Janine Collet

SPECIFIC CARE ON THE INTERFACE OF MENTAL HEALTH AND NURSING HOME

Specific Care on the Interface of Mental health & Nursing home

“SpeCIMeN”

Janine Collet

The research in this thesis was conducted at the School of Mental Health and Neuroscience (MHeNS), Department of Psychiatry and Psychology and at Care and Public Health Research Institute -CAPHRI-, Department of Family Medicine (section Elderly Care Medicine); both at Maastricht University, Maastricht, The Netherlands.

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Contents

Chapter 1

General introduction

CASE-VIGNETTE

Let me introduce our patient. Peter is a 72 year old widower who does not have children. He was admitted to a nursing home (NH), because of his intensive 24 hour care needs due to advanced Parkinson's disease. His history does not include psychiatric disorders or psychiatric treatment, but he is known to have some cognitive decline and both narcissistic and borderline personality traits. During the first three months after admission to the NH he presented with many behavioural disturbances. Peter showed disqualifying behaviour to both fellow patients and their family members, and played upon the nursing staff continuously. The nursing staff felt discouraged, burned out, and only responded in countertransference. They suggested a transfer to a mental healthcare institution (MH). After a multidisciplinary patient discussion with the nursing staff, the NH elderly care physician and the NH psychologist, it was decided to request psychiatric consultation from the department of old age psychiatry. Unfortunately, neither multiple sessions of advice, support, and psycho-education to the NH care team provided by a consultative psychiatric nurse together with a psychiatrist, nor adjustment of pharmacotherapy, did sufficiently calm down the situation. Subsequently a so called "time-out period" was requested, and a six-week admission for diagnostics at the geropsychiatric unit in the MH was arranged. Within these six weeks, a clearly structured and closely monitored, personalized care plan, with specific interest to the patient's personality traits, ensured behavioural stabilization. When arrangements were made to transfer Peter from the mental healthcare setting, back to his former NH-ward, the nursing staff of this ward indicated they do not want him to return to their ward. (We will meet Peter again at the end of the general discussion).

DCD-PATIENTS

A patient as described in this case-vignette, having combined physical, psychiatric and or cognitive conditions, is referred to as a double care demanding (DCD) patient [1]. DCD-patients require a combination of psychiatric, physical, and or psychogeriatric care [2, 3]. They benefit from collaborative psychiatric and somatic medicine approaches, for example from multidisciplinary care teams that deliver integrated mental and physical health care [2, 4].

Up till now however, different types of long-term care (LTC) are provided to older people with disabling psychiatric illnesses, advanced dementia, and physical disabilities. The absolute dichotomization into two categories of psychiatric treatment in MH care on the one hand and NH care (composed of either psychogeriatric care or physical care) on the other hand creates regulatory and funding restrictions that hamper the realization of the complementary benefits, both sectors may have. Health care insurance companies may not reimburse the costs of extended physical care within a MH, and vice versa the costs

for psychiatric treatment in a NH. Therefore, the probability exists, that both psychiatric patients with comorbid dementia and/or physical problems, and NH-residents with co-morbid psychiatric disorders do not receive the care they need [3, 5]. This is even more relevant in the light of the current health care transformations in Western society. First there is a continuing process of deinstitutionalization of psychiatric care services, which has decreased the number of psychiatric hospital beds in most industrialized countries [6, 7]. The so-called asylum function for older adults with chronic mental illness has since then been partly taken over by NH facilities [8, 9]. Second, there is the trend of keeping frail older people community dwelling as long as possible [10]. Consequently, merely old patients with very complex care demands are admitted to LTC facilities [11].

Up to 24% of all newly admitted NH-residents have a mental disorder [12]. Depression, anxiety, and agitation occur frequently in institutionalized elderly persons and often predict decreased quality of life and increased disability [13, 14]. Major depressive disorder was prevalent in 5% to 25% of older LTC-residents worldwide [15], whereas the prevalence of anxiety disorders in NHs varied from 3.2% to 20% [16]. According to the National Nursing Home Survey there is a 3.6% prevalence of schizophrenia and a 1.5% prevalence of bi-polar disorders in American NHs [15]. Previous Dutch studies showed that neuropsychia-tric symptoms were present in more than 80% of the patients with dementia living in NHs [17], and that 35% of all NH-residents have severe behavioural problems, often resulting in a need for psychiatric consultation [18, 19]. Furthermore, 8% and 14% of the Dutch NH-residents suffered from major and minor depression respectively [20]. The prevalen-ce of anxiety disorders was 5.7%, while a further 29% of them suffered from sub-clinical anxiety [21].

Vice versa people with severe mental illness (SMI) have in general poorer physical health [22]. They have on average higher rates of morbidity and loss of life expectancy of 10 to 20 years compared to non-psychiatric cohorts [23, 24]. Medical comorbidity has measurable negative effects on the psychiatric outcomes of psychiatric inpatients [25]. Nutritional and metabolic diseases, cardiovascular diseases, respiratory tract diseases, and musculoskele-tal diseases are more prevalent among people with SMI [26]. The prevalence of type II di-abetes in inpatients with schizophrenia or bipolar disorder is twofold compared to general populations, and symptoms of cardiovascular disease are twice as often present in indivi-duals with SMI [27]. They have higher rates of medical emergency room visits and longer lengths of medical hospitalizations [28]. Therefore, focusing on health related lifestyle and somatic health should be an integral part of the treatment for SMI inpatients [29].

DCD CARE-SETTINGS

In the Netherlands, MHs traditionally provide recovery and rehabilitation focused care

to patients with (persistent) SMI, living at home or in need of hospital expertise. Several Dutch MHs have developed specific geriatric psychiatry units for 24-hour integrated multidisciplinary care for frail elderly with combined psychiatric and physical care needs.

Dutch Nursing Homes (NHs) traditionally provide 24-hour care to patients with a diversity of physical and psychogeriatric disorders that are not in need of hospital expertise, but cannot be cared for at home. NH-patients are admitted to domestic styled facilities for regular somatic and psychogeriatric care or for geriatric rehab. Some Dutch NHs have developed specific units for specific target populations like DCD-patients [30].

A survey among all Dutch NHs, performed in 2007, showed that 8.4% of all NH-residents could be considered to be DCD-patients who exceeded the regular NH care possibilities. To them, no specific psychiatric care is often offered, and a great variety in the organization of care for NH DCD-patients exists. Specific training of staff in caring for DCD-patients is limited. The NH-staff clearly indicated the need for more expertise in the recognition of mood and behavioural problems and of more expertise regarding the interaction with DCD-patients. Though 80% of the NHs cooperated with MH-services outside the NH, the intensity of the liaison was in general limited, consisting mostly of a consultation possibility for individual patients (90%) and occasional staff-education (38%). In practice, the availability of NH-psychologists and specially trained NH-staff was very limited [31].

Results of a survey among all 27 Dutch MHs providing integral care to older SMI-patients showed that 83% of these MHs offer consultation to NHs. One third of these MHs had the possibility to use an outreaching psychiatric team, 61% offered training to NH-staff and 73% offered the possibility of a diagnostic or a time-out admission for NH DCD-patients. One third of the MH admissions of NH DCD-patients were for diagnostic reasons, and two thirds were time-out requests from the NH staff, because of severe agitation and/or aggression of the DCD-patient, that could not be managed by the NH. MH-staff further estimated, that seven percent of the DCD-patients residing in the MH could be transferred to NH care, provided a specialized DCD-unit would be present [32].

A recent review of the literature on well-being of DCD-patients suggests that an accepting and non-stigmatizing environment, with availability of specialist psychiatric care, encouraging autonomy, and providing effective treatment for depression, results in a higher well-being of this specific target group [33].

CHALLENGES IN CARE FOR DCD-PATIENTS

Professional caregivers in combined care settings will certainly be challenged, as they must be competent to address a combination of physical, psychiatric and cognitive care

needs. This challenge of skills might have implications for their experienced work-related stress and therefore may have an impact on their work-related well-being and risk for burnout. Staff burnout has been associated with a higher tendency to leave the nursing profession, which can be a specific threat to a sustainable workforce regarding the care for DCD-patients [34, 35].

Some studies state that mental health nurses are in a favorable position to identify physical problems in psychiatric patients at an early stage, and to initiate, and coordinate effective treatment [22, 36]. MH nursing staff however may feel less competent and less equipped to provide appropriate physical care and treatment, because they often have insufficient physical health-care education and training to meet the physical care demands of DCD-patients [37, 38]. Moreover, reporting and recognition of physical complaints is often delayed in patients with SMI, while their physical problems potentially provoke or aggravate behavioural problems. Their psychiatric illness actually contributes to multimorbidity and associated vulnerability [39, 40]. Therefore it has been indicated that MHs should focus structurally and more often on the physical demands of DCD-patients [41], and that nurses working in MH care should be knowledgeable about the physical health care issues associated with SMI [42].

In addition, NH nursing staff may feel burdened by the behavioural problems of mentally ill patients and their often lack of motivation to accept adequate treatment. The interpretation of symptoms and care needs of DCD-patients in the NH setting can be difficult, as the presentation of their complaints can be influenced for instance by the presence of a personality disorder [5]. The behaviour of DCD-patients on the NH-ward can also be troublesome and even disruptive for other patients and their relatives. Nurses who are trained and qualified to provide psychiatric care are rarely employed within NHs, and specific training in psychiatric care for personnel is limited [43, 44]. Even though the majority of the NHs nowadays have some form of collaboration with a regional MH service, in practice the provided MH care is still limited, and according to the NH staff, not adequately covering the mental health needs of DCD-patients [31, 43, 45].

This implies that more comprehensive integrated models allowing for adequately combined care across settings are probably needed to improve the quality of care of DCD-patients and to tackle DCD staff's problems in dealing with this challenging patient group. These services should be multidisciplinary, multidimensional and structural, addressing neuropsychiatric, medical, psychosocial, environmental and staff issues [3, 23]. So far, there is no evidence-based delineation with regard to the responsibility of the mental health institution versus the nursing home with regard to DCD-patients. The quality requirements regarding DCD-care remain yet undefined and are only underpinned by practice based evidence [46]. Both the appropriateness of SMI patients being admitted to NHs,

and of patients with behaviour disorders whose needs are not met by NHs being admitted to MHs, may therefore stay a controversial issue [45, 47].

AIMS AND OUTLINES

Given the aforementioned, DCD-patients present a particular challenge to LTC services within both MHs and NHs. As scientific evidence was virtually non-existent at the start of this thesis, the "Specific Care on the Interface of Mental health and Nursing home (SpeCIMeN)"- study was initiated. The presence of specialized DCD-units in some Dutch MHs and NHs offered the unique possibility to study the DCD-population across settings, and to explore their differences and similarities.

The aim of this study was threefold:

1. To explore the characteristics and the care needs of DCD-patients;
2. To explore the characteristics and work-related wellbeing of nursing staff caring for DCD-patients;
3. To define the necessary elements for adequate care to DCD-patients, by combining expertise from both psychiatric care and nursing home care and taking into account barriers and facilitators.

Knowledge of the physical, psychological and psychiatric care needs of DCD-patients, will provide insight into the necessary care components for DCD-patients, the required competences for healthcare professionals providing care for DCD-patients, and is also essential to create policy, e.g. about the accessibility of the various healthcare institutions for this target group. More specifically our study addressed the following questions:

What are the established elements of successful interventions combining both psychiatric and nursing home care for DCD-patients?

In Chapter 2 we present the results of a systematic literature review, that was set up as a starting point for our study, to identify the available evidence on types and outcomes of integrated interventions combining both psychiatric care and nursing home care for DCD-patients. Results will provide insight into the necessary care components, to develop the most efficacious care for DCD-patients.

What are the similarities and differences in characteristics and care needs of DCD-patients in the NH and MH setting respectively?

In Chapter 3 we focus on the physical and mental health related characteristics of DCD-patients in both the MH and NH setting. We performed an explorative observational

cross-sectional study to collect data on demographics, psychiatric and physical morbidity, care dependency, neuropsychiatric symptoms, and perceived quality of life of DCD-patients admitted to specialized DCD-units in either a MH or a NH. The findings of this study are relevant for future planning of services for DCD-patients.

Are the care characteristics of DCD-patients related to the mental well-being of their nursing staff?

In Chapter 4 we investigate the impact of caring for DCD-patients on the mental well-being of their nursing staff. Data on demographics, level of education, perceived competence and levels of burnout of the DCD-nursing staff are collected and possible correlations with DCD-patient characteristics are explored. With this study we aim to identify key-elements for both optimal selection, allotment and support of DCD-nursing staff. The findings of this study are relevant for planning of services and training to maximize well-being of staff and DCD-patients, taking into account both the differential impact of care characteristics of these patients and staff characteristics in different DCD-settings.

What are the facilitating or obstructing factors to treat DCD-patients, according to DCD-staff in the NH and MH setting respectively?

Chapter 5 presents a qualitative study with a focus group design, addressing the perceived needs and wishes of nursing staff and other multidisciplinary staff currently caring for DCD-patients in specialized DCD-units across both settings. As nursing staff has a key role in the care for DCD-patients, it is especially important to examine and describe their viewpoints. The perceived facilitators and barriers to (inter) professional collaboration within and between settings are identified and further explored and elaborated on in Chapter 6 with a detailed description of a DCD case. The findings of these studies are important to be able to develop tailored interventions to provide optimal care for DCD-patients as well as a sustainable workforce with minimal costs of burnout.

Finally in Chapter 7 the main findings of the various studies included in this thesis are summarized, methodological considerations are discussed, put into perspective, and compared to existing literature. Next to this recommendations for clinical practice and future research are formulated.

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Chapter 2

Efficacy of integrated interventions combining psychiatric care and nursing home care for nursing home residents: a review of literature

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ABSTRACT

Background Nursing home residents needing both psychiatric care and nursing home care for either somatic illness or dementia combined with psychiatric disorders or severe behavioural problems are referred to as Double Care Demanding patients, or DCD-patients. Integrated models of care seem to be necessary in order to improve the wellbeing of these residents.

Objectives Two research questions were addressed. First, which integrated interventions combining both psychiatric care and nursing home care in DCD nursing home residents are described in the research literature? And second, which outcomes of integrated interventions combining both psychiatric care and nursing home care in DCD nursing home residents are reported in the literature?

Method A critical review of studies that involve integrated interventions combining both psychiatric care and nursing home care on psychiatric disorders and severe behavioural problems in nursing home patients. A systematic literature search was performed in a number of international databases.

Results Eight intervention trials, including four RCTs (2b level of evidence) were identified as relevant studies for the purpose of this review. Seven studies, three of which were RCTs, showed beneficial effects of a comprehensive, integrated multidisciplinary approach combining medical, psychiatric and nursing interventions on severe behavioural problems in DCD nursing home patients.

Conclusions Important elements of a successful treatment strategy for DCD nursing home patients include a thorough assessment of psychiatric, medical and environmental causes as well as programs for teaching behavioural management skills to nurses. DCD nursing home patients were found to benefit from short-term mental hospital admission. This review underlines the need for more rigorously designed studies to assess the effects of a comprehensive, integrated multidisciplinary approach towards DCD nursing home residents.

INTRODUCTION

In line with the current trend to keep frail elderly people at home as long as possible, only elderly people with very complex care demands are admitted to nursing home facilities. Consequently, nursing homes are confronted with a growing number of older residents with somatic illness or dementia on the one hand and psychiatric disorders or severe behavioural problems on the other. Serious medical and psychiatric illnesses frequently coalesce in this patient group, blurring the boundaries of psychiatry and somatic medicine [1]. Numerous studies have shown a high prevalence of psychiatric co-morbidity in these elderly subjects [2-7]. Residents needing both psychiatric care and nursing home care for either somatic illness or dementia combined with psychiatric disorders or severe behavioural problems are referred to as Double Care Demanding (DCD) patients [8, 9]. A recent survey among Dutch nursing homes showed that 8.4 percent of all patients residing in a nursing home could be qualified as DCD-patients [9]. Collaborative approaches to psychiatry and somatic medicine are therefore important in the treatment of these complex patients [10, 11].

Although well-designed health economy studies on the cost of DCD-patients are rare, additional costs are very likely to be incurred, as a higher level of treatment, support and care is required for these patients [12, 13]. Psychiatric symptoms in these DCD-patients lower the residents' quality of life, increase the risk of impaired self-care, which subsequently increases the burden of formal care and thus the costs of caring [12, 14]. Additionally, severe behavioural problems are associated with indirect costs because they lead to an increase in the burden on professional caregivers and have an impact on their personal health [15-17].

The number of studies on the efficacy of non-pharmacological interventions for the management of severe behavioural problems in nursing home patients is growing. Most of these studies, however, focus primarily on dementia patients [18-27]. An empirical exploration shows that frail elderly psychogeriatric patients with functional psychiatric pathology can be successfully reactivated [28]. A review of controlled trials of psychotherapy in long-term care facilities reported improvements in one or more dimensions of psychological wellbeing in half of the studies [29]. Psychiatric hospitalisation has been shown to offer effective and efficient treatment for both behavioural disturbances in patients with Alzheimer's disease as well as for depressive disorders in elderly subjects with co-morbid medical conditions [30-33].

Psychiatric care is hardly ever available for DCD-patients in nursing homes. Fewer than 20% of these patients receive treatment from a mental health clinician [9, 34]. Several studies criticize the way in which mental health services are being provided to nursing

homes. They state that the least effective model is the traditional consultation liaison service in which a psychiatrist provides a one-time consultation on an as needed basis [35-40]. Even though the majority of the nursing homes have some sort of collaboration with a regional Mental Health service, in practice the mental health care that is provided is still mostly limited to the prescription of medication by a consulting psychiatrist, and, according to nursing home staff, does not cover DCD-patients' needs adequately [9, 36, 41, 42].

This means that more comprehensive and more integrated models that make adequate psychiatric care available in nursing home settings as well are needed in order to improve the quality of care of DCD nursing home patients and to tackle nursing home staff's problems in dealing with this difficult patient group. Optimal services should be multidisciplinary, multidimensional and structural; addressing neuropsychiatric, medical, psychosocial, environmental and staff issues [35, 43].

Two questions will be addressed in this study. First, which integrated interventions combining both psychiatric care and nursing home care in DCD nursing home residents are described in the research literature? And second, which effects of these integrated models combining both psychiatric care and nursing home care in DCD nursing home residents are reported in the literature?

METHODS

Search strategy

We conducted a systematic literature search in Medline, PsychInfo and PubMed to identify articles published in medical journals (up until January 2008) reporting on research regarding comprehensive or integrative interventions combining both psychiatric care and nursing home care for DCD-patients. An advanced search was performed using the Medical Subject Headings "Residential care", "Nursing Homes", "Long Term Care", "(Geriatric) Psychiatry", "Mental Disorders", "Agitation", "Hospitalisation", "Psychotherapy" and "Mental Health Services". Furthermore the free text words "Dementia-", "Behaviour-", "Intervention", "Multidisciplin*", "Interdisciplin*", "Integrated" and "Comprehensive" were used to include those subjects relevant to our study. Results were limited to studies that were comparative, published in English or Dutch, described subjects aged 55 years or older and included an abstract. Moreover we manually searched the reference lists of included studies to identify any relevant studies that had not yet been included.

Before reviewing the abstracts, criteria were established to determine whether a study was relevant for the purpose of our review.

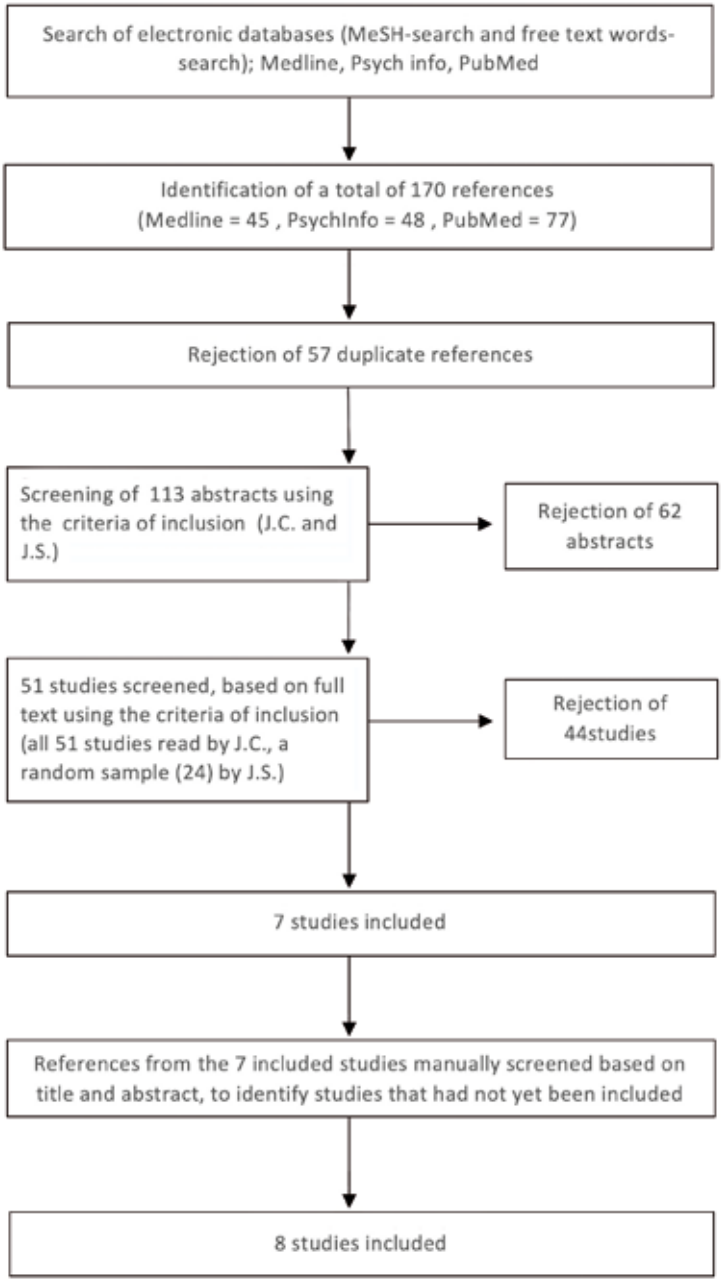
Abstracts were included if they met *all* of the following criteria:

1. a study population of nursing home patients suffering from either somatic illness or dementia combined with psychiatric disorders or severe behavioural problems
2. studies using an inpatient intervention combining both psychiatric care and nursing home care
3. studies yielding quantitative data of a comprehensive intervention combining both psychiatric care and nursing home care

Selection of studies

Figure 1 shows the process of inclusion and exclusion of articles. The computerized, indexed search eventually resulted in a total of 170 articles. A total of 57 duplicates were excluded. Two reviewers (JC and JS) independently assessed the relevance of the remaining 113 articles by reading the abstracts. They selected those abstracts for which full paper retrieval was appropriate. Disagreement between reviewers about whether to include a particular study was resolved by discussion. Eventually both reviewers excluded 62 studies as non-relevant, following the algorithm of inclusion. The main reasons for the exclusion of studies were that care was given to DCD-patients living at home; the study was a programme description; the study was designed as a review. One reviewer (JC) read all the remaining 51 articles in full, while the second reviewer (JS) read a random sample of 24 articles. To increase the objectivity and consistency of the decision to include or exclude a paper based on reading the full text, a data-extraction form was developed. Besides being used for selection, this form was used to score all relevant items with regard to study characteristics, composition of the teams, diagnostic assessments, results and conclusions. Studies were excluded if, in spite of the keywords, the study did not relate to an intervention that combined both psychiatric care and nursing home care. After excluding the irrelevant studies, seven studies remained. A manual search of the references for these studies yielded one additional study for inclusion, so a total of eight studies were included for further review.

Figure 1. Flowchart showing the search strategy



Methodological quality

The methodological quality of the included studies was assessed and reported in accordance with the guidelines of the Dutch Institute for Health Care Improvement (CBO). With regard to experimental studies they recommend an evaluation of selection bias, performance bias, detection bias and attrition bias. Each source of potential bias was assessed with respect to the following quality elements: randomization, allocation concealment, baseline comparability, blinding of participants or providers, blinding of outcome assessors, reporting of attrition rate, the use of intent-to-treat analyses and the use of validated tools. With regard to observational studies they recommend an evaluation of definition of the study population, selection bias, follow-up/completeness of dataset, confounders, blinded outcome assessments and reliable results (www.cbo.nl).

Data extraction

Data extracted from the included studies comprised: a description of methods used, the participants, the intervention and its characteristics, the measured outcomes and the methodological quality. Because the studies were expected to be heterogeneous with respect to methods, participants and interventions, they were qualitatively described in detail. The results on methodological quality of the included observational and experimental studies are presented in Table 1, while the other main characteristics of all the selected studies, together with level of evidence are presented chronologically in Table 2.

