

Grip on Challenging Behaviour

Development, implementation and evaluation of a care programme for the management of challenging behaviour on dementia special care units

door

Sandra Annelies Zwijsen

geboren te Harmelen

The study presented in this thesis was performed within the EMGO Institute for Health and Care Research (EMGO+), Department of General Practice & Elderly Care Medicine of the VU University Medical Center, Amsterdam, The Netherlands. The EMGO+ Institute participates in the Netherlands School of Primary Care Research (CaRe), which has been acknowledged by the Royal Dutch Academy (KNAW).

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Grip on Challenging Behaviour

Development, implementation and evaluation of a care programme for the management of challenging behaviour on dementia special care units

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Chapter 1

General introduction

Introduction

This thesis is about managing behaviour, more specifically about managing the “challenging” behaviour of people with dementia living in nursing homes. Challenging behaviour is, in this thesis, defined as every form of behaviour that challenges the resident and/or people surrounding the resident (e.g. care and treatment providers, relatives, other residents).

Behaviour from people with dementia can be challenging for themselves, for it can be accompanied by negative feelings or by negative reactions in the environment. It can also be challenging for relatives in watching the person with dementia behave in an agitated or inappropriate way. In addition, because of a lack of a shared world¹ between carers and people with dementia, the possibility to communicate about the reasons and solutions for the behaviour with the person with dementia is limited. This inability to react in an appropriate way to reduce the behaviour can be very frustrating and challenges both the carers and the person with dementia. Consequently, the term “challenging behaviour” implies that coping with behaviour requires attention and a proactive attitude from people in the environment.

Nursing home care in the Netherlands

This thesis is based on research which was conducted in the Dutch nursing home population. In the Netherlands, approximately 65,000 people live in nursing homes². Nursing home care in The Netherlands distinguishes between people with predominantly somatic illnesses (who live in somatic units, 57% of the admitted people) and people with dementia and dementia-like disorders (who live in dementia special care units, DSCUs, 43% of the admitted people). To be admitted to a DSCU, an indication is needed from the care needs assessment centre (centrum indicatiestelling zorg, CIZ³) which states that the person to be admitted can no longer safely live on his or her own and admittance to a DSCU is necessary (Dutch: ‘BOPZ artikel 60 verklaring’). This means that most people living in DSCUs have a moderate to severe form of dementia.

The care on Dutch DSCUs is characterised by the presence of a multidisciplinary team consisting of the care staff, a psychologist, an elderly care physician (a physician who is specialised in the care of nursing home residents after having completed a three year training programme⁴) and several other paramedic disciplines. These disciplines are employed by the nursing homes, and that means their expertise is easily available when needed. In contrast, in most other countries, not all of these disciplines are available, and when they are they are usually part of other external organisations.

The care staff in Dutch nursing homes consists primarily of people with vocational education as either licensed practical nurses (verzorgenden, educational level 3) or nurse assistants (helpenden, educational level 2) and of unlicensed nurse assistants (ongediplomeerden, no nursing education). Licensed practical nurses have completed 3 years of vocational education

on caregiving and nursing skills. Nurse assistants have completed two years of vocational education on caregiving and supporting people with personal care and housekeeping.

Challenging behaviour in Dutch dementia special care units

In Dutch nursing homes, much emphasis is placed on creating a home-like environment in which care is provided with respect for personal needs and preferences⁵. Combined with the presence of a multidisciplinary team, there are excellent preconditions for optimal psychogeriatric care compared to other countries. However, this is not reflected in the prevalence rates for challenging behaviour or the use of psychoactive medication, which do not differ from other developed countries⁶⁻¹¹.

On average, 80% of the people living in Dutch DSCUs show some form of challenging behaviour and many behavioural symptoms are persistent over time, which suggests that treatment is either insufficient or ineffective^{6,12}. What is more, over two thirds of the residents are prescribed psychoactive medication and despite guidelines stating that attempts should be made to discontinue the use of psychoactive medication, one third of the DSCU population is prescribed such medication for over 24 months¹⁰. It seems that although, in general, the quality of care for people with dementia has gone through a positive development during the last decade, these developments have not yet had their effect on the management of challenging behaviour. For example, only a minority of the nursing homes screens for challenging behaviour on a regular basis and the expertise on how to efficiently manage challenging behaviour is often lacking¹³. Next to this, although several discipline specific guidelines on managing challenging behaviour are already apparent¹⁴⁻¹⁶, the implementation of these guidelines is unsatisfactory. Care for people with dementia with challenging behaviour could likely be improved when positive developments like the availability of a multidisciplinary team, availability of psychosocial interventions, and attention given to personal needs and preferences would be incorporated in the approach to challenging behaviour.

Approaches to challenging behaviour

In recent decades, more and more attention is being paid to viewing people with dementia as people who are still experiencing, feeling, thinking, and communicating despite their illness. The work of Kitwood¹⁷, Feil¹⁸, Clare¹⁹ and many others (for example²⁰⁻²²) has been important for the evolvement of care for people with dementia in which they are increasingly treated as full persons rather than as people who have 'lost their mind'. This view on dementia resulted in the development of models that might explain the behaviour of people with dementia as a result of underlying problems rather than as a sheer result of neuron degeneration. For example, in a biopsychosocial model, the behaviour of people with dementia is explained as a combination of biological (organic/somatic), psychological,

and social factors. This means that the behaviour is seen as a combination of characteristics of the person with dementia, the (social) environment and the interaction between the person with dementia and the environment (Figure 1). Elaborating on this model and on the work of Kitwood, Cohen-Mansfield developed the unmet-needs framework²³, which states that challenging behaviour is a result of the unmet (biopsychosocial) needs of the person with dementia, and that the solution of the challenging behaviour lies in resolving those unmet needs. These and other kinds of psychosocial explanatory models of challenging behaviour can be useful in reducing the behaviour, although guidance on how to use these models in daily practice is obviously needed²⁴.

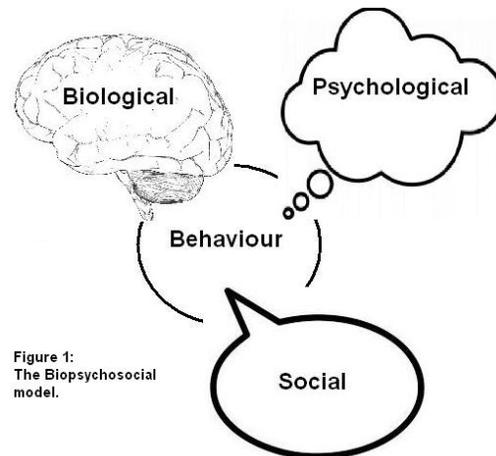


Figure 1:
The Biopsychosocial
model.

In line with the view that challenging behaviour is a sign of unmet needs or other discomfort, many psychosocial interventions have been developed to better adapt and adjust to the needs of people with dementia and the supposed reason behind the challenging behaviour. For example, staff education programmes on managing challenging behaviour have been effective²⁵. In addition, there is evidence that music therapy and multisensory treatment have a short-term effect on behaviour²⁶ and promising results are reported on individualised behavioural interventions²⁵. However, the effects of these interventions remain modest²⁵⁻²⁷.

An explanation could be that in spite of evidence suggesting that only individually tailored interventions will truly result in obvious effects²⁵, there is no clear guidance on how to analyse behaviour in a way that selects those who could benefit from specific interventions. Although the explanatory models on challenging behaviour paint a general picture, they do not give concrete directions on how to approach and manage challenging behaviour.

