- That clinically relevant neuropsychiatric symptoms were common in residents with MPM and that these symptoms tended to be persistent. Hyperactivity was the most prevalent and persistent symptom cluster;
- That 88% of the residents with MPM used at least one psychotropic drug and that about 6 months later only 14% of all prescriptions of psychotropic drugs was reduced in dose or stopped;
- That the average number of resident needs reported by the resident was lower than those reported by the nursing staff, but the proportion of unmet needs was higher in the residents' view than in the view of the nursing staff.

Discussion of the main findings

Characteristics of NH residents with MPM

Both the systematic review of the literature and the MAPPING study have shown that NH residents with MPM are a very heterogeneous group.^{1,2} This implies, for instance, that a 72-year-old man with psychotic depression, complicated with tardive dyskinesia and serious diabetes insipidus as a result of chronic use of psychotropic drugs, lives together in a GP-NH unit with an 85-year-old man with Parkinson's disease with burdensome neuropsychiatric symptoms such as depression, delusions and hallucinations, and also with a 58-year-old woman with depression, panic attacks, and a mixed personality disorder with dependent and histrionic features, and concomitant multiple sclerosis.

Some of the residents primarily have a long existing chronic psychiatric disorder and additional physical problems. Other residents primarily have physical disorders that are accompanied by neuropsychiatric symptoms, a relapse of existing psychiatric conditions triggered by physical problems, or are physically frail residents having a late onset psychiatric disorder.

However, despite this heterogeneity, similar characteristics and care needs of residents seem to underlie the choice for admission to a GP-NH unit. The MAPPING study showed that residents with MPM were younger, and were more often male and unmarried than other NH residents. They had a considerable number of chronic somatic and psychiatric conditions, and used various medications with high rates of polypharmacy. Cognitive impairment, especially due to a disturbed function of the frontal lobe, and neuropsychiatric symptoms occurred frequently. These findings were fully in line with the results of our preceding systematic review. In October 2018 we re-conducted the PubMed search as used in that literature review. This did not yield any other results in terms of patient characteristics or needs.

It is understandable that NH residents with MPM are relatively young. After all, people with severe mental disorders are more likely to engage in lifestyle behaviours that constitute risk factors for physical diseases such as tobacco consumption, physical inactivity and consuming unhealthy diets.³ Partly because of this, the life expectancy of people with severe mental disorders is reduced by 10 to 20 years.⁴

Psychotropic drug use by NH residents with MPM

Of the residents who participated in the MAPPING study, 88% used at least one psychotropic drug. This is in line with previous studies showing that psychotropic drugs were frequently used by nursing home residents.⁵⁻¹⁰

Most of the research on psychotropic drug use in NH residents involved those with dementia. Prescription of psychotropic drugs to treat dementia-associated neuropsychiatric symptoms is controversial, because of their modest effect and the risk of drug-related adverse events.¹¹⁻¹³ Recent research¹⁴ showed that only 10% of the psychotropic drugs used for neuropsychiatric symptoms in nursing home residents with dementia was prescribed fully appropriately. In terms of indication, 36% of the psychotropic drug prescriptions was fully appropriate. Yet, in contrast to residents with dementia, a higher rate of the prescriptions of psychotropic drugs may be appropriate in those with MPM if these are indicated for a resident's psychiatric condition. Etchepare *et al.* (2016) investigated the compliance of psychotropic drug prescription with practice guidelines for older patients in patients aged 65 years and over who were hospitalized in psychiatric units.¹⁵ They found an appropriate indication in 72% of the antipsychotic prescriptions. Most prescriptions appeared to consider the need for appropriate monitoring of physical tolerance and symptomatic efficacy. The monitoring of neurological and cognitive tolerance and metabolic blood testing was less frequent. The authors recommended that practice guidelines should be taken into account when prescribing antipsychotics in the studied population to reduce the risk of adverse events, and that the risk/benefit ratio should be reassessed regularly.

In this context, we have found that 6 months after the baseline assessment only 14% of all prescriptions of psychotropic drugs was reduced in dose or stopped. This can partly be explained by the chronic nature of psychiatric disorders in our study population. However, several non-resident-related factors, such as the mindset of physicians and nurses towards neuropsychiatric symptoms and psychotropic drug use, knowledge of effectiveness and side effects of psychotropic drugs, interdisciplinary communication and cooperation, staffing levels, the availability of resident activities, and access to consultants, can contribute to a so-called 'prescribing culture'.^{16,17} This culture might explain the variation in the use of psychotropic drugs that cannot be explained by resident case mix.¹⁸ This should be further investigated in future studies.

Needs of NH residents with MPM

The systematic assessment of care needs in our study showed differences between the perspectives of residents and nursing staff. The average number of needs reported by the nursing staff was higher than in the residents' opinion, but the proportion of unmet needs was higher in the residents' view. These findings are in agreement with other studies among LTC residents.^{19,20}

This also holds for our finding that depression and anxiety were associated with the number of unmet needs.²¹⁻²³ Unfortunately, our study design did not allow conclusions on

the direction of a possible causal relationship between these variables. Residents with depression may have a negative view on the provided care and therefore experience more unmet needs. However, perhaps it is (also) vice versa like Blazer *et al.* (2007) demonstrated in their study in community-dwelling older adults. They found that the perception of unmet basic needs was a highly significant predictor of future depressive symptoms.²¹

Because research also showed that the presence of unmet needs is a strong predictor of less favourable health perceptions and a lower quality of life,²⁴ and that unmet needs lead to more challenging behaviour and an increased caregiver burden,²⁵ attention for needs is of great importance. Fulfilling unmet needs will be a key to improving resident quality of life.^{25,26}

Methodological considerations

In this study, an extensive set of data was collected. Since the interviews were conducted by two elderly care physicians who are familiar with the MPM resident group and their professional carers, the data are of good quality and there were only few missings. Residents and nursing staff generally gave frank answers to questions, as the interviewers had no professional relationship with either of them. Nevertheless, some methodological considerations can be mentioned.

Identification of the target population and representativeness of the study

As stated before, NHs are faced with a growing number of residents with co-occurring physical and geronto-psychiatric disorders. The MAPPING study is designed to increase knowledge about these residents, but they do not comprise a well-defined group of residents. Therefore, we have operationally defined the study population by using clear inclusion and exclusion criteria. We have decided to exclude residents with dementia from our study population, because neuropsychiatric symptoms and needs of NH residents with dementia have previously been studied and these were expected to be different from those in residents with MPM without dementia.

Study participants were recruited from specialized geronto-psychiatric units in several Dutch NHs. This has been a deliberate choice in order to assure that the supportive environment around the included residents would be as similar as possible. However, it appeared that the participating GP-NH units had 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. These criteria resulted in different resident profiles in the GP-NH units. Nevertheless, because we applied inclusion criteria at the individual resident level and not at the level of the unit, these differences probably had only a limited influence on the results. Furthermore, the representativeness of our study population may have been reduced to some extent, because residents who met the inclusion criteria, but who were staying in a NH unit that is not specialized in geronto-psychiatric care, did not participate in the MAPPING study. Possibly, residents with MPM residing in such units have less complex characteristics, care needs and/or challenging behaviour. Therefore, they could be underrepresented in our study population. On the other hand, residents with severe symptoms may be underrepresented because these residents were not able to participate in the interviews and could therefore not be included in the study. Finally, the representativeness of our cohort has been favourably influenced by the good geographical distribution of the participating NH-GP units.

Study design and methods used

Cross sectional design

Because little was known from the literature about NH residents with MPM, the first aim of the MAPPING study was to describe the characteristics of these residents. We have explored these in a cross-sectional study design with as many participants as possible within a given timeframe. Regrettably, the consequence of using a cross-sectional design is that no conclusions can be drawn about causal relationships. Nevertheless, the cross-sectional data provided interesting points of attention for clinical practice and directions for future research.

The number and timing of the assessments

In the longitudinal part of the study, we have been able to assess each participant twice.

The assessment at baseline was performed 6-8 weeks after admission. There were two considerations for choosing that time point. Firstly, it would take a few weeks before the informed consent procedure had been completed and the appointments for the interviews had been scheduled. Secondly, the admission itself could be a stressful event for the new resident. We expected that residents would be accustomed to their new residence after 6 weeks and that therefore, at the time of the first assessment, a resident's behaviour would not be significantly affected by stress due to the admission itself. For financial and organizational reasons, we could perform only one follow-up assessment. We have decided to plan these 6 months after the baseline assessment. Due to small patient

numbers and the timing of the assessments, interpretation of the longitudinal data was challenging. For example, our finding that the NPI total score showed a significant increase between the baseline and the second assessment, was unexpected. Based on our practical experience, we actually had expected a decrease of neuropsychiatric symptoms in most residents. Although the increase of the NPI total score might indicate that residents with MPM do not receive optimal care in a GP-NH unit, the moment of the baseline assessment may also explain this finding. Many residents may have experienced a lot of admission-related stress and have subsequently responded positively to the new social contacts and activities, and to the personal attention they received from the staff that was aiming to draw up an individual care plan. As a result, the neuropsychiatric symptoms may have decreased in the first 8 weeks of admission. If so, the increase of the NPI total score may be interpreted as a (partial) return to the pre-admission level. To gain more insight into the course of neuropsychiatric symptoms in residents with MPM after admission to a nursing home, a baseline assessment before admission and the first follow-up assessment shortly after admission, would be necessary.

Assessment instruments

To explore characteristics of NH residents with MPM, we principally used assessment instruments of which feasibility and validity for NH residents has been shown in previous studies. Most of these instruments proved to be well applicable in our research population. If such instruments were not available, we used assessments that are common in mental health care, e.g., the mini-SCAN.²⁷ Our experiences with the mini-SCAN were positive. The interviewers were able to use the mini-SCAN adequately after a one-day training. The mini-SCAN also seems a suitable instrument for clinical purposes in the NH setting, if assessment of the present episode of a psychiatric disorder is desired. We have some reservations about using the Camberwell Assessment of Need for the Elderly (CANE)²⁸ in the nursing home setting. Not all items were equally applicable for the nursing home setting, e.g. financial benefits, and some showed floor- or ceiling effects, e.g. caring for another or household activities.