Table 1. Methodological quality of included studies

Observational studies	Kunik (1996)	Holm (1999)	Wiener (2001)	DeYoung (2002)
Definition of study population	+	+	+	+
Selection bias	+	+	-	-
Follow-up	-	-	+	+
Confounders	+	+	-	-
Blinded outcome assessment	-	-	-	+
Results	+	+	-	-
Total (max 6)	4	4	2	3

Experimental studies	Rovner (1996)	Proctor (1999)	Opie (2002)	Brodaty (2003)
Randomized	+	+	+	+
Allocation concealed	+	+	-	+
Comparable baseline characteristics	+	+	+	+
Blinded providers/participants	-	-	-	-
Blinded outcome assessors	-	+	+	+
Attrition rate reported	+	+	+	+
Intention to treat analysis	+	-	-	-
Validation of tools	+	+	+	+
Total (max 8)	6	6	5	6

Table 2. Main characteristics of selected studies

Study	Level of Evidence*	Design	Participants	Setting	Intervention	Instruments	Outcomes
Kunik et al. 1996	3	Retrospective cohort, based on ongoing data base effort Follow-up 22-53 days (median 37 days)	Country: USA Number: 41 DCD, 22 somatic illness & psychiatric disorder 19 dementia Mean age: 70.6±6.1, 100% male Referral: physician of nursing home	Geropsychiatric inpatient unit of a Veterans Affairs medical hospital	Comprehensive evaluation by a multidisciplinary team, followed by multidisciplinary treatment, including pharmacotherapy, individual, family and group therapies	HRS-D/HAM-D BPRS CMAI RSSE GAF	Decrease in violence, psychosis and depression Increase in Global functioning No difference between the two groups of DCD nursing home patients
Rovner et al. 1996	2b	Randomized Controlled Trial Follow-up 6 months	Country: USA Number: 81 DCD with dementia and somatic illness, 42 IG 39 CG Mean age: IG 82.0±8.0, 79% female Mean age CG 81.2±7.2, 76% female Referral: research nurse	Nursing home, with 250 beds, divided over 6 nursing units. Intervention patients continued to reside in their usual room, but were moved during the day to an activities room	Combination of activity program (applied by a creative arts therapist and two nursing aids) on weekdays from 10 AM to 3 PM, psychotropic drug management and weekly educational meetings with a psychiatrist	MMSE CMAI PGDRS DSM-III-R RUGS	Significant decrease of behaviour disorders, restraint use and antipsychotic use in intervention group
Holm et al. 1999	3	1 year prospective collected data Follow-up 7-152 days (median 25 days)	Country: USA Number: 164 DCD with dementia & somatic illness 30% depression, 25% psychosis, 20% bipolar Mean age: 81±8, 45% male, 55% female Referral: screening by registered nurse following admission criteria	Special inpatient unit of 16 beds in general hospital, with audiovisual equipment in each room	Individualized treatment plan, based on repeated multidisciplinary assessments. Pharmacotherapy is used to treat diagnosable psychiatric conditions. Specific activities and tasks are designed for each patient Treatment also includes individual or group sessions with a psychologist and/or occupational therapist	ACL RAGE FIM	79%- 92% improvement on behaviour, cognition and Activities of Daily Living
Proctor et al. 1999	2b	Randomized Controlled Trial Follow-up 6 months	Country: United Kingdom Number: 105 DCD with dementia 54 IG 51 CG Mean age IG: 83.4±5.5, 79% female Mean age CG:82.7±9.1, 86% female Referral: care staff	10 residential homes and 2 nursing homes, paired according to size	Training and education intervention, in which all staff followed seminars, given by old-age psychiatric hospital outreach team and an experienced psychiatric nurse visits weekly to give advice and support to individual workers	AGECAT organic AGECAT depression Chrichton scale Barthel index	Significant improved scores for depression and cognition

Wiener et al. 2001	3	Case series Follow-up at 10 weeks in nursing home, after median stay of 15 days in hospital	Country: USA Number: 15 DCD with dementia Mean age 79±9, 67% male, 33%female Referral: nursing home	Geriatric psychiatry unit of a psychiatric university hospital	Person centred program to evaluate contributors to agitation, initiate pharmacological treatment and identify behavioural and social interventions that can be implemented in the nursing home after discharge. Aftercare through consultation for nursing home staff	BARS CMAI NHSA AIMS GAF DSM-IV	Improvement in Global functioning and decrease in agitation. At follow-up in Nursing Home after 10 weeks still detectable; 60% in severity and 75% in frequency of behaviour
Opie et al. 2002	2b	Randomized Controlled Trial Follow-up 8 weeks	Country: Australia Number: 99 DCD with dementia, 48 early intervention(EG) 51 late intervention(LG) Mean age EG/LG: 83.9, 73% female Referral: nursing home staff	Nursing homes	Individually tailored medical, pharmacological, psychosocial and nursing interventions, targeting specific behaviour. In a 4-week period a multidisciplinary consultancy team supplies detailed behaviour plans to staff	MMSE CMAI BAGS GDS	Decrease in restlessness, physical aggression and verbal disruption, at follow-up after 1 month in 75% still detectable
DeYoung et al. 2002	3	One-group time series, quasiexperimental, patients were their own controls Follow-up at 3 months (n=32) and 6 months(n=19)	Country: USA Number: 32 DCD with dementia (87% also with medical diagnosis) Mean age 73±21, 53% male Referral: conventional nursing facility or hospital	Special 32-bed unit in Long-term Care setting, including an environment with controlled temperature, sound and lighting.	A totally structured psychosocial activity program during morning, afternoon and evening, 7 days a week, including rehabilitative therapies and counselling services. Program is executed by especially trained staff. Follow-up services to nursing home are provided.	NHBPS CMAI	Reduction of number of Aggressive, Agitated or Disrupted behaviour
Brodaty et al. 2003	2b	Randomized Controlled Trial Follow-up 24 weeks	Country: Australia Number: 86 DCD with dementia 34 depression 33 depression & psychosis 19 psychosis Mean age 82.9±8.9, 72% female Referral: passing after applying of designed screening filter	Nursing homes	1. Psychogeriatric case management: psychological, social and pharmacological treatment supervised by geriatric psychiatrist and administered by a multidisciplinary team; one team member is case manager. 2. Psychiatric consultation: management plans provided in writing to NH-staff and general practitioner. Multidisciplinary team available for further consultation during 12 weeks 3.Care as usual: continuing of whatever received current treatment	AMTS BEHAVE-AD EBAS-DEP FAST CSD NPI SAPS GDS CRI HRS-D/HAM-D CIRS DSM-IV	All 3 groups improved from pre-treatment to post treatment on depression and psychosis

*Level of Evidence: *=According to the Centre for Evidence Based Medicine, University of Oxford 2001; www.cebm.net and The Dutch Institute for Healthcare Improvement (CBO);www.CBO.nl*
Participants: USA= United States of America, DCD = double care demanding patients, IG = intervention group, CG = control group
Intervention: AM = Ante Meridian, PM= Post Meridian, NH-staff = nursing home staff
Instruments: MMSE = Mini-Mental State Examination, HRS-D/HAM-D = Hamilton Depression Rating Scale , BPRS = , CMAI = Cohen-Mansfield Agitation Inventory, RSSE = Rating Scale for Side Effects , GAF = Global Assessment of Functioning scale, PGDRS = Psychogeriatric Dependency Rating Scale, DSM = Diagnostic and Statistic Manual of Mental Disorders (III-R = third edition revisited, IV= fourth edition) , RUGS = Resource Utilization Groups, ACL = Allen Cognitive Level test, RAGE = Rating Scale or Aggressive Behaviour in the Elderly, FIM = Functional Independence Measure, AGECAT = Automatic Geriatric Examination for Computer-Assisted Taxonomy, Chrichton scale = a behaviour rating scale to assess behavioural characteristics of residents, Barthel index = an activity of daily living index, NHSA= Nursing Home Scale for Agitation, BARS = Brief Agitation rating Scale, AIMS = Abnormal Involuntary Movement Scale, BAGS = Behaviour Assessment Graphical System, GDS = Geriatric Depression Scale, NHBPS = Nursing Home Behaviour Problem Scale, AMTS= Abbreviated Mental Test Score, BEHAVE-AD = Behavioural Pathology in Alzheimer's Disease Rating Scale, EBAS-DEP = Even Briefer Assessment for Depression, FAST = Functional assessment Staging, CSD = Cornell Scale for Depression in Dementia, NPI = Neuro Psychiatric Inventory, SAPS = Scale for the Assessment of Positive symptoms, CRI = Resident Classification Index, CIRS = Cumulative Illness Rating Scale.

RESULTS

Study Characteristics

Eight studies were identified as relevant for the purpose of this review: Kunik et al., 1996; Rovner et al., 1996; Holm et al., 1999; Proctor et al., 1999; Wiener et al., 2001; Opie et al., 2002; DeYoung et al., 2002; Brodaty et al., 2003. (Table 2). The selected studies consisted of one retrospective cohort study (3 level of evidence), three prospective case series (3 level of evidence) and four randomized controlled trials (2b level of evidence). The effects of comprehensive intervention on severe problem behaviour in DCD nursing home patients were measured in all the studies. Follow-up periods ranged from seven days to six months. The studies were predominantly conducted in the United States (n=5).
Although the populations of all the studies included consisted of DCD nursing home patients, the interventions of three studies took place within a psychiatric or other hospital. In one study subjects were hospitalized for the duration of their treatment and afterwards followed up within the nursing home. Although most study samples comprised DCD-patients with a diagnosis of dementia (n=5), three studies included both DCD-patients with a primary somatic condition as well as DCD-patients with a diagnosis of dementia. There was an average of three co-morbid somatic diseases, with diabetes, cerebrovascular disease and cardiovascular disease most present [44-46].

Participants varied from 70.6±6.1 to 82.9±8.9 years of age. With one exception [45], all the studies consisted of a mixture of female and male subjects. The proportion of female participants varied from 33% to 86%. The sample sizes of the studies ranged from 15 to 164.

To be included in the hospital programs, the nursing home patients' problem behaviour had to be unable to be successfully treated within the nursing home itself and also unable to be treated on an outpatient basis. This problem behaviour had to be threatening and require close observation. Problem behaviour was defined as violent behaviour or other disruptive behaviour, psychosis or depression [44, 45, 47]. The inclusion criterion for the special care unit programme was referral from a nursing home or a hospital for untreatable disruptive behaviour that otherwise made referral to a psychiatric hospital necessary [48]. Two out of four randomized controlled studies carried out within the nursing home demanded a DSM-IV diagnosis of dementia and disruptive neuropsychiatric symptoms (psychosis, depression or agitation/aggression) observed several times each day [49, 50]. One randomized study [46] included, according to the research psychiatrist, participants with a positive diagnosis of dementia and the presence of disruptive behaviour observed by a research nurse. There was no MMSE cut-off score for eligibility. The fourth randomized study [51] allowed care staff within each of the 12 nursing and residential homes to select the 10 residents who were the most difficult to care for.

Methodological quality

The overall score for the methodological quality of the experimental studies (table 1) ranged from 5 to 6 (maximum 8). The author of one study [46] reported that outcomes were not assessed blindly, which may be a source of bias. The study with lowest methodological quality used a design in which allocation was not concealed, providers and participants were not blinded and intention-to-treat analyses was not made (Opie et al., 2002). The overall score for methodological quality of the observational studies ranged from 2 to 4 (maximum 6). One study showed very low methodological quality, due to selection bias, lack of adequate correction for confounders and non-blinded outcome assessment (Wiener et al., 2001).

Characteristics of Interventions

As summarized in Table 3, the teams involved in the interventions comprised at least four disciplines up to a maximum of six disciplines. Certified psychiatric nurses were part of the multidisciplinary team in all of the eight selected studies. In six of the eight selected studies a psychiatrist and a psychologist (sometimes specializing in geriatrics) were part of the multidisciplinary team. A physician was part of the multidisciplinary team in five of the eight selected studies. The physician involved could be a geriatrician, an internist or a general physician.

The multidisciplinary interventions included a comprehensive assessment of the psychiatric disorders or severe behavioural disorders in the DCD nursing home patients. The patients' history was described in all the studies as part of the assessment procedure, although data collection occurred in different ways. Standardized full physical, psychological and/or neuropsychological and psychiatric examinations were all performed in four studies [44, 45, 47, 49]. Three of the four remaining studies used only psychological and/or neuropsychological and psychiatric examinations [46, 50, 51]. The other study [48] does not clearly describe the examinations performed. Wiener also performed a nursing assessment of each patient's activities in daily life, while Kunik, Holm and Wiener examined the global functioning of all patients.

All of the included studies used individualized treatment plans with integrated tailored psychosocial, nursing, medical and pharmacological interventions [44-51]. Individual or group psychotherapy was offered in three studies [44, 45, 48, 49]. DeYoung, Rovner, Brodaty and Proctor provided training and education for nursing staff to ameliorate their understanding of problem behaviour.

Table 3. Disciplines involved in multidisciplinary assessment teams

	Kunik (1996)	Rovner (1996)	Holm (1999)	Proctor (1999)	Wiener (2001)	Opie (2002)	DeYoung (2002)	Brodaty (2003)
(Geriatric)psychiatrist	+	+	*	+	+	+	-	+
(Gero)psychologist	+	+	+	+	-	+	-	+
Certified (psychiatric) nurses	+	+	+	+	+	+	+	+
Activity therapist	-	+	+	-	-	-	+	-
Social worker	+		+	-	+	-	+	-
Neurologist	-	-	*	-	+	-	-	-
Physician (geriatrician, internist, general)	+	+	+	-	+	+	-	-
Certified behaviour technicians	-	-	-	-	-	-	+	-
Registrar in psycho geriatrics	-	-	+	-	-	-	-	+
Pharmacist	-	-	+	-	-	-	-	-

*Notes: + = permanent member of multidisciplinary team; - = not a member of multidisciplinary team; * = member of multidisciplinary team only if necessary*

Reported outcomes of interventions

Seven studies reported positive effects on reducing agitation and physical aggression at the last follow-up after the intervention. The two most important outcomes reported were a decrease in the levels of general psychiatric symptoms (especially depression and agitation or aggression) [44-48, 50, 51] and improvement in global functioning (cognitive and functional status) [44, 45, 47]. One of the four randomized controlled trials which examined these outcomes, found no significant difference between nursing home patients who received psychiatric services and a comparison group that received care as usual. This study did however reveal a trend towards greater improvement in behavioural disturbance in the case management group, but lacked sufficient power to determine the significance of the size of the effect [49]. Two other RCTs concluded that multidisciplinary mental health consultancies, delivered within the nursing home, were associated with a significant decrease in neuropsychiatric behaviour and improvement in depression [50, 51]. Sustained positive outcomes as regards agitated and aggressive behaviour as well as regards overall functioning were detectable in 60% to 75% of all patients [47, 50]. This could indicate that the reported positive effects on both psychiatric behaviour and global functioning tend to remain over a longer period of time. The four uncontrolled studies found that multidisciplinary services were associated with a decrease in agitated and physical aggressive behaviour and an increase in global functioning among 53% to 90% of the patients who received these services [44, 45, 47, 48]. None of the selected studies reported data on cost effectiveness or on nursing home staff functioning. The intensity of baseline mental health services received before inclusion in any of the intervention studies remains unclear.

DISCUSSION

The most striking outcome of our review is that there were only few intervention studies of DCD nursing home patients. Ultimately, we were able to include only eight intervention studies of a comprehensive, integrated multidisciplinary intervention for DCD nursing home patients, of which only four were randomized controlled studies with a 2b level as maximum level of evidence [46, 49-51]. All of these eight studies were aimed at the reduction of severe neuropsychiatric behaviour (psychosis, depression and agitation) in a group of DCD nursing home patients with dementia. Somatic co-morbidity was only clearly stated in one randomized clinical trial [46] and in two uncontrolled studies [44, 45].
This review shows beneficial effects of a comprehensive, integrated multidisciplinary approach combining medical, psychiatric and nursing interventions on severe behavioural problems in DCD nursing home residents. This comprehensive, integrated multidisciplinary approach can be pursued in either a special unit of a long term care setting [48], a nursing home [46, 49-51] or an inpatient unit of a psychiatric or other hospital [44, 45, 47].

The sustained effects of these multidisciplinary interventions tend to be positive [47, 50]. In contrast, Brodaty found a non-significant difference in favor of the intervention group [49]. His study, however, not only lacked sufficient power, but also used a study design that was considered to be too complex. Opie also recommends the use of a simple study design in the complex area of work within a nursing home. Like Brodaty, she states that their study design was highly complex, derived from the premise that nursing homes would be reluctant to act solely as "controls". In retrospect, staff was so concerned by residents' behaviour, that allocation to a control group with later access to specialist treatments would certainly have been acceptable [50]. Short term psychiatric hospital treatment benefits nursing home residents with and without dementia, who are admitted for severe problem behaviour [44, 45, 47]. The used multimodal treatment approach however made it impossible to identify the specific therapeutic ingredients responsible for this improvement [45]. One explanation for this improvement could be the lack of adequate psychiatric assessment and treatment within the nursing home itself [45]. A different explanation could be that treatment decisions within the nursing home may be heavily dependent on observations by staff with varying levels of training and experience [44]. Draper states in his study that 17% of all nursing home residents referred to a geriatric outreach team in Sydney could only be effectively treated by means of a short admission (of 10-90 days' duration) to a psychiatric hospital [43]. However, psychiatric hospitalizations, despite their necessity, have limitations of high cost, short length of stay and the inherent difficulty of treating a behavioural problem outside the nursing home environment. In both inpatient settings (nursing home and psychiatric hospital) a person-centered, intensive intervention is favored. This is in accordance with the findings of Snowdon in his article on needs and

developments of psycho geriatric services in long term care facilities [52].

All the studies included have several methodological shortcomings. In one experimental study the outcomes were not assessed blindly, which may be a source of bias [46]. The experimental study with lowest methodological quality used a design in which allocation was not concealed, providers and participants were not blinded and intention-to-treat analyses was not made [50]. One of the included observational studies showed very low methodological quality, due to selection bias, lack of adequate correction for confounders and non-blinded outcome assessment [47].

In general, sample sizes were small, varying from 15 to 164. The eight studies included differed in their design, in the research instruments used to assess behavioural problems and in patient groups, which presumably had different behavioural problem pathogenesis. Follow-up time was in general short, and sustained effects of the applied intervention were measured in only two studies [47, 50]. The possibility of overlooking relevant studies on integrated interventions for DCD nursing home patients should also be mentioned. Negative results are not always published and results that are regarded as only regionally interesting will not be pushed in scientific journals and might therefore have been unavailable to international readers. Most of the studies included were conducted in the USA, with only one study being performed in Europe [51].

Cultural differences between countries in terms of the presence, the types and preferences of institutional care should be considered. There are substantial differences in the design of organization of long term care or nursing home care, in reimbursement policies and in the provision of formal and informal care. Employment of different types of physicians and nursing home staff should also be considered. Most nursing homes are irregularly visited by general practitioners, who sometimes collaborate with geriatricians, neurologists or internists. In Europe, Dutch nursing homes are unique in employing their own physicians who have completed a specialist training programme in both geriatric medicine and basic psychiatry training [53]. Neither cost-effectiveness nor patients' quality of life was the object of interest in either of the studies included. Distress and job satisfaction may also be a relevant combination of variables to measure in nursing home caregivers to define the effectiveness of a comprehensive intervention for psychiatric problems or severe behavioural problems in DCD nursing home patients.

Although Bartels [35] has suggested that optimal mental health services for nursing home patients should be multidisciplinary, addressing medical, psychiatric, psychosocial, nursing, and environmental issues, these findings cannot be completely confirmed by the data available from the randomized controlled trials we included. This means that this review neither clarifies more precisely the best way to handle psychiatric disorders or

severe problem behaviour in DCD nursing home patients nor does it give any definite answers to whether multidisciplinary teams involving psychiatrists and psychiatric nurses are essentially superior. The ideal composition of the team is still not well defined, nor is the ideal setting to provide mental health services for nursing home residents with psychiatric disorders or severe problem behaviour. Is also stays unclear which interventions have to be integrated and what are the ingredients and context factors that are responsible for the efficacy of the intervention. Many relevant questions remain unanswered. Which competencies are crucial for nursing home staff? Which interventions are the most cost-effective in dealing with psychiatric problems or severe behaviour disorders in DCD nursing home patients? Is a psychiatric inpatient setting the most efficacious and cost-effective delivery site for treating nursing home residents? Can psychiatric care be provided efficiently within the nursing home? Is a formally organized multidisciplinary intervention team as effective as a group of specially trained nursing home staff collaborating with extrinsic mental health staff? And what will be the effect of lengthening the follow-up period (six to twelve months) for nursing home residents after psychiatric intervention?

Given the current level of concern about DCD nursing home patients and the ever growing number of these patients due to the ageing of the population, it is important that they receive the most effective and efficient care they deserve. More rigorously designed studies must therefore be conducted to assess the effects of a comprehensive multidisciplinary approach toward DCD nursing home patients as well as to assess the best setting in which to provide this approach. These studies must have sufficient power to detect small effects, tailor recommendations to the individual, lengthen the follow-up period and be undertaken across multiple sites. Studies should also focus on identifying those patients who improve and those who do not, to better target individuals for whom more intensive interventions may be warranted. Future studies should involve randomized clinical trials focusing not only on reducing problem behaviour, but also on cost-effectiveness, staff satisfaction and patients' quality of life.

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Chapter 3

Characteristics of double care demanding patients in a mental healthcare setting and a nursing home setting: results from the SpeCIMeN study

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ABSTRACT

Background: Older patients suffering from a combination of psychiatric disorders and physical illnesses and/or dementia are called Double Care Demanding patients (DCDs). They present a particular challenge to long-term care services. Special care units for DCDs within Dutch nursing homes (NHs) and mental healthcare settings (MHs) offer a unique opportunity to obtain more insight into the characteristics and care needs of this specific population.

Methods: This explorative observational cross-sectional study collected data from 163 DCDs admitted to either a NH or a MH that provides specialized care for DCDs. Data on demographics, psychiatric and physical morbidity, care dependency, neuropsychiatric symptoms, and perceived quality of life were collected and similarities and differences between both DCD groups are described.

Results: Neuropsychiatric symptoms were highly prevalent in all DCDs but were significantly more prevalent among the MH-DCDs. The MH-DCDs often suffered from multiple psychiatric disorders, and over one-third had a psychotic disorder. Cognitive disorders were far more prevalent among NH-DCDs. The severity of comorbidities as well as care dependency were equally high among all DCDs. NH-DCDs expressed more satisfaction in overall experienced quality of life.

Conclusions: The institutionalized elderly DCD population is very heterogeneous. Specific care arrangements are necessary because the severity of a patient's physical illness and the level of functional impairment seem to be equally as important as the patient's behavioural, psychiatric and social problems. Further research should assess the adequacy of the setting assignment and the professional skills needed to provide the most appropriate care for elderly DCDs.

INTRODUCTION

Due to the ongoing process of deinstitutionalization of psychiatric care services problems may arise for the most disabled chronic psychiatric patients, who are in need of physical care or even nursing. These patients suffer from multiple disorders and have combined mental (psychiatric and/or psychogeriatric) and physical conditions and are mostly older people [1-3]. Among them are chronic psychiatric patients with dementia, but also dementia patients with or without a psychiatric history who were admitted to a psychiatric hospital due to behavioural disturbances that could not be dealt with in a nursing home. Another subgroup consists of younger patients with chronic alcohol abuse, posttraumatic encephalopathies and degenerative diseases of the central nervous system [4]. These double care demanding patients (DCDs) need a combination of physical, psychogeriatric and psychiatric care [5,6]. Up till now different types of long-term care (LTC) are provided to older people with advanced dementia, disabling psychiatric illnesses and physical disabilities. In the Netherlands tight networks of regional Nursing Homes (NHs) and regional integrated Mental Healthcare settings (MHs) exists. Traditionally, NHs provide LTC for either psychogeriatric or physically disabled patients and MHs provide LTC for patients with chronic mental illnesses.

Earlier studies have shown that DCDs benefit from collaborative psychiatric and physical medicine approaches, e.g., from multidisciplinary care teams that deliver integrated mental and physical healthcare [6-8]. The absolute categorization of psychiatric treatment on the one hand and nursing home care (composed of either physical care or psychogeriatric care) on the other hand creates both regulatory and funding restrictions. Health Care insurance companies may not reimburse the costs for physical care within a MH and vice versa the costs for psychiatric treatment in a NH. Consequently, both NH-residents with comorbid psychiatric disorders and psychiatric patients with comorbid dementia and/or physical disabilities will not always receive the type of care that they need [2, 5, 9, 10]. Not receiving the most appropriate care can have a negative influence on NPS and quality of life [11-13].

Although the traditional asylum function for older adults with severe mental illness (SMI) has largely been taken over by nursing homes [14], a study by the Dutch Trimbos Institute found that, according to NH-personnel, 8.4% of the Dutch NH-residents were DCDs who surpassed the capabilities for psychiatric treatment available in their own NH department [15]. Properly trained nurses who are qualified to provide psychiatric care for elderly people are rarely employed within NHs, and specific psychiatric training for personnel is limited [1, 16, 17].Molinari et al., 2008; Dutch Health Care Inspectorate, 2007). Patients diagnosed with SMI have a high prevalence of physical disorders, are less competent in interpreting physical symptoms and have a reduced life expectancy [18-20]. The Dutch

Inspectorate of Healthcare has stated that Dutch MHs continue to display insufficient attention to the somatic needs of DCDs, and official guidelines for how to identify and treat somatic complications are still lacking [21,22].

DCDs thus present a particular challenge to long-term care services within both NHs and MHs. Some Dutch NHs and MHs are already operating special care units for DCDs (DCD-units), offering a unique opportunity to study this population. Knowledge of the characteristics and care needs of DCDs in both settings is essential to improve care services to better meet the specific needs of these DCDs. Although the term DCD-units is used for both settings it is very likely that DCDs in NHs and MHs will differ in psychopathology, physical comorbidity and ADL deficits. The present study will explore the similarities and differences of DCDs who are admitted to either NH of MH, and addresses the following research questions: what are the physical (in terms of medical problems and care dependency) and mental health-related characteristics (in terms of mental problems and neuropsychiatric symptoms) of these DCDs, and what is their perceived quality of life. The findings of this study are relevant for planning of services that should take into account different patterns of needs among elderly DCDs.

METHODS

Design

This study is part of an explorative observational cross-sectional study on the Specific Care on the Interface of Mental health and Nursing homes (SpeCIMeN). Residents from two types of care settings for DCDs were included in the study: the mental health care setting and the nursing home setting. Data were collected from November 2013 through April 2015.

Participants

The study was performed in the southernmost part of Limburg, a province of the Netherlands. NH organizations and MHs in the region were approached to identify specialized DCD-units based on our definition: specialized units for patients with a combination of psychiatric, physical and/or psychogeriatric care needs. All of these by the organization identified DCD-wards were included into the study with the ward as the unit of interest.

Four specialized DCD-units, on two locations, within a Dutch MH (Mondriaan) with a total of 76 beds and seven specialized DCD-units within two Dutch NH organizations (Envida and Meander) with a total of 110 beds were identified and included in the study. All of the specialized NH-DCD-units were situated within psychogeriatric NHs.

The DCD-units within the MH varied from 14 to 20 patients, while the DCD-units within

the NHs varied from 8 to 20 patients. DCD-patients had to be admitted to the specialized care unit at least six weeks prior to the study before they could be included. Patients who were temporarily admitted to the specific DCD-unit because of admission problems elsewhere in the NH or MH were excluded from the study.

Procedure

The local Medical Ethics Committee approved the study (number 134049) and considered it not to be subject to the Medical Research Involving Human Subjects Act. The study was also approved by the Board of directors and the Client Advisory councils of the participating institutions. Patient participation was voluntary, and data collection was conducted confidentially and anonymously. Eligible patients were included in the study after informed consent from the patients or their legal representatives was obtained.

Data were collected through various methods. Medical files were intensively studied to collect information on psychiatric and somatic morbidity. Direct patient measurements of cognition, mood disturbances and perceived quality of life were obtained. Finally, the vocational nurses who acted as the primary responsible caretakers of the DCDs provided data on care dependency, and current behaviour.

Measurements

Data collection from medical files

Baseline characteristics (such as age, sex, marital status, time of institutionalization, level of education and representation) and somatic illnesses were retrieved from the patient's record.

All current physical disorders were collected from data on both the medical diagnosis, the available laboratory results (e.g. in confirming kidney failure) and medication use, as stated within the patients' medical record. The severity of all confirmed somatic diagnoses was scored using the 14-item version of the Cumulative Illness Rating Scale (CIRS) 14-item version [23]. This scale measures multimorbidity in light of all medical problems encountered in a geriatric population. The theoretical scores range from 0 to 56 based on scoring the severity of co-occurring medical conditions from 0 (no problem) to 4 (extremely severe problem). In this study, the severity of co-occurring medical conditions was scored excluding the "psychiatry" CIRS-subscale.

Psychiatric illnesses were retrieved from the medical records and classified according to the Diagnostic and Statistical Manual of Mental Disorders. All DSM-classifications made by a psychiatrist or trained psychologist and stated in the patients' medical record were accepted. Both axis I and axis II classifications were noted (DSM-IV-TR. Vol.4th edition, Text Revision. 2000).

Data collection on patient level

Direct measurements

Patient cognition was measured using the Dutch standardized version of the Mini Mental State Examination (MMSE) [24].

Feelings of anxiety and depression were assessed using the Dutch translation of the original Hamilton Anxiety and Depression Scale (HADS) [25,26]. The HADS contains a 7-item subscale for depression and for anxiety. Each item has a severity score range from 0 (no problem) to 3 (severe problem). A trained research assistant interviewed the patients. Items were read out loud, and patients were asked to choose one of the four possible severity scores for each item.

Overall experienced quality of life was assessed using the Manchester Short Assessment of Quality of Life (MANSA). This is an abbreviated six-item version of the original 16-item scale, as used in the Dutch cumulative needs for care monitor [27,28]. These items address patients' satisfaction with general quality of life, living situation, social relationships, physical health, psychological health and quality of care. Items are scored on a 7-point Likert-scale ranging from 1 (not satisfied) to 7 (very satisfied).

Data provided by vocational nurses

To measure patients' needs and care dependency, we used the Care Dependency Scale (CDS) [29,30]. The CDS measures to what extent the patient is able to perform activities independently. It consists of fifteen categories, all of which are scored using a 5-point Likert-type scale. Responses range from '1 =completely dependent' to '5 = almost independent'. Patients with a total CDS score of ≤68 are classified as care dependent.

Neuropsychiatric symptoms (NPS) were assessed using the Dutch version of the Neuropsychiatric Inventory (NPI) [31, 32]. The NPI includes 12 neuropsychiatric symptoms. The frequency and severity of each symptom are rated on a five-point (0-4) and four-point (0-3) Likert scale, respectively. The frequency and severity scores are then multiplied. NPI-symptoms were considered relevant when the multiplied scores were ≥4. Agitation and aggression were further specified with the Dutch version of the Cohen-Mansfield Agitation Inventory (CMAI-D) [33, 34]. The CMAI is a 29-item nurse-based rating scale. All of the items are rated on a 7-point scale (1-7) ranging from 'never' to 'several times an hour'.