It is pitiful that the approach to challenging behaviour lags behind in psychogeriatric care. After all, the term psychogeriatric stems from the three ancient Greek words *psyche* (ψυχή spirit, mind), *geron* (γερου, elderly), and *iatros* (ιατρεία treating, healing) and, therefore, literally means treating the elderly mind. Yet, although for most somatic geriatric care, protocols are developed (for instance, ulcer prevention protocol, bathing protocols) for the pure 'psychogeriatric' care, e.g. care for the elderly mind, general protocols on how to act or what to do are mostly absent. One of the reasons for the absence of clear guidance on how to manage challenging behaviour might be the complexity and diversity of behaviour seen in people with dementia. Indeed, several guidelines emphasise that challenging behaviour should always be approached with a unique, individually attuned treatment plan^{14;15;28;29}, which seems to be the opposite of using a standard protocol. Nonetheless, to be able to reach such an individual approach, guidelines also emphasise the importance of early

detection and multidisciplinary analyses of the behaviour. However, clear guidance on how to properly work together, how to structurally analyse behaviour, and how unravel the needs and preferences of residents is lacking. Prescribing medication is stated as a last resort option in the guidelines on challenging behaviour, but without guidance on how to develop a treatment plan that is based on thorough multidisciplinary analysis and that contains individualised interventions, it sometimes can feel like the only option indeed³⁰.

In recent years, several initiatives have been developed to offer guidance when dealing with dementia and challenging behaviour (for example³¹⁻³³). These initiatives, however, usually do not have a scientific basis or the effects have not been studied in scientific trials. To create evidence-based guidance for the management of challenging behaviour that can help multidisciplinary teams generating individualised management of challenging behaviour, the care programme Grip on Challenging Behaviour (GRIP) was developed. The care programme is based on the evidence-based guidelines^{14-16;29;34} combined with explanatory models on challenging behaviour. The care programme guides care staff, psychologists, and elderly care physicians through the process of detection, analysis, treatment, and evaluation of the treatment of challenging behaviour. By using the care programme, not only are people helped in approaching challenging behaviour in a structured way, it is also hoped that, in the long run, residents with challenging behaviour are treated in a way that does credit to the specialty of caring for the elderly mind.

Outline of the thesis

Chapter 2 and 3 are a description of the study protocol and the development of GRIP. The rationale behind the research design and methods are explained and the development and content of GRIP is outlined.

In **chapter 4**, the process evaluation of implementing the care programme on 17 dementia special care units is described. For future implementation, it is important to know what hinders and what contributes to good implementation. Furthermore, to interpret the effects of using the care programme, knowledge on the degree of implementation is necessary. This chapter, therefore, contains information about both the actual implementation (reach, feasibility, relevance, etc.) and the barriers and facilitators to implementation.

Chapter 5 concerns the effects of using the care programme on challenging behaviour, psychoactive medication, and restraint use. The care programme aims at preventing challenging behaviour and on diminishing existing challenging behaviour. Moreover, the performance of a structured, multidisciplinary analysis and the training could decrease the prescription of psychoactive medication.

Chapter 6 and 7 involve the care staff of dementia special care units. Keeping the changing composition of the population and economic situation in mind it is of the utmost importance that interventions aimed at reducing burnout and improving job satisfaction of care staff are developed. First, **chapter 6** describes the distress that is experienced when professional carers encounter challenging behaviour. In **chapter 7**, the effects of using GRIP on burnout, job satisfaction, and job demands of care staff are shown.

Chapter 8 is the general discussion, which will reflect on the aims and results of the earlier chapters. The methodological strengths and limitations of the study are discussed and the implications of this study for clinical practice will be described.

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Chapter 2

Coming to grips with challenging behaviour: a multidisciplinary care programme for managing behavioural problems in nursing home residents with dementia. Study Protocol.

Abstract

Background

Behavioural problems are common in nursing home residents with dementia and they often are burdensome for both residents and nursing staff. In this study, the effectiveness and cost-effectiveness of a new care programme for managing behavioural problems will be evaluated.

Methods/Design

The care programme is based on Dutch national guidelines. It consists of four steps: detection, analysis, treatment and evaluation. A stepped wedge design will be used. A total of 14 dementia special care units will implement the care programme. The primary outcome is behavioural problems. Secondary outcomes will include quality of life, prescription rate of antipsychotics, use of physical restraints and workload and job satisfaction of nursing staff. The effect of the care programme will be estimated using multilevel linear regression analysis. An economic evaluation from a societal perspective will also be carried out.

Discussion

The care programme is expected to be cost-effective and effective in decreasing behavioural problems, workload of nursing staff and in increasing quality of life of residents.

Trial registration

The Netherlands National Trial Register (NTR). Trial number: NTR 2141

Background

Many nursing home (NH) residents with dementia suffer from behavioural problems (BPs) like aggression, apathy and agitation. In a recent Dutch study, BPs were present in 80 percent of the residents¹. BPs are associated with high costs, diminished quality of life of residents and a high workload for nurses¹⁻³.

Antipsychotics and physical restraints are frequently used to treat BPs^{4,5}. However, the use of antipsychotics may have serious negative side effects like extrapyramidal symptoms and increased risk of stroke⁶⁻⁸ and the use of restraints may result in decreased functional status and quality of life⁹.

Various studies have shown that treatments with less adverse effects can be used to manage BPs as an alternative to antipsychotics and physical restraints. For example, Cohen-Mansfield and colleagues¹⁰ observed a positive effect of individualized psychosocial interventions, such as pain treatment, electronic massagers and individualized music. Furthermore, Livingston et al. found in their review that staff education and psychological and psychosocial treatments were effective¹¹. Davison et al.¹² also found a significant decrease in BPs through the use of psychosocial interventions in people with dementia in whom individualised pharmacological treatment failed to work.

In line with these studies, recent professional dementia guidelines emphasise the use of a systematic multidisciplinary approach to treat BPs and stress the importance of psychosocial interventions and staff training¹³⁻¹⁶. They also underline that the use of antipsychotics should be restricted as much as possible. Although these guidelines have been developed in collaboration with long-term care professionals, implementation in actual practice is difficult. Unfortunately, this is also the case in Dutch NHs¹⁷, although the presence of various care disciplines offers excellent conditions for a multidisciplinary approach.

A key problem in implementation of guidelines on BPs seems to be that guidelines do not include a structured, methodology-based approach how to manage BPs¹⁸. For example, an implementation plan on how different disciplines should work together in managing BPs, is often lacking. Therefore, we developed a care programme entitled: 'Grip on Challenging Behaviour'. This care-programme, which offers a comprehensible structure of the care processes, is made practically applicable and ready to implement. It is based on the guidelines, fits with daily practice, and describes how new working methods are related to and can be integrated in the present care process following a step-by-step plan. This chapter describes the design of the study that evaluates the effectiveness and cost-effectiveness of this care programme for managing BPs in NH residents with dementia.

Methods /Design

Aim

The aim of this project is to evaluate the effectiveness and cost-effectiveness of a multidisciplinary care programme for managing BPs in NH residents with dementia. The care programme proposes an evidence- and practice-based standardisation of all consecutive steps in the management of BP: detection, analysis, treatment and evaluation (see figure 1). Cooperation between disciplines is also prearranged and structured.

Intervention

In the first step, the care programme offers a screening tool to detect symptoms of BPs, next to the usual (daily) observation and detection of BPs by nurses. When (symptoms of) BPs are detected, structured forms are used to analyse the behaviour in the next step of the care programme. The nursing staff starts the analysis, after which the elderly care physician and the psychologist continue analysis when necessary. The outcome of the analysis is discussed in pre-arranged multidisciplinary team meetings in which the members of the multidisciplinary team choose the treatment option (or options) they consider appropriate, resulting in a written treatment plan (third step). Psychosocial interventions are first line treatment options and psychotropics or physical restraints should only be used when psychosocial interventions have no or not enough effect. In the fourth step, treatment is evaluated. Standard scales are used for rating BPs when evaluating the effect of interventions. When treatment outcomes are unsatisfactory, alternative treatment options may be chosen and/or a new analysis will be done.