Furthermore, when we designed our study, a comprehensive instrument to assess quality of life among our research population was not available. Therefore, we used the three questions about perceived quality of life from the TOPICS-MDS²⁹ together with two instruments on social wellbeing (SWON³⁰ and RISE³¹) to get an impression of some relevant areas of quality of life. In the meantime, the Laurens Well-Being Inventory for Gerontopsychiatry (LWIG) has been developed.³² This instrument consists of 30 items within 3 dimensions, physical well-being, social well-being, and psychological well-being, with 0, 3, and 2 subscales, respectively. The subscales are for social well-being: positive social experience, negative social experience, and communal living, and for

psychological well-being: affect and self-worth. The LWIG may possibly yield more comprehensive information about the quality of life in our study population.

Measuring challenging behaviour

In our study we were interested in the occurrence and severity of challenging behaviour and we wondered whether this behaviour would change in the first months after admission to the nursing home. However, challenging behaviour can be conceptualized in many different ways and this has resulted in different assessment instruments.³³

We have chosen to use the NPI-NH because this is a validated assessment instrument in our study population, and has been used extensively in previous research in NH residents.³⁴

Therefore, in the MAPPING study, challenging behaviour was explored from a symptom approach. For completing the NPI, information is provided by a licensed nurse who has observed the patient over the past four weeks. This nurse is expected to unravel behaviour in neuropsychiatric symptoms as described in the NPI. Although not systematically monitored, two aspects came forward during the interviews. Firstly, scoring neuropsychiatric symptoms on the NPI appeared to be a difficult task for the nursing staff. Secondly, severity scores seemed to be influenced by the attitude of the nurse in relation to the resident's behaviour.

Finally, studying challenging behaviour by assessing neuropsychiatric symptoms with the NPI and thus operationalizing challenging behaviour as symptoms implies a narrowing down that may be potentially inaccurate and misleading.^{35,36} Considering behaviour from the viewpoint that it is a signal, i.e. has a function, implies it is important to investigate what the cause of the behaviour might be.³³ In practice, this might be more sensible than assessing behaviour as the occurrence and severity of neuropsychiatric symptoms.

Complement to the study design

Based on the average resident flow and the desired power of the study, we have calculated the number of participating GP-NH units needed. Even though we succeeded in including that number of units, the number of included residents was behind schedule from the start. The admission rate of new residents to the participating units proved to be lower than expected. Furthermore, the number of newly admitted residents with dementia and/or an inability to give informed consent, was higher than expected. Therefore, we have added a complementary study to the original one, as described in chapter 4. By combining the residents from the primary sample who completed the follow

up assessment and those who were added secondarily, the sample size of the cross-sectional study was sufficient to be able to present an overview of the characteristics and care needs of NH residents with MPM. Unfortunately, we did not achieve the desired power of the longitudinal study. Because of this, we could not, for example, investigate the personality traits assessed with the HAP as potential determinants of the course of neuropsychiatric symptoms. This had been our aim, because we hypothesized that personality traits could be predictors of persistent behaviour in NH residents with MPM, as has been shown in mental health care research.³⁷⁻³⁹

Implications and Recommendations

Clinical practice

Residents with MPM, a particular group?

The MAPPING study has shown that GP-NH units in the Netherlands house a very heterogeneous group of residents with MPM. Therefore, it is not surprising that some people question whether it is a particular group of residents that should best be housed in a separate special care unit. Our study does not provide a definitive answer, but does provide starting points.

Based on the comparison of the results of the MAPPING study with the characteristics of other categories of NH residents described in the literature, the conclusion can be drawn that residents with MPM appeared to be different from other groups of NH residents as to a variety of characteristics. This applied, for example, to age and gender distribution, and to the most common marital status. Also, the nature and severity of the multimorbidity and associated drug use in residents with MPM differed from those in other NH resident groups. Furthermore, differences were found in cognitive impairment, neuropsychiatric symptoms, care dependency, and care needs. Hence, we think these results justify the view that residents with MPM form a particular group that needs a specific care approach. This requires specialist knowledge and skills of the staff, systematic assessment of behaviour, and a supportive environment that is appropriate for these residents as will be detailed below.

Specialist knowledge and skills

Our study has shown that residents with MPM had multimorbidity that was composed of a wide variety of physical and psychiatric disorders. Therefore, signs, symptoms and care needs can be presented in different ways, complicating their interpretation.

An additional difficulty is that guidelines mostly focus on a single disease whereby the issues arising from multimorbidity are neglected. Hence, all professionals involved in the care of residents with MPM must have broad knowledge of physical and psychiatric conditions and their mutual influence and should be able to apply this knowledge in the diagnostic and therapeutic process.

Supporting a heterogeneous group of residents with MPM is a challenge for the nursing staff. One resident, for example, benefits from a restrictive approach, while the other should be encouraged. Challenging behaviour of the residents presents itself in various ways and can be very persistent. Residents cannot always get along and they can influence each other's behaviour significantly. The nurses are expected to care for each resident tailored to their individual needs, to keep an eye on the group process at the same time and, if necessary, to intervene adequately. As the nursing staff largely consists of certified nurse assistants, the question arises whether this may be a task that is too complex for them. Nurses can only succeed and take pleasure in this difficult task if they have sufficient knowledge and skills. So, the management of the unit should make it possible for all team members to acquire the knowledge and skills needed for guiding this specific group of residents.

Supportive environment

Housing a heterogeneous group of residents with MPM requires special attention of the staff to the living environment of these residents. Some suggestions for implementation of a suitable supportive environment have been described in chapter 2.

Several NHs are experimenting with therapeutically using the nursing home environment, namely Sociotherapeutic Living Environments (SLE).⁴⁰ In SLE, supply of care, therapeutic guidance, daily activities and social and physical aspects of housing are methodically aligned, in order to achieve the best possible quality of life. Within one GP-NH unit different living groups can be organized, based on residents' social, psychological and physical care needs. A living group consists of residents who have the same predominant care needs, for example the need for structure, clear guidance, and limiting stimuli, or the need for encouragement, stimuli, and group activities. In this way, residents can live together with people with more or less similar characteristics and care needs, as a result of which there will probably be fewer conflicts between residents and a more peaceful atmosphere in the living rooms. It is also expected that it is beneficial for the nursing staff to work in SLE, because it allows them to mainly support those residents with whom they can optimally use their personal qualities by working in a competency-oriented way.

Systematic assessments

The assessments that were carried out in the context of the MAPPING study have yielded a lot of information that also would have been valuable for the individual care plan of the resident. In fact, for considering which support seems best suited for the resident's needs, assessment of symptoms and impairments is helpful, for example, impairment in frontal lobe functions. However, for most of the participating organizations, it appeared that the assessment of newly admitted residents was less protocol-based and extensive than that of our study.

Moreover, systematically performing reassessments was found not to be common practice.

In mental health care, assessments are performed periodically in the context of the (compulsory) Routine Outcome Monitoring (ROM). Although not all research results are unambiguous, various systematic reviews and meta-analyses have shown that the use of ROM in order to adjust treatment can be effective.^{41,42} Therefore, it is recommendable to periodically perform a limited set of applicable assessments on behaviour, needs and well-being. Despite our reservations about the NPI-NH and the CANE, these instruments can be used to assess behaviour and needs respectively until more suitable instruments have been developed. Furthermore, the LWIG seems to be a promising instrument for measuring physical, social, and psychological well-being in NH residents with MPM. Therefore, it is worthwhile to gain practical experience with this instrument. The (course of the) scores could be used as clinical feedback and then be introduced as topics for the evaluation meeting with the patient about his or her individual care plan. The latter requires specific attention, because research in mental health care has shown that the results of ROM were not automatically used in clinical practice.⁴³

Well-being

The ultimate goal of care provided to NH residents with MPM is to facilitate them in achieving the best possible quality of life. The participants of the MAPPING study rated their quality of life with an average score of 6.1 on a scale of 1 to 10. This is lower than the average score of 7.3 found by the Netherlands Institute for Social Research (SCP) in their research among a broader group of NH residents.⁴⁴

In their systematic review, Van der Wolf *et al.* (2017) have presented an overview of determinants that were found to be related to the level of well-being in gerontopsychiatric LTC residents.⁴⁵ They found that specialized care, specifically the presence of mental health-care workers, was associated with increased well-being outcomes. A larger social

network size and perceived amount of personal freedom were also related to higher well-being, whereas depression and patient perceived stigmatization were related to reduced well-being.

The importance of assessing depressive symptoms and unmet needs has already been discussed above. However, stigmatization seems to be a subject that is often overlooked in NH care. Furthermore, it has not received any formal attention in our study, although both interviewers noticed feelings of shame, exclusion, and discrimination in several residents, possibly indicating (self-)stigmatization. According to the socio-cognitive model of Watson *et al.* (2005), self-stigmatization is the result of the application and internalisation of negative stereotypes associated with mental illness and public stigma.⁴⁶ Their socio-cognitive model also highlights the likely negative outcomes of self-stigma, including reduced self-esteem and self-efficacy, and the 'why try' effect.⁴⁶ Recently, Tzouvara *et al.* (2018) have investigated the self-stigma experiences among older adults with mental health problems residing in LTC facilities.⁴⁷ They found that public and self-stigma were both present in this population and were manifested through fear, reluctance towards social interaction, shame, secrecy, and withdrawal. They provide various recommendations, among others that NHs need to find ways of creating an atmosphere of belonging, sharing, and compassion so as to boost social relationships and reduce loneliness.⁴⁷

Therefore, we recommend to add mental health care workers to the multidisciplinary NH team on a permanent basis in order to provide specialized care that support residents with MPM to improve their quality of life. This team must actively detect any depressive symptoms, unmet needs and feelings of (self)stigmatization, and, together with the resident, look for interventions that contribute to addressing these. Attention to the perceived amount of freedom and to social relationships is a requirement. In the case of SLEs, NHs have to take these into account, both in the design of the SLEs and in linking a resident to a particular SLE. Finally, to facilitate social activities, volunteers could make a valuable contribution.