Based on previous factor analyses of both NH and MH populations [34, 35], the agitation items were clustered into three factors: non-aggressive physical behaviour (pacing, hiding, hoarding, general restlessness, inappropriate dressing or disrobing, handling things inappropriately, and trying to get to different places), aggressive physical behaviour (hitting, pushing, scratching, grabbing, cursing or verbal aggression, spitting, and strange

noises) and agitated verbal behaviour (constant unwarranted requests for attention/help, complaining, repetitive sentences or questions, and negativism). CMAI symptoms were considered relevant if they occurred at least once a week (a score ≥3).

Statistical Analysis

The Statistical Package for Social Sciences (SPSS), version 21 was used for the statistical analysis. The analysis consisted of conducting descriptive statistics of basic patient characteristics, psychiatric illnesses, NPS, somatic illnesses, care dependency and perceived quality of life. Explorative bivariate comparisons between patient groups on the prevalence of medical conditions, psychiatric diagnoses and neuropsychiatric symptoms were performed using Chi-square tests for nominal or ordinal variables and independent-samples t-tests for scale variables. For variables that had an abnormal parametric distribution, analyses were performed using the Mann-Whitney-U-test. P-values of 0,05 or less were considered to be statistically significant.

RESULTS

A total of 163 patients were included, 83 from special DCD-wards of NHs (maximum 110 beds) and 80 from special DCD-wards of a MH (maximum 76 beds; 4 patients were transferred to NHs during the inclusion period and then 4 newly admitted patients were included into the study during the inclusion period). All of the specialized care-units had somewhat different criteria for admission. Some units included patients with a specific psychiatric history in combination with cognitive decline or physical disability; others included patients with very severe neuropsychiatric symptoms due to specific types of dementia in combination with physical disability and/or a history of psychiatric treatment. Data collection from patient records was complete. Proxy information about patients was collected in 70 out of 80 MH-DCDs (87,5%) and in 71 out of 83 NH-DCDs (85,5%). Reasons for non-response were (severe) illness or internal transfer of primary responsible vocational nurses. Direct information from patients was collected in 50 out of 80 MH-DCDs (62,5%) and 57 out of 83 NH-DCDs (68,7%). Refusal and serious hearing or vision impairment were reasons for the non-participation of patients.

Table 1. Demographic characteristics of DCD-patients (DCDs) in MH and NH

Characteristics		All DCDs	MH[a] (*n*=80)	NH[b]	*p*[e]
Age (years)	Mean (SD)	68.2 (8.9)	71.6 (8.1)	64.9 (8.5)	<0.001
	Range	47 – 94	49 – 94	47 – 87	
Gender (*n*,%)	Male	88 (54.0)	36 (45.0)	52 (62.7)	0.024
Representation (*n*,%)	Family	56 (34.4)	13 (16.5)	43 (52.4)	<0.001
	Ap.trustee[c]: family	50 (30.7)	27 (34.2)	23 (28.0)	
	Ap.trustee[c]: law firm	55 (33.7)	39 (49.4)	16 (19.5)	
Marital status (*n*,%)	Married	38 (23.3)	8 (10.3)	30 (36.6)	<0.001
	Unmarried	46 (28.2)	32 (41.0)	14 (17.1)	
	Divorced	58 (35.6)	29 (37.2)	29 (35.4)	
	Widowed	18 (11.0)	9 (11.5)	9 (11.0)	
Education[d] (*n*,%)	Low	104 (63.8)	63 (78.8)	41 (49.4)	<0.001
	Middle	50 (30.7)	15 (18.8)	35 (42.2)	
	High	9 (5.5)	2 (2.5)	7 (8.4)	
Length of stay (*n*,%)	>1 year	132 (81)	61 (76.2)	71 (85.5)	0.131

Note: [a]MH = Mental Healthcare setting, [b]NH = Nursing Home; [c]Appointed trustee; [d]Low = primary school, middle = secondary school & lower vocational education, high = upper vocational education & university; [e]Chi-square (except age = Mann-Whitney U test), significance level is 0.05

Demographic characteristics

Demographic characteristics of all of the included individuals are shown in table 1. The mean age of the DCDs was 68 years, with younger DCDs in the NH group. Within the NH-DCDs, there were almost two times more men than women. Many of the MH-DCDs had never been married. Participants' educational level was low for most of the DCDs, with a distinct higher percentage of lower education within the MH group. Most of the DCDs had been institutionalized for longer than one year. The MH-DCDs were mostly represented by appointed trustees, while NH-DCDs usually had family members serve as representatives.

Table 2. Somatic- and care characteristics of DCD-patients (DCDs)

		All DCDs (*n*=163)	MH[a] (*n*=80)	NH[b] (*n*=83)	*p*[g]
CDS[c]	Mean (SD)	45	43.9 (13.8)	46.1 (17.1)	0.38
	Range	17-74	18-71	17-74	
CIRS total[d]	Mean(SD)	15.2 (5.0)	15.4 (4.7)	14.9 (5.3)	0.97
	Range	2-31	7-31	2-27	
Cardiac	N (%)	57 (35.0)	34 (42.5)	23 (27.7)	0.05
Vascular		80 (49.1)	41 (51.2)	39 (47.0)	0.59
Hematological		34 (20.9)	24 (30.0)	10 (12.0)	0.01
Respiratory		134 (82.2)	65 (81.2)	69 (83.1)	0.75
Ophthalmological & ORL[f]		113 (69.3)	54 (67.5)	59 (71.1)	0.62
Upper gastrointestinal		94 (57.7)	41 (51.2)	53 (63.9)	0.10
Lower gastrointestinal		120 (73.6)	58 (72.5)	62 (74.7)	0.75
Hepatic & pancreatic		63 (38.7)	19 (23.8)	44 (53.0)	<0.001
Renal		31 (19.0)	17 (21.2)	14 (16.9)	0.48
Genitourinary		140 (85.9)	76 (95.0)	64 (77.1)	<0.001
Musculoskeletal		123 (75.5)	60 (75.0)	63 (75.9)	0.89
Neurological		105 (64.4)	49 (61.3)	56 (67.5)	0.41
Endocrine, metabolic		48 (29.4)	28 (35.0)	20 (24.1)	0.13
Multimorbidity[e]	Mean(SD)	7.0 (2.2)	7.1 (2.1)	6.9 (2.3)	0.95
	Range	1-12	3-12	1-12	

Note: [a] MH = Mental Healthcare setting, [b] NH = Nursing Home; [c] Care Dependency Scale; [d] Cumulative Illness Rate except psychiatric illness; [e] Amount of medical conditions; [f] ORL = Otorhinolaryngology; [g] Mann-Whitney U test, significance level is 0.05

Physical health-related characteristics

Multimorbidity and care dependency are shown in table 2.

Overall, the DCDs had a mean of 7 comorbid conditions, with a mean disease severity score of 15,2 and a high prevalence of cardio-vascular, pulmonary, neurological and gastrointestinal problems. All of the DCDs showed a clear nursing care dependency, with a mean care dependency score of 45 (range 17-74; cut-off score ≤ 68).

Table 3. Psychiatric Diagnoses

	All DCDs (*n*=163)	MH[a] (*n*=80)	NH[b] (*n*=83)	*p*[e]
DSM-IV axis I diagnosis				
(A) Psychotic disorders total	30 (18.4%)	29 (36.2%)	1 (1.2%)	<0.001
Schizophrenia (*n*)	21	20	1	
Schizo-affective	6	6	-	
Psychosis NOS[c]	3	3	-	
(B) Cognitive disorders total	79 (48.5%)	13(16.2%)	66 (79.5%)	
Dementia[d] NOS (*n*)	29	5	24	
Korsakoff/alcohol related	32	1	31	
Alzheimer and/or Vascular	9	1	8	
Cognitive problems	9	6	3	
(C) Affective disorders total	5 (3.1%)	4 (5.0%)	1 (1.2%)	
Depression (*n*)	4	3	1	
Bipolar	1	1	-	
(D) >1 axis I diagnosis total ABC	49 (30.1%)	34 (42.5%)	15 (18.1%)	
Psychotic & cognitive (n)	24	17	7	
DSM-IV axis II diagnosis				
Personality Disorder Diagnosed (*n*,%)	38 (23.3)	18 (22.5)	20 (24.1)	0.048
Personality Disorder Probable	34 (20.9)	12 (15.0)	22 (26.5)	
No Personality Disorder	66 (40.5)	32 (40.0)	34 (41.0)	
Intellectually Disabled	25 (15.3)	18 (22.5)	7 (8.4)	

[a]MH = Mental Healthcare setting, [b]NH = Nursing home, [c]NOS = not otherwise specified, [d]Lewy Body Dementia & Frontal Temporal Lobe Dementia & Young Onset Dementia, [e]Chi-square, significance level is 0.05

Mental health-related characteristics

In table 3, both axis I and axis II diagnoses are represented. Over one third of the MH-DCD's had a psychotic disorder and the presence of multiple axis one diagnosis was 2 times higher among the MH group. Cognitive disorders were 4 times more often present among the NH group. A personality disorder was diagnosed in almost one-quarter of all of the DCDs. More than one-fifth of the MH-DCDs were intellectually disabled. The mean cognitive functioning of the participants did not differ between groups (table 4), with a large range of MMSE-scores among all of the DCDs. The mean depression score was higher for NH-DCDs. A high percentage of clinically relevant neuropsychiatric symptoms was reported in all of the DCDs (table 5). The mean total NPI-score was higher in MH-DCDs, with a significantly higher prevalence of the NPI symptoms delusions, hallucinations and anxiety. The mean total CMAI- score was similar for all of the DCDs, but the CMAI factor-scores showed a greater prevalence of both verbally agitated and physically non-aggressive behaviour in MH-DCDs.

Table 4. Cognitive functioning, Anxiety and Depression

		All DCDs (*n*=107)	MH[a] (*n*=50)	NH[b] (*n*=57)	P[e]
MMSE[c]	Mean (SD)	18.2 (7.4)	17.4 (7.4)	18.8 (7.5)	0.253
	Range	2-30	4-30	2-30	
HADS[d] Anxiety	Mean (SD)	6.2 (3.8)	6.9 (4.2)	5.7 (3.4)	0.111
	Range	1-18	1-18	1-16	
HADS[e] Depression	Mean (SD)	11.7 (3.7)	10.3 (3.7)	12.8 (3.3)	<0.001
	Range	3-18	3-15	4-18	

[a]MH = Mental Healthcare setting, [b]NH = Nursing home, [c]Mini Mental State Examination , [d]Hospital Anxiety and Depression Scale, [e]Mann-Whitney U test, significance level is 0.05

Table 5. Neuropsychiatric symptoms

	All DCDs (*n*=141)	MH[c] (*n*=70)	NH[d] (*n*=71)	*p*[e]
NPI [a]				
Total Mean (SD)	29.5 (21.1)	32.6 (19.5)	25.9 (22.5)	0.009
Clinical relevant items (%)				
Agitation/aggression	46.2	54.2	38.4	0.056
Anxiety	21.4	33.3	9.6	<0.001
Apathy	37.2	37.5	37.5	0.949
Restlessness	16.6	20.8	12.3	0.168
Depression	24.8	25.0	24.7	0.962
Eating disorder	15.2	20.8	9.6	0.059
Hallucinations	22.8	33.3	12.3	0.003
Disinhibition	35.9	38.9	32.9	0.450
Irritability	46.9	54.2	39.7	0.081
Sleep disturbance	17.2	15.3	19.2	0.534
Euphoria	15.9	15.3	16.4	0.848
Delusions	42.8	59.7	26.0	<0.001
CMAI [b]				
Total Mean (SD)	48.6 (17.3)	50.9 (19.7)	46.1 (14.5)	0.241
Clinical relevant items (%)				
Fact. physical aggression	54.9	59.7	50.0	0.241
Fact. aggression, not physical	60.8	69.0	52.8	0.047
Fact. verbally agitated	64.5	76.1	52.9	0.004

[a]NPI = Neuro Psychiatric Inventory, clinical relevant score ≥4; [b]CMAI = Cohen Mansfield Agitation Inventory, clinical relevant score ≥3; [c]MH = Mental Healthcare setting, [d]NH = Nursing home; [e] Chi-Square, significance

Quality of life related characteristics

The majority of the patients expressed satisfaction with their quality of life, with higher satisfaction rates in the NH-DCD group for given care, treatment and psychological well-being (Table 6).

Table 6. Patients perceived quality of life

MANSA[c] (Percentage (%) of satisfied DCDs)	All DCDs (*n*=108)	MH[a] (*n*=50)	NH[b] (*n*=58)	*P*[d]
Life as a whole	56.0	45.8	58.6	0.213
Living arrangements	65.0	55.1	65.5	0.337
Social relationships	69.0	54.0	72.4	0.060
Psychological wellbeing	64.0	52.1	67.2	0.027
Physical wellbeing	61.0	52.1	62.1	0.191
Care & treatment	74.0	55.1	81.0	0.006

[a]MH = Mental Healthcare setting, [b]NH = Nursing home; [c]Manchester Short Assessment of Quality of life, adapted version; [d]Chi-square, significance level is 0.05

DISCUSSION

To our knowledge, this is the first study to report and compare data on DCDs who are institutionalized in specialized units in either MH or NH settings.

The elderly DCD population was a rather heterogeneous group in terms of mental and physical health. As expected, mental health problems were clearly more prominent in the MH group. However, although we expected them to be more prominent in the NH group, physical health problems were equally divided between the groups. In both groups, nursing care dependency was clearly present. While more than half of all of the DCDs were satisfied with their perceived quality of life, the NH-DCDs expressed an overall higher satisfaction rate.

In the present study, no differences between DCD groups were found regarding the severity of physical comorbidity (as expressed in the CIRS total score) or care dependency scores. As stated before NHs are supposed to be more specialized in clinical conditions, meaning that MH-DCDs that also have important clinical problems might be in disadvantage.

The high prevalence of cardiovascular, pulmonary, neurological and gastrointestinal problems was consistent with earlier studies on psychiatric inpatients in both MH and NH [19, 36-38].

Compared to a group of NH-residents with comorbid anxiety and depression our study found a higher comorbidity rate (7.1 versus 3.7) [39].

Contradictory findings on care dependency exist within the literature. Compared with our study, Aschbrenner found lower rates of care dependency in newly admitted NH-DCDs, while Fullerton found that NH-residents with schizophrenia had comparable care dependency scores [40, 41]. Although cognitive disorders were far more prevalent among NH-DCDs than MH-DCDs, it was striking that the MMSE-scores did not differ between the groups. This might be explained by the natural decline in cognitive functioning with ongoing schizophrenia and the proven significantly lower cognition rates in older patients with schizophrenia compared to older adults without schizophrenia and is consistent with the findings in earlier studies [40, 42, 43]. It could however also point to the fact that cognitive problems in MH settings are overlooked.

The mean total NPI-score in NH-DCDs in our study was higher compared to both a non-DCD NH dementia population (25,9 versus 16,9) and a group of Young Onset Dementia patients (25,9 versus 24,9) [44, 45]. The finding that MH-DCDs had high levels of NPS with even more verbal disruption is consistent with the findings of McCarthy et al. [46]. A higher prevalence of delusions in the MH-DCDs could be explained by the high percentage of diagnosed psychotic disorders. White et al. found that a more severe level of delusions was an important characteristic of elderly psychiatric patients who could not be discharged to a NH from a psychiatric hospital [12]. This could indicate that accommodation within a MH-DCD-unit would be preferable for DCDs who present with a more severe level of delusions. The MH-DCDs in this study were less satisfied with their overall experienced quality of life. This could be due to the known social withdrawal, flat affect and lack of motivation that occurs in the general SMI population [47].

Our study showed interesting demographical differences. Compared to the usual NH-population, there were twice as many men and the mean age was approximately 20 years younger in the NH-DCDs [48]. This could be explained by the fact that a large proportion of the NH-DCDs suffered from ARD or Frontal-Temporal Lobe Dementia (FTD). ARD and FTD are more prevalent among people who are younger than 65 years old, and ARD is also more prevalent among men [49, 50]. Consistent with earlier findings relatively many MH-DCDs were not married or divorced and had no family representation [51]. Lower educational levels in MH-DCDs have also been reported by Fullerton [40]. The high prevalence of intellectually impaired MH-DCD patients could also explain the lower educational level within these DCDs.

METHODOLOGICAL CONSIDERATIONS

The primary strength of this study is that various sources of information such as medical records, patient reports and proxy information were combined during data collection. Furthermore, a comprehensive study of patient's medical records could be accomplished for all of the included patients. This study may be limited in its power to demonstrate representative characteristics of the DCD population because of the use of a selected cohort of patients in the south of Limburg without a direct comparison to a non-DCD-population in either NH or MH.

Another possible limitation is the choice to use bivariate analysis to compare the characteristics between the two settings, because we included subjects on DCD-ward level. On individual patient level however, bivariate analysis may not be sufficient from a statistical point of view. Despite these limitations, this study was a first important explorative step in gaining deeper insight into the specific characteristics of DCDs in both the NH and MH setting.

CONCLUSIONS AND POSSIBLE IMPLICATIONS

The elderly DCD population in both settings was heterogeneous in many regards. The MH-DCDs had a similar level of considerable care dependency and comorbidity as the NH-DCDs. This stresses the importance of giving enough attention to physical care within a MH by allotting of personnel capable of supervising clinical diseases in the MH setting. There could be a mismatch between the type of patients and the type of care offered. The MH-DCDs clearly differed from the NH-DCDs as evidenced by a higher prevalence of psychotic symptoms and psychiatric morbidity.

The heterogeneity of DCDs and the resulting care complexities challenge the skills of professional caregivers in both settings, as they must be able to address both somatic care needs as well as psychiatric and psychogeriatric care needs. Given the high amount of neuropsychiatric symptoms and the variation in psychiatric diagnoses and in dementia subtypes, professional caregivers are required to constantly switch between different approaches of care; sometimes a more restrictive or structuring approach is needed, and sometimes a more supportive or validating approach is more appropriate. Further knowledge is needed on the professional competencies required to deliver the most effective care for DCDs.

In light of the heterogeneity of the group and the partitions in providing care, the question of which type of care is most appropriate for which type of DCD patient remains to be answered.

This suggests that not only the criteria for admission to specialized MH- or NH-DCD units and the transfer to a regular care unit need to be addressed, but the regulatory or funding barriers and reimbursement policies need to be considered as well. The heterogeneity of the group raises the question what the usefulness is of the concept DCD. The relevance of the concept is the way it can be used to inform policies of organizing beds in a health care system inasmuch one does not overlook the needs and clinical supervision of patients in the MH setting, nor the needs of the patients and psychiatric training of nurses in the NH setting. Further research is needed to investigate these topics in more detail, using both qualitative and quantitative data.

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Chapter 4

Well-being of nursing staff on specialized units for older patients with combined care needs

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ABSTRACT

Introduction: In older patients, psychiatric illnesses frequently exist in tandem with physical illnesses, requiring nursing care that is specific to these combined care needs. The impact of caring for these patients on the mental well-being of nursing staff is unknown.
Aim: To investigate if care characteristics of patients with combined care needs are related to the mental well-being of nursing staff.
Method: Well-being of nursing staff was studied within a larger exploratory observational cross-sectional study that examined the differences and similarities of specialized combined care units in Dutch mental health care and nursing home settings.
Results: Nursing staff across settings, with more than 5 years' of work experience, felt competent in caring for patients with combined care needs. No significant effects of care characteristics of patients with combined care needs on the work-related well-being of nursing staff were shown. Both mental health nursing staff and older employees, however, were found to be more at risk of burnout.
Implications/Conclusion: Staff well-being might benefit from placing patients with combined care needs together, so care is focused. The presence of specialized care units can allow for both targeted and focused allocation of nursing staff to these units and provision of specific training.

INTRODUCTION

A large percentage of older adults have multiple morbidities, and have combined mental (psychiatric and/or cognitive) and physical problems [1 - 3]. These older patients with combined care needs require a combination of physical, psychological, and/or psychiatric care [4, 5].

Traditionally, nursing homes provide long-term care (LTC) for either cognitive or physically disabled persons and mental health care institutions provide LTC for persons with chronic mental illnesses. Earlier studies have shown that older patients with combined care needs benefit from collaborative psychiatric and physical medicine approaches, such as from multidisciplinary care teams that deliver integrated mental and physical care [4, 6, 7].
Research in these combined care settings for patients with combined care needs is scarce and only consists of describing demographic characteristics, physical morbidity, and psychiatric morbidity of this specific patient group. Results from these studies show that patients with combined care needs tend to be younger, more often male, unmarried, have severe challenging behaviour, a high amount of physical comorbidities, high care dependency and cognitive impairment [8 - 10].

Professional caregivers in combined care settings will be challenged by these care complexities, as they must be able to address both somatic care needs as well as psychiatric and psychogeriatric care needs [8,10]. Several studies looking at combined care needs in general settings, confirm this challenge of skills. Blythe et al. stated that mental health care nursing staff often lack enough training to meet the physical care demands of patients with combined care needs [11]. According to Beck et al., nurse assistants are primarily educated to provide physical care and Gabrowski et al. found evidence for nursing home nurses to be under qualified to provide psychiatric care for elderly people [12, 2]. Nursing home nurses themselves have expressed a need for more training in psychiatric care to be able to meet the needs of patients with combined care needs [13, 14].

This challenge of skills could have implications on nursing staff's experienced work-related stress and may therefore have an impact on their well-being and risk for burnout. Staff burnout has been associated with a higher tendency to leave the nursing profession [15,16]. Insight into factors influencing the work-related well-being of nursing staff for patients with combined care needs is therefore essential to create both a healthy work environment and a sustainable workforce related to care for this specific group.
Previous studies in general settings showed that patient characteristics can influence work-related well-being of nursing staff and that results are not consequently pointing in one direction.

Residents' challenging behaviour was found to be a stressor for nursing home nurses, and it had an impact on their general health, job satisfaction, and work-ability [17, 18]. A study by Testad et al., however, showed that agitation and dementia severity are not related to carer stress [19].

In addition nursing staff characteristics, such as workload, work experience, and educational level have been identified as factors to cause job stress [20, 21], while lack of adequate staffing was the most frequently mentioned stressor in a study on job burnout comparing psychiatric hospital and community nurses [22]. A recent meta-analysis of the influence of age on the three dimensions of burnout syndrome (emotional exhaustion, depersonalisation, and personal accomplishment) in nurses indicated that younger age was a significant factor in the emotional exhaustion and depersonalisation of nurses, although it was somewhat less influential in the dimension of personal accomplishment [23]. Wynd found that registered nurses who scored the highest on levels of professionalism had many years of experience in nursing practice and higher educational degrees [24]. Mental health care nursing staff with an average of 13 years of work experience reported positive attitudes towards their role in the physical care for psychiatric patients; they felt more confident about both performing routine physical health observations and their technical skills [25]. In a multilevel study of general hospital nurses, nurse self-efficacy on an individual level was the strongest predictor of the burnout dimensions exhaustion and depersonalisation [26]. Queiros et al. found that mental distance is influenced by age, gender, and job satisfaction, and that personal accomplishment is influenced by work experience [27]. Perceived competence in providing dementia care has been associated with increased job-satisfaction [18, 28].

Environmental characteristics, such as small scale living facilities with more personalized care were reported to reduce care staff stress [28 - 30]. Pekkarinen et al. concluded that work stressors might be reduced by specializing care, so that residents with similar care needs are placed together and care is focused [31]. This is important for staff and patient well-being as nurses working in an environment with lower mental distress hold a less negative attitude towards patients, and their personal accomplishment is higher [32, 33].

AIM

The primary aim of this study is to explore the work-related well-being of nursing staff in relation to patient characteristics in specialized units for older patients with combined care needs in both the nursing home setting as well as the mental health care setting. The study addresses the following research question: what are the personal characteristics (educational level, work experience, age, and gender) and the work-related well-being characteristics (mental problems, job satisfaction, perceived self-efficacy, and burnout) of

the nursing staff caring for older patients with combined care demands?

Because of the traditional categorization in physical care and psychiatric care, and therefore a better training level of nursing staff related to only one of these care domains, we hypothesized that care dependency, physical care demands and intensity of neuropsychiatric symptoms in patients with combined care needs will be correlated to higher symptoms of job burnout and work-related distress in nursing staff across settings. Consistent with results from earlier studies in different settings, we expected higher educated, more experienced, and highly (self-rated) competent nursing staff to show fewer symptoms of burnout and work-related mental distress. Data on these specific nurse characteristics were therefore also collected.

The findings of this study are relevant for planning of services and training to maximize well-being of staff and patients in specialized units for combined care needs, taking into account both the possible differential impact of care characteristics of these patients as well as staff characteristics in different specialized care settings.

METHOD

Design

This study was part of a large exploratory observational cross-sectional study on the "Specific Care on the Interface of Mental health and Nursing homes" (SpeCIMeN). Patients and nursing staff from two types of care settings for patients with combined care needs were included: the mental health care setting and the nursing home setting. Data were collected from November 2013 through April 2015.

The first part of the SpeCIMeN study investigated both the personal and care characteristics and the perceived quality of care of patients with combined care needs residing in specialized care units in both settings. The results of the first part of the SpeCIMeN study have been published elsewhere [8].

The present study explores the work-related well-being of nursing staff working in specialized units for patients with combined care needs across the nursing home and the mental health care setting, related to the care characteristics of these patients and nursing staffs' personal characteristics.

Participants

Participants (both patients and nursing staff) were recruited from nursing homes and mental health care institutions with specialized units for older patients with combined care needs, situated in the southernmost part of Limburg, a province of the Netherlands.

To be included, these specialized combined care units needed to fulfil the criteria of delivering integrated multidisciplinary care for older patients with care needs on the combination of psychiatric, cognitive, and physical care problems.

Four specialized units within a mental health care institution and seven specialized units within two nursing home organisations were identified and included in the study, with a total inclusion of 80 patients with combined care needs in a mental health care setting, and 83 nursing home patients, respectively. The specialized units within the mental health care setting varied from 14 to 20 persons, while these units within the nursing homes varied from 8 to 20 persons.

Patients were included if: 1) they stayed for at least six weeks on the specialized unit;
2) they had a clear combination of psychiatric, cognitive, and physical care problems; and 3) informed consent to participate in the study was given either personally or by an officially appointed legal representative. Patients were excluded if they: 1) refused to participate; and 2) were temporarily admitted to the specialized unit because of admission problems elsewhere.
All nursing staff with permanent employment contracts, working on specialized units for patients with combined care needs in either a nursing home (n=96) or a mental health care setting (n= 53), were invited to participate in this study. They were included if they: 1) gave informed consent to participate in the study; and 2) worked in direct care with patients with combined care needs. Nurses were excluded if they: 1) had a temporarily employment contract; 2) refused to participate in the study; or 3) were absent because of sickness, during a period of more than 6 weeks.

Procedure

Patients

We asked the unit physician (psychiatrist or elderly care physician) to identify and inform all patients able to participate in our study. These patients, their representatives and their professional caretakers received an information letter giving details about the nature of the study, the purposes, duration and possible consequences in a form they could understand. If needed the information was given orally. We further explained that confidentiality was ensured and that permission might be revoked at any time by the patient or the legal representative without further consequences. We then asked the patient or the legal representative to sign the informed consent. All interviews were conducted by a certified elderly care physician (researcher JC) or a trained research assistant. If we sensed any distress in participants during the interview, we offered them the opportunity to return at a more favorable time, skip questions or discontinue participation. Medical files were intensively studied by the researcher (JC), to collect information on psychiatric and somatic morbidity. Vocational nurses, who were the primary responsible caretakers

of the patients with combined care needs provided data on care dependency and current behaviour.

Nursing staff

All nursing staff with permanent employment contracts working on specialized combined care units within a mental health care setting (n = 53) or a nursing home (n = 96) received a letter explaining the study and an informed consent form at their work address. After obtaining informed consent from the nursing staff, a paper questionnaire was given to them at their work address. Approximately 20 minutes were needed to complete the questionnaire. The questionnaire contained questions on basic personal characteristics, work satisfaction, feelings of competence, work-related mental health problems, and burnout. In case of non-response after 8 weeks, a reminder was sent by mail.