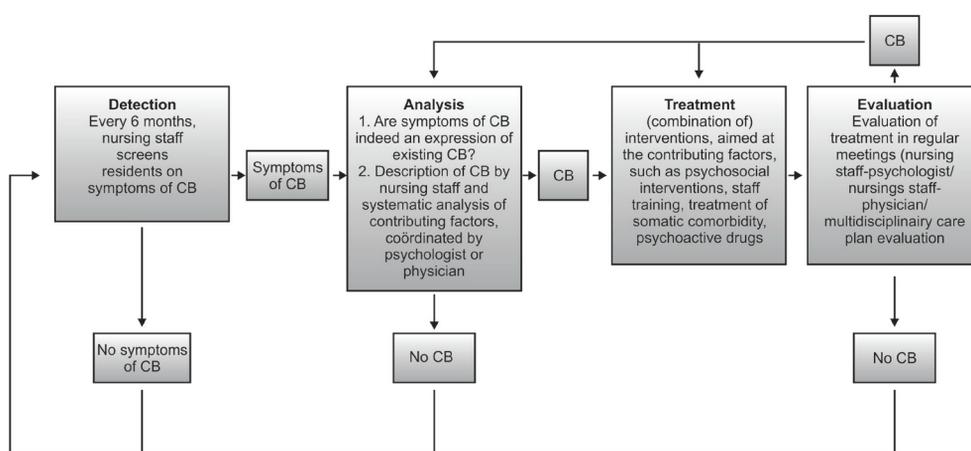


Figure 1: Components of the care programme 'Grip on Challenging Behaviour'. CB = Challenging behaviour.

Design

The care programme will be implemented using a stepped wedge design (Table 1). A stepped wedge design is a type of cross-over design in which different clusters (in this case dementia special care units (SCUs)) cross-over from control-condition to intervention over time¹⁹.

In this study, fourteen participating units are randomly divided over five groups. Four groups consist of three dementia SCUs from three different NHs, one group consists of two dementia SCUs from two different NHs.

Six measurement cycles will take place: one measurement cycle every four months during a period of twenty months. The first measurement cycle is a baseline measurement on all participating units. After each measurement cycle, except the last one, a new group will start the intervention. The moment after which measurement cycle a group of units will start is randomised.

A process analysis will be carried out during the study on the actual provision and use of the components of the care programme and on barriers and facilitators of implementation. The process analysis will consist of qualitative interviews with key persons within the NHs.

Table 1: Stepped wedge design

	T0	T1	T2	T3	T4	T5
Group 1	0	1	1	1	1	1
Group 2	0	0	1	1	1	1
Group 3	0	0	0	1	1	1
Group 4	0	0	0	0	1	1
Group 5	0	0	0	0	0	1

0 = control (usual care)

1 = intervention (care programme)

Each group consists of three or four DSCUs. Measurements are repeated every four months

Sampling

We calculated the sample-size using the following assumptions: On average, a dementia SCU houses 20 residents. Based on a previous study, we expect that 5% of the residents' (legal) representatives will not give informed consent¹. We expect no further attrition, because newly admitted residents will replace discharged and deceased residents during the study. For the primary outcome, we assume that our care programme leads to a 10 point decrease of BPs, measured with the Cohen-Mansfield Agitation Inventory (CMAI)²⁰. Based on a Dutch study in NH patients²¹, we assume a mean Intra Class Correlation Coefficient of 0.1. for clustering of BPs within a unit and a mean score of 47.7 (SD = 16.6) on the CMAI in NH patients with dementia.

Based on these assumptions and a significance level (alpha) of 0.05 and a power (beta) of 0.80, 14 dementia SCUs with 6 measurements are needed in a stepped wedge design.

The participating dementia SCUs will be recruited from NHs that collaborate with the VU University Medical Center (Amsterdam) and the Radboud University Nijmegen, Medical Center.

The dementia SCUs participating in this study are not allowed to exchange staff between SCUs, in order to avoid carry-over effects, and thus dilution of the effect.

Patient characteristics

Sociodemographic variables (e.g., age, gender, and length of stay) and the use of physical restraints will be collected from resident charts.

Severity of dementia will be determined by elderly care physicians, using the Global Deterioration scale (GDS)²². The GDS is a validated seven-point scale that describes seven different stages of dementia ranging from “subjectively and objectively normal” to “severe dementia”.

Data about psychotropic drug use (including antipsychotics) will be derived from the NH pharmacists’ electronic registration system and will be classified according to the Anatomical Therapeutic Chemical (ATC) classification system²³.

Behavioural problems will be measured using the Cohen-Mansfield Agitation Inventory (CMAI) and the Neuropsychiatric Inventory - Nursing Home version (NPI-NH). To our knowledge, the CMAI is the only instrument specifically addressing agitation and aggression, with an adequate validity and reliability for the Dutch version^{24;25}. The CMAI will be used in primary effect analyses that focus on agitation and aggression, which are the most prevalent and most stressing BPs⁴.

The NPI-NH is a version of the Neuropsychiatric Inventory²⁶ that is adjusted to the NH setting. The questionnaire contains twelve items which each measure the frequency and severity of a neuropsychiatric symptom. It was developed for rating by professional caregivers within institutions^{27;28}. The Dutch version proved to be valid and reliable²⁹.

Quality of life of residents will be measured with the Qualidem, a Dutch dementia specific observational quality of life instrument. With this instrument, nursing staff can rate quality of life of the resident over the last week. The Qualidem has nine subscales: Care relationship, Positive affect, Negative effect, Restless tense behaviour, Positive self image, Social relations, Social isolation, Feeling at home and Having something to do. The Qualidem was proven to be valid and reliable, although some items are not applicable to patients with severe dementia (GDS state 7)^{30;31}.

Nursing staff characteristics

Characteristics of the nursing staff (e.g. gender, working experience) are collected through the use of a questionnaire.

Workload of nursing staff will be assessed using the Dutch version of the Maslach Burnout Inventory³², the Utrechtse Burnout Scale-C³³. The UBOS measures three components of workload and burnout: emotional exhaustion, depersonalisation and decreased personal accomplishment.

Job satisfaction will be measured using two subscales of the Leiden quality of work questionnaire³⁴. The two subscales measure job satisfaction and work and time pressure.

The attitude of nursing staff to dementia care will be measured using the approaches to dementia questionnaire (ADQ)³⁵.

Special dementia care unit characteristics

The Special Care Unit Environmental Quality Scale (SCUEQS) is used for the characteristics of the physical environment. The SCUEQS is a summary scale comprised of items from a larger observational instrument (the TESS-NH) which gathers data on the physical environment of a long-term care facility. The eighteen items measure maintenance, cleanliness, safety, lighting, physical appearance/homelikeness, orientation/cuing and noise³⁶. In addition information about nursing staff- resident ratio and educational level of nursing staff will be gathered.

Data analysis

The CMAI-score and the NPI-NH score will be used as a primary outcome. Age, gender, length of stay, dementia severity, prescription of antipsychotics and of other psychotropics will be used as covariates. For the primary and secondary outcome analyses, multilevel linear regression and multilevel logistic regression analyses will be used. These analyses will calculate effects on neuropsychiatric symptoms, quality of life (Qualidem), prescription rate of antipsychotics, workload and job satisfaction of nursing staff and use of physical restraints.

Economic evaluation

The economic evaluation will be conducted from a societal perspective. We will measure and value all relevant costs, such as costs of the structured care programme, prescription of antipsychotics and hospital admission. Data will be collected using NH registries. Standardised case report forms will be used to measure the time invested by NH staff (e.g. recreational therapist, nursing staff, psychologist, elderly care physician) in both the intervention and the usual care condition. Absence rate of nurses will be retrieved from the participating NHs.

The EuroQol (EQ-5D) proxy version³⁷ will be used to measure quality adjusted life years (QALYS). Missing data on cost and outcomes will be imputed using multiple imputation according to the MICE algorithm³⁸.

A cost-effectiveness analysis will be conducted comparing the difference in total mean costs to the difference in effects on BPs; a cost-utility analysis will estimate the incremental costs per QALY. Bootstrapping will be used to estimate uncertainty of the incremental cost-effectiveness ratios (ICERs), which will be presented on cost-effectiveness planes. Cost-effectiveness acceptability curves and net monetary benefits will also be calculated³⁹. Sensitivity analysis will include the most important cost-drivers.