Policy makers

With aging, the number of disorders increases and as a result, there is more co-occurrence of physical and mental health care needs. However, in the Netherlands, there is a clear split between the mental and physical health care sector. Both have to deal with different applications of laws, rules and financing, which can cause various bottlenecks in continuity and quality of care, especially in patients with complex physical, mental, and social problems.⁴⁸⁻⁵⁰ This is particularly harmful to patients with MPM as soon as the necessary physical and mental health care do not connect seamlessly, and also in case

of too much overlap between the two sectors. To prevent these undesirable situations, collaborative practice appears to be a basic prerequisite.⁵¹ Collaborative practice happens when multiple health care workers from different professional backgrounds work together with patients, families, and each other to deliver the highest quality of care.⁵² Collaborative practice works best when it is organized around the needs of the population being served and takes into account the way in which local health care is delivered.⁵² In the interest of patients with MPM, a continuum of suitable care should be realized regionally. There are also some examples of a further integration of both sectors in the form of a joint ward for patients with MPM.^{53,54} From the perspective of the residents' care needs, this is a logical step. Residents can benefit from the expertise of health care workers from both sectors. Moreover, the health care professionals can learn from each other directly. Therefore, it is recommendable to gain more experience with such forms of cooperation. However, from a policy perspective, this is considered quite a challenge. Currently, laws, rules and the financing system are barriers to a real collaborative practice. As a first step, policy makers have to eliminate these barriers.

Training

As early as 1915 Rosenau wrote that “The student should know something of everything and everything of something”,⁵⁵ a view that was adopted in the current T-shaped education.⁵⁶ T-shaped professionals have a deep dedication, specialist knowledge and skills in their own expertise, the vertical bar on the T. In addition, they have skills and competences to connect with people from other disciplines, the horizontal bar on the T. Both bars need attention to achieve a further professionalization of care for patients with MPM.

Training of the various professional groups

In the Netherlands, the initial training of care professionals consists largely of mono-disciplinary training of generalist knowledge and skills. Training of specialist knowledge and skills, for example that which is necessary for specialist care for patients with MPM, mainly occurs through post-initial education and further training. The extra knowledge and skills that are necessary for professionals differ per discipline. Without aiming to be complete, here are a few suggestions.

During the three-year vocational training, each elderly care physician in training completes an internship of 6 months in a mental health institution that provides community-based services for patients with gerontopsychiatric conditions.⁵⁷ Although trainees may encounter all psychiatric disorders, the focus of this internship is on dementia. Therefore, more NH-GP units should offer the opportunity to complete a

3-month optional internship to trainees who want to acquire extra knowledge and skills on diagnostics and treatment of residents with psychiatric disorders other than dementia. Likewise, it would be desirable if a trainee in psychiatry for the elderly would do an internship in a nursing home to promote appropriate referrals, cooperation, and consultation.

The psychologist in the team of the GP-NH unit must also have additional knowledge and skills in diagnostics and treatment of residents with psychiatric disorders other than dementia. More often than in residents with dementia, psychologists must have time and skills to give individual psychotherapy. In this respect, cognitive behaviour therapy, problem solving therapy, and life review therapy are evidence-based and empirically validated treatment methods for older adults.⁵⁸ Given the growing evidence for EMDR treatment efficacy in adults and its user-friendliness in the elderly compared with other psychotherapeutic interventions, it is increasingly applied in daily NH practice. Empirical research into its efficacy in residents with MPM is strongly recommended.⁵⁹

As mentioned earlier, supporting a heterogeneous group of residents with MPM is a challenge for the nursing staff, who hardly came into contact with these residents during their initial training. They mainly acquire the necessary extra knowledge and skills through on-the-job training and collaboration with experienced professionals being role models. Accordingly, it is important that the management of the unit takes this into account when putting together the nursing team and also ensures that mental health care professionals are part of the team.

Finally, to complement the predominantly physical care, all the professionals should be trained in counselling strategies. They must be able to recognize the influence of their own behaviour when interacting with these residents, for instance, to prevent challenging behaviour caused by countertransference.

Interprofessional training

Because care for patients with MPM involves various professionals from different sectors of healthcare and because professionals have traditionally been trained in one sector, collaboration and sharing knowledge and experience, are not self-evident. One of the preconditions to achieve collaborative practice is interprofessional education.^{52,60} Interprofessional education occurs when representatives from two or more professions learn about, from and with each other to enable effective collaboration and improve health outcomes. Each professional learns skills for working in an interprofessional team and, as a result, becomes competent to do so.

It is advisable to develop an interdisciplinary course for the core disciplines involved in the LTC for patients with MPM. In collaboration with the Radboudumc Health Academy, the Radboudumc Department of Primary and Community Care recently developed an interdisciplinary course for professionals working with people with young onset dementia that could serve as an example.⁶¹

Research

During the MAPPING study, various new research questions have arisen. Several of these have already been mentioned in the previous chapters of this thesis. Nevertheless, a few of the topics will be emphasized here.

- The MAPPING study provided important information on the characteristics and care needs of NH residents with MPM who reside in GP-NH units. It would be interesting to expand this knowledge to patients with MPM who reside elsewhere, such as at home, in a mental health care facility, or at a NH unit for somatic care without specialist geronto-psychiatric care. This may provide information about the influence of the setting on, inter alia, challenging behaviour, (un)met needs, and the perceived well-being of the patient.
- A longitudinal study with more assessment points, of which at least one is performed prior to the admission to a LTC facility (NHs as well as mental health care facilities), can provide more insight into the course of challenging behaviour in LTC residents with MPM. Regrettably, the influence of personality traits on (the course of) neuropsychiatric symptoms, behaviour, and care needs has remained an unexplored issue that is yet to be investigated. To draw conclusions about the influence of personality traits on the course of neuropsychiatric symptoms, more participants are required than the number that could be included in the MAPPING study.
- Our study has shown that the CANE was feasible for use in a research setting as a needs assessment tool that can yield important new information. However, we recommend the development of a nursing home version of the CANE that is applicable for getting insight into needs of NH residents in daily practice. It would be preferable if one needs assessment instrument was valid and reliable for use in all NH residents. However, if clinimetric research shows that this cannot be realized, specific versions will have to be developed, among others for residents with MPM.
- Our research did not investigate which specific interventions could contribute to decreasing neuropsychiatric symptoms and unmet needs and to improving the well-being of residents with MPM. Therefore, this question remains for future research. It would be interesting, for example, to explore the structural deployment of mental health care professionals recommended above, both as a member of the team and in a consultant role. Other relevant topics for intervention research could be: psychosocial

interventions and daily activities that are attuned to the wishes and capabilities of these residents of whom several are relatively young. Labour-related activities may contribute more to a sense of being useful than the recreational activities that are common in a nursing home.

- Research is needed for a better insight into all aspects of the supportive environment that maintain and enhance well-being of NH residents with MPM.

Finally, not all data collected in the MAPPING study were used in this thesis. This offers opportunities for medical students or elderly care physicians in training who want to carry out an academic traineeship, by exploring, for instance, personality or apathy.

These recommendations for future research correspond well to the ‘knowledge agenda for geriatric psychiatry’ prepared by the Dutch Knowledge Centre for Geriatric Psychiatry.⁶² Goals articulated in this knowledge agenda regard disseminating existing knowledge and implementing it in practice, developing new training courses to overcome missing knowledge of professionals, and setting priorities for research.

Conclusion

This thesis concludes that NH residents with MPM are a heterogeneous group that nevertheless as a whole appeared to differ from other groups of NH residents in a variety of characteristics and in their care needs. The co-occurrence of various physical and psychiatric disorders, accompanied by impairment of cognitive functions, implies that NH residents with MPM have an increased chance of getting off balance, of showing challenging behaviour, and of experiencing less well-being. In addition, well-being is negatively affected by unmet needs, and a lack of social relationships and activities, which are prevalent in these residents. For optimizing their well-being, NHs have to provide specialist care tailored to the specific needs of these residents. Hopefully, this thesis is an impetus for, firstly, developing a standard of care that is appropriate for NH residents with MPM, secondly, for training professionals to provide the desired care, and thirdly, for performing new research aimed at the further professionalization of NH care for these residents.

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CHAPTER 9

Summary

Samenvatting

Data management

Dankwoord

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Summary

Mental-physical multimorbidity (MPM) is common in older people. Nevertheless, surprisingly little is known about one of their most vulnerable groups: patients with both chronic psychiatric and physical care needs requiring residential long-term care (LTC). The size of this group is expected to increase over the upcoming years, due to a greying society and increased prevalence of multimorbidity with aging.

As a result of deinstitutionalization in mental health care, LTC facilities have partly taken over the traditional asylum function of psychiatric hospitals. While residents with MPM are experienced as different from the traditional residents in nursing homes (NHs), this clinical experience cannot be substantiated by empirical results. This omission is described in **chapter 1** and has stimulated us to set up the **MAPPING** study, i.e. a study among residents with **mental and physical problems** residing in Dutch **nursing homes**).

The overall aim of the MAPPING study is to increase the knowledge of the characteristics and care needs of nursing home (NH) residents with MPM without dementia and to gain insight into the resident-related factors affecting changes in neuropsychiatric symptoms after admission to a geronto-psychiatric nursing home (GP-NH) unit. The following research questions were specifically formulated for this thesis:

- 1 What are the characteristics and care needs of NH residents with MPM?
- 2 What changes in resident behaviour have occurred eight months after admission and what is the influence of various patient-related factors on these changes?

Such research is necessary to develop an appropriate care program, to identify the associated preconditions, and to solve bottlenecks in laws, regulations and funding.