Measurements

Nursing staff characteristics

Personal characteristics, such as gender, age, level of professional education (low = low vocational training [nursing assistants], medium = medium vocational training [certified vocational nurses], and high = high vocational training [bachelor degree nurses]) and level of work experience (< 5 years or ≥ 5 years) were retrieved from the self-report questionnaire.

Work satisfaction was measured by asking professionals to grade their work satisfaction on a scale from 1 to 10. A higher score expresses more work satisfaction.

Self-rated competence was measured using the Dutch version of the General Self-Efficacy Scale [34]. This validated and reliable questionnaire (Cronbach's alpha = 0.80) measures the style of problem solving related to the nursing job and consists of 10 statements that must be answered on a four-point Likert-scale. Answers could vary from 1 (not at all relevant) to 4 (very relevant), meaning that total self-efficacy score varies between 10 and 40. A higher sum-score indicates a better style of problem solving and therefore a higher level of self-rated competence. Additionally, professional caregivers were also asked to grade their experienced level of competence in problem solving on a scale of 1 to 10. A higher score correlates with a greater feeling of competence.

Mental distress such as anxiety, depression, and social withdrawal were measured using the General Health Questionnaire (GHQ-12). The 12-item version is reliable for nursing staff (Cronbach's alpha = 0.76). It has a 4-point response scale, varying from 0 (not at all) to 3 (much more than usual). A higher sum-score corresponds with a higher amount of work-related mental health problems [35].

Burnout was measured using the Utrecht Burnout Scale (UBOS), which is the Dutch version of the Maslach Burnout Inventory [36, 37]. We used the UBOS-C, because this version specifically measures the work-related psychological state of individuals who have an occupation with frequent client interaction. UBOS-C provides a reliable (Cron-

bach's alpha = 0.79) and valid measure of experienced pressure at work. The results can be used for both individual assessment and for comparison of groups. UBOS-C consists of 20 items that can be answered on a 7-point scale, ranging from 0 (never) to 6 (every day). Three subscales are available: 1) emotional exhaustion measures feelings of being emotionally overextended and exhausted by one's work (eight items; a higher score means more exhaustion); 2) depersonalisation assesses impersonal responses towards clients (five items; a higher score means more depersonalisation); and 3) personal accomplishment examines feelings of competence and achievement in work (seven items; a higher score means more personal accomplishment). Means of emotional exhaustion, depersonalisation, and personal accomplishment were calculated with eight, five, and seven items, respectively [37]. Responses for each subscale were categorized as low, moderate or high in accordance with normative data derived from a sample of 1907 mental health professionals in LTC facilities. These normative cut-points are applied for both the nursing home and the mental health setting (See Table 1).

Table 1. UBOS normative data (n=1907[a])

UBOS- subscales (range 0-6)	Low	Moderate	High
Emotional exhaustion	0.39 - 1.12	1.13 - 2.49	2.50- 3.98
Depersonalization	0.01 - 0.59	0.60 - 1.79	1.80 - 3.18
Accomplishment	3.30 - 4.13	4.14 - 5.42	5.43 - 5.98

[a]Categorization of low, moderate and high burnout according to normative data. This sample included mental health nursing staff and nursing home staff (Schaufeli & van Dierendonck, 2000)

Patient characteristics - Data collected from medical files

Baseline characteristics, such as age, sex, time of institutionalization, and level of education were retrieved from the patient's medical record.

Current physical disorders were collected from data on both the medical diagnosis, the available laboratory results, and medication use, as stated within the patients' medical record.

Severity of all physical disorders was scored using the 14-item version of the Cumulative Illness Rating Scale (CIRS) 14-item version [38]. This scale measures multimorbidity in light of all medical problems encountered in a geriatric population. The theoretical scores range from 0 to 56 based on scoring the severity of co-occurring medical conditions from 0 (no problem) to 4 (extremely severe problem). In this study, the severity of co-occurring medical conditions was scored excluding the psychiatry CIRS-subscale.

Psychiatric illnesses were classified according to the Diagnostic and Statistical Manual of Mental Disorders. All DSM classifications made by a psychiatrist or trained psychologist and stated in the patients' medical record were accepted. Both axis I and axis II classifications were noted (DSM-IV-TR. Vol.4th edition, Text Revision. 2000).

Patient characteristics - Data provided by vocational nurses

Patients' needs and care dependency were measured using the Care Dependency Scale (CDS) [39, 40]. CDS was shown to have excellent reliability for several countries (Cronbach's alpha = 0.95–0.97) and it can be used for assessment purposes, both at the group and individual levels [41]. The CDS measures a patients' ability to perform activities independently. It consists of 15 categories that are scored using a 5-point Likert-type scale. Responses range from 1 to 5, where 1 is completely dependent and 5 is almost independent. Patients with a total CDS-score of ≤68, are classified as care-dependent.

Neuropsychiatric symptoms (NPS) were assessed using the Dutch version of the Neuropsychiatric Inventory (NPI) [42, 43]. Content validity of the NPI is high which was rated by a panel of 10 experts in geriatric psychiatry. Inter-rater reliability ranged from 93.6% to 100%, depending on the subdomain. Test-retest reliability was high, with a Pearson correlation of 0.79 [44]. The NPI includes 12 neuropsychiatric symptoms. The frequency and severity of each symptom are rated on a 5-point (0-4) and 4-point (0-3) Likert scale, respectively. The total score equals the product of frequency and severity scores. NPI-symptoms were considered clinically relevant when the total scores were ≥4.

Ethical considerations

The local Medical Ethics Committee of the Maastricht University Medical Centre approved the study (number 134049) after reviewing the study protocol, and considered it to be not subject to the Medical Research Involving Human Subjects Act. The study was also approved by the Board of Directors and the Client Advisory councils of all the participating institutions. Patients and nursing staff participation was voluntary, and data collection was conducted confidentially and anonymously. Informed consent to participate in the study was given either personally or by the patient's officially appointed legal representative.

Statistical analyses

Categorical variables are presented as the number (%), while numerical variables are presented as the mean (standard deviation [SD]) or median (interquartile range (IQR), i.e. 25th–75th percentile), where appropriate. Comparisons between nursing staff groups (mental health care setting versus nursing home setting) were performed using chi-square tests for nominal or ordinal variables and independent-samples t tests or Mann-Whitney U tests where appropriate for numerical variables.

Four analyses were performed using a linear mixed model in which a random intercept for the specialized unit was used to account for the correlation between professionals from the same specialized unit. The first analysis examined the effect of the independent variables setting, care dependency, physical comorbidity, and neuropsychiatric symptoms of residents with complex care needs on the dependent variable GHQ-12 score (work-related mental health problems), whereas the other three analyses examined these effects on the dependent variable UBOS-C subscales (emotional exhaustion, depersonalisation, and personal accomplishment). In all four analyses, types of setting were combined (n = 100 for combined settings) and all independent variables (either numerical or binary) were included simultaneously into the model.

In addition, relevant background variables such as gender, age, educational level (categorical: low or medium/high) and work experience (<5 or ≥5 years) were also included in these analyses. Because of the exploratory nature of the study, no adjustment for multiple testing was made and we focused on the size of the observed effects. Multi-collinearity was tested using Variance Inflation Factors (VIFs). IBM SPSS Statistics for Windows, (version 21.0) was used for the statistical analyses. A p-value ≤ 0.05 was considered statistically significant.

RESULTS

The questionnaire was completed by 37 of the 53 professionals with a permanent employment contract, working within a mental health care specialized unit (response rate, 70%) and by 73 of the 96 professionals with a permanent employment contract, working in a nursing home specialized unit (response rate, 76%). Reasons for non-response were absence because of illness or lack of interest in participating.

Demographic characteristics of nursing staff

The basic characteristics of the nursing staff are presented in Table 2.
Except for the educational level ($p < 0.001$), there was no significant difference between groups in terms of demographic characteristics. Nursing staff in both settings consisted predominantly of females aged 40–49 years. The majority of the staff had more than 5 years of work experience in caring for patients with combined care needs.

Table 2. Basic characteristics of nursing staff in mental healthcare and nursing home settings

Characteristics		All nurses (*n*=110)	MH nurses (*n*=37)	NH nurses (*n*=73)
Age (years) , Mean (SD)		42.4 (10.7)	40.1 (10.5)	43.2 (10.8)
Female, *n*(%)		95.0 (86.4)	34.0 (91.9)	61.0 (83.6)
Work experience in	< 5 years	11.0 (10.0)	3.0 (8.1)	8.0 (11.0)
specialized unit, *n* (%)	≥ 5 years	99.0 (90.0)	34.0 (91.9)	65.0 (89.0)
Working hours, Mean (*SD*)		28.9 (5.8)	28.2 (6.3)	29.3 (5.5)
Level of education, *n* (%)	low	26.0 (23.6)	6.0 (13.5)	20.0 (28.8)
	medium	62.0 (56.4)	15.0 (40.5)	47.0 (64.4)
	high	21.0 (19.1)	16.0 (43.2)	5.0 (6.8)

MH = mental healthcare setting; NH = nursing home setting; Low = low vocational training (nursing assistant), Medium = medium vocational training (certified vocational nurses), High = high vocational training (bachelor degree nurses).

Work-related mental health characteristics of nursing staff

The mean scores on GHQ-12, self-efficacy, and all subscales of UBOS-C, and grading of competence in problem solving and job satisfaction are presented in Table 3. GHQ-12 scores indicated moderate levels of mental distress in nursing staff in both types of settings. Both groups of nursing staff showed similar strong feelings of competence in problem solving. For the UBOS-C, mean overall scores on the emotional exhaustion scale indicated low levels of emotional strain for both groups of nursing staff. Mean overall depersonalisation scores indicated low levels of mental distance, with a significant higher score (moderate level) for the mental health care nursing staff. Mean overall accomplishment scores showed a moderate level of personal accomplishment for both groups, with a significantly higher score for nursing home nurses. Nursing home nurses also showed a significantly higher level of job satisfaction.

Table 3. Competence, mental health and job burnout of nursing staff in mental health care and nursing home settings

Measurement	All nurses (*n*=110) *Mdn (IQR)*	MH (*n*=37) *Mdn (IQR)*	NH (*n*=73) *Mdn (IQR)*	*U*[a]	*Z*[a]	*p*[a]
GHQ-12[b]	9.00 (6.00)	10.00 (7.00)	9.00 (5.00)	1141.00	-1.33	.183
Self-Efficacy	30.00 (4.00)	30.00 (3.50)	31.00 (4.00)	1210.50	-.79	.431
UBOS[c] - emotional exhaustion	1.00 (0.88)	1.13 (0.81)	0.88 (1.16)	1086.50	-1.68	.094
UBOS[c] - depersonalisation	0.20 (0.60)	0.60 (0.80)	0.10 (0.40)	723.50	-4.12	<.001
UBOS[c] - accomplishment	4.43 (1.29)	3.71 (1.43)	4.57 (1.00)	716.50	-3.94	<.001
Grade of competence [d]	8.00 (1.00)	8.00 (0.00)	8.00 (1.00)	1173.00	-1.10	.270
Grade of job satisfaction [d]	8.00 (1.00)	7.00 (1.00)	8.00 (0.00)	905.00	-3.03	.002

Mdn = Median; IQR = Inter Quartile Range (P_{25}-P_{75}); MH = Mental Healthcare setting; NH = Nursing home setting.
[a]Mann-Whitney U-test: significance level is 0.05.
[b]General Health Questionnaire, twelve items.
[c]Utrecht Burnout Scale: range 0-6: norms see Table 1.
[d]Grade on a scale from 0-10.

Table 4. Behavioural and care characteristics of patients with combined care needs in mental healthcare and nursing home settings

Measurement	All CCN (*n* = 163) Mean (*SD*)	MH (*n* = 80) Mean (*SD*)	NH (*n*=83) Mean (*SD*)	*p*[a]
Multimorbidity (count)	7.0 (2.2)	7.1 (2.1)	6.9 (2.3)	0.945
Care Dependency Scale	45 (15.5)	43.9 (13.8)	46.1 (17.1)	0.376
Cumulative Illness Rating Score	15.2 (5.0)	15.4 (4.7)	14.9 (5.3)	0.969
Neuropsychiatric Inventory (total)	29.5 (21.1)	32.6 (19.5)	25.9 (22.5)	0.009

CCN = patients with combined care needs; MH = Mental Healthcare setting; NH = Nursing home setting.
[a]Chi-square : significance level is 0.05

Characteristics of patients with combined care needs

Table 4 shows the relevant behavioural and care characteristics as collected within the SpeCIMeN study.

Patients were predominantly males aged 60–69 years. The majority of them were institutionalized for more than 1 year. One-third of the patients in mental health care had a psychotic disorder, and in 40% of those patients, multiple axis one diagnoses were present. Cognitive disorders, mainly frontotemporal lobe dementia, and alcohol-related dementia were reported in three-quarters of the patients in nursing homes. Personality disorders

were diagnosed in one-quarter of all patients. Overall, patients had seven comorbid conditions and they all showed a nursing care dependency. Patients in a mental health care setting had more neuropsychiatric symptoms, with a higher prevalence of delusions, hallucinations, and anxiety.

Variables associated with work-related well-being in nursing staff

Although effects of characteristics of patients with combined care needs (NPI, CDS, CIRS) on job burnout or work-related mental distress of nursing staff were not significant, the LMM analyses showed that for both groups of nursing staff, a higher amount of neuropsychiatric symptoms was associated with higher rates of both emotional exhaustion (1 point higher NPI-score results in 0.02 point higher emotional exhaustion) and work-related mental distress (1 point higher NPI-score results in 0.11 point higher GHQ-score). It also showed that a higher amount of physical illness severity in patients was associated with both lower emotional exhaustion rates (1 point higher CIRS-score results in 0.07 point lower UBOS-emotional exhaustion-score) and work-related mental distress (1 point higher CIRS-score results in 0.37 point lower GHQ-score).

Within the LMM analyses, several effects were found for both basic personal characteristics of nursing staff and type of setting. A lower level of education was significantly associated with lower rates of depersonalisation and lower rates of personal accomplishment. Older professionals had significantly higher rates of emotional exhaustion and showed a tendency toward higher feelings of depersonalisation and lower rates of personal accomplishment. For setting, significantly higher rates of depersonalisation and lower rates of personal accomplishment were found for mental health care nursing staff.
Table 5 shows the estimated effects that were obtained from linear mixed model (LMM) analyses.

Table 5. Effect of NPI, CDS, CIRS, basic characteristics of nursing staff and type of setting on GHQ-12 and UBOS subscales

Outcome variable	Explorative variables*	Estimated effect (B)	95% CI		
			Lower	Upper	*p*
GHQ-12	NPI	0.11	-0.00	0.23	.057
	CDS	-0.00	-0.13	0.13	.992
	CIRS	-0.37	-0.77	0.03	.068
	Education (low/medium &high)	-2.1	-5.0	0.78	.150
	Work experience (<5 years / ≥ 5 years)	-3.1	-6.8	0.65	.105
	Gender (male/female)	-2.4	-5.4	0.65	.122
	Age	-0.01	-0.11	0.10	.886
	Setting (MH/NH)	-0.11	-2.7	2.5	.936
UBOS - emotional exhaustion	NPI	0.02	-0.00	0.04	.089
	CDS	-0.01	-0.04	0.02	.256
	CIRS	-0.07	-0.16	0.02	.089
	Education (low/medium &high)	-0.30	-0.71	0.11	.145
	Work experience (<5 years / ≥ 5 years)	0.01	-0.51	0.54	.958
	Gender (male/female)	0.04	-38	0.46	.856
	Age	0.02	0.00	0.03	**.028**
	Setting (MH/NH)	0.01	-0.49	0.52	.953
UBOS - depersonalization	NPI	0.01	-0.01	0.02	.311
	CDS	-0.01	-0.02	0.01	.486
	CIRS	-0.03	-0.07	0.01	.184
	Education (low/medium &high)	-0.34	-0.64	-0.03	**.030**
	Work experience (<5 years / ≥ 5 years)	0.02	-0.37	0.40	.939
	Gender (male/female)	-0.10	-0.42	0.22	.536
	Age	0.01	-0.00	0.02	.066
	Setting (MH/NH)	0.39	0.11	0.66	**.006**
UBOS - accomplishment	NPI	-0.01	-0.04	0.02	.492
	CDS	0.02	-0.02	0.05	.207
	CIRS	0.05	-0.06	0.16	.282
	Education (low/medium &high)	-0.60	-1.0	-0.17	**.007**
	Work experience (<5 years / ≥ 5 years)	-0.29	-0.85	0.27	.308
	Gender (male/female)	0.51	0.06	0.96	**.027**
	Age	-0.02	-0.03	0.00	.055
	Setting (MH/NH)	-0.92	-1.6	-0.27	**.012**

*95%CI = 95% Confidence Interval; p = significance level is 0.05; UBOS = Utrecht Burnout Scale; GHQ-12 =General Health Questionnaire 12 items; NPI = Neuro Psychiatric Inventory (measures neuropsychiatric symptoms); CDS =Care Dependency Scale (measures ADL dependency); CIRS = Cumulative Illness Rating Scale (measures severity of physical co-morbidity); MH= Mental Healthcare setting; NH = Nursing Home setting. * Mean difference: NPI, CDS and CIRS per unit increase, Age per year, multicollinearity diagnostics showed no collinearity problem (all VIFs ≤ 1.66).*

DISCUSSION

To the best of our knowledge, this is the first study to report and compare data on the mental well-being of nursing staff working on specialized units for patients with combined care needs across the nursing home and the mental health care setting and the possible relationship with the care characteristics of these patients.

The findings show that, although neither group showed high levels of burnout, mental health nurses, working on specialized units for patients with combined care needs clearly experience more mental distress than nursing home nurses. Mental health care nursing staff showed significantly higher depersonalisation, lower personal accomplishment, and a lower level of job satisfaction, and were, therefore, more at risk for burnout. Compared to nursing home nurses, mental health care nursing staff thus seems to respond less personally towards patients with combined care needs and they also experience a significantly lower sense of achievement when interacting/working with these patients.
Possible explanations for these differences between settings could be the differences in patient characteristics, such as the psychiatric multimorbidity in mental health care patients, or the differences in workplace characteristics, like the organizational position of the specialized care unit or the nursing staffs' experienced appreciation within the organization [32, 33]. But contrary to what we expected we did not find a relationship between patient characteristics and staff well-being across both settings. Based on our previous study we expected that due to a higher prevalence of neuropsychiatric symptoms in mental health care patients with combined care needs, well-being of nursing staff would be more compromised in this setting as they have to encounter higher instances of challenging behaviour. The fact that we did not find a difference between both settings might suggest that within both settings, a fair allotment of personnel to specialized units already exists, meaning that current staff is equally capable of dealing with both clinical diseases as well as neuropsychiatric symptoms.

We did find a tendency that for both groups of nursing staff, a higher amount of NPS in persons with combined care needs is associated with higher rates of both emotional exhaustion and work-related mental distress. This finding is consistent with studies in dementia care settings [17, 18]. Results also showed a tendency toward a higher amount of physical illness severity in persons with combined care needs that is associated with both lower emotional exhaustion rates and work-related mental distress in nursing staff in both settings. This result is consistent with earlier findings showing that work experience has a positive effect on job performance and a more positive attitude towards physical care for patients with a mental illness [25, 27]. Further exploration and confirmation using additional research is needed to be able to attach the correct value to these tendencies found in our study.

Looking into staff demographic characteristics we found that both the mean age and work experience of staff was similar in both settings. We further found that nursing staff in both settings were mainly female, which is not surprising, because worldwide nursing is still a female-dominated profession. There was a significant difference in the educational levels across settings, with low education levels for 29% of nursing home nurses. But this did not result in differences in feelings of self-efficacy and levels of mental distress as these were similar in both settings, indicating that educational level alone is not an indicator of work-related mental well-being of nursing staff in these specialized units. Possibly years of work experience are more important in relation to self-efficacy than educational level. In our study the nursing staff in both settings had more than 5 years of work experience on specialized units, thereby affirming earlier study results, that in gaining more experience, nursing-staff in both settings probably became more qualified to take care of patients with combined care needs [24, 25]. But the educational level was related to other aspects of staff well-being. A lower level of education was significantly associated with lower rates of depersonalisation and lower rates of personal accomplishment. Age of the staff also appeared to be relevant, as older professionals had significantly higher rates of emotional exhaustion and showed a tendency toward higher feelings of depersonalisation and lower rates of personal accomplishment. This finding is contradictory to the results of a recent study of Gomez-Urquiza, where younger age was a significant factor in both emotional exhaustion, personal accomplishment and depersonalisation of nurses [23].

WHAT THIS PAPER ADDS TO EXISTING EVIDENCE

The present study shows that, across settings, nurses showed a highly perceived self-efficacy in combination with strong feelings of self-rated competence, when working on specialized units for patients with combined care needs. Mental health nurses and older nurses however experience more mental distress in working with this specific group of patients, than nursing home nurses. The study suggests that there is no significant relationship between care characteristics of patients with combined care needs and mental distress in nurses who are working on specialized units for these patients.

Our study findings affirm the findings of Pekkarinen that work stressors may be reduced by placing patients with similar care needs together in specialized LTC-units, so that care can be focused [31]. They also affirm the findings of Quiros, Robson, and Wynd that nurses with more work experience show both a higher job performance and a more positive attitude towards physical care for patients with mental illness [24 - 27]. The results of both the present and earlier studies can therefore serve as building blocks for management to organize focused care for patients with combined care needs on specialized units, with an optimal selection of experienced and educated nursing staff.

STRENGHTS AND LIMITATIONS OF THE STUDY

This study is a first exploratory step toward gaining deeper insight into the mental distress and burnout of nursing staff, working on specialized units for patients with combined care needs. Although there was a high response rate in both settings, the study may be limited in its power to demonstrate representative characteristics of nursing staff because of the use of a selected cohort of predominantly female nursing staff, without a direct comparison to nursing staff in non-specialized care units. Because this is a Dutch study, its representativeness of other countries remains unknown. The findings pertaining to the LMM should be treated with caution because the sample size is relatively small (n=100), with a large variance (4-17) in participating nursing staff per unit, and thus the reliability on unit level, and generalizability of the findings is limited. Because we used a general self-efficacy questionnaire and measure of competence, no conclusions can be drawn about the confidence that nursing staff have in providing physical care versus psychiatric care.

IMPLICATIONS FOR RESEARCH AND PRACTICE

Study results show that nursing staff, working on specialized combined care units across settings, with more than 5 years' work experience, feels competent in caring for patients with combined care needs. They do not experience high feelings of burnout and experience high feelings of self-efficacy and accomplishment. Nevertheless, management should be especially attentive to mental health nursing staff caring for patients with combined care needs. They seem to be more at risk of burnout, as they indicate a lower level of work satisfaction and a higher degree of depersonalisation. Older employees in combined care settings also deserve more attentiveness, as they demonstrate lower feelings of accomplishment and a higher degree of depersonalisation. To provide in a sustainable workforce, it is important for healthcare organization leaders to focus both on just allotment of personnel and on implementing strategies that provide adequate support to nursing staff. Several psychological empowerment programs for nurses were shown to be successful in improving nurses' physical and mental health and quality of work life; improving patient satisfaction; and reducing associated costs of burnout [22, 46 - 48]. Future studies can be worthwhile to identify nursing staffs' specific needs, e.g. their skills and confidence in providing physical care versus psychiatric care, their coping styles and their perceived facilitators or barriers in the organization of care for older patients with combined care needs to develop and implement a tailored intervention program for this group of nursing staff.

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Chapter 5

Experiences and needs of nursing staff caring for double care demanding patients; a qualitative study

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ABSTRACT

Nursing staff has a key role in the multidisciplinary care for patients with combined mental (psychiatric and/or psychogeriatric) and physical problems (DCD-patients). This study explores the experiences and needs of DCD-nursing staff in Dutch mental healthcare (MH) and nursing home (NH) settings, to identify factors to provide optimal care for DCD-patients. A qualitative approach was used, consisting of five semi-structured focus group interviews with DCD-staff (n = 28) from MH- and NH-settings in the Netherlands. Five levels of factors were identified: (1) Patient-related factors (complexity of combined care needs, and complexity of behavioral problems); (2) Informal care-related factors (misapprehension of DCD-complexity, and involvement of volunteers); (3) Professional care-related factors (competences and attitudes, well-matched multidisciplinary team, and collaborative care between MH- and NH-settings); (4) Living and work environment-related factors (staff availability and continuity, and facility requirements); and (5) Organization-related factors (clear DCD-care policy, and provision of specific training and coaching). DCD-staff stressed the importance of team-efficacy, depending on commitment, mutual trust, and good communication- and collaboration skills; of experiencing a psychologically and physically safe work-environment; and of empowerment through the acknowledgement of the specificity of DCD-care and the teams' specific qualities regarding DCD-care. These findings can be used to optimize DCD-care.

INTRODUCTION

Many older people suffer from multiple morbidities, with combined mental (psychiatric and/or psychogeriatric) and physical problems [1, 2]. These so-called double care demanding (DCD) patients require a combination of physical, psychogeriatric and psychiatric care [3, 4], and usually end up in long-term care (LTC) facilities.

Different types of LTC are provided to older people with physical disabilities, advanced dementia or disabling psychiatric illnesses. In the Netherlands, tight networks of regional nursing homes (NHs) and integrated mental healthcare institutions (MHs) exist. Traditionally NHs provide LTC for either physically or cognitively disabled older patients, while MHs provide LTC for patients with chronic mental illness. Earlier studies showed that DCD-patients benefit from a multidisciplinary approach, including a collaborative approach of psychiatric, physical, and nursing interventions [5].

For economic reasons, the number of psychiatric hospital beds has decreased in many Western countries, including the Netherlands [6]. Since then, worldwide, a heterogeneous range of LTC-facilities has partly taken over the traditional asylum function for older adults with severe mental illness (SMI). Whether these facilities address the psychiatric care needs adequately has been questioned [7]. A study by the Dutch Trimbos Institute found that, according to NH-personnel, 8.6% of the Dutch NH-residents were DCD-patients who surpassed the capabilities for psychiatric treatment available in their own NH-department [8]. Qualified psychiatric nurses are still rarely employed within NHs, and specific psychiatric training for personnel is limited [9]. Despite the knowledge that patients with SMI have a high prevalence of physical disorders and are less competent in interpreting physical symptoms [10], it has been stated that MHs should focus greater attention on the physical needs of DCD-patients and should provide official guidelines to help identify and treat physical complications [11]. Based on these challenges encountered in providing appropriate care for DCD-patients, some Dutch NHs and MHs developed specialized care units to allow targeted allocation and care for this specific group of patients.

Results from explorative studies on these specialized DCD-units have shown that the group of DCD-patients is quite heterogeneous in both the MH- and the NH-setting [12, 13]. They tend to be young, more often male, and to have low family support. All DCD-patients displayed a high amount of neuropsychiatric symptoms, ADL-care dependency, and physical multimorbidity [12, 13], although, expectedly, psychopathology was more prominent in the MH-DCD-group [12]. The high care dependency and the variation in neuropsychiatric patient characteristics present a challenge to the nursing-staff across both settings, as they must address somatic care needs, as well as psychiatric and psychogeriatric care needs. Research into the impact of caring for DCD-patients on the mental well-being of

nursing staff showed that well-being and performance of nursing staff might benefit from specializing care so that patients with similar care needs are placed together, and care is focused. Study results also showed that despite the overall finding of relatively high levels of self-efficacy and job satisfaction, MH-nursing staff seemed to be more at risk for burnout. Differences in patient characteristics or work experience of nursing staff across settings could not explain this finding [14].

As nursing staff have a key role in the care for DCD-patients, it is especially important to examine and describe their viewpoints in order be able to develop tailored interventions to provide optimal care for DCD-patients as well as a sustainable workforce with minimal costs of burnout. We, therefore, performed a qualitative study with the following research question: "What are the perceived needs and wishes of nursing staff caring for DCD-patients on specialized DCD-units"?