Discussion

The aim of this study is to measure the effectiveness and cost-effectiveness of an evidence- and practice based care programme for managing BPs in NH residents with dementia. Primary outcome is the effect on prevalence of BP. Secondary outcomes are the effect on quality of life, use of antipsychotics and physical restraints and on workload and job satisfaction of nursing staff. Additionally, an economic evaluation will be carried out.

We assume that implementation of the care programme will result in a decrease of BPs and, subsequently, in an increase of the quality of life of the residents. We also expect lower costs that will most likely be the result of a decrease of behavioural-problem related extra care, a decrease of medication, fewer admissions to hospital and also by a lower absence rate of nursing staff. Implementation is also expected to result in a lower workload and higher job satisfaction among nursing staff.

The chosen design to implement and evaluate the care programme is suitable for our purposes. Not only does the stepped wedge design increase the power of the study by enabling between-groups and within-group analyses, it also ensures that implementation of the care programme occurs in all participating care units, which likely increases motivation for participating in the study⁴⁰. Except for the EQ5D, which is used to calculate QALYs, the chosen outcome parameters are all commonly used in the field of nursing home medicine and are also suitable for the population of severely demented patients^{22;24;27;31}.

The study has some limitations that should be mentioned. One limitation of the study is that, although data collection will be done by research assistants who are blinded for the trial condition, the NH staff will be aware of receiving the intervention, which may cause bias. To limit this bias, nursing staff will not be informed about the scores on the outcome measures. Another limitation is that we use proxy measures only, which may not be as reliable as patient measures⁴¹. However, in advancing stages of dementia, cognition and communication decrease, which makes the use of proxy measures inevitable⁴¹. Nevertheless, the described care programme for managing BP in NH residents with dementia and the chosen stepped wedge design seem very appropriate for our research goals.

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Chapter 3

Coming to grips with challenging behaviour:
The development of a care programme.

Abstract

Background

Current guidelines and theories on the origin of challenging behaviour in dementia indicate that a structured multidisciplinary approach to its management is necessary. In the Grip on Challenging Behaviour study, a care programme was developed to improve the management of challenging behaviour.

Methods

In developing the care programme, the overlapping parts of dementia care guidelines were supplemented with discipline-specific parts. Three meetings with experts were arranged to further develop the structure of the care programme and to ensure a good fit with practice.

Results

The care programme consists of four steps: detection, analysis, treatment, and evaluation. For each step, forms were developed to guide and structure the process and assign responsibilities for each discipline. As well as a description of the development and the content of the care programme, this paper presents two case studies in which the programme was used.

Conclusion

The Grip on Challenging Behaviour care programme provides a way for dementia special care units to manage challenging behaviour in a structured way and with a multidisciplinary approach making use of their own resources.

Background

Challenging behaviour is very common in people with dementia. Over 80% of nursing home residents with dementia have been found to show signs of challenging behaviour at any given time¹. Moreover, recent research shows that almost every resident with dementia will display challenging behaviour at some point during their stay in the nursing home².

The term 'challenging behaviour'^{3;4} is relatively new, succeeding names like disturbed behaviour, neuropsychiatric symptoms, and behavioural and psychological symptoms of dementia. The different ways of naming the behaviour show the gradual evolution from explaining it as a result of organic deterioration to a psychological model of behaviour and finally to a model in which the behaviour is seen as a combination of characteristics of the person with dementia, the social environment, and the interaction between the two^{5;6}.

The concept of challenging behaviour, however, is quite ambiguous. For example, it is unclear how severe the behaviour must be to be classified as challenging and to whom the behaviour must present a challenge. Behaviour can be challenging to nursing staff or other residents, but behaviour that mainly affects the quality of life of the resident themselves (e.g. through apathy or depression) should not be overlooked either. Nonetheless, problems of definition also exist when using other terms. What is more, where other terms simply state that the behaviour is present, 'challenging behaviour' implies that coping with the behaviour requires attention and a proactive attitude; the behaviour challenges both the person with dementia and the environment to find ways to better understand the reasons why it occurs.

Understanding and then choosing the right treatment for challenging behaviour is not straightforward either. Perhaps one resident should be urged to be more active, while another resident should get less stimulation. Some residents would benefit from getting help to express their feelings; others should be offered help to turn their thoughts to more positive matters. In some instances medication might be indicated, whereas in most cases psychosocial interventions are preferred. Obviously, before choosing a treatment, a thorough analysis should be made of what constitutes the challenging behaviour and what causes the behaviour to occur and persist.

These considerations about how to manage challenging behaviour in dementia are far from new. Indeed, they have been considered in several evidence-based guidelines⁷⁻⁹. However, in practice the management of challenging behaviour is often unstructured and poorly organised¹⁰. Wetzels et al.² showed that almost all residents of dementia special care units (DSCUs) develop behavioural symptoms in a 2-year follow up period, and many symptoms are persistent over time, implying that treatment is either insufficient or ineffective. Also, although guidelines state that prescription of psychoactive drugs should be a last resort, this type of medication is prescribed to almost two thirds of the residents of Dutch DSCUs¹¹. It is clear that publishing guidelines is not enough to improve the management of challenging behaviour. A tool is needed that converts the abstract ideas of the guidelines into a method that can be used in practice and that connects the guidelines of different disciplines, so that

a structured, evidence-based multidisciplinary approach to challenging behaviour arises. For the Grip on Challenging Behaviour project, a care programme was developed that structures the steps of detection, analysis, treatment, and evaluation of treatment of challenging behaviour. The programme is directed at care staff, psychologists, and physicians and emphasises multidisciplinary collaboration. The care programme was based on the available guidelines, which were transformed into four practical, ready-to-use steps. In this paper, the development and content of the Grip on Challenging Behaviour care programme are described.

Methods

Step 1: Merging the guidelines

The first step of the development of the care programme was to examine the national guidelines on the management of challenging behaviour. Two of the researchers (MS and SAZ) closely examined the guidelines for elderly care physicians^{12;13}, psychologists¹⁴, and care staff¹⁵ for common ground and differences (Box 1). Because the care programme was initially developed for the Dutch situation, the Dutch guidelines were used as a foundation. However, these guidelines are adaptations from the international evidenced-based guidelines of the IPA⁷ and NICE⁹.

All of the different guidelines follow a stepwise approach to assessing challenging behaviour, which was adopted in the care programme. The process starts with an exploration of the behaviour and the situation; the actual approach differs depending on the discipline. Next, analysis of the possible causes is necessary. Again, in the guidelines the main focus of the analysis differs for each discipline: the physician guidelines have more focus on physical causes and medication whereas the psychologist guidelines emphasise analysis of the environment and psychological causes. The next step is the treatment plan, for which a clear treatment goal should be stated according to the guidelines. The guidelines for physicians and psychologists describe an array of possible treatments and stress that the treatment should primarily be focused on the cause of the behaviour. The guidelines for nursing staff on the other hand list the psychosocial treatment options that are indicated for each behavioural symptom. Next, according to the nursing guidelines, it should be clear who is responsible for executing and evaluating the treatment. The guidelines for psychologists and physicians end with a separate, more elaborate, chapter on how to evaluate treatment. In short, according to the guidelines it is important that a thorough analysis of the behaviour takes place before treatment is started. Also, a clear treatment goal should be described. The guidelines differ in the extent to which they advise on how to actually perform a good analysis. Also, the starting point of the process is different: the guidelines for physicians begin with advice on how and when detection of challenging behaviour should take place; the other guidelines start when challenging behaviour has somehow already become

apparent. In developing the outline of the care programme, the overlapping parts of the guidelines were used, such as the stepwise approach and the clear stating of the treatment goal, and were supplemented with the several discipline-specific parts of the guidelines.