In **chapter 2**, based on our clinical experience, we stated that NH residents with MPM should be regarded as a separate group with specific characteristics and care needs. We also outlined the preconditions for specialist nursing home care in this group. We described the desired composition and competences of the multidisciplinary team and the necessary collaboration with other healthcare professionals, for both somatic and psychiatric consultation and co-treatment. Attention was also paid to the living environment of these residents. In this regard we listed a number of suggestions for the design of a sociotherapeutic environment and for daytime activities that are adjusted to the wishes and capabilities of these residents. We argued that reimbursement policies should at least enable consultation, the provision of psychotherapies, staff education, and evaluation of the sociotherapeutic environment. Finally, we made several recommendations regarding a research agenda, which includes, for example, research into the care needs of these residents, and the required knowledge and skills of the professionals involved.

Chapter 3 provides a systematic review of the literature on prevalence, characteristics and care needs of residents with MPM without dementia living in LTC facilities. Although 17 relevant papers were included, only one limited study described multimorbidity of a wide range of chronic psychiatric and somatic conditions in LTC residents. All other studies addressed psychiatric comorbidity in patients with a specific chronic somatic disease or vice versa, somatic comorbidity in patients with a particular psychiatric disorder. Therefore, reported prevalence rates of MPM (range 0.5% – 84.9%) were not telling. Nonetheless, two findings clearly emerged from the literature. First, LTC residents with MPM were younger than other LTC residents and secondly, they had more cognitive impairment (without having dementia) and problem behaviours. Remarkably, no studies were found that examined care needs of residents with MPM.

The design of the MAPPING study is described in **chapter 4**. Initially, the study was designed as a cohort study of residents with MPM who were newly admitted to a GP-NH unit, containing a baseline within six to eight weeks after arrival in the GP-NH unit and one follow-up assessment at eight months. Since the admission rate of new residents to the participating units was lower than expected, a second group consisting of participants who already lived in the participating units, was included. For this group, the same inclusion criteria were applied, but only a single measurement was performed.

Data on all participants were gathered by self-report questionnaires, clinical interviews and clinical testing, as well as extracted from the medical records. We collected data on demographic variables, psychiatric history and actual diagnosis, personality, neuropsychiatric symptoms, cognitive functioning, chronic somatic diseases, and finally quality of life and care needs. Characteristics amenable to changes were reassessed at follow-up.

The empirical results of the MAPPING study are described in chapters 5 through 7 of this thesis.

Chapter 5 explores the characteristics, behaviour, and care dependency of residents with MPM without dementia, living in GP-NH units, stratified by those referred from mental healthcare services (MHS) and other healthcare services (OHS). It showed that the majority of the residents had cognitive impairment, despite exclusion of those with dementia. Particularly the prevalence (69.6%) and severity of frontal impairment were high. Furthermore, just over 90% of the residents had clinically relevant neuropsychiatric symptoms. Comparison of those referred from MHS and OHS showed that the MHS group was younger, had more chronic psychiatric disorders and used more antipsychotic drugs than the OHS group. Residents referred from OHS needed more support with getting (un)dressed and showed more complaining and negativistic

behaviour than those referred from MHS. We concluded that the two subgroups were rather heterogeneous with respect to their physical and psychiatric multimorbidity, but more or less similar regarding the consequences of these diseases for behaviour and care dependency. Because the consequences are the basis of the daily care, we stated that it seems appropriate to accommodate and support residents of both resident groups together once care has become more crucial than cure.

Chapter 6 focuses on (un)met care needs of residents with MPM both from the residents' and nursing staff's perspectives and on determinants of unmet needs.

Residents with MPM reported on average twelve care needs of which almost a quarter remained unmet. Nursing staff indicated on average fifteen care needs per resident of which only 10% remained unmet in their view. The highest numbers of met care needs were reported in the physical and environmental domains. Most unmet needs mentioned by the residents pertained to the social domain. The nursing staff reported most unmet needs in the psychological domain. Different views between resident and nursing staff about unmet needs were most common in the areas accommodation, company, and daytime activities. In addition, nearly half of the residents reported that they had no need regarding behaviour while the nursing staff's scores indicated that the resident did require some kind of support.

Furthermore, we found that depression, anxiety and care dependency were the most important determinants of residents' unmet needs.

In conclusion, this study has highlighted that residents and nursing staff may have different perspectives on needs. In clinical practice, it may be challenging to bridge the gap between residents' and nurses' views satisfactorily. Therefore, we have recommended an open dialogue between resident and nurse about needs, wishes and expectations regarding care, in order to get the most optimal person-centred care plan. Moreover, the nursing staff should have broad knowledge of medical and psychiatric conditions and their mutual influence and should be able to apply this knowledge in their work. In order to discuss and implement interventions that are acceptable for both the resident and the caregivers, the nursing staff needs to show leadership and coaching skills, such as skills to collaborate, to ensure shared decision making and to empower others. Regularly training these skills should strengthen the nursing staff in long-term care facilities accordingly.

Chapter 7 describes the natural course of neuropsychiatric symptoms (NPS) of residents with MPM in the first eight months after admission to a GP-NH unit and associations with change in NPS between two measurements in this period.

Overall NPS were very frequent. Over 95% of the residents had one or more clinically relevant symptoms at baseline and/or six months later, of which irritability was the most prevalent and persistent symptom and the symptom with the highest incidence. Moreover, the overall severity of neuropsychiatric symptoms, as well as the score of the hyperactivity cluster and that of the mood/apathy cluster, increased significantly over time. Although these increases in symptom severity were small and not considered clinically relevant, the high level of neuropsychiatric symptoms should deserve further attention in future studies. The main recommendation was to examine the impact of a sociotherapeutic environment, staff training, and psychotropic drug reviews as potential strategies to improve neuropsychiatric symptoms.

Finally, in **chapter 8** we discuss the main findings against the background of the recent literature. Fully in line with the results of our preceding systematic review, we found that residents with MPM in our sample were younger in age, and they were more often male and unmarried than other NH residents. They had a considerable number of chronic somatic and psychiatric conditions, and used various medications with high rates of polypharmacy. Cognitive impairment, especially due to a disturbed function of the frontal lobe, and neuropsychiatric symptoms occurred frequently. Furthermore, several methodological considerations were addressed including the identification of the target population, the number and timing of the assessments, the assessment instruments, the complement to the study design, and the representativeness of the study. Finally, implications and recommendations for clinical practice, policy makers, training, and future research were provided. For example, we advised adding mental health care workers to the multidisciplinary NH team on a permanent basis to provide specialized care that supports residents with MPM to improve their quality of life. This team should actively detect depressive symptoms, unmet needs and feelings of (self) stigmatization, and, together with the resident, look for interventions that address these. We also recommended the development of an interprofessional training for the core disciplines involved in long-term care for patients with MPM. Finally, we identified relevant topics for new research, such as the influence of personality traits on the course of neuropsychiatric symptoms, psychosocial interventions and daily activities, and all aspects of the supportive environment that maintain and enhance well-being of NH residents with MPM.

This thesis concludes that NH residents with MPM are a heterogeneous group that nevertheless as a whole appeared to differ from other groups of NH residents in a variety of characteristics and in their care needs. The co-occurrence of various physical and psychiatric disorders, accompanied by impairment of cognitive functions, implies that NH residents with MPM have an increased chance of getting off balance, of showing challenging behaviour, and of experiencing less well-being. In addition, well-being is

negatively affected by unmet needs, and a lack of social relationships and activities, which are prevalent in these residents. For optimizing their well-being, NHs have to provide specialist care tailored to the specific needs of these residents. Hopefully, this thesis is an impetus for, firstly, developing a standard of care that is appropriate for NH residents with MPM, secondly, for training professionals to provide the desired care, and thirdly, for performing new research aimed at the further professionalization of NH care for these residents.

Samenvatting

Inleiding

Onderzoek wijst uit dat ouderen vaak meerdere chronische aandoeningen tegelijkertijd hebben. Dit wordt multimorbiditeit genoemd. Multimorbiditeit kan bestaan uit verschillende lichamelijke aandoeningen, maar ook uit een combinatie van lichamelijke en psychiatrische aandoeningen. Het aantal ouderen met lichamelijke en psychiatrische multimorbiditeit is de laatste jaren toegenomen. Deze trend zal in de komende jaren doorzetten, onder andere door de dubbele vergrijzing. Het aantal ouderen in de samenleving neemt toe en ze worden bovendien gemiddeld steeds ouder.

Daarnaast is er nog een andere ontwikkeling. Het beleid in de geestelijke gezondheidszorg is vanaf het begin van de jaren tachtig gericht op ambulantisering: de zorg zo veel en zo lang mogelijk organiseren in de directe leefomgeving van cliënten. Veel psychiatrische instellingen hebben daarom hun bedden voor langdurig verblijf fors afgebouwd. Mensen met chronische psychiatrische zorgvragen die moeilijk voor zichzelf kunnen zorgen, zijn veelal aangewezen op beschermde woonvormen waar structuur en begeleiding worden geboden. Wanneer zij ook lichamelijke problemen krijgen en behoefte hebben aan geïntegreerde psychiatrische en lichamelijke zorg, wordt hiervoor steeds vaker een beroep gedaan op verpleeghuizen.

Ook in de ouderenzorg wordt de zorg bij voorkeur thuis of in een kleinschalige woonvorm verleend. Daarom komt het verpleeghuis tegenwoordig pas in beeld wanneer de zorgvraag te ingewikkeld of te zwaar wordt voor ambulante zorg. De complexiteit van de problematiek van mensen die in een verpleeghuis zijn opgenomen, neemt daarmee toe. Om daarop te kunnen inspelen ontwikkelen verpleeghuizen zich in toenemende mate tot specialistische zorg- en behandelcentra. Dit doen zij zowel voor de meest complexe bewoners binnen de traditionele doelgroepen (somatic en psychogeriatric) als voor relatief nieuwe doelgroepen, zoals bewoners met psychiatrische en lichamelijke multimorbiditeit. De specialistische zorg voor deze groep bewoners wordt ook wel gerontopsychiatrische verpleeghuiszorg genoemd.