METHODS

Study design

We conducted a qualitative focus group study. Focus groups are effective to gain in-depth insights from different perspectives and to capture the interaction between participants [15]. Because of the complexity of the subject, we purposefully worked with small sample size groups of four to eight participants [16]. We organized five focus group meetings from April 2017 to December 2017. Four groups consisted of nursing staff. A fifth focus group was performed to verify if the needs and wishes of the nursing staff were recognized and supported by the other multidisciplinary team members. Relevant aspects of this study are reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) [17].

Setting

The study was performed in Limburg, the most Southern province of the Netherlands. MH- and NH-organizations were approached to identify suitable wards for our definition of a specialized DCD-unit: "specialized units for patients with a combination of psychiatric, physical, and/or psychogeriatric care needs". The multidisciplinary team composition on these DCD-wards varied (see Table 1). Two focus group interviews with nursing-staff were organized in an NH, and three focus group interviews (two with nursing staff and one with a mixture of MH- and NH-multidisciplinary staff) were organized in an MH-setting, to realize triangulation of sites. The interviews were held in a quiet meeting room, conducted in Dutch and lasted approximately 90 min each.

Table 1: Composition of multidisciplinary team in different settings

Occupation of team member	MH setting	NH setting
Certified vocational nurse	+	++
Bachelor degree nurse	++	+
Specialized nurse*	+	+
Social worker	+	+
Physiotherapist	+	+
Occupational therapist	+	+
Health care psychologist	+	+
Clinical psychologist	+	-
Geriatric psychiatrist	+	Consultation basis
Elderly care specialist	+	+
Geriatrician	+	Consultation basis

*Note: + = present; ++ = highly present; * = Specialized in behavioral problems*

Participants

The participants consisted of general nursing staff and other representatives of the multidisciplinary team (specialized nurses, nurse-managers, psychologists, physicians). A combination of purposeful and criterion sampling was used to achieve a range of diverse participants from different DCD-units with variation in experience and education [16]. Employees from DCD-units in MH- and NH- settings with a permanent contract were recruited. Potential participants were informed about the study in writing, with the possibility to ask questions. In total, 21 nursing staff members and 7 multidisciplinary team members agreed to participate. Sampling ended when data saturation was achieved [18]. In accordance with the methodological guidelines, data saturation occurred after four focus group sessions, with a total of 19 participants [15]. A fifth focus group session was organized to gain a multidisciplinary perspective into the subjects derived from the previous interviews.

Data collection

We used an interview guide with open questions during all focus groups. A question route was defined; starting with general issues and then moving towards more specific issues for more in-depth information (see Appendix1).

To sensitize participants of the first four focus groups, we asked them to write a case with which they could illustrate successful or problematic DCD-care in advance. The participants of focus group five were asked to read a summary of data of the first four focus group interviews previously. This priming method is a derivative of the sensitizing phase of the context-mapping

approach, in which participants are triggered and motivated to think about the subject prior to the actual session, thereby maximizing the efficiency of the interviews and capturing the most relevant topics [19]. At the start of the focus group meeting, we informed participants about the aim and method of the study and asked them to fill in a consent form. Then, all participants briefly introduced themselves. During the interviews, the focus was clearly on the experiences of the DCD-nursing staff in their daily work with DCD-patients. The interviewer encouraged participants to talk freely about what they considered important. A second researcher was present to facilitate the meeting and to report observations as field notes.

Data analysis

All focus group interviews were audiotaped and transcribed verbatim. We used the qualitative data analysis Software Nvivo -11 [20] to organize and code the transcripts from the interviews. We analyzed both the transcripts and our field notes with an inductive content analysis approach, starting with the breaking down of transcripts into open codes, based on the content they display. Subsequently, we grouped the coded material into subcategories and broader categories, and finally into a set of key themes based on shared concepts [16]. Two independent researchers (JC, DA) first coded the transcripts. Discrepancies in coding were discussed and, in case of permanent disagreement, a third researcher (MdV) was consulted. The research team decided on the final set of key themes and subcategories. To allow for scientific publication, we translated the quotes from Dutch to English.

Trustworthiness:

We used purposive sampling to enhance the transferability of the results. We documented the recruitment process and interview schedule. The interviewers (JC, DA, and JS) were familiar with the patient group but did not work with the participants directly. We pursued the credibility of the research by investigator triangulation, which entails double coding all conducted interviews and field notes. After every interview, peer-debriefing sessions with the research group were performed to reflect on the research process, on the analysis and the interpretation of the data, and on data saturation. To increase accuracy, validity, and credibility, we performed a member check. We sent the main findings to all nursing staff participants, giving them the opportunity to comment and verify these findings [21].

RESULTS

Participants

A total of 28 nursing staff and multidisciplinary team members agreed to participate in the study. Two nursing staff members canceled due to sickness just before the planned interview, yielding a total of 19 nursing staff members and 7 other multidisciplinary team members. The sample consisted of 13 MH-participants and 13 NH-participants. The mean age of the participants was 44 years and mean work experience was 15.2 years. All participants were involved

in the member check. Table 2 shows the characteristics of these participants in detail.

Table 2: Characteristics of included participants

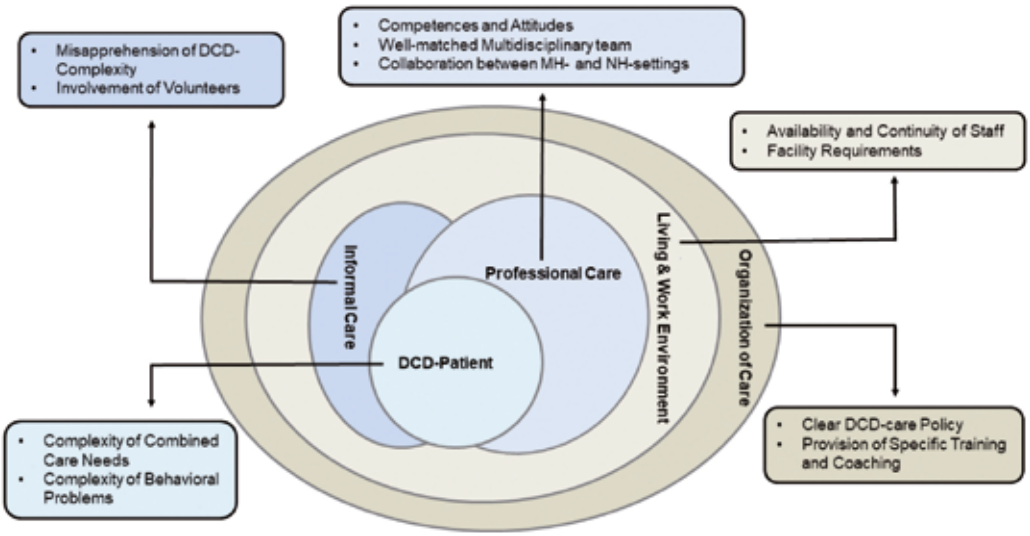
Participant	Professional background	Sex (F/M)	Age (years)	Work Experience (years)	Age (*M*, years)	Work Experience (*M*, years)
M.1.1	Bachelor nurse	M	22	2		
M.1.2	Master nurse	F	44	7		
M.1.3	Bachelor nurse, geriatrics	F	48	19		
M.1.4	Bachelor nurse	F	32	8		
M.1 (total)					**37**	**9**
M.2.1	Senior bachelor nurse	F	50	10		
M.2.2	Bachelor nurse	F	48	7		
M.2.3	Master nurse; unit manager	F	40	16		
M.2.4	Master nurse; mental health expert	F	39	15		
M.2.5	Master nurse; unit manager	M	40	21		
M.2.6	Bachelor nurse; unit manager	M	34	3		
M.2 (total)					**42**	**12**
N.1.1	Certified vocational nurse	F	54	15		
N.1.2	Certified vocational nurse	F	26	2		
N.1.3	Certified vocational nurse	F	62	41		
N.1.4	Bachelor nurse (behavioural expert)**	M	48	18		
N.1 (total)					**48**	**19**
N.2.1	Bachelor nurse	F	25	1		
N.2.2	Bachelor nurse *	F	62	10		
N.2.3	Certified vocational nurse *	F	60	30		
N.2.4	Bachelor nurse; unit coordinator	M	42	22		
N.2.5	Master nurse; unit coordinator	F	54	30		
N.2 (total)					**49**	**19**
MN.1	Team manager (NH)	F	50	30		
MN.2	Nursing specialist Mental Health (MH)	F	42	14		
MN.3	Health Care Psychologist (MH)	F	39	16		
MN.4	Social worker (NH)	F	63	36		
MN.5	Elderly care specialist (MH)	F	44	10		
MN.6	Elderly care specialist (NH)	M	35	4		
MN.7	Nursing specialist Mental Health (MH)	F	33	12		
MN (total)					**44**	**17**

*Legend: **M.1**: Focus group 1 with MH general nurses in direct DCD-care; **M.2**: Focus group 3 with MH nurses with managerial or coordinating tasks, next to DCD-care; **N.1**: Focus group 2 with NH general nurses in direct DCD-care; **N.2**: Focus group 4 with NH nurses with managerial or coordinating tasks, next to DCD-care; **MN**: Focus group 5 with mixed MH/NH multidisciplinary team members; **NH**: Nursing home; **MH**: Mental Health Care Institution; *: with first responsibility in the care for a number of DCD-patients; **: followed specific courses and has an advisory role in complex behavior.*

Focus group interviews

Inductive content analysis of all focus group interviews resulted in a set of five key-levels of factors regarding the needs and wishes experienced by DCD-nursing staff: (1) patient-related level, (2) informal care-related level, (3) professional-related level, (4) living and work environment-related level, and (5) organization of care-related level. The coherence of these five key-levels, within the DCD-setting, is displayed in Figure 1. Several categories were identified within the key-levels and further illustrated by quotes. Each quotation is assigned the code of its respondent, corresponding with the list of participants as presented in Table 2.

Figure 1: Key-levels of factors regarding the experiences and needs of DCD-staff



Patient-related factors

The complexity of combined care needs

In both settings, most participants have consciously chosen to work with DCD-patients. For all participants, the complexity of combined psychiatric, physical, and/or psychogeriatric care needs makes DCD-care unique, inspiring, interesting, and rewarding. It provides an opportunity to be creative and think outside the boxes.

"There are often puzzling problems that can't be easily solved. It is usually through working very intensively with patients and their family that you get to know their background and history so that you eventually understand what is going on." (N1.4)

The complexity of combined care needs and the heterogeneity of patients, however, also provide challenges for the nursing staff. In both settings, patients' increasing physical care demands were stressed. Especially patients with personality disorders were perceived as highly demanding because they can be hurtful and disqualifying. MH-nursing staff expressed that assessing the severity and seriousness of physical complaints is often complicated by the presence of psychiatric symptoms.

"This patient had a narcissistic personality disorder and did not accept any care. We could not connect with him in any way." (N2.2)

"I find it very difficult whether to take the patient seriously and pay attention to his pain. To what extent is it dismissed as something psychiatric? Finding that balance is very complicated. I do not want to nourish the patient in something that does not exist, but I do not want to deprive the patient either." (M1.2)

The complexity of behavioral problems

Unpredictable and unintelligible behavior, especially agitation and both verbal and physical aggression towards nursing staff and fellow DCD-patients are experienced as highly demanding, and stressful. These behaviors have a negative impact on nursing-staffs' well-being and a feeling of safety. The growing amount of younger and physically strong patients increases the impact of physical aggression even more. The shifting boundaries regarding aggression, thereby almost allowing and accepting aggression as part of the job were also stressed.

"Both the frequency and intensity of aggression incidents increase. This is worrying and also makes staff more anxious about running evening shifts or night shifts". (M2.3)

"The risk exists we will push our boundaries, over and over again, because we realize that this behavior is not intentional, but due to the illness". (N2.2)

Informal care-related factors

Misapprehension of DCD-complexity

Communication and collaboration with family and friends are often hampered by their lack of understanding of the complexity of DCD-patients' problems and the required interventions. Verbal and physical aggression of family members towards both staff and the DCD-patients was described as very challenging in both settings.

"We do have problems with non-cooperative family members, who do not understand the needs of the patient, may act aggressively and refuse to adhere to treatment plans." (M1.1)

The importance of the timely involvement, informing, and educating of family members and representatives was stressed. The provision of background information by the family is experienced as very worthwhile. Informative consultations with a physician or a psychologist are found to be necessary to inform family and representatives of treatment possibilities so that expectations are realistic. The availability of open access informative courses regarding specific psychiatric diseases and other topics are experienced as supportive in the MH-setting.

"We should certainly explain the symptoms and course of certain syndromes. I think adequately informing family members might ease things." (M1.3)

Involvement of volunteers

If the family is not involved, as is often the case in especially the MH-DCD-setting, volunteers can be deployed to take over 'family tasks', such as guidance to a dentist appointment or social events outside the DCD-unit. Although the nursing staff generally welcome these volunteers, several problems were mentioned. Nursing staff stressed that 1) Volunteers should never be a replacement for certified nurses; 2) Volunteers must never act without consultation of nursing staff because of their difficulties interpreting complex psychiatric behavior; and 3) Clear rules regarding confidentiality of patient data and task allocation are needed.

"I notice a tendency of shifting tasks from qualified nurses to volunteers. Volunteers in different places of the organization, including the nursing-unit and the restaurant are getting too much responsibility. They are dealing with a very difficult population." (M3.6)

Professional care-related factors

Competencies and attitudes

Affinity with and commitment to DCD-patients and DCD-care, as well as having a learning attitude, being a team-player and a good communicator were mentioned as needed conditions for all team members in all focus groups. The complexity of the target group requires specific competencies. One has to be open-minded, able to negotiate, apt in crisis management, reflective, creative, and patient. Nursing staff in both settings felt confident and competent in working with DCD-patients, because of their sufficient knowledge and skills in both the psychiatric and physical care domains. MH-nursing staff perceived being able to provide structure and boundaries to be essential, while in the NH-setting a focus on providing affectionate care was mentioned. From a multidisciplinary perspective, the importance of mutual trust and openness and of both dedication to DCD-care and creativity in finding solutions to complex and unusual situations was also underpinned.

"Mutual trust is essential so that you feel free to comment and ask questions, without feeling guilty or stupid about not knowing something" (MN.4)

Well matched multidisciplinary team

Every focus group underlined the importance of good teamwork. Participants discussed the relevance of both nursing staff collaboration and multidisciplinary collaboration. A working atmosphere with mutual trust, appreciation, and respect was perceived as facilitating, and a strong hierarchical environment as hindering. The importance of honest, respectful and open communication towards both colleagues, patients, and relatives was emphasized. This entails listening, asking the right questions, expressing expectations, and taking each other seriously. It is also important to know each other's expertise. Discussing and evaluating difficult situations and getting support from colleagues are important factors in creating a feeling of safety and unconditional trust. Participants emphasized that DCD-care requires a well-matched team, where all team members are on the same page and stick to the treatment plan.

"If you know you can trust your team, then you are not afraid". (N2.5)

"You must be able to apply individual treatment plans; otherwise, you do not belong in DCD-care. Patients will play you off against colleagues and will treat you disrespectfully if you don't keep up with the agreements made." (N1.3)

Participants highlighted the necessity of a multidisciplinary approach in working with DCD-patients. Addressing complex issues from different perspectives helps to find solutions. All team members should be easily accessible, open to feedback, and committed to DCD-care. Incidents in patient care should be discussed in a low-threshold manner. The employment of specialized behavioral expert nurses is facilitating, because of their expertise, supervising, and mediating role. The unit-leader has a valued connecting role within the team, by ensuring that any problem is discussed, reported (for instance aggression incidents), and evaluated.

"Both the physician and the psychologist are always aware of the teams' problems. This is facilitating and supportive." (N2.2)

Collaboration between MH- and NH-settings

The collaboration was seen as essential in the referral of NH-DCD-patients for either psychiatric diagnostic examination or therapy and vice versa of referral of MH-DCD-patients, who no longer need intensive psychiatric care. Knowing and accepting each setting's limits of professional competence, low thresh-hold professional contacts between settings and the provision of accurate information about the care needs of a DCD-patient were

perceived as facilitating in this referral process.

"The NH-psychologist simply called to ask if we (MH-setting) were familiar with the patients' behavior and if we could provide specific behavioral advice?" (MN 7).

The severity of psychiatric symptoms (unpredictable behavior especially), the existence of waiting lists, unfamiliarity with judicial authorization, and the prevailing stigma about psychiatric patients were mentioned as the main obstacles in transferring DCD-patients from a MH- to a NH-DCD-unit. Participants also indicated that cultural differences or domain thinking between settings could obstruct their collaboration.

"No nursing home wants to have schizophrenics with many delusions." (M2.3)

"I think they (MH-setting) would only be able to handle her if she was tranquilized and kept isolated". (N1.3)

Living- and work environment-related factors

Staff availability and continuity

All participants stressed that DCD-patients are very vulnerable and need a permanent team with as few changes as possible to create a safe living environment. They often need individual guidance to be able to perform appropriate daytime activities. The availability of sufficient nursing staff was perceived as a bottleneck in both the evening, weekend, and night shifts. MH-staff especially expressed a feeling of frustration, because they cannot apply their professional skills to de-escalate aggressive DCD-patients properly due to staff shortages. Across settings, a feeling of demotivation was described, because ever more tasks, such as administration and cleaning, are requested at the expense of their actual nursing work. From a multidisciplinary perspective, the importance of availability and continuity of nursing staff to facilitate good teamwork was also stressed.

"It feels unsafe when there is no supervision in the living room. You never know what happens. Then I worry about the safety of the residents." (N1.4)

"Nurses often feel understaffed. This increases their workload in dealing with these complex patients. When nurses are overburdened and get annoyed, this subsequently has a negative impact on collaboration, communication, and patient care." (MN.7)

Facility requirements

Oversight and supervision must be guaranteed at all times to create safety for both patients and staff. DCD-units should have sufficient safe indoor (multiple rooms) and outdoor space so that stimuli can be varied, and patients are not irritated by being too close

together. There must be private and strippable bedrooms with private bathrooms, where strict room treatment can be applied if needed. The NH-nursing staff recommended the use of doors with the possibility of opening the upper part separately, to enable contact with staff or fellow DCD-patients within a secure environment. Although camera surveillance is helpful, this should never replace face-to-face contact with a DCD-patient. MH-staff stressed that the use of supportive electronic devices could even trigger aggression, as psychotic and distrustful patients for instance simply do not understand "that soothing voice coming from the wall".

"If one patients' behavior changes, the other patients will join. They reinforce each other's behavior ". (MN 5)

Organization-related factors

Clear DCD-care policy

Managers should be familiar with the target group and acknowledge their complexity and their specific care requirements. All participants wanted to feel valued for their expertise in DCD-care and liked to be more involved in DCD-policy within their organization. Clear admission criteria are required to ensure patient admission to the most appropriate DCD-setting and to prevent admission of non-DCD-patients to a specialized DCD-unit. These patients will not receive the most appropriate care, while the therapeutic climate of the actual DCD-patients becomes disrupted.

"Someone, who is introduced beforehand as being very calm, but actually screams 24 hours a day…. If you can no longer rely on admission information, ….. what can you do? "(MN7)

Family or representatives should be better informed at admittance to the unit, that a transfer or relocation will be arranged if specialized DCD-care is no longer needed. The NH-staff felt more empowered and supported by their management, while the MH-staff experienced minimal influence on the admittance of appropriate DCD-patients and felt less acknowledged by the management.

"If we analyze it as a team and have a well-motivated story, the management will not hesitate to temporarily facilitate extra finances or resources." (MN.6)

"I think we have limited influence on who gets admitted to our unit. Patients are on a waiting list, and they will just arrive." (M.2.2)

The MH-multidisciplinary staff mentioned the sometimes frustrating search for care-transition possibilities of a small group of DCD-patients with therapy-resistant behavioral pro-

blems, without the prospect of substantial recovery. They thought that it could improve patients' quality of life just to accept their life-long need for MH-DCD-care.

Provision of specific training and coaching:
The currently provided training in both the psychiatric and physical care domains was experienced as rather basic. Nursing staff wanted to be challenged with more-in-depth training in geriatrics, pharmacotherapy, and challenging behavior. A wish for more specific training in counseling strategies and in recognizing the influence of their own personal characteristics when interacting with DCD-patients or family members was also expressed. The nursing staff especially indicated a need for team coaching. They need time to reflect, to get to know and trust each other, to recognize personal pitfalls, and to learn from each other and identify solutions together. Sharing difficult situations with fellow team members prevents them from becoming emotionally exhausted.

"Due to cutbacks, team coaching programs no longer exist. I think it is essential to talk about self-reflection, about how we look at the patient population, and how patients perceive us. Nowadays, we are only busy to get through the day, to get through the week, to keep the beds occupied." (M2.6)

Participants stressed that in general too little attention was paid to psychiatry within the educational nursing schools. Special interest was requested for the supervision of new colleagues and student-nurses. Enough time and "manpower" are needed for this so-called training-on-the-job, to share DCD-experience, knowledge, and skills as best as possible and to create a sustainable workforce.

"We still receive trainees who know nothing about psychiatry. It is almost as if you would put a trainee in the intensive care unit immediately. "(M2.4)

DISCUSSION

The aim of this qualitative focus group study was to identify the experiences, needs, and wishes of nursing staff and other multidisciplinary team members in the daily care for DCD-patients. Results showed that experiences of DCD nursing staff could be described on five levels: (1) Patient-related factors (complexity of combined care needs, and complexity of behavioral problems); (2) Informal care-related factors (misapprehension of DCD-complexity and involvement of volunteers); (3) Professional care-related factors (competencies and attitudes, well-matched multidisciplinary team, and collaborative care between settings); (4) Living- and work environment-related factors (staff availability and continuity, and facility requirements); and (5) Organization-related factors (clear DCD-policy and provision of specific training and coaching).

The complexity of the target group shows both advantages and disadvantages to nursing staff, and several preconditions and unmet needs were expressed. We will discuss these findings in more detail.
As a starting point of successful multidisciplinary DCD-care, "motivation for", "affinity with", and "commitment to" the target group were mentioned. In different settings, this so-called work engagement counterbalances work-related stress reactions and has a positive influence on the well-being of nursing staff, despite their high workload [22]. Also, the results show the importance of knowing each other and of building mutual trust and respect among all team members for creating a psychologically safe environment that enables staff to collaborate effectively in DCD-care. This is in line with the findings of van Dongen et al., who found that mutual trust and respect are important preconditions for effective inter-professional collaboration [23].

In line with our previous findings, DCD-nursing staff across settings felt motivated and competent in providing care to DCD-patients, despite the complexity of their combined mental and physical care needs [14]. Aggressive behavior, however, from both patients and family, was perceived as highly demanding and stressful to all DCD-staff. Our finding that nurses sometimes almost try to "sympathize" with the aggression expressed by the patient or family is rather alarming. Aggression incidents are known to have a severe emotional and psychological impact, which may negatively affect nurses professional performance [24]. We know that communication about safety between hospital leaders and unit-managers regarding aggression incidents might improve patient safety and registered nurses' (RNs) trust in hospital management [25]. A more recent study, however, demonstrated that addressing patient and visitor aggression remains challenging due to: 1) The main use of formal incident reports for statistical purposes, instead of also serving as a tool to enhance communication between nursing staff and management; and 2) A lack of awareness in the organization and scant financial resources [26]. Our study results actually stress the importance of the implementation of strategies to prevent DCD-patient and family aggression, the need of adequate training to cope with this aggression, and the need to change nurses' perceptions and attitudes that violence is acceptable and "comes with the job" [27].

DCD-patients are vulnerable and need both individual guidance and a permanent team to create continuity of care. This underlines the findings of Orchard et al., who describe continuity of care as a key element of interprofessional collaborative practice [28]. Sufficient availability and continuity of nursing staff and the experienced facilitating role of expert nurses were expressed across DCD-settings. Up until now, however, no consistent evidence exists between the amount of nursing staff, the educational level of team members, and the quality of care [29]. There is some evidence that the employment of registered nurses (RNs) reduces aggressive behavior, but no consistent relationship was found

between the presence of baccalaureate-educated RNs and quality of care [30, 31]. Further research to establish the most appropriate skills-mix, therefore, seems necessary.

The present study indicated that the quality of DCD-care is to a great extent influenced by team- efficacy and team support. Higher teamwork, supportive leadership, and colleagues are known important factors related to a better quality of care [32].

Participants emphasized the need for several communicative and collaborative competencies to be able to offer effective multidisciplinary and tailored care to DCD-patients. This is in line with the findings of Backhaus et al. that better communication, coordination, and a higher rating for multidisciplinary collaboration were significantly associated with a higher grade for the overall quality of care in psychogeriatric wards [33]. It also affirms the finding that nurses with effective communication and negotiation skills are indispensable in achieving an effective dialogue with DCD-patients to optimize their individual care plans [34].

Our participants stressed the importance of individual- and team-coaching and training in counseling strategies to recognize and reflect on the influence of their own personal characteristics when interacting with DCD-patients, families, volunteers, and other team members. Team training can improve interprofessional collaboration and trust and enhance team performance [35, 36]. Training on the job was perceived as especially necessary for trainees and newly graduated nurses, who might be inadequately equipped with the needed skills to work with DCD-patients. This is in line with the findings of previous studies stating that, according to clinically based colleagues; the “newly qualified” are not work-ready and benefit from supportive preceptorship in adopting necessary clinical and managerial skills [37, 38].

Supporting employees by providing access to training, sufficient resources, and support from supervisors is called structural empowerment. Compared to the NH-nursing staff, the MH-nursing staff felt less empowered; not feeling involved in decision-making processes and not feeling the acknowledgment of the specificity of DCD-care were perceived barriers. Van Bogaert et al. demonstrated positive associations between characteristics of empowerment (e.g., balanced workload, and decision latitude) and low feelings of burnout, job satisfaction, and low turnover intentions in (psychiatric) hospital nurses [39]. Supportive managers and a supportive nursing team were crucial for structural empowerment, while lack of time and perceived work demands were viewed as barriers [40].

A need for adequate DCD network care or an adequate chain supply of DCD-services was stressed. Management should provide clear admittance criteria. Multidisciplinary teams from both the MH- and the NH-setting must work together to provide continuity in

DCD-care. Clear agreements are needed for consultation of MH-professionals to an NH-DCD unit and for referral of NH-DCD patients to psychiatric treatment that is not possible in the nursing home. The transition of DCD-care from an MH-setting to the NH-setting, and vice versa, involves exchanging complete patient information, as well as showing mutual trust and respect for each other's expertise. This is congruent with earlier studies, concluding that liaison psychiatry or short admittance of NH-patients to a psychiatric hospital could be helpful [5, 41].

STRENGHTS AND LIMITATIONS

To our knowledge, this is the first focus group study to identify the nursing staff's experiences and needs in the daily care for DCD-care in multiple settings, also focusing on a multidisciplinary perspective. Another strength of our study is the mixture of participants involved in the various focus groups, thereby providing an in-depth perspective on the needs of DCD-nursing staff. All participants expressed personal views, and by using a moderator who was not directly working with the interviewed professionals, we limited bias. Unfortunately, not all multidisciplinary team members were able to join, and therefore the present study does not include the perspective of a psychiatrist, a physiotherapist, or an occupational therapist. Although we recognize the importance of the perspectives of these multidisciplinary members, during our study, data saturation occurred after four focus group sessions and the fifth session did not result in new themes or explanations but confirmed and acknowledged the results generated thus far. Finally, though our sample is likely to be representative of Dutch DCD-nursing staff in NH- and MH-settings, the number of DCD-units included is modest, and the representativeness for other DCD-settings and other countries remains unknown.

CONCLUSION AND RECOMMENDATIONS

The complexity of combined care needs of DCD-patients is challenging and demanding. Pressure is clearly experienced on many levels. All participating staff members stressed the importance of the provision of a psychological and physical safe work-environment. Nurses must be able to rely on each other, on the multidisciplinary team, and on the support of their management. They need the security of a well-matched team with continuity of care, of coaching trajectories, and training of specific skills on both the psychiatric and somatic care domains. Interventions that focus especially on the strengthening of team efficacy, collaboration and communication skills, and the mutual understanding between management and DCD-staff seem to be desirable.