Box 1: Summary of the Dutch guidelines on challenging behavior

Physicians:	by who and when should behaviour be detected→ describe the behaviour→ analyse possible causes (multidisciplinary) → state a clear treatment goal→ kinds of treatment→ evaluation
Psychologists:	exploration of the (urgency of the) behaviour→ analyse the situation→ make a diagnostic and functional analysis→ state a clear treatment goal→ kinds of treatment → evaluation
Nursing staff:	define who suffers from the behaviour→ describe the behaviour→ determine cause of behaviour→ determine treatment, treatment goal and treatment supervisor; treatments per behavioural symptoms are suggested

Step 2: Meetings with the experts

The next step in developing the care programme was to arrange three meetings with a group of care professionals. This group consisted of three psychologist researchers (authors SAZ, DLG, and AMP) with expertise in dementia and the quality of life of nursing home residents, an elderly care physician researcher (author MS) involved in the development of the guideline on challenging behaviour for physicians, a psychologist representative of the Dutch association of psychologists who was involved in the development of the guideline on managing challenging behaviour in nursing homes, a representative of the Dutch association of elderly care physicians, a representative of the Dutch association for care staff, and a nurse and a nurse assistant both working in the nursing home setting. The purpose of involving this group of people was to ensure a good fit between the care programme and actual practice, to make the care programme easy to use in daily care.

The first meeting was used to outline the background and aim of the project. The first two steps of the care programme—detection and analysis of challenging behaviour—were discussed. This meeting focused on which discipline should be involved at different points. With input from this first session, the forms and structure for the first two steps in the care programme were further developed.

In the second session, the forms were presented to the expert group. The remarks that were made in this session were used to fine-tune the forms. In the second session the next two steps in the care programme —treatment and evaluation—were discussed. Particularly, the way in which behaviour should be measured for evaluation and by whom were discussed and ideas for the training sessions to introduce the care programme were assembled.

In the third and last session the structure of the care programme was discussed. For instance, agreements were made about who should fill in which form, how multidisciplinary consultation could be prearranged, and who would be responsible for which part of the care programme. After the last session, the final care programme was put together by the project team, which consists of three elderly care physicians and three elderly care psychologist.

Results

The care programme

The Grip on Challenging Behaviour care programme consists of four steps.

Step 1: Detection

The goal of this step is to detect signs of challenging behaviour early on, to prevent it from escalating or being overlooked—as is often the case with, for example, apathy and depression^{16;17}. Care staff initiate this step, and other disciplines can support it by emphasising the importance of early detection.

To better detect all possible symptoms of challenging behaviour, the care programme introduces the use of a screening tool. The tool used is the NPI-Q, a shortened version of the Neuropsychiatric Inventory¹⁸. The NPI-Q examines 12 possible symptoms of challenging behaviour, enabling scoring of its severity (range: 1–3) and the emotional distress it causes (range: 0–5). The screening tool should be filled in every 6 months by two or more members of the care staff. In the development of the care programme, the experts expressed concerns about the possibility of care staff getting demoralised in using the care programme if every form of slightly aberrant behaviour were classified as behaviour for which the care programme should be used. Therefore, after thorough deliberation it was determined that a cut-off score of 2 for severity or 3 for emotional distress could be seen as an indicator of the presence of clinically relevant challenging behaviour and could be used to detect signs of challenging behaviour. When a resident scores above the cut-off score, the next step in the care programme is commenced. By introducing the screening tool, the care programme provides a new way to pick up on signs of challenging behaviour at an early stage, which can prevent the behaviour from developing into an acute and unmanageable situation. It also forces care staff to discuss signs of challenging behaviour in a structured way, which should lead to increased awareness and also to earlier detection of symptoms.

Step 2: Analysis

When symptoms of challenging behaviour are detected (either in normal daily care or via the screening tool in step 1), the analysis of the behaviour begins. The goal of this step is to get a clearer picture of the behaviour and its possible causes. The analysis is started by the care staff and followed up by the physician, the psychologist, or both disciplines.

The care staff starts the analysis using a form. This analysis form was designed for structured gathering of information on the situation, the environment, and the feelings surrounding the challenging behaviour. The 13 questions on the form were derived from the recommendations in the guidelines about clarifying and analysing behaviour (for examples of the questions on the form, see Boxes 2 and 3). The form is not a measurement tool of any kind, but filling in the form supports care staff to reflect on the situation and generate possible solutions. It also helps the psychologist and physician to start their own analyses. The form contains questions regarding the behaviour, the time and place of occurrence of the behaviour, its possible causes, and the actions already being undertaken by the care staff. After filling in the analysis form, care staff can call in either the physician (if they suspect somatic causes or in case of 'acute' behaviour, which points to possible delirium) or the psychologist (when psychosocial causes are suspected). If a psychologist was not part of the care team then an external geropsychologist would be consulted or, if this was also not an option, another discipline with expertise in analysing challenging behaviour would be involved.

Both the physician and the psychologist have their own analysis form, which they fill in when they decide the behaviour should be further examined and treated. The analysis form for the physician consists of a checklist to rule out physical causes, a check of the prescribed medication, and a checklist to rule out psychiatric diagnoses, i.e. delirium, psychotic disorders, depression, anxiety disorder, sleep disorder, or personality disorder. The analysis form for the psychologist consists of several diagnostic options and ends with a functional analysis of the behaviour^{19;20}. An extra form was developed to help the psychologist with questions to guide an extensive exploration of the behaviour. Both the physician and the psychologist may refer to each other and end their analysis with a conclusion about the possible causes of the behaviour as a start for step 3, treatment.

Step 3: Treatment

When the care staff, psychologist, and/or physician have finished their analysis, a meeting is arranged between the involved disciplines to discuss the results of the analysis. The goal of the next step is to make a treatment plan containing a clear treatment goal. The psychologist or physician is responsible for this step, depending on their involvement during the analysis. The treatment goal should be stated as specifically as possible, e.g. 'the resident is not pacing more than once a day for a maximum of 5 minutes', instead of 'the resident is less restless'. The current situation should then be rated on a 10-point scale (e.g. resident

does not pace at all = 0; resident is constantly pacing = 10). On the treatment form, an evaluation date should also be planned.

The actual treatment is based on the functional analyses of the psychologist and physician. Exact indications for psychosocial interventions such as music therapy and reminiscence are not specified in the literature, therefore the choice for these interventions relies on hypotheses of the causes of the behaviour, the individual preferences of the resident, and the availability of treatment options in the nursing home. The use of psychoactive drugs or restraints should be prevented as much as possible, which should be a logical consequence of following the steps of the care programme in aiming the treatment at the underlying causes rather than the behaviour itself.

Step 4: Evaluation

The goal of this last step is structured evaluation of the results of the intervention. The psychologist or physician is responsible for this step, depending on who drew up the treatment plan. At the time point that was agreed on the treatment form, the involved disciplines sit down together to evaluate the treatment. First, the current situation is again rated on a 10-point scale to determine whether improvements have taken place. Next, either the psychologist or the physician runs through the evaluation form with the care staff. For this, a flowchart is used in which one has to fill in, first, whether the treatment goal has been achieved, next, whether all actions that were agreed on have taken place and, finally, whether these actions should be continued. By following the flowchart, a decision can be made about which steps should be taken next: stopping or continuing treatment (if the treatment goal was achieved after intervening), using another treatment, or revising the analysis (if the treatment goal was not achieved when all planned actions were undertaken).

The forms that are filled in are kept together in one place at the DSCU, preferably as part of the patient's record. The forms are filed under an agenda form, on which every step that is taken is noted with a date and the name of the person responsible for that step. This not only helps to clarify who does what at which time point, it also forces disciplines to actually meet on the DSCU when forms should be discussed.

To clarify the way the care programme can be used, two case studies of its use are presented below. For each case, some of the questions from the analysis using the care staff form are presented.

Case 1, Mr.K.

After filling in the detection form, care staff detected that MrK showed symptoms of agitation and disinhibition. Symptoms of aberrant motor behaviour and night-time disturbances were also apparent, but they did not exceed the cut-off for detecting clinically relevant challenging behaviour. Because symptoms were detected, the care staff filled in

the analysis form, describing Mr K's behaviour (Box 2). They sent the form to the unit's psychologist, who decided to have a meeting with the whole care team in response. During this meeting, the behaviour of Mr K was discussed using questions from one of the behaviour exploration forms for the psychologist.