De ervaring die in een aantal verpleeghuizen met deze bewoners is opgedaan, wijst er sterk op dat zij niet dezelfde kenmerken en zorgvragen hebben als andere bewonersgroepen in het verpleeghuis. Er is tot nu toe echter geen wetenschappelijk onderzoek dat deze ervaring onderbouwt. Om een passend zorgprogramma te kunnen ontwikkelen voor de gerontopsychiatrische doelgroep in verpleeghuizen is dergelijk onderzoek noodzakelijk. Dit onderzoek kan bovendien helpen om eventuele knelpunten in de uitvoering van zo'n zorgprogramma vast te stellen en om hiervoor oplossingen aan te

dragen. Denk hierbij bijvoorbeeld aan knelpunten in de wet- en regelgeving en in de financiering.

Met het voorgaande als uitgangspunt hebben wij als onderzoeksgroep vanaf 2011 onder de naam **MAPPING** een studie verricht bij een groep verpleeghuisbewoners met psychiatrische en lichamelijke multimorbiditeit. Mapping staat daarbij voor: *a study in residents with mental and physical problems residing in Dutch nursing homes*. Dit proefschrift is de afsluiting van dat onderzoek.

In Nederland wordt onderscheid gemaakt tussen psychogeriatricie, voor ouderen met dementie, en *gerontopsychiatrie*, voor ouderen met psychische problemen van allerlei aard. De MAPPING-studie richt zich op de bewoners die in een verpleeghuis zijn opgenomen met gerontopsychiatrische zorgbehoeften; bewoners met dementie zijn uitgesloten van het onderzoek.

Hoofdstuk 1 van dit proefschrift beschrijft de achtergrond en de hoofddoelstellingen van het onderzoek. Met de MAPPING-studie willen we op de eerste plaats meer te weten komen over de kenmerken en zorgbehoeften van verpleeghuisbewoners met psychiatrische en lichamelijke multimorbiditeit. Daarnaast willen we meer inzicht krijgen in de bewonersgebonden factoren die van invloed zijn op gedragsveranderingen na opname op een gerontopsychiatrische verpleeghuisafdeling. Bewonersgebonden factoren zijn kenmerken van de persoon zelf, bijvoorbeeld leeftijd en geslacht, maar ook persoonlijke eigenschappen, lichamelijke en psychiatrische aandoeningen, medicijngebruik en de mate van afhankelijkheid van zorg.

Hiertoe hebben wij de volgende vragen geformuleerd:

- 1 Wat zijn de kenmerken en zorgbehoeften van bewoners met psychiatrische en lichamelijke multimorbiditeit die zijn opgenomen op een gerontopsychiatrische verpleeghuisafdeling?
- 2 Welke gedragsveranderingen laten bewoners zien, acht maanden na opname op een gerontopsychiatrische verpleeghuisafdeling en wat is de invloed van verschillende bewonersgebonden factoren op deze veranderingen?

In **hoofdstuk 2** beargumenteren wij vanuit onze praktijkervaring en -kennis waarom verpleeghuisbewoners met psychiatrische en lichamelijke multimorbiditeit als een aparte groep met specifieke kenmerken en zorgbehoeften moeten worden beschouwd. Daarnaast worden de randvoorwaarden geschetst voor passende specialistische verpleeghuiszorg voor deze bewonersgroep.

Dit hoofdstuk gaat in op de gewenste samenstelling en competenties van het multidisciplinaire zorgteam. Daar moeten naar onze mening in ieder geval een specialist ouderengeneeskunde, een GZ-psycholoog en een Hbo-opgeleide verpleegkundige deel van uitmaken. De leden van het multidisciplinaire team moeten beschikken over de specifieke kennis en vaardigheden die nodig zijn om zorgvragen, symptomen en gedrag van bewoners met psychiatrische en lichamelijke multimorbiditeit goed te kunnen interpreteren. Bovendien moeten zij kunnen samenwerken met professionals uit de tweede lijn, zowel voor lichamelijke en/of psychiatrische consultatie als voor medebehandeling. In dit hoofdstuk besteden we ook aandacht aan de woonleefomgeving voor deze groep bewoners. Wij doen suggesties voor de inrichting van een sociotherapeutisch leefmilieu dat enerzijds de eigen verantwoordelijkheid van de bewoner bevordert en anderzijds structuur biedt. Het is belangrijk om te zorgen voor voldoende zinvolle dagbesteding, aangepast aan de wensen en mogelijkheden van de bewoners. Tot slot breken wij een lans voor regelgeving en financiering die consultatie, (psycho)therapie, scholing van medewerkers en de evaluatie van het sociotherapeutische leefmilieu mogelijk maakt.

Samenvatting van de bevindingen

In **hoofdstuk 3** doen we verslag van ons systematische onderzoek van de wetenschappelijke literatuur. We hebben zeventien relevante artikelen gevonden en bestudeerd om antwoord te krijgen op drie vragen:

- 1 *Hoe vaak is er in verpleeg- en verzorgingshuizen sprake van multimorbiditeit van lichamelijke en psychiatrische aandoeningen (zonder dementie)?*

Deze vraag levert zeer uiteenlopende antwoorden op, omdat verschillende combinaties van lichamelijke en psychiatrische aandoeningen zijn onderzocht. Twee voorbeelden: van de bewoners die suikerziekte hebben, heeft bijna een derde ook een depressie en van de bewoners met een psychiatrische ziekte heeft ruim een op de vijf ook chronische longaandoeningen.

- 2 *Welke kenmerken en welke zorgvragen hebben verpleeg- en verzorgingshuisbewoners met een combinatie van lichamelijke en psychiatrische problemen (zonder dementie)?*

In vergelijking met de gemiddelde somatische verpleeg- of verzorgingshuisbewoner blijken de onderzochte bewoners jonger, vaker van het mannelijk geslacht en ongetrouwd te zijn. Daarnaast is er volgens de literatuur vaker sprake van probleemgedrag en zijn er meer cognitieve problemen, terwijl op het gebied van de *algemene dagelijkse levensverrichtingen* (ADL) de hulpbehoefendheid vaak minder groot is. We hebben

geen studies gevonden waarin de zorgvragen van deze specifieke groep bewoners is onderzocht.

3 *Zijn er risicofactoren voor de multimorbiditeit van lichamelijke en psychiatrische aandoeningen?*

In vijf van de zeventien artikelen is hier iets over te vinden. In alle vijf gaat het over het verband tussen lichamelijke aandoeningen en depressie. In deze onderzoeken komen de volgende vijf risicofactoren naar voren: pijn, een beroerte, het aantal lichamelijke aandoeningen (hoe meer aandoeningen, des te groter het risico op een depressie), functionele beperkingen en een negatieve gezondheidsbeleving.

In **hoofdstuk 4** beschrijven we het onderzoeksprotocol van de MAPPING-studie. Om antwoord te kunnen geven op de vraag naar kenmerken en zorgbehoeften van bewoners met psychiatrische en lichamelijke multimorbiditeit, werden gegevens vastgelegd van bewoners die minimaal zes maanden waren opgenomen op een gerontopsychiatrische verpleeghuisafdeling.

De gegevens werden verkregen uit de dossiers en met (korte) neuropsychologische testen, semi-gestructureerde interviews en zelfrapportage-vragenlijsten. De gegevens betreffen demografische variabelen, de psychiatrische voorgeschiedenis en actuele psychiatrische diagnoses, neuropsychiatrische symptomen, persoonlijkheidskenmerken, het cognitief functioneren, de chronische somatische aandoeningen, de zorgbehoeften en de kwaliteit van leven van de bewoners.

Bij ongeveer de helft van de deelnemers aan ons onderzoek zijn deze gegevens ook vastgelegd twee maanden na de opname op de gerontopsychiatrische verpleeg-huisafdeling. Hierdoor kunnen we vaststellen welke gedragsveranderingen (zoals de af- of toename van prikkelbaarheid, agressie, somberheid, angst en apathie) zich in een periode van zes maanden hadden voorgedaan en welke bewonersgebonden factoren van invloed zijn op deze veranderingen.

Hoofdstuk 5 beschrijft de kenmerken, het gedrag en de zorgafhankelijkheid van de 142 onderzochte bewoners. De groep die door de geestelijke gezondheidszorg is doorverwezen (de GGZ-groep) is vergeleken met de groep die is doorverwezen vanuit thuis, een verzorgingshuis, een verpleeghuis of een ziekenhuis (de VVT-groep).

Bewoners met dementie waren zoals vermeld uitgesloten van het onderzoek. Desondanks blijkt een meerderheid van de onderzochte bewoners cognitieve beperkingen te hebben. Met name de aanwezigheid (70%) en de ernst van functiestoornissen in

de voorhoofdskwabben van de hersenen scoren hoog. Bij 90% van de bewoners zijn klinisch relevante neuropsychiatrische symptomen gevonden.

De vergelijking tussen de GGZ-groep en de VVT-groep laat zien dat de GGZ-groep jonger is, meer chronische psychiatrische stoornissen heeft en meer medicijnen tegen wanen en hallucinaties (antipsychotica) gebruikt dan de VVT-groep. Bewoners in de VVT-groep hebben meer hulp nodig bij aan- en uitkleden, hebben vaker een negatieve houding en vertonen meer steun zoekend gedrag. Hieruit trekken wij de conclusie dat de twee subgroepen weliswaar verschillen in de wijze waarop de multimorbiditeit vorm krijgt, maar dat zij min of meer gelijk zijn als we kijken naar de gevolgen die deze aandoeningen hebben voor gedrag en zorgafhankelijkheid. Het is dus niet nodig voor deze twee subgroepen aparte afdelingen of specifieke zorgprogramma's te ontwikkelen.

Hoofdstuk 6 doet verslag van de (zorg)behoefte van de deelnemers. Verpleeghuizen willen met persoonsgerichte zorg een bijdrage leveren aan de kwaliteit van leven van de bewoners. Dat kan alleen wanneer de individuele behoeften van de bewoners bekend zijn. Van 142 bewoners hebben we de behoeften in kaart gebracht met de *Camberwell Assessment of Need for the Elderly* (CANE). Met deze vragenlijst zijn de zorgbehoeften op 23 levensdomeinen geïnventariseerd. Een paar voorbeelden van deze domeinen: woonsituatie, huishouden, persoonlijke verzorging, eten/drinken, recreatie, mobiliteit, gezelschap, intieme relaties, gedrag en psychische stress.