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Appendix 1. Semi-structured interview guide

Introduction to focus group session

- Introduction of the interviewer and observer
- Consent for audio recording
- Short introduction on the background and aim of the focus group: *we want to collect qualitative data from nursing staff concerning their needs, wishes and perceived problems in caring for DCD-patients on specialized DCD-units*
- Duration and procedure of focus group session
- Point out that all information is confidential and relevant

Round of introduction

Introduction of the participants: professional background, work-experience and reason to work with DCD-patients.

Questions regarding the DCD-patient:

1. What are the challenges in working with DCD-patients?
2. Can you describe specific complex patient characteristics?
   a. Which patient characteristics are enervating or rather exhausting?
3. What do you experience as helping in dealing with this specific group of patients?
4. How do you handle challenging or difficult behavior?
5. Are there patients where you feel you fall short in care options?
   a. Can you illustrate this with a case?

Questions regarding providing DCD-care:

1. Can you describe your experiences in working in DCD-care?
   a. What is going well, what are you proud of, what are the challenges and where do you see opportunities for improvement?
   b. Can you illustrate this with a case?
2. What are your needs to provide optimal DCD-care? What is the most desirable situation?
   a. For instance: Do you need specific training to work with DCD-patients, or do you need specific tools or competences to care for DCD-patients?
3. Are there any regulations that you are supported by or that are bothering you in delivering DCD-care?

Summary of the focus group session: Provide a summary of the mentioned subjects, and inform if there is any relevant information, that has not been discussed, yet.
Member check: After completion of all focus group sessions, we will present a summary of the discussed topics. We will ask you to check if you can relate to this overview and if there are any topics missing.

Chapter 6

Elderly people with complex, combined care needs: the need for tailored collaborative care

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ABSTRACT

Elderly people with combinations of psychiatric, physical and cognitive health problems – patients with complex, combined care needs – can benefit from integrated care. On the basis of a case description, we examine constraints that hamper the provision of integrated medical and psychiatric care or that hinder access to such care in the Netherlands.
A collaborative care model can create an effective basis for organizing integrated care to patients with complex needs. In every region, existing cooperative arrangements involving general hospitals, mental health services, nursing homes and support from primary care providers need to be improved, and preferably articulated into regional care programs for patients with complex needs. In settings where 24/7 long-term residential care and treatment is required, the knowledge and capabilities of mental health institutions and nursing homes need to be structurally combined. As part of the collaborative care model, difficult-to-place patients will benefit from a expert-transfer-team with placement powers authorized by the regional care needs assessment center and health insurers.

INTRODUCTION

Within the category of older people who have multimorbid health issues and associated impairments in daily functioning, the Health Council of the Netherlands highlighted back in 2008 the need for a specific focus on patients with complex multimorbidity [1]. This specific subgroup of patients with complex, combined care needs exhibit combinations of psychiatric, physical and cognitive health problems. Such patients are known to benefit from integrated care provision consisting of combinations of medical, social and mental health care [2].

As a series of recently published treatment guidelines shows, a number of Dutch professional medical associations now emphasize the need for complex care to people with such combinations of health problems [3-5]. Yet effective integrated treatment of such patients still remains a huge challenge [6].

Health professionals' limited knowledge and experience with respect to this patient subgroup can lead to inadequate care and treatment [7, 8]. In practice, care provision frequently falters or stagnates [9]. Particularly in situations where physical health problems overlap with psychiatric or behavioural problems, it is difficult to get a patient admitted to the appropriate health care setting. Discussion arises as to where, and from whom, the patient can receive optimum care and treatment. If the situation at home is no longer manageable, the task of arranging an appropriate residential admission can be frustrating, because the patients fail to fit into a 'standard' health care admission template. Hospitals or nursing homes often claim inability to cope with the behavioural problems, whilst mental health facilities cannot provide the necessary physical care. The following case description for Mr. B will illustrate the challenges and obstacles presented by the combined care needs of this target group. We will use this example to formulate a series of recommendations.

CASE DECRIPTION

Introduction

Mister B was a married man, aged 87, formerly a farmer. His partner and his three children described him as unstable, conceited, rigid, demanding and manipulative. At home, he had regularly threatened suicide. His general practitioner (GP) described the patient as a contrary and obstinate man who found fault with everybody. Known medical problems were atrial fibrillation, cardiac insufficiency, angina pectoris, TIAs and prostate hypertrophy.

In mid-2016, Mr. B's GP referred him to the Regional Institute for Community Mental Health Care (RIAGG) at his daughter's urgent request, due to symptoms of distrust and

suspicion and verbal aggression against his 85-year-old wife. In cognitive screening using the Mini-Mental State Examination (MMSE), he scored 29 of 30 points. His home situation became unmanageable and unsafe for his wife due to escalating behavioural problems, such as refusal of ADL care, paranoia and verbal aggression (including calling out at night). In the fall of 2016, the patient was admitted to the inpatient old age psychiatry unit of the regional mental health care institution on a court order.

Complications

On his second day in this unit, the patient was transferred to hospital with acute chest pains. An acute myocardial infarction was diagnosed, necessitating stent placement. The patient exhibited post-operative confusion and restlessness. The consulted hospital psychiatrist advised an antipsychotic drug, on the basis of a delirium diagnosis. The patient refused necessary medical checks, was verbally and physically aggressive and was disruptive to other patients and to nursing staff. After consultation between the cardiologist and the hospital psychiatrist, he was transferred to the hospital's medical psychiatry unit (MPU). He walked out of the unit, refused care and unsettled other patients. Because the MPU in question was not certified under the Psychiatric Hospitals Compulsory Admissions Act (BOPZ), he could not remain hospitalized there against his will. The old age psychiatry unit was then requested to readmit the physically unstable patient. Following extensive consultation between the hospital and the mental health facility, the patient returned to the old age psychiatry unit on the second post-operative day. Due to restlessness with fall risk, he was confined to a Posey bed, which is permitted as an alternative to a restraint belt for patients with fall risk, restlessness, or wandering behaviour attributable to delirium or dementia.

Clinical course of psychiatric hospitalisation

The patient experienced several infections and was frequently short of breath, with advancing heart failure. The psychiatric medication was adjusted due to adverse interactions with the poor cardiac function. The patient's stability was fragile and he was even thought to be approaching death. After treatment of a respiratory infection, however, he unexpectedly regained strength and his restlessness diminished. Physiotherapy helped to restore safe mobility, so that care could be delivered in a normal bed. In his ADL care, he needed guidance and help in showering. Demanding and manipulative behaviour persisted towards nursing staff and family members. He was accusatory and believed he was being disadvantaged and robbed. He was verbally aggressive, and at times physically threatening, when he failed to get his way. He would shout and clench his fist but never strike anyone. In the spring of 2017, psychological screening revealed a cluster B personality disorder and mild impairments of orientation, episodic memory and executive function.

Together with the nursing staff, a health psychologist drew up a plan for interaction with the patient, which helped to further stabilize his behaviour. He reported being homesick

and wanting to go home. Several family consultations were held to discuss future management. As continuing the hospitalisation with judicial authorisation was no longer justified, it was decided to work towards placement at home, with support from home care, participation in daycare, and aftercare provided by the community mental health service.

The patient was discharged mid-2017 with a detailed handover report for the GP, the community mental health service and the home care agency. Four weeks later, the patient once again began to exhibit aggression and resistance to care towards both his partner and the home care workers. He refused any kind of community-based daycare. Antipsychotic and sedative medication was started. The patient became incontinent of urine and refused to change clothes and use incontinence aids. He experienced frequent falls, prompting the tapering of the psychotropic medication, which was seen as a possible cause of the regression. A sharp increase in motor and verbal restlessness ensued. The informal care system lapsed once more into crisis after three months of the patient's home stay, and the family requested the GP to have the patient admitted to a Long-term care facility.

Interface of mental health and nursing home
In view of the need for 24-hour residential care and support in a safe environment, nursing home admission seemed indicated. The patient however refused this admission.
Moreover, the social work section of the regional nursing home agency reported that sufficient appropriate care would probably not be available in a conventional nursing home unit. It recommended admission to a dedicated geriatric psychiatry unit within a nursing home facility, where the entire team was trained in dealing with patients with complex combined service needs. A precondition would be a service eligibility decision on dual grounds (a psychiatric disorder in combination with physical disease or dementia).
However, the Care Needs Assessment Centre (CIZ) rated the physical care needs as insufficient, and no dementia diagnosis had been made during the previous psychiatric hospital stay. Admission to the specialized nursing home unit was hence not possible as of yet.

The family was traumatized and incapable of caring for the patient at home any longer. On grounds of deteriorating status, he again underwent a court-ordered admission to the old age psychiatry unit of the mental health care facility in September 2017. Despite treatment focused on providing daily structure, behavioural regulation and activation, the patient failed to return to the level of functioning achieved during his first inpatient stay. He remained verbally and physically aggressive and regularly required one-to-one guidance. Devices and measures such as camera supervision, a safety recliner and a Posey bed were needed to ensure safety on account of his aggression and fall risk. On the basis of the overall clinical picture observed during this hospital stay, the diagnosis of early-stage dementia was made. In combination with the cluster B personality disorder, this enabled

the issuing of an eligibility decision on dual grounds in November. To bridge the gap until a suitable nursing home bed became available (the spring of 2018), the patient remained hospitalized in the old age psychiatry unit of the mental health facility.

To optimize the transfer, the nursing home team made acquaintance with the patient in the old age psychiatry unit. During this visit, the established interaction plan was discussed and explained to the nursing home team. The patient was then transferred to the specialized nursing home unit with continued judicial authorisation and with a written handover report. There, he remained recalcitrant, angry, demanding and verbally and physically aggressive. A weekly behavioural consultation was held in which the patient's behaviour and the interaction plan were evaluated by an elderly care specialist, the nursing staff, a psychologist and a behavioural expert (a psychiatrically trained nurse). His personal care was manageable only after administration of sedatives. Recurring infections and advancing heart failure presented challenges that continuously required addressing the interplay between the patient's physical and mental functioning. Regular care evaluations were held with the family. They showed resignation and sadness at the persisting difficult behaviour of the patient. In late 2018, he died of pneumonia.

DISCUSSION

The man described above is a typical example of an older patient with a combination of psychiatric, physical and cognitive health problems. The description highlights a number of obstacles that compel care providers and organisations to develop creative and competent forms of collaboration. We now describe the key characteristics of this constellation of problems.

Complex behaviour

Mr. B had been known throughout his life to exhibit 'very difficult' behaviour, deriving from his personality. Now that he had reached old age and had become dependent due to a combination of physical and mental health problems, the care system at home came to a complete halt. Professionals in general hospital wards showed themselves to be insufficiently trained for dealing appropriately with his behaviour. Other hospital patients suffered considerable distress. The patient's non-compliance formed a heavy burden both to his family and to professionals. It seriously complicated the process of arranging appropriate care.

Vulnerability

The interplay between physical and psychiatric disorders (complex multimorbidity) frequently triggered new tipping points. There was a fragile equilibrium that spawned unpredictable turns of events. A diagnostic admission to an old age psychiatry unit transmuted into a general hospital admission prompted by acute cardiac complications. An expectation

of approaching death had to be revised after full recovery from a respiratory infection. Patient management intentions had to be continually re-planned and reviewed.

Compartmentalization and differentiation
The cardiology department had the expertise to deliver the physical medical treatment, but not the psychiatric care. The hospital's psychiatric medical unit then proved unable to deliver involuntary care because it lacked the appropriate certification. The psychiatric hospital had to take over the physically unstable patient and try to deliver the necessary medical care. The nursing home could only deal with the behavioural problems in a specialized unit with very limited availability. So basically the patient did not fit in anywhere. Not only did he refuse to cooperate in the delivery of appropriate care, but a suitable diagnosis was also lacking on which a clear eligibility determination could be based. Mr. B's complex combination of care needs thus required integrated knowledge and diagnostics of both psychiatric and physical health issues, a tailored array of services, as well as an eligibility decision specifying dual grounds.

Legal issues
The patient was admitted to the old age psychiatry unit of a mental health facility on the basis of a court hospitalisation order. His condition then stabilized to an extent that there was no longer any justification for maintaining the court order. A well-planned discharge followed and the patient returned home. The consequence was that the informal care system, the general practitioner, the home care service and the community mental health providers were burdened once again with a persistently complex patient.

WHAT COULD HAVE BEEN DONE DIFFERENTLY?

- Earlier GP recognition of premonitory behavioural changes might have drawn attention to the need for specialized mental health care at an earlier stage, despite the patient's lack of compliance. His wife and children might have then felt better supported. Recent research has confirmed the importance of timely primary care detection of personality disorders in older people [10].

- If the patient could have stabilized while admitted to the 24-hour integrated medical and psychiatric care unit, that might have enabled earlier clarity about future patient management. It is known, however, that most of these integrated medical and psychiatric units lack written agreements for services within a continuum [11].

- Case consultations by the attending practitioners were persistently bilateral. The mental health facility encountered dilemmas when the grounds for the patient's

involuntary hospitalisation order were no longer present. Although the patient was deemed mentally competent in his expressed desire to return home, concerns existed about the sustainability of the family support system. If such dilemmas could have been discussed in cross-cutting, joint consultations involving the GP, the home care organization, the community mental health service and the family, that might have resulted in different solutions and in more effective coordination. The unsuccessful placement at home might have then been avoided.

- One of the participating organisations should have been unambiguously charged with the coordination of the care, thus making it clear to everyone who must be contacted in the event of deterioration in the patient's functioning. In this perspective, community aftercare provided by the old age psychiatry unit itself might have been more suitable than the renewed referral back to the community mental health care service [12, 13].

- Had more geriatric psychiatry expertise been present in the conventional nursing home units, and had more specialized nursing home capacity been availble, the patient's stay in the old age psychiatry unit could have been shorter.

- This case example illustrates both the formidable challenge of providing Mr. B with effective integrated treatment, as well as the risk of delivering inadequate care due to the service gaps between organisations [14]. Research has shown that this category of older patients is highly varied, exhibiting a wide range of functional, behavioural, medical and social support needs. They therefore require the best possible patient-tailored care. In case scenarios of this kind, factors such as the extent of patient instability, non-compliance and behavioural unpredictability, in combination with a high level of care dependency and degree of medical comorbidity, constitute the most salient grounds for placement in a specialized nursing home or in a mental health institution. In both such settings, the 24-hour availability of specialized, multidisciplinary expertise is essential[15, 16].

RECOMMENDATIONS

The category of older people with complex combinations of mental and physical care needs demonstrates the necessity of intensive collaboration between professionals in primary care, mental health care, secondary medical care and nursing home care. The collaborative care model – which is premised on a multidisciplinary approach to patient care, a well-structured patient care plan, monitoring by case managers, and interprofessional communication – can be an effective basis for organizing care delivery [17, 18]. It facilitates anticipatory action to avert crises such as those experienced by Mr. B.

In settings where 24-hour long-term residential care and treatment are necessary for this specific category of patients, the knowledge and capabilities of mental health institutions and nursing homes need to be structurally combined. For mental health institutions, that means employing enough medically oriented doctors (elderly care specialists or clinical geriatricians) and nurses to ensure an adequate focus on physical health aspects in this type of patients. For nursing homes, it means that a specialized unit must be available with a multidisciplinary team that possesses knowledge and skills in the fields of geriatric medicine and old age psychiatry. Easy-access consultation with a mental health agency should also be available [4, 19].

In every region, existing collaborative arrangements involving general hospitals, mental health services, nursing homes and support from primary care providers need to be improved, and preferably articulated into regional care programs for patients with highly complex needs. Particular focuses in such programs should be (1) how, and by whom, appropriate care can be delivered at any time needed; (2) which organisations will qualify themselves to address specified care needs; (3) how professional development will be sustainably embedded in the organisations; (4) how much bed capacity will be needed; (5) how the admission process for those beds will function; and (6) where and how mental health services will ensure adequate treatment for those complex patients whose behaviour escalations preclude temporary or permanent placement at home, in conventional nursing homes or in ordinary hospitals [19, 20].

As one element of the collaborative care model [16], *an expert-transfer-team* could be created in every region for dealing with difficult-to-place patients like Mr. B. It would be composed of experts representing all the participating organisations. They would discuss the service needs of individual patients, make proposals for their optimal placement, and actually arrange the placement. That would ensure 'matched care' for such patients – that is, the most appropriate care in the most appropriate setting [21].

Such a collaborative care model should be founded on trust and confidence in the good intentions of the professionals involved, not to evade responsibility, but to take on joint responsibility. The Dutch health care system is still compartmentalized, and funding barriers pose an additional challenge in practice to developing the most effective health care models. That holds risks for individual patient care. The expert-transfer-team ought to be granted placement authorization by the Care Needs Assessment Centre (CIZ) and health insurers in its region, to avoid hindrance from the funding walls [4, 18, 19].

To ensure optimal care for complex patients with combined mental and physical care needs, we must transcend the boundaries of the various care sectors, acknowledging the need and the responsibility of working together creatively and competently to ensure tailored collaborative care.

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Chapter 7

General discussion

INTRODUCTION

This thesis is about double care demanding (DCD) patients; patients who need 24 hour surveillance and multidisciplinary care, because of their combined complex physical, psychiatric and or cognitive conditions. In the Netherlands these patients are housed in either a specialized mental healthcare setting (MH) or a specialized nursing home setting (NH).

This thesis explores the differences and similarities across the MH and the NH-setting with regard to the characteristics and the care needs of DCD-patients, as well as the characteristics and work-related wellbeing of nursing staff caring for these DCD-patients. Next to this attention is given to the necessary elements for adequate care to DCD-patients, by combining expertise from both psychiatric care and nursing home care and taking into account the currently present barriers and facilitators.

Different approaches, including a systematic literature review, observational cohort studies, a focus group study and a detailed case report were applied.

This general discussion first presents an overview of the main results, followed by some reflections, positioning them in a broader perspective. Thereafter strengths and limitations of the study will be discussed, and finally, implications and recommendations for clinical practice, and future research will be made.

MAIN FINDINGS

Characteristics and care needs of DCD-patients

Chapter 3 showed that there is substantial heterogeneity in the DCD-population in terms of mental and physical health in both the nursing home (NH) and the mental healthcare (MH) setting. Overall, patients showed moderate levels of care dependency, and an average of seven comorbid somatic diseases. The majority of participants showed cognitive impairment, and personality disorders were prevalent in one-quarter of all DCD-patients. Intellectual disability was prevalent in at least 20% of MH DCD-patients. The overall prevalence of neuropsychiatric symptoms (NPS) was high, with significant higher rates of symptoms of delusions, hallucinations, aggression, and anxiety, and also chronic psychiatric disorders being more frequent in MH DCD-patients. NH-patients were younger and predominantly males. MH patients had fewer family support, were lower educated, often unmarried, and expressed a lower perceived quality of life in comparison to NH DCD-patients. Qualitative findings in Chapter 5 showed non cooperativeness and sometimes even aggressive behavior of family members in especially the MH-setting.

Characteristics and well-being of nursing staff

Chapter 4 showed that nursing staff in both DCD-settings consisted predominantly of females with more than 5 years of work experience in caring for DCD-patients. NH nursing staff had a significant lower level of education (29% nursing assistants). Overall, nursing staff experienced low levels of burnout, high levels of self-efficacy and strong feelings of self-rated competence. MH nursing staff experienced a lower job-satisfaction and more feelings of depersonalization. Nursing staff with a lower educational level, a higher age, or working in a MH setting showed lower rates of personal accomplishment. Chapter 4 further demonstrated that well-being of nursing staff is not significantly associated with DCD-patient's neuropsychiatric symptoms, care dependency or severity of physical comorbidity. Results from the qualitative study in Chapter 5 confirmed that nursing staff in both settings felt confident and competent in providing care to DCD-patients. The complexity of combined physical and mental care needs were seen as an opportunity to be creative and think outside the boxes. But, non-compliant, and unpredictable, often aggressive behavior of -younger and physically stronger- patients and sometimes also of family members was experienced as highly demanding and distressing.

Necessary elements for adequate care to DCD-patients

Results of the focus group study in Chapter 5 showed that a multidisciplinary care approach is necessary in working with DCD-patients, to be able to address their combined care demands from different perspectives. E.g., chest pain, heart palpitations and abdominal pain could be symptoms of a heart attack, but can also fit with anxiety problems. Chapter 5 also demonstrated, that next to having enough knowledge of psychiatric and physical problems, all members of the multidisciplinary team must be committed and motivated for working with DCD-patients. They also must be team-players, and have a learning attitude. Mutual trust, knowing each other's expertise, sticking to the patient's treatment plan and creativity were essential in finding solutions to complex and unusual situations. A psychologically and physically safe work and living environment was emphasized as an absolute condition in both NH and MH settings. The need for adequate DCD network care between nursing homes and mental healthcare institutions in a continuum was stressed by all professionals working on DCD-units. Interprofessional collaboration within and between MH and NH care settings was found to be necessary, especially focusing on mutual referrals of NH DCD-patients for either psychiatric diagnostic examination or therapy and vice versa for transfer of MH DCD-patients who no longer need intensive psychiatric treatment. Low thresh-hold professional contact and provision of accurate patient information between care settings, concerning both the physical comorbidity and psychiatric problems, was found to be essential. Chapter 6 made clear, that both the care complexity and case complexity of DCD-patients also asks for intensive collaboration between primary care, mental health care, secondary medical care and nursing home care.

REFLECTIONS ON SEVERAL CHALLENGES IN THE CARE FOR DCD-PATIENTS

This section provides a more in depth perspective on the study findings, as well as a comparison with the scientific literature on the main issues we encountered in our studies. These issues are discussed on the patient-related level, the professional-related level, and the organization of care-related level.

Patient-related level

Complexity of combined care needs

Chapter 3 showed that DCD-patients overall, have a care dependency that is comparable to frail and disabled nursing home patients [1], and also a high prevalence of somatic diseases, especially cardiovascular, pulmonary, neurological, and gastrointestinal problems. These results accord with a recent study with a fairly resembling study population of patients with mental-physical multimorbidity [2], and with other studies on psychiatric inpatients in both mental healthcare settings and nursing homes [3-5]. Nursing homes are expected to be more specialized in the physical conditions of their residents, than MH-settings. The finding of overall comparable high levels of somatic comorbidity and care dependency therefore affirms the importance of giving enough attention to the physical care of MH-patients [6].

Consistent with results from other studies, an overall high prevalence of neuropsychiatric symptoms was found [2, 7]. This finding underlines the need of sufficient staff expertise to adequately meet the psychological needs of DCD-patients in all settings, even though MH staff might be expected to manage behavioural problems more adequately.

A high prevalence (25%) of personality disorders was found across settings [2]. Nursing staff in both settings emphasized the challenges and need for communication and counseling skills in the interaction with patients with personality disorders, especially to prevent countertransference (Chapter 5). Behavioural counseling by nurses can enhance quality of life in elderly with a personality disorder, but there is a lack of evidence-based approaches. Based on principles of cognitive therapy, and guided by a psychologist, the treatment protocol *Cognitive Model for Behavioural Interventions* can provide an alternative nursing approach for personality disorders [8].

In line with another Dutch study, DCD-patients overall showed moderate impairment in cognitive functioning, even if a dementia diagnosis was absent [2]. Decline in cognitive functioning is known to occur in older SMI patients [9, 10]. Therefore these results stress the importance of not overlooking cognitive deficits, as different (psychological) approaches might be needed.

Well-being and social network

MH DCD-patients are less satisfied with their Quality of Life (QoL), especially regarding their psychological well-being. Low levels of family support in MH DCD-patients could play a role in this, as an overview of determinants of well-being in elderly LTC-residents with chronic mental disorders showed that having a small social network was related to lower well-being [11]. In line with previous studies, MH DCD-patients have fewer family support. Family care givers have often experienced stress in managing the psychiatric symptoms of older SMI patients. They are more likely to have increased levels of psychological distress, especially if they are female, have a low income, and poor health [12-14]. This affirms the importance of timely involving, informing and supporting of family, appraising their caregiving experiences, as mentioned in Chapter 5.

DCD-patients overall showed co-occurrence of somatic, psychiatric, and cognitive problems. It seems not their primary diagnoses, but the pile-up of their problems, the nature of their neuropsychiatric symptoms and their deficiencies in daily functioning and social network determine the content of their need for 24-hour care in an inpatient DCD-setting [2, 15, 16]. These divers and complex needs increase the risk that MH DCD-patients do not receive the most appropriate care, which could have a negative influence on their neuropsychiatric symptoms, and hence their quality of life [17, 18].

Professional care-related level

Needed skills mix

As stated before, DCD-patients overall showed a variety of combinations of physical problems, mental disorders, ADL dependency, neuropsychiatric symptoms, and cognitive decline [16]. Therefore, all members of the multidisciplinary team and nursing staff must have sufficient knowledge of both psychiatric and medical conditions, to be able to identify, interpret and treat signs of mental and physical disruptions. Input of at least a psychiatrist (in the MH setting), an elderly care physician or other physician with similar expertise, a healthcare psychologist, and both regular and specialized nurses is needed to assess and treat the patient's complex care demands from different angles [19-21].

As most professionals will be skilled mainly in either the physical or mental care domain, a combined focus on both domains in additional training will be important. Training of MH-staff should include an extra focus on the capability of identifying, monitoring and supervising clinical diseases [22, 23], while training in NH-staff should include an extra focus on behavioral management skills, and effective communication and negotiation skills, which are shown to be indispensable in achieving an effective dialogue with DCD-patients [24]. Study results in Chapter 5 further confirm that training on the job, learning and coaching from experienced professionals, is of utmost importance in gaining sufficient knowledge to provide tailored care [25, 26].

Teamwork, well-being and safety

Study results in Chapter 4 showed no significant relationship between care characteristics of DCD-patients and mental distress in nursing staff, with over 5 years of work experience in DCD-care. These findings may confirm, that in gaining more experience, nursing staff becomes more qualified and also shows a more positive attitude towards the overall care for patients with mental illness [4, 27]. All participants in our study were highly motivated and consciously chose to work with DCD-patients. This work engagement may have counterbalanced their work-related stress, thus positively affecting their performance and well-being [28, 29]. The focus group interviews highlighted that aggressive and non-compliant behaviour from patients and sometimes family, can be highly demanding to all multidisciplinary team members, and especially to the nursing staff. Aggression incidents have a serious impact on the emotional and psychological well-being of nurses and can adversely affect their professional performance [30, 31]. Our study results therefore point up the importance of continuous communication about safety within and between staff and management, the need of adequate training to cope with aggression, of the implementation of strategies to prevent aggression, and the need for follow-up support after encountering aggression incidents [31-34].

In accordance with previous study results, a working environment with mutual trust, appreciation, support, respect, availability and continuity of care was found to be crucial to facilitate and enable good teamwork, and hence improve the quality of care [35-37]. Next to this, the facilitating role of (baccalaureate) registered expert nurses was stressed in both settings. In line with other studies, they were found to serve as role models and mediators in our study. In the NH-setting they facilitated communication between nursing-staff, multidisciplinary staff, family and management [38]. In the MH-setting they served as guiding, supervising experienced colleagues, facilitating interpretation and evidence-based follow-up of somatic illnesses [39]. There is some scientific evidence that employment of expert nurses reduces aggression [40], but no consistent relationship was found between the presence of registered nurses and quality of care in nursing homes [41].

Collaboration on the interface of nursing home and mental health

In line with previous study results and guidelines, Chapter 5 showed that knowing and accepting each settings' limits of professional competence, low thresh-hold professional contacts between settings and provision of accurate patient information, with regard to both physical and psychological care needs is facilitating [35, 42]. As demonstrated in both Chapter 5 and Chapter 6, the prevailing stigma about psychiatric patients and the severity of (unpredictable) psychiatric symptoms were barriers in transfer of DCD-patients from a MH setting to a NH DCD-unit. The stereotype of patients diagnosed with mental illness to be dangerous, incompetent and to blame for their illness is a known barrier for access

to adequate care [43, 44]. This finding stresses that knowledge dissemination on mental illnesses and their implications remains an important issue, that should be given sufficient attention when transferring MH DCD-patients to a nursing home [45].