It became clear that certain residents triggered Mr K's memories of his past working experiences and experiences with homecare, which made him violent to those residents. It also seemed that Mr K enjoyed helping out with simple tasks or being offered another activity like drinking coffee. The psychologist pointed out that the challenging behaviour did not start as abruptly as one might think and suggested that if the care staff observed Mr K carefully they would be able to distract him with pleasant activities before his behaviour escalated into hitting another resident.

The results of this analysis from the psychologist were written down on the analysis form. The psychologist gave the care staff practical advice and together with the care team they made a treatment plan and a clear treatment goal ('Mr K is less often irritated by specific other residents and irritation should not last as long as it does now'), which was written down on the treatment form. The team agreed on evaluation in 1 months' time. After 1 month, the care staff confirmed on the evaluation form that they had followed the treatment plan and the behaviour was rated as happening less often and being far less serious.

Box 2: Questions from the care staff analysis form of mr.K.

Could you describe the behaviour?(what do you see, what is problematic about the behaviour)?
<i>Mr. K. often hits another resident, mostly Mrs. G and she ends up with a black eye.</i>
How often is this behaviour apparent?
<i>Almost every day</i>
Did something in the direct surroundings happen before this behaviour occurs? (e.g. music, other sounds, someone entering, interaction with care staff)
<i>Yes, often there are other residents in the hallway or in the living room.</i>
Where does the behaviour take place?
<i>Living room, hallway</i>
At which time points does the behaviour occur?
<i>Several different time points</i>
Did something happen to the resident before the behaviour took place?
<i>No, if he enters the living room he instantly goes to a resident and hits them.</i>
What did you already try to do about the challenging behaviour?
<i>Removing other residents from the living room</i>

Case 2: Mrs. V.

The detection form for Mrs V showed symptoms of agitation, depression, apathy, and night-time disturbance. Care staff filled out their analysis form, through which it became clear that Mrs V often complained of feeling nauseated and refused the care that was being offered (Box 3). The physician had already ruled out physical causes so the care staff sent their form to the psychologist. After looking through the file on Mrs V, the psychologist decided to further analyse the behaviour in a meeting with the member of the care staff responsible for Mrs V and in a one-to-one meeting with Mrs V herself.

It became clear that Mrs V was an insecure woman who needed lots of confirmation and structure. Her memory and executive functioning were severely impaired, making it hard to take stock of situations. Her feelings of insecurity and fear of failure expressed themselves in feeling sick. Mrs V did not seem to be clinically depressed. The psychologist advised the care staff to offer structure by, for example, explaining each small step of the process of getting dressed in the morning. It was also important that Mrs V be persuaded to undertake pleasurable activities (and if the problems persisted, a thorough examination of her personality might be appropriate).

The advice was written down in a treatment plan and on the treatment form a clear goal was described ('Mrs V complains of feeling sick no more than three times a week'). The evaluation date was set for 1 month later, after which it seemed Mrs V was feeling better and the situation had become more acceptable for both the care staff and Mrs V herself.

Box 3: Questions from the care staff analysis form of Mrs V.

Could you describe the behaviour?(what do you see, what is problematic about the behaviour?)
<i>In the morning, MrsV. complains she is feeling nauseated. She refuses care at such moments.</i>
How often is this behaviour apparent?
<i>Every day</i>
For whom is this behaviour challenging (resident/family carer/care staff/other residents)?
<i>Both for mw. herself and for care staff</i>
At which time points does the behaviour occur?
<i>In the morning and during the day</i>
Are there situations in which the behaviour does not occur?
<i>Sometimes it helps if you provide clear information and direction</i>
What could be the cause of the behaviour?
<i>Psychological?</i>
What did you already try to do about the challenging behaviour?
<i>We consulted the physician and have talked about it with her. There was no effect, we can not find out why she is feeling this way</i>

Discussion

The national and international guidelines that were used to develop the care programme clearly follow the currently prevailing view that challenging behaviour should be seen as a symptom of an underlying problem rather than a direct result of cognitive and organic deterioration. Algase et al.²¹, Cohen-Mansfield²², Kovach et al.²³, and others have proposed that challenging behaviour is an expression of distress that arises from physical or psychological unmet needs, and that finding and resolving the unmet needs should be the focus of treatment. In yet another model—the model of lowered threshold—it is assumed people with dementia are more vulnerable to environmental stimuli, which makes them experience more stress than other elderly people²⁴. When the threshold of stress is exceeded, symptoms of challenging behaviour may appear. The adaptation-coping model of Droëts²⁵ focuses on the coping process of people with dementia and explains challenging behaviour as a (possibly improper) way of adapting to the situations that arise from being cognitively impaired. These models do not exclude one another but rather are supplementary to each other. In accordance, the care programme contains aspects of the different models and emphasises thorough and complete analysis of the behaviour, situation, and environment. Two earlier attempts to introduce a more structured multidisciplinary approach to challenging behaviour showed positive effects^{26;27}. However, both of these studies involved consulting external professionals. The Grip on Challenging Behaviour care programme provides a way for DSCUs to manage challenging behaviour in a structured way and with a multidisciplinary approach by making better use of their own resources, as a result of which the care programme is more likely to be embedded in usual care.

Limitations

There are some limitations to the care programme. It was based on Dutch guidelines on challenging behaviour in dementia in long-term care, which presume that both a psychologist and a physician are available for analysing and treating the behaviour. Although it is preferable that a psychologist be involved in the process of managing behaviour, not every long-term care facility has this option. In these cases, an external geropsychologist should be consulted. If another discipline with expertise on challenging behaviour was involved, it would be prudent for this discipline to use the extra form for extensive exploration of the behaviour. Also, in the training sessions prior to implementation of the care programme, extra attention should be given to the analysis being performed by a different discipline to psychology.

In addition, the development process was supported by consulting a group of experts on challenging behaviour. Although this consultation and the background of the authors gives the care programme external validity, the validity is based on the Dutch situation. Translating the care programme for international use might require some culture-specific adaptations.

Conclusion

Because the published guidelines were not being sufficiently used in daily care, the Grip on Challenging Behaviour care programme was developed as a way to structure the management of challenging behaviour on DSCUs. The programme consists of four steps: detection, analysis, treatment, and evaluation. Initial implementation indicates that the use of the care programme can indeed support DSCUs in structuring the management of challenging behaviour and can relieve some of the burden on care staff.

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Chapter 4

Coming to grips with challenging behaviour.
Process evaluation of the implementation of a
care programme.

Abstract

Background

The Grip on Challenging Behaviour care programme for managing challenging behaviour was implemented on the Dementia Special Care Units of 17 Dutch nursing homes. A process evaluation of the implementation of the care programme was performed to determine the quality of the implementation and the lessons to be learned for future implementation.

Methods

The care programme was implemented according to a stepped wedge design. First order data (data on recruitment, reach, relevance and feasibility) were used to determine the validity of the study, second order data (intervention quality and the barriers and facilitators for implementing the care programme) were used to describe the implementation process. Two structured questionnaires were administered to care staff and key stakeholders and semi structured interviews were held on the units.

Results

University affiliated and non-affiliated nursing homes from different parts of The Netherlands participated. The resident participation rate was over 95% and the participation rate for the trainings sessions was 82%. Respondents considered the care programme relevant and feasible. The degree of implementation was not optimal. The barriers and facilitators in implementing the care programme could be divided into three categories: organisational aspects, culture on the unit and aspects of the care programme itself.

Conclusions

The recruitment, reach, relevance and feasibility are sufficient to allow for analysis and generalisation of the effects of the care programme, but the degree of implementation should be taken into account in further analysis. Future projects that involve implementation should consider the specific features of the organisation and the cultural orientation of the unit to better adapt to specific needs.

Trial registration

The Netherlands National Trial register, under number NTR 2141, registered on 11-dec-2009. Randomisation took place in November 2010, the first intervention group started using the intervention in February 2011.