Voor het inventariseren van de zorgbehoeften van een bewoner, hebben we zowel de betreffende bewoner als een direct betrokken verzorgende afzonderlijk van elkaar geïnterviewd. De bewoners geven gemiddeld aan behoeften te ervaren op bijna twaalf domeinen, waarvan nagenoeg een kwart onvervuld is. De inschatting van de verzorgenden wijkt daar iets van af. Zij denken dat bewoners gemiddeld op bijna vijftien gebieden één of meer behoeften hebben, waarvan naar hun idee iets meer dan één tiende onvervuld is.

Over de *vervulde* behoeften zijn bewoners en verzorgenden het aardig met elkaar eens. De geboden ondersteuning in het verpleeghuis blijkt goed tegemoet te komen aan behoeften rond het huishouden, medicatie, geld, voeding en zelfzorg.

De opvallendste verschillen in visie tussen bewoners en verzorgenden blijken te bestaan op de domeinen gedrag en wonen. Bijna de helft van de bewoners geeft aan geen problemen te ervaren op het gebied van het eigen gedrag, terwijl de verzorgenden aangeven dat deze bewoners hierbij wel degelijk begeleiding nodig hebben. De verzorgenden zien het verblijf in het verpleeghuis in alle gevallen als een vervulde behoefte van de bewoners op het domein van wonen. Ruim een kwart van de bewoners

geeft echter aan onvervulde behoeften te hebben op dit gebied. Zo laten bewoners zich soms ontvallen dat ze hun kamer te klein vinden, of dat ze het vervelend vinden douche en toilet met iemand anders te moeten delen.

Er bestaat dus op sommige gebieden een verschil tussen de ervaring van behoeften door de bewoners zelf en de visie daarop van de verzorgenden. Dat is niet verbazingwekkend. De behoeften van de bewoners zijn reëel, maar niet altijd even realistisch of aanvaardbaar binnen de context van multimorbiditeit en verblijf in het verpleeghuis. In de persoonsgerichte zorg gelden de behoeften van de bewoners als uitgangspunt. Maar soms moeten die behoeften, of de vervulling daarvan, worden aangevuld of gecompenseerd door professionele interventies die zowel voor de bewoner als voor de zorgverlener aanvaardbaar zijn. Om dergelijke interventies te bespreken en acceptabel te maken, moeten de zorgverleners over vaardigheden beschikken op gebieden als gespreksvoering, leiderschap en coaching. Voor een goede uitvoering van hun taak is het van belang dat medewerkers in de langdurige zorg deze vaardigheden regelmatig trainen.

Hoofdstuk 7 beschrijft het natuurlijke beloop van de neuropsychiatrische (gedrags) symptomen van bewoners met psychiatrische en lichamelijke multimorbiditeit in de eerste acht maanden na opname op een gerontopsychiatrische verpleeghuisafdeling. We hebben onderzocht of bepaalde persoonskenmerken samenhangen met verandering in gedrag. Op basis van de gevonden resultaten hebben we daarover geen duidelijke conclusies kunnen trekken.

Neuropsychiatrische symptomen blijken zeer vaak aanwezig te zijn. Vrijwel alle bewoners hebben één of meer klinisch relevante symptomen bij de eerste meting, twee maanden na opname, en de tweede, zes maanden later. Het gaat daarbij om symptomen als wanen, hallucinaties, somberheid, angst, euforie, apathie en ontremming. Prikkelbaarheid is het meest voorkomende symptoom, én het meest volhardende. Prikkelbaarheid ontwikkelt zich bovendien in zes maanden tijd het vaakst als nieuw symptoom.

De ernst van de neuropsychiatrische symptomen neemt toe tussen de eerste en de tweede meting. Deze toename is klein en klinisch niet-relevant. Toch verdient het beloop van neuropsychiatrische symptomen verdere aandacht in nieuw onderzoek, omdat een afname van deze symptomen de kwaliteit van het leven van de bewoners gunstig kan beïnvloeden.

In **hoofdstuk 8** ten slotte, bespreken we de methodologische aspecten van het onderzoek en gaan we in op de mogelijke gevolgen van onze bevindingen voor de praktijk.

Op de eerste plaats adviseren we om ggz-professionals op structurele basis toe te laten treden tot de multidisciplinaire teams van gerontopsychiatrische verpleeghuisafdelingen. Wij denken dat dit kan leiden tot verbetering van de kwaliteit van de (specialistische) zorg aan verpleeghuisbewoners met psychiatrische en lichamelijke multimorbiditeit.

Ook adviseren wij de multidisciplinaire teams om individuele bewoners actief te screenen op depressieve symptomen en onvervulde behoeften en om vervolgens samen met de bewoner te zoeken naar interventies die deze symptomen en gevoelens kunnen afzwakken.

Ten derde doen we de aanbeveling een inter-professionele training te ontwikkelen voor de kerndisciplines die betrokken zijn bij de zorg voor de verpleeghuisbewoners die het onderwerp zijn van deze MAPPING-studie

Ten slotte doen we een aantal suggesties voor relevante onderzoeksthema's, zoals: de invloed van persoonlijkheidskenmerken op het beloop van neuropsychiatrische symptomen en de invloed van psychosociale interventies en dagbesteding op het welbevinden van verpleeghuisbewoners met psychiatrische en lichamelijke multimorbiditeit.

Conclusie

Ons onderzoek laat zien dat verpleeghuisbewoners met psychiatrische en lichamelijke multimorbiditeit een heterogene groep vormen, maar er zijn duidelijke aanwijzingen dat deze groep als geheel verschilt van andere groepen verpleeghuisbewoners wat betreft kenmerken en zorgbehoeften.

Bewoners met psychiatrische en lichamelijke multimorbiditeit hebben een verhoogde kans om zowel lichamelijk als psychisch uit balans te raken als gevolg van hun complexe multimorbiditeit in combinatie met cognitieve functiestoornissen en medicatiegebruik. Daardoor kan probleemgedrag ontstaan of toenemen. Bovendien ervaren deze bewoners meer onvervulde behoeften en hebben zij minder sociale relaties en activiteiten, wat een negatieve invloed kan hebben op hun welbevinden.

Om het welbevinden van deze bewoners te optimaliseren, moeten verpleeghuizen gespecialiseerde zorg bieden die is afgestemd op de specifieke behoeften van verpleeghuisbewoners met psychiatrische en lichamelijke multimorbiditeit. Ons onderzoek wil een stimulans zijn om 1) een zorgstandaard te ontwikkelen voor deze bewoners, 2) een (interprofessionele) training voor zorgprofessionals te ontwikkelen waardoor zij in staat zijn om de gewenste zorg te bieden, en 3) nieuw onderzoek uit te voeren dat gericht is op de verdere professionalisering van de verpleeghuiszorg voor deze bewoners.

Data management

Dit proefschrift is gebaseerd op de resultaten van onderzoek dat werd uitgevoerd in overeenstemming met de Verklaring van Helsinki (<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>) en de Gedragscode voor Gezondheidsonderzoek.¹

De gegevens die in het kader van de MAPPING studie zijn verzameld, zijn gearchiveerd volgens de Findable, Accessible, Inoperable and Reusable (FAIR) principes.²

Informed consent

Informed consent is verkregen voor deelname aan de MAPPING studie. Daarnaast is een aparte informed consent verkregen voor het benaderen van een naaste ten behoeve van het invullen van vragenlijsten.

Alle informed consent formulieren zijn als papieren versie opgeslagen in het afgesloten archief van de afdeling eerstelijns geneeskunde (M245.-2.053).

Beveiligde data-opslag

Gedeeltelijk werden de data op papier verzameld en daarna ingevoerd in een digitale database (FileMaker Pro Database). De overige data werden tijdens het interview direct ingevoerd in deze database.

Alle originele gegevens die op papier zijn vastgelegd, zijn opgeslagen in het afgesloten archief van de afdeling eerstelijns geneeskunde (M245.-2.053).

Alle originele gegevens in de digitale database als ook bestanden voor analyse zijn opgeslagen op de H:\schijf van de afdeling Eerstelijns geneeskunde van het Radboudumc in map H:\OZ-GGZ\Mapping. De data zijn geanonimiseerd opgeslagen en worden bewaard voor een periode van 10 jaar.

Prof. Dr. D.L. Gerritsen is projectleider. Na afloop van de bewaartermijn neemt zij het besluit of data vernietigd kunnen worden of, indien gewenst, voor een langere periode beschikbaar moeten blijven (bewaartermijn wordt dan opnieuw vastgesteld). Het Radboudumc is verantwoordelijk voor dagelijkse back-up van de files op de H:\schijf.

Soort data

Kwantitatief:

- Vragenlijsten, opgeslagen in de H:\OZ-GGZ\Mapping map in .fmp12 bestanden.
- De data zijn verwerkt in SPSS en opgeslagen in .sav bestanden.

Literatuurstudie:

- De zoekstrategie is per literatuur database opgeslagen in Word-format, de resultaten van de zoekstrategie zijn opgeslagen in EndNote, .enl bestanden
- Alle full-text artikelen van geïnccludeerde studies zijn opgeslagen als .pdf bestanden
- Alle data-extracties en tabellen zijn opgeslagen in Word .docx bestanden.

Beschikbaarheid data

Alle data zijn 'on reasonable request' beschikbaar bij de co-promotor prof. dr. D.L. Gerritsen. Bij een verzoek zal zij overleggen met de promovenda drs. J.M.A. van den Brink of data beschikbaar worden gesteld.

¹ *Code of Conduct for Health Research, (2004).*

² *Wilkinson MD, Dumontier M, Aalbersberg IJ, Appleton G, Axton M, Baak A, et al. The FAIR Guiding Principles for scientific data management and stewardship. Sci Data. 2016;3:160018.*

Dankwoord

Als parttime buitenpromovenda heb ik meer dan 10 jaar lang mijn werk in het verpleeghuis gecombineerd met onderzoeksactiviteiten. In de loop der jaren groeide het aantal mensen dat direct of indirect heeft bijgedragen aan het verwezenlijken van dit proefschrift. Al die mensen wil ik hiervoor welgemeend bedanken.