Organisation of care-related level

Policy and facility requirements

Focus group interviews showed several prerequisites for adequate policy regarding the care for DCD-patients. Managers in both settings should acknowledge the complexity and specific care requirements of DCD-patients. Clear criteria for admission are needed to ensure DCD-patient admission to the most appropriate facility, and prevent "shopping with patients", as illustrated by the case in Chapter 6. Within all DCD-facilities oversight and supervision, preferably with face-to face-contact, must be guaranteed at all times, to be able to de-escalate on time and create safety for both patients and staff. Video surveillance can be used for managing safety and security. It enables 24 hour monitoring of patients, which has the potential to reduce violent and aggressive behaviour. The major disadvantage is that such observation is by nature intrusive, and diminishes privacy, a factor of huge importance [46]. Both indoor and outdoor space must be available, to be able to vary stimuli to patients and prevent them to be irritated by being too close to each other. As older psychiatric inpatients and NH-patients are more vulnerable physically and less able to withstand patient-to-patient aggression, specific attention has to be given to prevent this aggression [47, 48]. There must be private bedrooms with private bathrooms, where strict room treatment can be provided if needed. All of these mentioned facility requirements correspond with the earlier practice based established facility requirements for NH DCD-residents [49].

Nursing homes are facilities with a domestic-styled environment that provide 24-hour functional support and care for patients with ADL-dependency and complex health needs [50]. Psychiatric care environments are traditionally based on the concepts of a therapeutic milieu, providing containment (meeting of basic needs, providing physical care and safety), support (giving kindness to foster predictability and control), structure (having predictable roles and responsibilities), involvement (engagement in social activities), and validation (affirming a patient's individuality) [51]. Mahoney proposed a 'modernized' therapeutic milieu, that supports patient-centered care, continuous healing relationships, safety as a priority, and cooperation among clinicians and other professionals within a holistic practice [52]. Mahoney's therapeutic milieu therewith seems to combine the traditional psychiatric care environment with the more domestically styled nursing home environment. This concept might fit the needs of both NH and MH DCD-patients.

The need for integrated, comprehensive care

The case in Chapter 6 emphasizes that access to adequate care can be a challenge for

DCD-patients. Their complex combinations of mental and physical care needs, as demonstrated in Chapter 3, necessitate collaboration within and between health care professionals, not only in the NH and MH-setting but also in secondary medical care, and primary care. Integrated, comprehensive care is needed to improve overall quality of care, as was already shown in Chapter 2. To provide the necessary integrated physical and mental health care, and also prevent too much overlap between different health care sectors, collaborative practice is needed [53]. Collaborative practice is the cooperation of multiple health care workers with different professional backgrounds, together with patients and families.

As an effective basis for organizing this integrated care, the collaborative care model can be used. This model is premised on a multidisciplinary approach to patient care, a well-structured patient care plan, interprofessional collaboration and monitoring by case managers [54]. Collaborative care interventions are effective in improving mental, physical and social functioning, for depression, anxiety disorders, bipolar disorders, and schizophrenia [55, 56], and are also cost-effective [57].

As a part of the interprofessional collaboration between NH and MH, mental health consultation services to nursing homes should be incorporated. It is known that the traditional service in which a psychiatrist provides a consultation on an 'as needed basis' is not effective enough [58]. Consultation services should consist of a visiting mental health consultant who assesses problems, sees residents, meets with staff, provides education, discusses aspects of care that are broader than what is needed for an individual patient, recommends interventions, and provides support through ongoing liaison with facilities [59-61].

Case managers may be key to successful implementation of collaborative care [62], as they can unambiguously clarify to all collaborating health care providers, who must be contacted in the event of deterioration in a patients functioning [62, 63]. Employment of case managers trained in psychiatry, was effective in ameliorating the social functioning and reduction of hospital admissions of adults with SMI [64].

As described in the case in Chapter 6, an interprofessional "expert-transfer-team", could be an element within the collaborative care for DCD-patients, throughout the total care chain. In case of very difficult to place DCD-patients, this team discusses their service and treatment needs, makes proposals for their optimal placement, and actually arranges this placement, as they operate with authorization of the care needs assessment center (CIZ) and health insurers. That would ensure 'matched care' for DCD-patients, in other words, the most appropriate care in the most appropriate setting [21, 65].

STRENGHTS AND LIMITATIONS

This project represents a first exploratory step towards gaining deeper insight in the care characteristics of DCD-patients, the mental well-being of their nursing staff working on specialized DCD-units, and the perceived facilitators and barriers in current DCD-care in both the mental health care setting and the nursing home setting. An important strength of this research project is that several study designs including a systematic literature research, observational cohort studies, and a focus group study have been used.

Various sources of information such as medical records, patient reports and proxy information were combined during quantitative data collection. A comprehensive study of patients' medical records was accomplished for all included patients (n = 163).

In the qualitative focus group study we not only focused on the nursing perspective, but also on the multidisciplinary perspective to identify the facilitators and barriers in daily care for DCD-patients. The mixture of participants involved in the various focus groups provided an in-depth perspective on the experienced needs of DCD-nursing staff, to be able to provide optimal care for DCD-patients. Bias was limited by the use of a moderator who was not directly working with the interviewed professionals. Not all multidisciplinary team members were able to join the fifth -multidisciplinary- session. Data saturation however occurred after four sessions, and the fifth session did not result in new themes, but only confirmed the earlier results. We therefore believe that, despite recognition of the importance of receiving all team member perspectives, this has not provided limitations to our study results.

Our observational studies may be limited in their power to demonstrate representative characteristics of the DCD-population and their nursing staff, because of the use of a selected cohort of patients and nursing staff in the south of Limburg, without a direct comparison to a non-DCD population or nursing staff in non-specialized care units.
All included specialized care-units had somewhat different criteria for admission. Some units included patients with a specific psychiatric history in combination with cognitive decline or physical disability. Others included patients with very severe neuropsychiatric symptoms due to specific types of dementia in combination with physical disability and/or a history of psychiatric treatment.

Generalizability of the findings of the linear mixed model analysis (LMM) in chapter 3 may be limited, because of the relatively small sample size (n=100), and the variance in participating of nursing staff per unit.

Due to the use of a general self-efficacy questionnaire and measure of competence, no

definite conclusions could be drawn about the confidence that nursing staff has in providing physical care versus psychiatric care. However, this topic has been addressed in the qualitative part of our study (semi structured interviews of nursing staff).

The systematic review of the literature (chapter 2) should be seen as a starting point for our research project, because articles have been included up to and including 2008. To ensure incorporation of current and relevant scientific findings in this thesis, we re-conducted the PubMed search as used in Chapter 2, in January 2019. This search yielded 599 references, of which 493 references were excluded after screening of all titles and if needed the abstracts. After screening all remaining 106 abstracts, applying the inclusion criteria, 25 references remained. These 25 articles were read in full. Then 5 articles were excluded because they turned out to be "double publications" of 3 already included studies. Another 13 studies were excluded, because in closer reading they did not fulfil all of our inclusion criteria. Eventually 7 intervention studies, all of which were RCT's, could be included supplemental to the purpose of our original literature review [66-72]. Results of these studies affirmed our previous review results that a comprehensive, integrated, multidisciplinary approach, combining medical, psychiatric, psychological and nursing interventions show beneficial effects on severe behavioural problems in NH DCD-patients. They also showed that the use of an extensive medical and psychiatric assessment, a personalized treatment plan, provision of individual or group psychotherapy, as well as teaching behavioural and assessment skills to nurses are important elements in improving NH DCD-patients' wellbeing, and reduction of depression prevalence.

RECOMMENDATIONS FOR DAILY PRACTICE, POLICY AND RESEARCH

This study may contribute to a better understanding of the needs, facilitators and barriers in current care for these patients with complex, combined care demands. In addition to the earlier described findings in this thesis, some recommendations for practice, policy, and further research will be made.

Clinical practice

Our study findings demonstrated that DCD-patients represent a challenging population. DCD-patients have a high patient complexity profile, with a low educational level, and simultaneous occurrence of problems in the physical, functional, psychological, and social domains. These problems influence each other and are intertwined, thus complicating the overall image. As the course of their problems is often unpredictable and uncertain, this creates a shaky balance and high vulnerability. Moreover, general routines and general, often single disease focused guidelines, do not "fit" in this patient group, with complex multimorbidity. DCD-patients also have a large demand for care and need input from many different care professionals and care providers.

Last, but not least, healthcare professionals or care providers must be able to act adequately on patient safety.

- Therefore, there is a need for DCD-facilities that can provide twenty-four hour availability of specialized, multidisciplinary expertise in a highly experienced and safe care environment.

- Multidisciplinary teams must consist of a skills mix of physically and psychologically skilled personnel, given the knowledge that the influence on mental and physical health in DCD-patients is bidirectional.

- The high intensity of care dependency and medical comorbidity in DCD-patients implies that adequate medical care must be available in both NH and MH settings. Mental health care settings in particular will have to adjust their care processes accordingly [6].

- Supporting the heterogeneous group of DCD-patients is especially challenging for the nursing staff, as they need to be able to address individual patient care needs and to organize a safe and stimulating living environment for all patients, family members, and volunteers. The high prevalence of personality disorders and neuropsychiatric symptoms in DCD-patients asks for adequate counselling, and guiding skills of all team members. Management should therefore facilitate the possibility of acquiring this knowledge. Management of NH-settings should be particularly attentive to providing training, as their nursing staff predominantly exists of lower educated certified nurse assistants.

- Next to individual training, interventions that focus especially on the strengthening of team performance through team coaching, training of reflexivity skills, and collaborative competencies are highly desirable.

Policy makers

Due to their complex combinations of mental and physical care needs, access to adequate care for DCD-patients is often challenging. As described in Chapter 5 and Chapter 6, collaborative practice within and between health care professionals, in both primary care, secondary medical care, mental healthcare and nursing homes is needed, within a regionally organized continuum of integrated, comprehensive care for DCD-patients.

- As in many western countries, the Dutch healthcare system is still very fragmentized, and at least four different funding-systems regarding the group of DCD-patients exist. As illustrated in Chapter 6, the absolute dichotomization into physical healthcare and

mental healthcare creates regulatory and funding restrictions that hamper the realization of the complementary benefits DCD-patients need because of their co-occurring physical and mental health needs. Policy makers need to take action to ameliorate this situation.

- DCD-patients who persistently refuse necessary care, and are endangering themselves or others, can be admitted for mental healthcare on the basis of a court hospitalization order. In the Netherlands psychogeriatric nursing homes and mental hospitals are certified to offer mental healthcare on the basis of such a court hospitalization. NH DCD-patients, who are persistently resilient to care, but have no diagnosis of dementia, can therefore only be admitted to a specialized MH-unit. This legal issue needs to be addressed and stresses the need for close collaboration on the interface of mental health and nursing home care.

- The LTC-system of the Netherlands is set out in the Chronic Care Act (WLZ). To be admitted to a nursing home, a service eligibility decision is required. This eligibility is granted by the Care Needs Assessment Centre (CIZ), and can be based on physical disability, somatic disorders, psychogeriatric disorders, intellectual disability, or sensory disability, but not on a mental disorder [73]. This system of artificial regulatory boundaries needs to be adapted in order to better serve DCD-patients with multi-domain problems.

- Chapter 5 demonstrated that DCD-patients' non-compliance, behavioural unpredictability and instability, are grounds to refuse admittance of a DCD-patient to a nursing home. Despite the ongoing deinstitutionalization of mental health care, a group of DCD-patients with persistent severe mental disorders, will continue to rely on intensive 24 hour care within a specialized MH-setting, in the sheltered environment of an institution's site [74]. Hence, enough "psychiatry bed capacity" remains necessary for this group of DCD-patients [75]. However, ongoing MH consultation services consisting of a visiting mental health consultant who assesses problems, sees residents, meets with staff, provides education, recommends interventions, and provides support, might provide a solution in also admitting less predictable DCD-patients to a specialized nursing home [59-61].

Further research

- The needs and quality of life of DCD-patients should be studied across settings, with tailored measurement instruments for this patient group, to define the necessary elements to optimize DCD-care and hence the quality of life of DCD-patients. Recently, the Laurens Well-Being Inventory for Gerontopsychiatry (LWIG) has been developed.

This might provide an interesting instrument for further research into the physical, psychological and social well-being of DCD-patients [76].

- Co-occurring presence of personality disorders in DCD-patients was perceived as highly demanding in both the NH and the MH-setting. Therefore the influence of personality traits on the wellbeing of both DCD-patients and nursing staff should be further explored.

- As described above results in Chapter 3 showed that MH DCD patients have very low family support, and a subsequent need for volunteers (Chapter 5). Family caregivers have often experienced stress themselves in the care for DCD-patients, while receiving little support [12, 13]. Hence it may be interesting to examine their support needs, to provide a more sustainable support system, and to relieve nursing staff.

- Chapter 2 and Chapter 5 showed that non-compliance and unpredictability of aggressive behaviour are the most salient reasons for admission of a DCD-patient to a mental healthcare facility. It remains unclear at what point transfer of a DCD-patient to a NH DCD-setting is appropriate and acceptable for the nursing home. These criteria for admission, and transfer to a NH DCD-unit should therefore be further addressed, as well as the desired and necessary support from mental health care.

- Future studies should also focus on the financial challenges in organizing adequate mental healthcare for NH DCD-patients, as reimbursement policies should at least enable mental health services as multidisciplinary psychiatric consultation, the provision of evidence based psychotherapies and of NH staff education [8, 60, 77-80].

- Up till now, we focused on defining the tasks of mental healthcare versus nursing home care with regard to care for DCD-patients. Looking at their heterogeneity and their similarities in care dependency, somatic multimorbidity, cognitive deficits and neuropsychiatric symptoms it seems logical to focus on combining the expertise of both the MH setting and the nursing home, by letting them blend into a LTC psychiatric nursing facility, where DCD-patients receive treatment and care from a multidisciplinary team employing the expertise of both settings [81]. It would therefore be interesting to compare the different DCD-settings in a MH, a NH and a combined facility, with respect to both patient well-being, staff well-being and cost-effectiveness.

NOW: BACK TO PETER, WHOM WE MET AT THE START OF THE GENERAL INTRODUCTION

The NH nursing staff expressed to be severely distressed, due to Peters previous behaviour. They had no confidence that his behaviour would have ameliorated and stabilized during his stay in the mental healthcare facility. A meeting with Peter, a delegation of

nursing staff and psychologists from both settings, the NH elderly care physician and the old age psychiatrist was arranged. Extensive psycho-education was given to explain Peters personality disorder and the consequences for his needed guidance. His lifelong need for somatic care and paramedic therapies to best treat his Parkinson's disease were also stressed. Transfer to a specialized NH DCD-unit was discussed. Peter and the NH-staff decided a transfer would be beneficial, because of his need for combined expertise on his mental and physical care needs, and his positive experience of increased well-being while receiving appropriate DCD care.

CONCLUSION

Combined mental health care and nursing home care expertise is essential to DCD-patients in need of Long-term care. Mental healthcare facilities and nursing homes should be part of a continuum of DCD care and must not be seen as, or regard each other as, the waste pit for the most severe DCD-cases. To ensure optimal care for DCD patients, we must transcend the boundaries of the various care sectors, acknowledging the need and the responsibility of working together creatively and competently to ensure tailored network care.

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Chapter 8

Summary

Summary

Due to the ongoing process of deinstitutionalization of psychiatric care services, the traditional asylum function for older adults with severe mental illness (SMI) has been partly taken over by nursing homes (NHs). Patients suffering from a mental health disorder and also in need of nursing home care (because of dementia and/or physical disorders), are patients with complex care needs. They present a particular challenge to long term care (LTC) wards within both NHs and mental healthcare institutions (MHs) as they often surpass the level of mental healthcare that can be offered in NHs, and, vice versa, the level of physical care that can be offered in MHs. As these patients have a combined need for both mental health care and nursing home care, we refer to this specific group of patients as *double care demanding patients* (DCD-patients) in this thesis. In daily practice it has been recognized that collaborative care models are needed for DCD-patients. Some specialized DCD-units in Dutch MHs and NHs have been developed accordingly. This offered the unique possibility to study the DCD-population across both settings, and to explore their differences and similarities.

This thesis reports on the results of the "Specific Care on the Interface of Mental health and Nursing home (SpeCIMeN)-study". Research questions covered the characteristics and the care needs of DCD-patients, the facilitators and barriers to DCD-care, and the necessary elements for successful tailored integrated and trans sectoral care, combining both psychiatric care and nursing home care. The results of this study are relevant for planning of services that should take into account different patterns of needs among elderly DCD-patients. Several study designs were applied including a systematic literature research, observational cohort studies, a focus group study and a case study.

The **first chapter** provides general background information about the concept of patients with combined physical, mental and psychological care needs, residing in either a mental health facility or a nursing home (NH). Up till now, different types of long-term care (LTC) are provided to older people with disabling psychiatric illnesses, advanced dementia, and physical disabilities. The absolute dichotomization into two categories of psychiatric treatment in mental healthcare on the one hand and nursing home care (composed of either psychogeriatric care or physical care) on the other hand creates regulatory and funding restrictions that hamper the realization of the complementary benefits, both sectors may have. Consequently, both NH-residents with comorbid psychiatric disorders and psychiatric patients with comorbid dementia and/or physical disabilities will not always receive the type of care they need. Given the current level of concern about DCD-patients, and the ever growing number of these patients, due to the ageing of the population it is important that they receive the most effective and efficient care the deserve.

In **chapter 2** the results of a systematic literature review are presented. The focus was on integrated interventions combining psychiatric care and nursing home care on psychiatric disorders and severe behavioural problems in NH patients. Eight intervention trials, including four RCT's were identified as relevant for the purpose of the review. Findings indicate, that the most effective approach for DCD-patients constitutes of an integrated care model with the following components: accurate observation and identification of comorbid psychopathology, assessment of psychiatric, medical and environmental causes, comprehensive medical and neurological assessment, thorough assessment of history of previous use of psychotropic medication, and programs for teaching behavioural management skills to nursing-staff. Several studies suggested the benefits of more intensive mental health (MH) services for nursing home (NH) DCD-patients. Short-term mental hospital admission for a more comprehensive assessment and interventions, benefits NH DCD-patients with and without dementia, who are admitted for severe agitated and disruptive behaviour, requiring continuous observation. Neither patients' quality of life, nor distress or job satisfaction of nursing staff were objects of interest in the studies included. All the included studies had several methodological shortcomings. In general sample sizes were small, follow-up time was short, and all studies differed in their design. This implies that no definite indications for the ideal composition of the multidisciplinary team, the ideal setting to provide mental health services for NH patients with psychiatric disorders, the ingredients and context factors that are responsible for the efficacy of the intervention, nor whether multidisciplinary teams involving psychiatrists and psychiatric nurses are essentially superior, could be given.

In **chapter 3** we explored the demographic, physical health-related, mental health-related, and quality of life related characteristics of DCD-patients in both the MH and NH-setting, as an essential first step to best meet their specific needs. This observational cross-sectional study demonstrated that DCD-patients overall had a mean age of 68 years, were more often male, low educated, and had been institutionalized for longer than one year. Family support was significantly more prevalent in NH DCD-patients, while most MH DCD-patients had legal representation. The prevalence and severity of care dependency and comorbidities were equally high among all DCD-patients, with cardiovascular, pulmonary, neurological and gastrointestinal problems being most prevalent. Overall DCD-patients showed a higher prevalence of neuropsychiatric symptoms than non-DCD patients. MH DCD-patients expectedly differed significantly in psychopathology from NH DCD-patients as evidenced by a higher prevalence of psychotic symptoms, anxiety symptoms, agitation and psychiatric morbidity. Personality disorders were diagnosed in almost one-quarter of all DCD-patients. Overall DCD-patients were satisfied with their quality of life, with significant higher satisfaction rates in NH DCD-patients for given care, and psychological well-being. These results stress the importance of giving enough attention to physical care within the MH, and the need for psychiatric training of nurses in the NH-setting. There

could be a risk of having a mismatch between the type of patients and the type of care offered. The heterogeneity of DCD-patients and the resulting care complexities emphasize the need for a skills mix of nursing-staff in both settings, as they must be able to address both the somatic care needs as well as psychiatric and psychological care needs. Our study shows that it is not the primary disease diagnosis (psychopathology or physical illness), but rather the accumulation of functional and behavioural problems that seems to be decisive for the demand for care in DCD-patients. Because of the heterogeneity of the DCD-population with a wide range of functional, behavioural, medical and social support needs, personal and customized care seems to be necessary, which is in line with the findings in chapter 2. Current admission criteria of DCD-patients to either to the NH setting or the MH setting seem to be mainly based on the severity and unpredictability of their behavioural problems, and not on their physical-related care needs.

The care complexities of DCD-patients could have implications for nursing staff's experienced work-related stress, and might have an impact on their well-being and risk for burnout. Therefore, as part of the observational cross-sectional study described above, we explored (**chapter 4**) the possible relationship between mental health-related and physical health-related characteristics of DCD-patients, and the mental well-being and demographics of the nursing staff caring for them. Because of the traditional categorization in physical care and psychiatric care, and therefore a better training level of nursing staff to only one of these care domains, we hypothesized that care dependency, physical care demands, and intensity of neuropsychiatric symptoms in DCD-patients would be correlated to higher symptoms of work-related distress in nursing-staff across settings. The mean work-experience (over 5 years) and the mean age (41 years) of nursing-staff was similar in both settings. A significant difference in the educational level was found, with low vocational training for 29% of NH-nurses. Still, feelings of self-efficacy and levels of mental distress were similar in both settings, indicating that the educational level alone is not an indicator of work-related mental well-being of nursing staff in DCD-units. Based on the study results as described in chapter 3 we expected well-being of MH nursing staff to be more compromised as they have to encounter higher instances of challenging behaviour, due to a higher prevalence of NPS and comorbid psychiatric illnesses in MH DCD-patients. Contrary to these expectations, no significant relationship between DCD-patient characteristics and staff well-being across both settings was found. We did find a tendency that for all nursing staff, a higher amount of NPS in DCD-patients is associated with higher rates of both emotional exhaustion and work-related mental distress. Nursing staff with more than 5 years of work experience overall felt competent in caring for DCD-patients, and showed a higher job performance. MH DCD-nursing staff in general was more at risk for burnout, as were older nurses in both settings.

Chapter 5 presents the results of a qualitative study, exploring the possible facilitating

and obstructing factors in DCD-care from the perspective of nursing-staff and other multidisciplinary team members. This qualitative study involved semi structured focus group interviews and a case description. Several preconditions and unmet needs in caring for DCD-patients overall were expressed. The starting point of successful multidisciplinary DCD-care is "motivation for", "affinity with", and "commitment to" this specific target group. Knowing each other and building of mutual trust and respect among all team members is necessary to create a psychologically safe environment that enables staff to collaborate effectively.

Five key-levels of factors regarding experiences and needs of DCD nursing- and other multidisciplinary-staff were mentioned.
They comprised of: 1. patient-related factors: the complexity of combined care needs, and the complexity of behavioural problems; 2. informal care-related factors: the often misapprehension of the complexity of DCD-patients' problems by family, and the risk of deployment of volunteers as a substitute for nursing staff; 3. professional care-related factors: the necessity of team player competencies and attitudes, of a multidisciplinary approach in working with DCD-patients, and of collaboration between MH and NH settings; 4. living- and work-related factors: sufficient availability and continuity of staff, and specific facility requirements like sufficient outdoor and indoor space and strippable private bedrooms, are necessary to provide for a safe environment, and 5. organization of care-related factors: there should be a clear DCD-policy, with clear admittance and transfer or relocation criteria. Nursing staff wants to be valued for their expertise, they want to be challenged with more-in-depth training in geriatrics and pharmacotherapy, in counselling strategies, challenging behaviour and in recognizing the influence of their own personal characteristics when interacting with DCD-patients and their family members.

Chapter 6 presents a detailed description of a DCD case, therewith further exploring and elaborating on the identified facilitators and barriers to (inter) professional collaboration within and between settings. Both the formidable challenge of providing effective integrated treatment to DCD-patients, as well as the risk of delivering inadequate DCD-care due to the service gaps between organisations, and funding barriers are illustrated. The necessity of intensive collaboration between health professionals in nursing homes, mental health care, secondary medical care and primary care is highlighted. The collaborative care model – that is premised on a multidisciplinary approach to patient care, a well-structured patient care plan, monitoring by case managers, and interprofessional communication – can form an effective basis for organizing care delivery. As part of the collaborative care model, a so called expert-transfer team could be created in every region, for dealing with very difficult-to-place DCD-patients. It would be composed of experts representing all the participating healthcare organisations. They would discuss the service needs of individual patients, make proposals for their optimal placement, and

actually arrange such placement. Expert-transfer teams ought to be granted authorisation by the center for assessment of long-term care (CIZ) and health insurers in their region, to avoid hindrance from funding walls. That would ensure personalized tailored care for DCD-patients.

Finally in **chapter 7** we give an overview is of the main findings of this thesis, integrate the results that were discussed in the different chapters and address theoretical and methodological considerations of the studies performed. Several implications for daily practice and further research are presented.

Samenvatting

Als gevolg van het voortgaande proces van extramuralisering in de geestelijke gezondheidszorg (GGZ) is het aantal bedden voor langdurig verblijf binnen veel psychiatrische instellingen afgebouwd. De zorg voor oudere volwassenen met chronische psychische stoornissen en zorgafhankelijkheid is sindsdien deels overgenomen door verpleeghuizen. Ouderen met een psychiatrische stoornis, die op grond van comorbide dementie en/of somatische problematiek ook verpleeghuiszorg nodig hebben, zijn patiënten met complexe zorgvragen. Zij vormen een bijzondere uitdaging binnen afdelingen voor langdurige zorg, zowel in verpleeghuizen als instellingen voor GGZ. Hun psychiatrische zorgvragen overstijgen vaak het niveau van psychische zorg dat in verpleeghuizen geboden kan worden, terwijl hun somatische zorgvragen de mogelijkheden van de GGZ overstijgen. Omdat het hier om een specifieke groep patiënten gaat, die een combinatie van psychiatrische én verpleeghuiszorg nodig hebben, worden zij in dit proefschrift patiënten met een dubbele zorgvraag (DZV-patiënten) genoemd. In de dagelijkse praktijk van de zorgverlening aan DZV-patiënten wordt erkend dat modellen van collaborative care nodig zijn. Vanuit deze erkenning zijn een aantal gespecialiseerde DZV-units opgezet in verpleeghuizen en instellingen voor GGZ. Dat bood ons de unieke kans, om de DZV-populatie in beide sectoren op deze specifieke units te onderzoeken en de verschillen en overeenkomsten in kaart te brengen.

In dit proefschrift bespreken we de resultaten van het onderzoek 'Specific Care on the Interface of Mental health and Nursing home (SpeCIMeN)'. De onderzoeksvragen waren gericht op 1. de kenmerken van DZV-patiënten en van hun verpleegkundige staf, 2. de factoren die DZV-zorg kunnen bevorderen of belemmeren, en 3. de elementen die nodig zijn om tot succesvolle integrale en trans-sectorale DZV-zorg te komen, waaraan zowel psychiatrische- als verpleeghuiszorg een bijdrage leveren. De resultaten van dit onderzoek zijn relevant voor het ontwerpen en plannen van zorgvoorzieningen, die rekening houden met de uiteenlopende zorgbehoeften van oudere DZV-patiënten. Er zijn verschillende onderzoeksmethoden toegepast, waaronder systematisch literatuuronderzoek, observerend cohortonderzoek, een focusgroep onderzoek en een casusanalyse.