Background

Challenging behaviour, like aggression or wandering, is a major issue in nursing homes for people with dementia. Over 80% of residents of dementia special care units (DSCUs) show some form of challenging behaviour¹, which effects both the quality of life of residents² and the (mental) health of nursing staff³. A structured way to detect, analyse, treat and evaluate treatment of challenging behaviour is often lacking⁴. Therefore, in the Grip on Challenging Behaviour study, a care programme was developed that offers a stepwise and structured approach to the management of challenging behaviour⁵. To determine the effects of the care programme, it was implemented on several Dutch nursing home wards.

In the nursing home setting, much effort is being put in improvement of care. Next to the Grip on Challenging behaviour project, projects to improve care for residents with depression, to improve medication administration, to prevent pressure ulcers and to better detect and treat pain are just a few other examples of recent attempts to establish evidence based care of high quality⁶⁻⁹. Implementing such new interventions in nursing homes is difficult, for the structure and culture of the nursing home setting is complex and heterogeneous. Therefore, as several researchers pointed out already, information about the degree of implementation in such studies is crucial for their credibility^{6;10;11}. For example, in all of the intervention studies mentioned above, the implementation of the strategies to improve care was complicated and not always completely successful, which has implications for both the interpretation of the trial results and the implementation in actual practice. After all, if a study lacks internal validity (either due to insufficient sample size or poor implementation of the intervention), analysis on the effects will be meaningless⁶. Also, knowledge on sampling and the quality of the intervention is important for the applicability of the findings in clinical practice. For clinicians and policy makers, applicability in practice and knowledge on implementation barriers and facilitators are of critical importance in their decision making. In other words, to ascertain true contribution of the intervention to actual practice, a process evaluation of the implementation of the Grip on Challenging Behaviour care programme is needed.

Although there is no consensus about the ideal method, several attempts have been made to make a general framework for process evaluation of implementation of interventions^{10;12;13}. Generally, these frameworks include ways to determine both internal validity (e.g. recruitment of participants, reach of the intervention, actual use of the intervention) and external validity (e.g. feasibility, acceptability). Recently, Leontjevas et al⁶, following earlier theories on process evaluation of implementation of interventions^{11;14;15}, proposed a model of first and second order process evaluation, which distinguishes between first order process data that assess sampling and intervention quality (internal and external validity; relevant for analysing effects and interpreting of results) and second order process data that concern knowledge on the barriers and facilitators for the implementation of the intervention (relevant for future implementation)⁶. For this paper, this model of first and second order process evaluation will be used to report about the implementation of the Grip on Challenging Behaviour

care programme. The aim of this paper is to determine the internal and external validity of the research conducted and to gain knowledge on barriers and facilitators for future implementation.

Methods

The process evaluation for Grip on Challenging Behaviour was conducted during the implementation and the research into the effects of the care programme. The methods of the effect study are described in detail elsewhere⁵.

Design

The care programme was implemented according to a stepped wedge design. By using this design, the participating Dementia Special Care Units (DSCUs) were randomly assigned to five intervention groups, which received the intervention at different time points. Measurements on challenging behaviour, quality of life, psychoactive drugs and restraints took place every four months as part of the effect study; after each measurement a new group of DSCU's was trained and started to use the care programme (Figure 1). This resulted in a measurement period of 20 months (February 2011- October 2012); after 16 months all DSCUs used the care programme.

Ethics

The study protocol⁵ is in accordance with the declaration of Helsinki, with the Dutch legislation on medical research and it is in agreement with the Conduct Health Research of the Dutch federation of Biomedical Scientific Societies. The Grip on Challenging Behaviour study was approved by the Medical Ethics Review Committee of the VU medical center. In accordance with Dutch legislation, the study can be performed without a review procedure by the committee and without obtaining informed consent of the (representatives of) the resident, because in the study, only observational data gathered by nursing staff as part of their daily work were used. However, all legal representatives of the residents were informed about the study and were given the opportunity to object to data of their proxy being used for research purposes at any time during the study.

The participants for the interviews on the implementation of the care programme gave their informed consent for being audiotaped and for their statements being used in the evaluation of the implementation.

	T0	T1	T2	T3	T4	T5
Group 1	0	1	1	1	1	1
Group 2	0	0	1	1	1	1
Group 3	0	0	0	1	1	1
Group 4	0	0	0	0	1	1
Group 5	0	0	0	0	0	1

Figure 1: Stepped Wedge Design.

0 = Control Condition (usual care)

1 = Intervention (care programme) Each Group Consists Of Three or Four DSCUs.

Participants

Although Dutch nursing homes typically house older people with mental or physical disabilities, they differ in, for example, the way care is organised, staff-patient ratio and employment of various disciplines^{16;17}. In the Netherlands, nursing home care is divided in care for people with predominantly somatic illnesses (somatic units) and care for people with dementia or dementia-like disorders (dementia special care units). Most nursing homes contain both somatic units and dementia special care units. For this research project, only dementia special care units (DSCU) of regular nursing homes were approached for participation.

On these DSCU's, care is provided by nursing staff with different levels of training in caregiving. Nursing assistants (who have completed two years of training on caregiving and supporting people with personal care and housekeeping) are involved in daily care tasks, like helping residents in and out of bed and assisting them with toileting. Certified nurse assistants (who have completed 3 years of training on caregiving and nursing skills) are also involved in medical care, like wound care and administering medication. Certified nurse assistants can also be certified to function as a responsible contact person for the resident, who is involved in the development and implementation of the individual care plan. A team leader (a registered nurse or a certified nurse assistant who also completed management training) is responsible for the day to day functioning of the care team. A psychologist and an "elderly care physician"¹⁸, who have a permanent position in Dutch nursing homes, are also part of the care team. Also, in some nursing homes, a registered nurse is also part of the care team. For the Grip on Challenging Behaviour care programme, every member of the care team (psychologist, physician, team leader, nursing staff) was invited to the training sessions, regardless of education level (trainees and temporary staff were also invited).

For each participating DSCU, a contact person was appointed whom the researchers could contact for updates on the implementation process and who could be contacted to make appointments for interviews. In most cases, the team leader was the contact person, but

the psychologist of the DSCU or one of the care staff members with an executive function could also function as contact person.

The care programme

The Grip on Challenging Behaviour care programme consists of four steps (Figure 2). The full content of the care programme is described elsewhere¹⁹.

The first step is detection. Challenging behaviour is usually detected by the care staff and reported to either the psychologist or the elderly care physician. In the care programme, this is called 'spontaneous observation'. To prevent challenging behaviour being overlooked, the use of a screening tool is also outlined in the care programme. Every six months, prior to the multidisciplinary care meeting, the care staff fills in the Neuropsychiatric Symptoms Inventory questionnaire (NPI-Q)²⁰ to detect challenging behaviour.

The second step is analysis. When care staff detects challenging behaviour (either spontaneous or via the screening tool), the care programme assists care staff to conduct a structured analysis by a form containing various questions concerning the challenging behaviour (e.g. what does the behaviour look like, to whom is it challenging, where does it take place, etc.). It was emphasised in the training that every care staff member could spontaneously detect signs of challenging behaviour. Once the analysis starts, the certified nurse assistant who is the responsible contact person for that resident gets involved and agreements are made about who should be involved in the follow up process. Next, the care staff calls in and hands over their filled in form to either the elderly care physician when they suspect a physical cause of the behaviour, or to the psychologist in case a psychosocial cause is more likely. Within the care programme, both the physician and the psychologist have their own analysis form, based on the guidelines of their own discipline. The physician and psychologist can consult or refer to one another if necessary. The analysis ends with a thorough description of the behaviour and the probable causes.

The third step is the treatment. Treatment should be focused on the (probable) causes identified during the analysis and can exist of various components, like education, psychosocial support, treatment of physical causes, psychosocial interventions, etcetera. The treatment plan consists of a treatment goal, the interventions to obtain this goal and the planning of an evaluation. The treatment plan is outlined on the treatment form and the current situation is rated on a ten point visual analogue scale. The rating scale is not an objective tool but it can be used to quantify feelings of severity of both the behaviour and/or the disruption it causes (i.e. resident does not pace at all = 1 – resident is constantly pacing = 10). At the bottom of the form, the evaluation date is planned.