In de rest van dit dankwoord beschrijf ik de weg die naar dit proefschrift heeft geleid en wil ik een aantal mensen specifiek bedanken voor hun unieke bijdrage in dit traject.

Mijn avontuur begint bij mijn coschap sociale geneeskunde in verpleeghuis Joachim en Anna. Ik weet nog goed dat ik dacht: “Jammer dat ik geplaatst ben in een psychogeriatrisch verpleeghuis, want wat kun je daar als dokter nou doen? Maar ach, die vier weken (min de kerstdagen en nieuwjaarsdag), die overleef ik wel”.

Hoe anders is het gelopen! Ik kwam terecht in een vriendelijke organisatie met een warm hart voor de bewoners en een ambitieuze groep dokters. Al na twee weken was ik gevallen voor de verpleeghuiszorg, voor het vakmanschap van de verpleeghuisarts en voor onderzoek! Dit is één van de meest cruciale keerpunten in mijn leven geweest, waar ik Piet van Kalmthout, Raymond Koopmans en Marie-Anne Bogaers nog altijd zeer dankbaar voor ben. Zoals in mijn Curriculum Vitae te lezen is, ben ik sindsdien aan Joachim en Anna, later De Waalboog, verbonden gebleven. Dat is te danken aan de vele fijne collega's, aan de ruimte voor vakinhoudelijke en persoonlijke ontwikkeling en aan de focus van de organisatie op specialisatie en op de kwaliteit van de bewonerszorg.

Daarnaast heb ik veel vertrouwen gekregen.

Al in het laatste jaar van mijn opleiding tot verpleeghuisarts werd ik de afdelingsarts van afdeling Sering waar een nieuwe doelgroep (somatic plus) zou komen. Bijna alles was nieuw. Als multidisciplinair team hebben we mogen pionieren. Lang niet alles ging in één keer goed. We hebben heel veel meegemaakt en verschillende ervaringen opgedaan; we hebben ons ontwikkeld op het gebied van de gerontopsychiatrische verpleeghuiszorg. Iedereen met wie ik op de Sering en later ook op de Jasmijn heb samengewerkt, wil ik hiervoor bedanken, met name Astrid Mulder (teamleider, later zorgmanager) en John Ekkerink (GZ-psycholoog) omdat ik met hen het langst en meest intensief heb samengewerkt en omdat ik veel van hen geleerd heb.

Als “jonge klare” werd ik manager Behandeling en Begeleiding en lid van het managementteam (MT). Ik bedank mijn MT-collega's omdat zij allen hebben bijgedragen aan mijn werkplezier en aan de ontwikkeling van allerlei vaardigheden waar ik tijdens

mijn promotieonderzoek veel profijt van gehad heb. Met name Barbara Versteegen en Theo Ebbers wil ik noemen, maar ook de bestuurders die mijn ambitie om onderzoek te doen, hebben gefaciliteerd. Dhr. Schellens, die mij bij herhaling heeft toevertrouwd hoe spannend hij het vond dat ik als buitenstaander de archieven van Joachim en Anna bestudeerde en daarover zou publiceren. Francis Pothof, die aan de wieg stond van het lidmaatschap van De Waalboog van het Universitair Verpleeghuisnetwerk Nijmegen (UVNN), de voorloper van het Universitair Kennisnetwerk Ouderenzorg Nijmegen (UKON). Zij gaf professionals de ruimte om zich te specialiseren. En ten slotte Emmy Janssen, die met verve de ingezette koers heeft voortgezet. Zij vond het belangrijk dat De Waalboog niet alleen participeerde in onderzoek van anderen, maar ook zelf onderzoek zou initiëren en uitvoeren. Toen De Waalboog een deel van het door het zorgkantoor toegekende budget mocht besteden aan een innovatie- of onderzoeksproject, zei Emmy tegen mij: “nu kunnen we met een eigen onderzoek beginnen en ik vind dat jij dit moet gaan doen.”

Zo begon ik in september 2008 als onderzoeker. Ik kreeg een aanwezigheidscontract bij de afdeling eerstelijns geneeskunde van het Radboudumc en ik kreeg een werkplek in één van de kamers aan de Paul Froelinglaan (route 106), waar toen nog zowel de medewerkers van de opleiding tot verpleeghuisarts als de onderzoekers op het gebied van de verpleeghuisgeneeskunde zaten. Maar ik kreeg heel veel meer dan dat: ik kreeg nieuwe collega's, die allen bereid waren met mij mee te denken en hun kennis met mij te delen. Collega's die vorderingen en knelpunten in hun onderzoek, maar ook lief en leed met elkaar bespraken tijdens “mag-ik-je-even-wat-vragen-” of koffiemomentjes en tijdens onze vele lunchwandelingen. Collega onderzoekers, bedankt! Ik ga jullie en mijn plekje tussen jullie in missen.

En ik kreeg een begeleidingsteam.

Raymond, het eerste jaar heb ik samen met jou gewerkt aan een onderzoeksvoorstel. We hadden de grote lijnen al wel besproken nadat je “ja” had gezegd op de vraag van Emmy of je het zag zitten om promotor te worden van het beoogde promotietraject. Toch voelde jouw mailtje met een aantal relevante artikelen en richtlijnen en de boodschap “begin je maar eens in te lezen” voor mij pas als de echte start. Daarna hebben we heel veel concept versies van het onderzoeksplan bediscussieerd. Je hebt me uitgedaagd om te blijven schrappen en schaven, net zo lang tot er een *haalbaar* plan lag.

En toen werd je formeel mijn promotor. Dat voelt nog steeds als een bekroning op onze jarenlange samenwerking binnen De Waalboog. Ook in de rol als promotor geef je alles wat ik van jou ken en wat ik zo waardeer in jou: je passie voor het vak ouderengeneeskunde, je gedrevenheid om het vak verder wetenschappelijk te

onderbouwen en om de kwaliteit van de ouderenzorg te verbeteren, je scherpe geest, je belangstelling en je betrouwbaarheid. Naast alle andere ballen, hield je de MAPPING-bal altijd mee omhoog, ook als dat eigenlijk niet in je agenda paste. Raymond, bedankt voor alles! Gelukkig zetten we onze samenwerking op vele fronten voort.

Mijn begeleidingsteam werd vervolgens uitgebreid met twee copromotoren, Richard Oude Voshaar en Debby Gerritsen. Ik wil andere promovendi niet jaloers maken, maar wat mij betreft kreeg ik hiermee een dreamteam.

Richard, jij weet ontzettend veel van de ouderenpsychiatrie en van onderzoeksmethoden. Ik heb ruimschoots gebruik van mogen maken van jouw kennis en ervaring. Je bereidde alle besprekingen zorgvuldig voor en had altijd scherp wat je wilde inbrengen. Nooit op de voorgrond en met veel respect voor de ideeën van de anderen, wist je vaak precies op het goede moment en met de goede woorden, nieuwe elementen in de discussie te brengen. Verder heb ik me vaak echt geholpen gevoeld door jouw concrete aanwijzingen en tekstvoorstellen. Je voelde precies aan wanneer ik die nodig had.

Op 1 mei 2011 werd jij benoemd tot hoogleraar in de ouderenpsychiatrie aan het Universitair Medisch Centrum Groningen. Gelukkig bleef je, nu als tweede promotor, in mijn begeleidingsteam. Veel kon via de mail en soms via skype, maar voor de inhoudelijke discussies kwam je zo veel mogelijk naar Nijmegen. Je hebt veel toegevoegd! Bedankt daarvoor.

Debby, jij was meer dan 8 jaar mijn directe begeleider. Ik ben je bijzonder dankbaar voor de manier waarop jij mij, met alle kwaliteiten die je hebt, door dit onderzoekstraject geloofdst hebt. Je bent vriendelijk, belangstellend, aandachtig, betrokken, slim, deskundig, trouw, accuraat en laagdrempelig. Ik kon altijd bij je terecht, maar als ik het eerst zelf wilde uitzoeken, was dat ook oké.

In de periode van analyseren en schrijven, intensiverde ons contact. In die tijd werden we ook collega's bij De Waalboog. We hebben gewerkt aan het onderzoekbeleid en samen praktijkonderzoek opgezet en begeleid. We hadden altijd veel te bespreken, soms meer over andere zaken dan over de MAPPING studie. We werden maatjes en dat zullen we blijven!

Op 1 april 2019 ben je benoemd tot bijzonder hoogleraar 'welbevinden van kwetsbare ouderen en mensen met een chronische ziekte in de langdurige zorg'. In mijn proefschrift sta je voor het laatst als copromotor, maar al wel als 'professor'. Verder heb je mijn promotie gekozen als de gelegenheid waar je voor het eerst in toga verschijnt. Je moet eens weten hoe eervol ik dat vind!

Voor de uitvoering van mijn onderzoek had ik de medewerking nodig van zorgorganisaties met een gerontopsychiatrische verpleeghuisafdeling en van bewoners die op deze afdelingen waren opgenomen. En dat is gelukt: 15 zorgorganisaties¹ hebben toestemming gegeven voor het uitvoeren van het onderzoek. Hier hebben 152 bewoners meegewerkt aan het invullen van de vragenlijsten, waarvan 64 twee keer. Dit betekende eveneens 216 interviews bij verzorgenden en verpleegkundigen. Daarnaast hebben 106 mantelzorgers hun medewerking aan de studie verleend.

Het enthousiasme voor mijn onderzoek en de bereidheid om mij hierbij te helpen, waren vaak groter dan ik verwachtte. Voor de afdelingsmedewerkers betekende mijn onderzoek extra werk. In eerste instantie werkten ze vooral mee omdat het *moest*. In de loop van de tijd zagen de meesten ook het *nut* van het onderzoek (“zo wordt duidelijk wat voor bewoners wij hebben en wat wij allemaal doen”) en begonnen ze het steeds *leuker* te vinden om mee te doen (“ik leer er zelf ook veel van”). De gesprekken met de bewoners waren stuk voor stuk bijzonder. De meeste bewoners hebben veel over zichzelf verteld. We hebben veel van hen geleerd.