Het **eerste hoofdstuk** beschrijft algemene achtergrondinformatie over het begrip 'patiënten met een combinatie van psychiatrische, somatische en/of cognitieve zorgbehoeften', die ofwel in een verpleeghuis ofwel in een psychiatrisch ziekenhuis verblijven. Tot op heden ontvangen ouderen met invaliderende psychiatrische stoornissen, gevorderde dementie of ernstige lichamelijke beperkingen verschillende types langdurige zorg. De absolute tweedeling in enerzijds psychiatrische behandeling in de GGZ en verpleeghuiszorg (onderscheiden in psychogeriatrische zorg en somatische zorg) anderzijds, creëert regulerings- en financieringsbeperkingen. Daarmee wordt de realisering van de meerwaarde die een afstem-

ming tussen de beide sectoren zou kunnen hebben, belemmerd. Hierdoor krijgen noch de verpleeghuisbewoners met comorbide psychiatrische problematiek, noch de psychiatrische patiënten in de GGZ met comorbide dementie en/of lichamelijke beperkingen, in alle gevallen het type zorg dat zij nodig hebben. De reeds geschetste zorgen over de huidige situatie van DZV-patiënten en hun verwachte groei in aantallen door de bevolkingsvergrijzing, benadrukt het belang van het kunnen geven van de meest doelmatige en effectieve zorg aan deze patiëntengroep.

In **hoofdstuk 2** presenteren we de resultaten van een systematisch literatuuronderzoek. We hebben de wetenschappelijke literatuur specifiek onderzocht op integrale interventies, waarin psychiatrische- en verpleeghuiszorg werden gecombineerd ten behoeve van verpleeghuispatiënten met psychische stoornissen en ernstige gedragsproblemen. Er werden acht relevante interventie-onderzoeken gevonden, waaronder vier gerandomiseerde klinische studies (RCTs). De meest doeltreffende benadering voor DZV-patiënten bleek te bestaan uit een model van geïntegreerde zorg met de volgende componenten: zorgvuldige observatie en identificatie van psychiatrische, somatische en psychosociale problematiek; een volledig lichamelijk en neurologisch onderzoek; inventarisatie van actuele en gebruikte psychofarmaca; scholing van verpleegkundigen en verzorgenden in het kunnen toepassen van gedragsinterventies. Een aantal studies benoemde de noodzaak van voldoende GGZ-voorzieningen voor DZV-patiënten in verpleeghuizen. DZV-patiënten (met of zonder dementie), met ernstig geagiteerd of verstorend gedrag waarvoor continue observatie noodzakelijk was, hadden baat bij een kortdurende opname in een psychiatrisch ziekenhuis.

De levenskwaliteit van DZV-patiënten, noch de arbeidsbelasting of de werktevredenheid van het personeel, kreeg aandacht in de geïncludeerde onderzoeken. Ook hadden alle onderzoeken methodologische tekortkomingen. Zo was de steekproefgrootte doorgaans klein, vonden vervolgmetingen erg snel plaats en was de onderzoeksopzet onderling verschillend. Het literatuuronderzoek leverde dus geen concrete aanwijzingen voor de ideale samenstelling van een multidisciplinair team, of de ideale omgeving om psychische zorg aan verpleeghuisbewoners met psychiatrische problematiek te leveren. Daarnaast bleef onduidelijk welke inhoudelijke en contextuele factoren de effectiviteit van een interventie bepalen, alsook of het betrekken van psychiaters en psychiatrische verpleegkundigen bij multidisciplinaire teams tot betere zorg leidt.

Hoofdstuk 3 beschrijft het onderzoek naar de kenmerken van DZV-patiënten in het verpleeghuis en de GGZ, als een noodzakelijke eerste stap om optimaal aan hun specifieke zorgvragen tegemoet te kunnen komen. Wij inventariseerden de demografische achtergrond, lichamelijke gezondheid, geestelijke gezondheid en ervaren kwaliteit van leven van de deelnemers. De DZV-patiënten in dit transversale observatieonderzoek waren gemiddeld 68 jaar, vaker man, laag opgeleid, en langer dan één jaar intramuraal opgenomen.

Familieondersteuning was significant vaker aanwezig bij de verpleeghuisbewoners, terwijl de meeste DZV-patiënten in de GGZ alleen wettelijke vertegenwoordigers hadden. De prevalentie en de ernst van zorgafhankelijkheid en lichamelijke comorbiditeit waren in beide groepen DZV-patiënten even groot, waarbij hart- en vaatziekten, longaandoeningen, neurologische problemen en maag- en darmziekten het meest frequent voorkwamen. De prevalentie van neuropsychiatrische symptomen was bij DZV-patiënten hoger dan bij bewoners zonder een dubbele zorgvraag. DZV-patiënten in de GGZ verschilden, zoals te verwachten viel, significant van DZV-patiënten in verpleeghuizen ten aanzien van hun psychopathologie, met een hogere prevalentie van psychotische symptomen, angstsymptomen, agitatie en psychiatrische morbiditeit in de GGZ-groep. Bijna 25 procent van alle DZV-patiënten had een diagnose van een persoonlijkheidsstoornis. Over het algemeen waren DZV-patiënten tevreden met hun kwaliteit van leven, waarbij de patiënten in verpleeghuizen hoger scoorden op zowel tevredenheid over de verleende zorg als met hun eigen psychisch welbevinden.

Bovengenoemde resultaten tonen het belang van aandacht voor somatische zorg binnen de GGZ enerzijds en van psychiatrische training voor verpleeghuispersoneel anderzijds. De heterogeniteit van DZV-patiënten, en de daaruit voortvloeiende zorgcomplexiteit, onderstrepen de noodzaak dat professionals in beide zorgsettingen een combinatie van vaardigheden nodig hebben om aan zowel de somatische, als de psychiatrische en psychologische zorgbehoeften van hun patiënten te kunnen voldoen. Ons onderzoek geeft aan dat niet de hoofddiagnose (psychopathologische dan wel somatische problematiek) bepalend is voor de zorgvraag van DZV-patiënten, maar de opeenstapeling van functionele en gedragsproblemen waarmee zij te maken krijgen. De heterogeniteit van de DZV-populatie – met haar verscheidenheid aan functionele, gedragsmatige, medische en sociale ondersteuningsbehoeften – maakt zorg op maat noodzakelijk voor deze groep, zoals ook bleek uit de bevindingen in hoofdstuk 2. De huidige criteria voor de opname van DZV-patiënten, zowel in verpleeghuizen als in GGZ-instellingen, lijken primair gebaseerd te zijn op de ernst en de onvoorspelbaarheid van hun gedragsproblemen, en niet op hun zorgbehoeften op somatisch gebied.

De complexiteit van de zorg aan DZV-patiënten zou gevolgen kunnen hebben voor de door verpleegkundigen en verzorgenden ervaren werk gebonden stress, met een navenante impact op hun welzijn en kwetsbaarheid voor burn-out. Als onderdeel van het bovenbeschreven transversale observatieonderzoek beschrijven wij daarom in **hoofdstuk 4** het mogelijke verband tussen het geestelijk welbevinden van de verpleging en hun demografische achtergronden enerzijds, en de kenmerken van DZV-patiënten in termen van psychische en lichamelijke gezondheid anderzijds. Door de traditionele tweedeling in somatische- en psychiatrische gezondheidszorg, is het verpleeg-en verzorgend personeel meestal op één van deze domeinen beter gekwalificeerd. Onze veronderstelling was daarom, dat de DZV-patiënt kenmerken zorgafhankelijkheid, somatische zorgbehoeften en intensiteit van neuropsychiatrische symptomen, gecorreleerd zouden zijn met het niveau van ervaren werk gebonden

stress van zorgverleners binnen het verpleeghuis en de GGZ.

In beide zorgsettingen was de gemiddelde werkervaring (meer dan 5 jaar) en de gemiddelde leeftijd (41 jaar) van het personeel gelijk. Er bleek een significant verschil in opleidingsniveau, waarbij 29% van het verpleeghuispersoneel een lagere beroepsopleiding had. Toch vonden wij in beide zorgsettingen vergelijkbare niveaus van zelfervaren persoonlijke bekwaamheid (*self-efficacy*) en van psychisch welbevinden; een aanwijzing dat opleidingsniveau alleen niet als indicator kan dienen voor werk gebonden psychisch welzijn bij zorgverleners in DZV-afdelingen. Op basis van de in hoofdstuk 3 beschreven resultaten hadden we verwacht dat het welbevinden van de GGZ-zorgverleners onder grotere druk zou staan, omdat zij vaker met verstorend gedrag te maken zullen hebben door de hogere prevalentie van neuropsychiatrische stoornissen en comorbide psychiatrische stoornissen. Wij vonden echter in beide settingen geen significant verband tussen DZV-patiëntkenmerken enerzijds en personeelswelzijn anderzijds. Wel zagen we een trend bij alle zorgverleners naar een hoger niveau van emotionele uitputting en verminderd werk gerelateerd psychisch welbevinden, wanneer hun DZV-patiënten een hogere mate van neuropsychiatrische stoornissen vertoonden. Over het algemeen voelden verpleegkundigen en verzorgenden met meer dan vijf jaar werkervaring zich competent in het verlenen van zorg aan DZV-patiënten en leverden zij hoge werkprestaties. De zorgverleners in de GGZ-setting, alsmede de oudere zorgverleners in beide settingen, hadden een hoger risico op burn-out.

Hoofdstuk 5 presenteert de resultaten van een kwalitatieve studie, die de mogelijke bevorderende en belemmerende factoren in de DZV-zorg verkent vanuit het perspectief van verpleegkundigen, verzorgenden en andere multidisciplinaire teamleden. Dit onderzoek is gebaseerd op semigestructureerde focusgroep-interviews en een casusbeschrijving. Een reeks aan algemene randvoorwaarden en onvervulde zorgbehoeften in de zorg voor DZV-patiënten kwam aan de orde in deze interviews. Het uitgangspunt van succesvolle multidisciplinaire DZV-zorg is 'motivatie voor', 'affiniteit met' en 'toewijding aan' deze specifieke patiëntengroep. Elkaar goed leren kennen en het opbouwen van onderling vertrouwen en respect tussen alle teamleden is noodzakelijk om een psychologisch veilige werkomgeving te creëren, waarbinnen effectieve samenwerking mogelijk is.

In het onderzoek kwamen vijf essentiële factoren naar voren uit de ervaringen en behoeften van het verpleegkundige-, verzorgende- en overige multidisciplinaire personeel, met betrekking tot de zorg voor DZV-patiënten. Dit zijn (1) *patiëntgebonden* factoren: de complexiteit van de gecombineerde zorgvragen en van de gedragsmatige problemen; (2) *mantelzorg gebonden* factoren: de misverstanden bij familieleden met betrekking tot de complexiteit van de problemen van de patiënten, en de risico's van inzet van vrijwilligers als vervanging van beroepskrachten; (3) *beroepsmatige* factoren: de noodzakelijkheid van teamcompetenties en attitudes, van een multidisciplinaire aanpak in het werk met DZV-patiënten, en van een goe-

de samenwerking tussen verpleeghuis en GGZ; (4) factoren in de *woon- en werkomgeving:* voldoende beschikbaarheid en continuïteit van personeel, en specifieke inrichtingseisen, zoals voldoende buiten- en binnenruimtes en stripbare éénpersoonskamers voor patiënten, om een veilige omgeving te waarborgen; (5) factoren met betrekking tot de *organisatie van de zorg:* een duidelijk geformuleerd DZV-beleid met eenduidige criteria voor opname en overplaatsing van DZV-patiënten.

Zorgverleners willen gewaardeerd worden om hun expertise. Ook zoeken zij uitdaging in de vorm van verdiepende scholingen op het gebied van geriatrie en farmacotherapie, counseling-strategieën, het omgaan met verstorend/ontwrichtend gedrag en in het onderkennen van de invloed van hun eigen persoonlijke eigenschappen in de interactie met DZV-patiënten en diens familieleden.

Hoofdstuk 6 bevat een gedetailleerde beschrijving van een DZV-casus, met een nadere bespreking en verdieping van de factoren, die de professionele samenwerking binnen en tussen de verschillende zorgsectoren kunnen bevorderen of belemmeren. De casus illustreert de enorme uitdaging van het geven van effectieve integrale behandeling en zorg aan DZV-patiënten alsook het risico op gebrekkige zorgverlening vanuit bestaande zorglacunes tussen organisaties en schotten in de financiering. De noodzaak van intensieve samenwerking tussen zorgprofessionals in verpleeghuizen, GGZ-instellingen, tweedelijns medische zorg en eerstelijns zorg wordt belicht. Het model van *collaborative care* – dat uitgaat van een multidisciplinaire aanpak van zorg voor elke patiënt, een gestructureerd zorgplan, zorg coördinatie door casemanagers en interprofessionele communicatie – kan een effectieve basis vormen voor de organisatie van de zorgverlening. Als onderdeel van dit model kan per regio een 'expert-transfer-team' worden samengesteld om de noodzakelijke zorg te coordineren van zeer moeilijk plaatsbare DZV-patiënten. Hierin bespreken deskundige vertegenwoordigers van alle betrokken zorgorganisaties de zorgvragen van de patiënt. Zij doen vervolgens niet alleen een voorstel tot beste plaatsing, maar zij realiseren deze plaatsing ook. Het transfer-team zou mandaat van alle zorginstellingen, van het indicatieorgaan voor langdurige zorg (CIZ) en de zorgverzekeraars in de regio moeten krijgen, zodat het niet door financierings-schotten gehinderd wordt. Met deze werkwijze moet de noodzakelijke persoonsgerichte zorg op maat voor DZV-patiënten gegarandeerd kunnen worden.

Tot slot geven we in **hoofdstuk 7** een overzicht van de belangrijkste bevindingen in dit proefschrift en integreren we de resultaten die in de verschillende hoofdstukken naar voren kwamen. We belichten de theoretische en methodologische overwegingen die in de uitgevoerde onderzoeken een rol speelden. Een aantal implicaties voor de dagelijkse praktijk en voor toekomstig onderzoek worden besproken.

Valorization addendum

In this chapter, the findings of this thesis are addressed with regard to their societal relevance and usability.

As in other Western Countries, in the Netherlands a policy of 'aging in place' and a continuing process of deinstitutionalization of psychiatric care services are encouraged. This means that older people will live at home as long as possible, even if they are frail and disabled. Only when their care needs become too complex and do exceed the possibilities of informal and formal home care, admission to institutional long-term care services is seen as inevitable. Consequently, merely old patients with long-lasting care demands are admitted to long-term care facilities. Among them, there are double care demanding (DCD) patients, who have very complex , and interconnected physical, psychiatric and or cognitive conditions.

Around 13% of all older people over 65 years of age in the Netherlands have a combination of psychological and physical limitations. Two thirds of them receive care and support at home, usually from general practice and home care services, and if necessary in combination with support from ambulatory mental health care services. Sometimes a short-term admission to a mental healthcare institution for diagnosis and initiating of psychiatric treatment is arranged. One third of this group is in need of specific long-term institutional care. Dutch nursing homes had a capacity of 92,000 long-term care beds in 2017. As mentioned earlier in this thesis, 8.4% of these nursing home beds were occupied by DCD-patients, who in fact do exceed the possibilities of a regular nursing home. The prevalence of institutionalized DCD-patients in mental health care facilities remains unknown.

Our study findings have demonstrated that DCD-patients overall represent a challenging and heterogeneous population for both nursing homes and mental health care facilities. They have a highly complex patient profile, with problems in all life domains, a high care dependency and challenging behavioural problems. Therefore, they require care from a specialized multidisciplinary team, skilled in offering tailored care related to the physical, psychiatric and social care domain and with special attention for the care environment and patient safety.

Some clear recommendations from experienced multidisciplinary teams were provided in this study to improve the quality of care for DCD-patients.

Supporting DCD-patients asks for extra knowledge and training in geriatrics, psychiatry, pharmacotherapy, adequate counseling and guiding skills of all team members. Interventions that focus especially on the strengthening of team performance through team coaching, training of reflexivity skills, and collaborative competencies are also highly desirable. Nurses want to be facilitated in acquiring some of these extra skills through training-on-the job in collaboration with *experienced role model nurses*. Aggressive and non-compliant behaviour from patients and sometimes family, is highly demanding to all multidisciplinary team members and necessitates adequate training to cope with this aggression. This implicates that management in both settings must facilitate the possibility of acquiring these needed skills and interventions. They must guarantee sufficient availability and continuity of nursing staff, provide continuous communication about safety within and between staff and management, implement strategies to prevent aggression, and provide follow-up support after encountering aggression incidents. With regard to the DCD-facility, oversight and supervision, preferably with face-to face-contact, must be guaranteed at all times, to create safety for both patients and staff.

When putting together the multidisciplinary team, management should compose a team of members that are highly motivated to work with DCD-patients, and specially focus on creating a working environment with mutual trust, appreciation, support, and respect, to facilitate and enable good teamwork.

This thesis clearly showed that DCD-patients need integrated care because of their complex combinations of mental, physical , and social care needs. Yet access to adequate integrated care and provision of accurate patient information is currently very challenging in the Netherlands, because there is a clear dichotomy between the mental health care and physical health care sector. Different applications of financing, rules and legislation in both these health care sectors, cause various obstacles in the continuity and quality of care for DCD-patients. To ease this unwished situation, and serve the best interest of DCD-patients, the cooperation of multiple health care workers with different professional backgrounds, and from different healthcare settings together with patients and families - so called collaborative practice - is needed within a continuum of appropriate integrated care for DCD-patients. It must be facilitated from a joint vision with regard to DCD-care and regionally organized, as this makes it possible to respond to the way local healthcare is delivered. Mental health consultation services to primary care and nursing homes should be incorporated as part of the care continuum for DCD-patients. These services should consist of visiting mental health consultants -like a psychologist, mental health nurse and psychiatrist- , who assess individual patient problems, provide education, suggest interventions, and provide evidence based psychotherapies and support through ongoing liaison. The deployment of case managers is the key to a successful implementation of collaborative network care, because they can improve communication

between the DCD-patient, the various care providers involved and informal care. This study demonstrated that severe behavioural unpredictability and instability, are grounds to not admit a DCD-patient to a nursing home. This implies that these specific DCD-patients must be cared for in a specialized MH-setting. Hence, enough "DCD-bed capacity" is still necessary in both settings.

In the case of very difficult to place DCD-patients, we recommend an *expert-transfer-team* as a valuable element within the DCD care continuum. This team discusses their service and treatment needs, makes proposals for their optimal placement, and actually arranges this placement, as they operate with authorization of all involved health care providers, the care needs assessment center (CIZ) and health insurers. That would ensure 'matched care' for DCD-patients, in other words, the most appropriate care in the most appropriate setting.

Really good cooperation requires the willingness to let others think along and decide what needs to change and to hand over functions and terrain if necessary. Cooperation agreements (transmural and intramural) between primary care, hospital, mental health care and nursing home for this target group must be improved and not laid down without obligation.

It is evident, that the system of artificial regulatory boundaries needs to be adapted in order to better serve DCD-patients with multi-domain problems. Policy makers therefore need to take action to eliminate the existing barriers in rules, legislation and financing systems that hinder real collaborative practice.

DISSEMINATION

Our study results will be widely disseminated to raise broad awareness to the problem of DCD-patients and to convince policymakers, health care insurance companies and health care professionals of the importance of our valorizing advices. They can also be used in the development and provision of interprofessional training programs. As described earlier, an interprofessional *"expert-transfer-team"*, is seen as a useful element within the collaborative care for DCD-patients, within a regional DCD-care continuum. In September 2019, a ZON-MW grant has been acquired to facilitate the development of such an expert-transfer-team. Currently a large mental health care organization (Mondriaan) and four large nursing home care organizations (Cicero, Envida, Meander, Sevagram) in the South of the province of Limburg have joined forces to collaborate within the project "the right care in the right place" to ameliorate the care for DCD-patients.

A future challenge could be to focus on combining the expertise of both the MH setting and the nursing home, by letting them blend into a LTC psychiatric nursing facility, where DCD-patients receive treatment and care from a multidisciplinary team employing the expertise of both settings. It might therefore be interesting for future research to compare the different DCD-settings in a MH, a NH and a combined facility, with respect to both patient well-being, staff well-being and cost-effectiveness.

Dankwoord

"Het begin van de wijsbegeerte is de verwondering" (Plato)

Meer dan 10 jaar heb ik mijn werk als specialist ouderengeneeskunde binnen Mondriaan ouderenpsychiatrie gecombineerd met wetenschappelijk onderzoek. Dat had ik nooit kunnen opbrengen zonder de inzet en aanwezigheid van veel lieve, betrokken mensen om mij heen. Ik wil iedereen, die op welke manier dan ook een steentje bijdroeg, hiervoor heel hartelijk bedanken. Een aantal van hen wil ik graag specifieker benoemen.

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De patiëntengroep met een dubbele zorgvraag én de gemotiveerde teams die hen optimale zorg willen bieden, ontmoette ik nu dus binnen de ouderenpsychiatrie. Langzaam

groeide de ambitie om de vele vragen, die ik in de praktijk tegen kwam, meer wetenschappelijk uit te diepen. Deze ambitie deelde ik met Noud Engelen en tijdens een bijeenkomst van het Dementieplatform Zuid, met Jos Schols en Frans Verhey. Dank dat jullie in mijn ambitie geloofden. Dank ook, dat jullie vervolgens Marjolein de Vugt vroegen deel van mijn begeleidingsteam uit te maken. Jullie vormden een gouden team, wat mij stimuleerde te promoveren. Jullie introduceerden mij in jullie netwerken, jullie spoorden mij aan en gaven mij de ruimte mijn eigen weg te vinden, maar stuurden ook op tijd bij en waren er, als ik het gewoon even niet meer wist.

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extramuraal een vanzelfsprekendheid werd. Dank voor onze waardevolle gesprekken, de levenslessen die je met mij deelde, maar ook voor je relativerend vermogen. Dank ook voor je gastvrijheid 'op de berg', waardoor de casusbespreking en de generale discussie tot de noodzakelijk verdieping kwamen.

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De eerste periode van mijn wetenschappelijke carrière bestudeerde ik de literatuur over mijn onderzoeksthema systematisch, om daarmee een onderzoeksvoorstel te kunnen onderbouwen. Dat leverde in 2010 een eerste internationale publicatie op, maar helaas nog geen subsidie om de uitgebreidere studie naar patiëntkenmerken op te zetten.

De kentering kwam, toen verpleeghuizen in de regio Zuidelijk Zuid-Limburg in 2012 de noodklok luidden over de toenemende groep bewoners met complexe psychiatrische problematiek. Daarmee werd het thema dubbelzorgvragers actueel. Zorgverzekeraar CZ stelde een financiële bijdrage uit het innovatiefonds beschikbaar, waardoor in 2013 de dataverzameling in het project SpeCIMeN daadwerkelijk kon starten.

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De leden van de manuscriptcommissie, Prof. dr. R.W.H.M. Ponds, voorzitter, Prof. dr. G.D.E.M. van der Weijden, Prof. dr. S.P.J. van Alphen, Prof. dr. R.T.C.M. Koopmans en Dr. D.J.A. Janssen, ben ik zeer erkentelijk voor het lezen en beoordelen van mijn manuscript.

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Curriculum Vitae

Janine Collet werd op 27 juli 1959 geboren in ‘s-Hertogenbosch.

In 1977 behaalde zij haar gymnasium bèta diploma aan Beekvliet te Sint Michielsgestel.

Vervolgens studeerde zij geneeskunde aan de universiteit van Maastricht. Tijdens haar coschappen raakte zij enthousiast over veel disciplines en besloot daarom na het behalen van haar artsendiploma in 1983 de opleiding tot huisarts te volgen. Dat is immers hét vak, waarbinnen alle deelgebieden van de geneeskunde aanbod komen.

Tijdens haar huisartsopleiding werd duidelijk, dat zij een voorliefde had voor het werken met (oudere) patiënten met complexe samengestelde problematiek. Haar huisartsopleider liet met genoegen de visites aan “nooit tevreden te stellen oudere dames in het verzorgingshuis” aan haar over. De huisartsopleiding heeft zij bewust uitgebreid met een keuzestage verpleeghuiszorg; een vakgebied dat zij eerder privé had leren kennen tijdens de ziekteperiode van haar vader, en waar zij nu van wilde weten of dit vakgebied bij haar als arts zou kunnen passen.

Deze verpleeghuisstage gaf haar het inzicht, dat werken met (zeer) kwetsbare patiënten met multimorbiditeit, het samen met een multidisciplinair team puzzelen en zoeken naar verbetering en optimalisering van hun kwaliteit van leven, haar veel uitdaging en voldoening geeft. De stageplek gaf ook het inzicht, dat zij niet in een grootschalig, hiërarchisch georganiseerd verpleeghuis wilde werken.

Na afronding van de huisartsopleiding in 1985 heeft zij tot begin 1989 parttime in verschillende huisartspraktijken gewerkt en daarnaast onderwijs gegeven aan het skills-lab van de faculteit geneeskunde van de universiteit Maastricht. Daar heeft zij onder meer het project ‘simulatiepatiënten’ verder vorm gegeven. In 1988 opende in Maastricht een nieuw, kleinschaliger, verpleeghuis “De zeven Bronnen”, met een zorgfilosofie, die volledig bij haar eigen ideeën over zorg aansloot. Zij maakte in 1988 de overstap naar dit verpleeghuis in combinatie met een parttime baan bij het skills-lab.

Vanaf 1989 ging zij definitief als verpleeghuisarts werken en besloot haar huisartsregistratie te laten verlopen. Naast haar werk op een chronische psychogeriatrie- en somatiek afdeling, kreeg zij de ruimte om een dag- en nachtbehandeling voor psychogeriatrische patiënten plus een afdeling voor gerontopsychiatrische patiënten op te zetten. Ook was zij opleider binnen de opleiding tot verpleeghuisarts (universiteit van Nijmegen) en begeleidde zij keuzestages van huisartsen in opleiding (universiteit van Maastricht). De doelgroep

ouderen met een combinatie van somatische, psychiatrische en cognitieve problematiek, die vaak als “te problematisch” binnen zowel de reguliere psychiatrie als de reguliere verpleeghuiszorg gezien werd, kreeg steeds meer haar voorliefde.

In 2002 maakte zij de overstap naar de ouderenpsychiatrie binnen Mondriaan. Na een fusie van ambulante geestelijke gezondheidszorg (GGZ), begeleid wonen en kliniek, lag er bij de Divisie Ouderen de uitdaging om geïntegreerde somatische en psychiatrische zorg voor ouderen, zowel ambulant als klinisch, te ontwikkelen en vorm te geven. Er was veel ruimte voor nieuwsgierigheid, ontwikkeling en optimalisering. De groep patiënten, die vanwege hun samengestelde problematiek eigenlijk zowel verpleeghuiszorg als psychiatrische behandeling nodig hadden (patiënten met een dubbele zorgvraag), kwam steeds duidelijker in beeld. In samenwerking tussen Mondriaan en Meander verpleeghuiszorg werd een afdeling voor gerontopsychiatrie in het verpleeghuis opgezet. Langzaam ontstond de ambitie om een aantal vragen uit de praktijk wetenschappelijk uit te diepen. In 2006 werd deze ambitie voor het eerst gedeeld en verkend met hoogleraren Schols en Verhey. Meerdere onderzoeksvoorstellen tot het verkrijgen van subsidie werden geschreven. Een onderbouwende literatuurreview vormde in 2010 de start van het onderzoek, maar het duurde uiteindelijk tot begin 2013 voor met de daadwerkelijke uitvoering en dataverzameling gestart kon worden.

Janine heeft haar onderzoeksactiviteiten altijd gecombineerd met haar functie van specialist ouderengeneeskunde (SO), waarbij zij zowel klinisch als ambulant werkt. Zij is stage-opleider voor de ambulante GGZ-stage binnen de opleiding tot SO (universiteit Nijmegen). Sinds 2019 is zij programmaleider van het zorgprogramma neuropsychiatrie binnen Mondriaan Ouderen en tevens specialismeleider neuropsychiatrie Mondriaan-breed. Zij is actief binnen diverse werk- en stuurgroepen ten behoeve van patiënten met een dubbele zorgvraag, waaronder het ‘Hersenletselteam Limburg’, het landelijk platform Gerontopsychiatrie binnen de V&V, en het ‘Expertpanel Persoonlijkheidsstoornissen bij Ouderen (EPO)’.

Janine is de trotse moeder van Anne, Jeroen en Sander en heeft een relatie met Boris Traa. In haar vrije tijd geniet zij van yoga, tennissen en hardlopen en bezoekt zij graag schouwburg voorstellingen.

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