Ik wil daarom alle bewoners, mantelzorgers, verzorgenden en verpleegkundigen die aan de MAPPING studie hebben meegewerkt, heel hartelijk bedanken. Als blijk van waardering draag ik de Nederlandstalige publieksversie van dit proefschrift aan hen op.

Gedurende de gegevensverzameling was Miranda de Valk mijn onderzoeksassistent. Miranda, je plande afspraken, deed interviews, verwerkte de gegevens in de database, en belde mantelzorgers als de vragenlijsten niet werden teruggestuurd. Je hebt me veel werk uit handen genomen. Dit klinkt als een goed functionerende onderzoeksassistent. Klopt, maar je hebt zo veel meer voor het onderzoek en voor mij betekend! Jij was mijn collega-onderzoeker, we deden het samen. Jij wist als geen ander wat ik aan het doen was. Bij jou kon ik spuien. Met jou kon ik de mooie of indrukwekkende verhalen delen. We konden sparren over de interpretatie van bepaalde antwoorden en dat heeft de kwaliteit van de data verbeterd.

Ik weet zeker dat jij met jouw uitstraling, enthousiasme en manier van communiceren indruk gemaakt hebt op bewoners en afdelingsmedewerkers. Je was een visitekaartje voor ons onderzoek. Je bent ook mijn ideale paranimf en gelukkig heb je daar “ja” tegen gezegd. Ik ben er trots op dat jij mij ter zijde zult staan tijdens de verdediging van mijn proefschrift.

¹ *Archipel | Atlant | Attent | Azora | Carint Reggeland | Hilverzorg | Laurens | Liemerije | Meriant | De Riethorst Stromenland | Tante Louise | Surplus | De Waalboog | Zorgaccent | De Zorggroep*

Ik ben de leden van de manuscriptcommissie: prof. dr. A.H. Schene, dr. J.C.C. Braspenning en prof. dr. J.P.H. Hamers, zeer erkentelijk voor het lezen en beoordelen van mijn manuscript.

Jos Blom bedank ik voor zijn tips voor fraaiere Engelse formuleringen en voor het herstel van mijn gedeukte zelfvertrouwen.

Peter Pickkers, fijn dat je mijn mentor wilde zijn. Vooral de rondleiding op de IC vond ik gaaf!

Als scientist practitioner kun je je alleen op je onderzoek focussen als je je geen zorgen hoeft te maken over de patiëntenzorg. Dit is mij gelukt door de flexibiliteit en de inzet van mijn collega SO's Anne, Daniëlle, Elske, Ewoud, Hillery, Jean-Pierre, Jule, Kim, Laurence, Lucy, Manon, Michelle, Miranda, Mirjam, Piet, Raymond en Renée, verpleegkundig specialisten Astrid en Wilfred en de aios en andere basisartsen die ons team steeds tijdelijk versterkten.

Collega's van de VOSON, ik heb jullie de laatste maanden minder aandacht kunnen geven dan ik zou willen. Na de zomer wordt dat beter.

Papa en Mama, vanuit een liefdevolle thuisbasis hebben jullie mij grootgebracht en altijd gestimuleerd om me te ontwikkelen.

Papa, ik was zes jaar toen jij promoveerde en ik kan me die dag nog heel goed herinneren. Jij verdedigde je proefschrift op dinsdag 1 juli 1969 des namiddags te 2 uur; ik doe dat precies 50 jaar later. Het is verdrietig dat je dit niet meer mee kunt maken. Ik weet zeker dat jij enorm van deze dag genoten zou hebben.

Mama, jij hebt me altijd gestimuleerd ervoor te zorgen dat ik op eigen benen zou kunnen staan: "alleen dan ben je in staat in vrijheid keuzes te maken". Je bent een geweldige moeder en je bent een wijze vrouw.

Mijn schoonouders geven mij al meer dan 30 jaar een tweede thuis. Rob en Sonja, ik ben heel dankbaar voor de vanzelfsprekendheid waarmee jullie je altijd hebben ingezet voor ons gezin. Hierdoor was het mogelijk om gezin en werk te combineren zonder uit balans te raken.

Mijn (schoon)broers en (schoon)zussen, Truus en Mark, Maike en Gerard, Jaap en Marjan, Wouter en Jolanda en hun kinderen Annemieke, Carlijn, Heleen, Wouter, Nienke, Jasper, Alje, Willem, Hanna en Jolijn, jullie verrijken mijn leven. We hebben het goed met elkaar!

Als tweede paranimf wilde ik daarom iemand uit de familie. Marjan, jij hebt mij op belangrijke momenten tijdens mijn onderzoek een stap verder geholpen. Met veel geduld heb je mij uitgelegd hoe ik in SPSS een aantal zaken handiger kon inrichten en met jou naast me durfde ik uiteindelijk toch mijn bestanden te “mergen”.

Daan en Lucas, mijn geweldige zoons, jullie waren al groot toen ik met mijn onderzoek begon en dat heeft veel voordelen. Jullie hadden er in ieder geval geen last van dat mijn vrije tijd deels gevuld werd met onderzoeksactiviteiten. Daan, mijn steun en toeverlaat voor al mijn computer vraagstukken. Jij hielp met de inrichting van de database waardoor een zeer efficiënte invoer en verwerking van gegevens mogelijk was. Lucas, met jou kon ik lekker filosoferen over het nut en de lol van onderzoek doen en over de echt belangrijke dingen in het leven. Je weet hoe gezellig en motiverend ik dat vind!

Maaïke en Loes, de vriendinnen van Daan en Lucas die ik liefkozend mijn meisjeskinderen noem, ik ben heel blij met jullie. Maaïke, het was leuk dat wij min of meer synchroon onze promotietrajecten hebben gedaan, dat scheidt een bijzondere band. Heel veel succes met de laatste loodjes! Loes, je bent nieuwsgierig, hebt een open mind en kunt goed schrijven. Je zou een ideale onderzoeker zijn, maar ik ken je minder positieve ervaringen met je scriptiebegeleiders. Ik hoop dat je je journalistieke en je onderwijshart kunt blijven volgen.

Koen, ik ga je niets nieuws vertellen, je weet wat je voor mij betekent. Jij kent mij inmiddels ruim 33 jaar en weet precies wat mij happy maakt en in balans houdt. Je geeft me alle ruimte om mijn ambities waar te maken, zolang ik er maar positieve energie van krijg. Als ik te vaak begin te zuchten en steunen, geef je tegengas. Hooguit één keer een subtiele hint, daarna recht voor z'n raap. Door en met jou ben ik gelukkig. Laat nu dat zwarte gat maar komen. Ik hoop dat we daar samen de hele zomer van kunnen genieten.

Curriculum vitae

Anne van den Brink werd op 21 mei 1963 geboren in Nijmegen. In 1981 behaalde zij haar Gymnasium diploma aan het Dominicus College in Nijmegen.

Aansluitend studeerde zij Geneeskunde aan de Katholieke Universiteit Nijmegen. Haar coschap sociale geneeskunde liep zij in het Nijmeegse verpleeghuis Joachim en Anna. Hier is zij gevallen voor de verpleeghuisgeneeskunde. In het kader van haar wetenschappelijke stage heeft zij vervolgens onderzoek gedaan naar de ontwikkeling van de verpleeghuiszorg in Nederland. Mede op basis hiervan schreef zij drie hoofdstukken in het boek "Psychogeriatrische verpleeghuiszorg in ontwikkeling" dat werd uitgegeven ter gelegenheid van het 25 jarig bestaan van Joachim en Anna.

In 1990 behaalde zij haar artsdiploma. Vervolgens heeft zij lesgegeven op (de voorloper van) het ROC Nijmegen en als waarnemer gewerkt in Joachim en Anna. Vanaf 1992 is zij vast aan dit verpleeghuis verbonden.

Vanaf september 1994 was zij gedurende twee jaar in opleiding tot verpleeghuisarts aan de Vrije Universiteit in Amsterdam en in de opleidingshuizen Kalorama in Beek/Ubbergen (somatiek) en Joachim en Anna (psychogeriatric). Haar scriptie "De toepasbaarheid van de Classificatie van Ziekten voor de Verpleeghuisgeneeskunde" werd in 1996 verkozen tot de beste scriptie van het jaar.

Na afronding van deze opleiding werkte zij gedurende twee jaar als verpleeghuisarts bij Joachim en Anna en bij Maria Mackenzie (cluster ouderen GGZ Nijmegen). Vervolgens heeft zij binnen De Waalboog (ontstaan door fusie tussen verpleeghuis Joachim en Anna en verzorgingshuis Nijevelt) haar functie als specialist ouderengeneeskunde op de afdeling voor bewoners met gerontopsychiatrische zorgvragen gecombineerd met de functie van manager van de dienst Behandeling & Begeleiding. Vanuit de perspectieven van beide functies was zij actief in diverse project- en stuurgroepen met als doel de randvoorwaarden voor de zorg voor cliënten met gerontopsychiatrische problemen binnen de VVT te verbeteren. In 2017 heeft zij hiervoor de NKOP Award ontvangen.

In 2008 kreeg zij de mogelijkheid een sluimerende ambitie waar te maken, namelijk het opzetten van een promotieonderzoek. Met de uitvoering hiervan is zij in 2011 begonnen, nadat opvolging in haar managementfunctie gerealiseerd was. Naast het onderzoek bleef zij in de praktijk werken als specialist ouderengeneeskunde. Hier is zij tijdelijk mee gestopt toen zij per 1 juli 2017 hoofd werd van de Vervolgopleiding

tot Specialist Ouderengeneeskunde aan het Radboudumc in Nijmegen (VOSON). Na afronding van het onderzoek zal zij ook deze draad weer oppakken.

Anne is getrouwd met Koen Weerheijm. Samen hebben zij twee zoons, Daan (1987) en Lucas (1991).