The fourth and final step is the evaluation. The care programme provides a flow chart that should be passed through during evaluation. Again, the current situation is rated on a scale from 1 to 10 to see if there is any improvement.

At the start of the implementation, all care staff, including the psychologist and physician receive a total amount of one day training (split up in two sessions). In the training, causes and mechanisms of challenging behaviour are discussed and the use of care programme is explained.

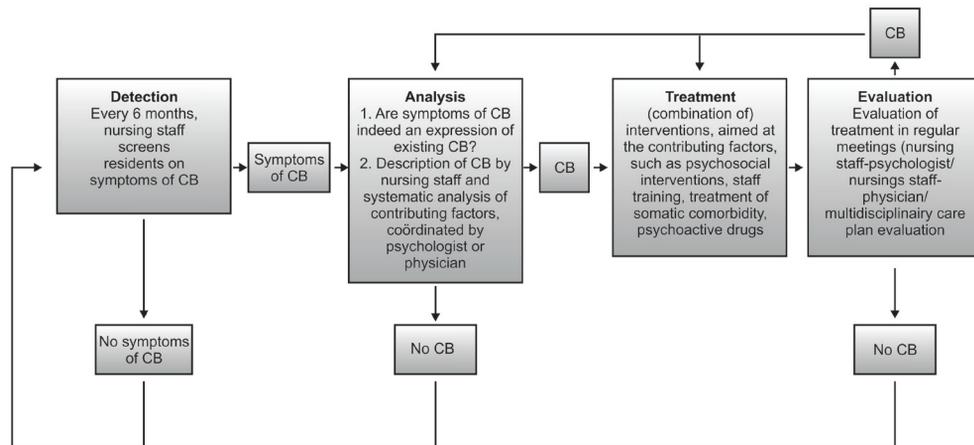


Figure 2: Outline of the Care Programme; CB= Challenging Behaviour

Process evaluation

As described earlier, the model of first and second order process data described by Leontjevas et. al.⁶ was used to conduct the process evaluation (Figure 3). First order process data consider the sampling quality (recruitment, randomisation and reach; external validity) and the intervention quality (relevance and feasibility of the care programme and the extent to which the programme was implemented; internal validity), second order data consider information on implementation (implementation components delivered and received and barriers and facilitators). Ideally, first order data should be evaluated before analysis of the actual effects of an intervention since the outcome of this evaluation can be used to correct or complete the analysis. Second order process data are more important for future implementation research and future implementation of the care programme. Although it is possible to evaluate second order process data in a later stage, in this paper both first and second order process data are presented together in order to get a complete picture of the implementation and the quality of the trial.

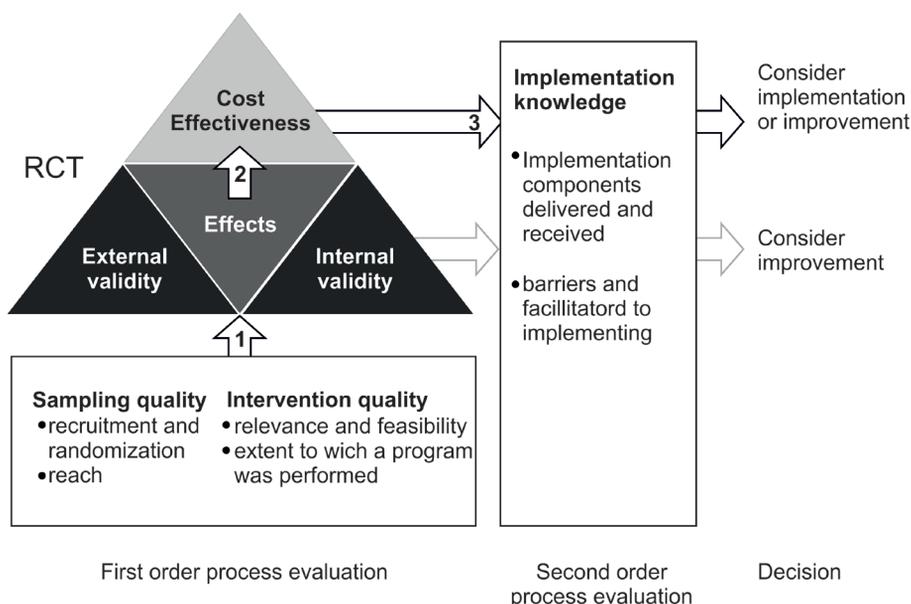


Figure 3: Framework of the First and Second Order Process Evaluation.

Sampling Quality: Description of recruitment and randomisation procedures and attendance rate of the training sessions. *Intervention Quality:* Indicators for feasibility and relevance of the care programme and measurement of the use of the separate steps in the care programme. *Implementation Knowledge:* Description of the number of implementation components provided and received and a description of the factors that (could) have influenced implementation. If first order process data confirm the validity of the study (1), effect and cost-effectiveness analysis may be used (2), together with implementation knowledge (3), for further implementation or improvement of the care programme. If validity is limited, implementation knowledge might be used to improve the care programme. This figure is adopted from Leontjevas et al.⁶

First order process data

The sampling quality was determined by a description of the recruitment of the DSCUs, the DSCU randomisation procedure and the reach (proportion of care staff receiving the training). The intervention quality (relevance, feasibility and extent to which the programme was performed) was determined with two separate questionnaires. After the second and third measurement in the effect study, the certified nurse assistants who were first contact persons for particular residents that were in the first and second intervention group (7 DSCUs) received a short questionnaire (Q1) (n=56) about their expectations and appreciation of the care programme (relevance and feasibility). The questions used for this evaluation were 'what do you think of the structure of the care programme (bad, not good, good, very good)?' and 'how much faith do you have in the care programme being able to decrease challenging behaviour on your DSCU (rating 1 to 10, 1 no faith at all; 10 being convinced the care programme will be able to decrease challenging behaviour)'. Next to this, a more extended digital questionnaire (Q2) was distributed among all team leaders, psychologists and elderly care physicians at the end of the study (n=48, representing 16 DSCUs, the 17th

DSCU moved to another location during the study and was therefore not included in any further analyses). This questionnaire contained items with pre-arranged answer categories (e.g. in which percentage of all cases with challenging behaviour, is this form used?: <25 %; 25-50%, 50-75%, >75%) and items with an open response (e.g. what were the barriers for implementation?). People either filled in the questionnaire themselves or it was filled by one of the researchers who held a telephonic interview with those participants who had not yet responded to the written invitation to fill in the questionnaire. Q1 and Q2 were both based on earlier research of Leontjevas et al.⁶. Descriptive functions of SPSS 20.0²¹ were used for analysis of the data.

Second order process data

Two methods were used describe the second order process data of implementing the care programme. The extended questionnaire described above (Q2) also contained open questions about the barriers and facilitators in implementing the care programme. Next to this, one of the researchers (SZ) held interviews for evaluation purposes with staff of the participating DSCU's. For the interviews, a topic list was used which contained topics on the feasibility and implementation of the several different steps of the care programme and on the implementation process of the care programme as a whole. The interviews took between 10-45 minutes (depending on the involvement of the participant in the implementation process). In total 51 interviews were held with 29 members of nursing staff (nursing assistants and certified nurse assistants), one recreational therapist, 12 physicians, 15 psychologists and 7 team leaders (some interviews were held with more than one person). All these interviews were audio taped and transcribed verbatim. Two of the researchers (SZ and MS) analysed the open questions in Q2 on reoccurring themes with regards to the barriers and facilitators in implementing the care programme. Subsequently, directed content analysis was used to confirm the themes that were found in Q2 in the transcripts of the interviews²².

Results

First order process data

Sampling quality

Recruitment and randomisation

The University Network of Organisations for Care for the Elderly of the VU university medical center (UNO-VUmc) and the University nursing home network (UKON) of the Radboud University Nijmegen Medical Center invited the affiliated nursing homes to let one of their

DSCUs participate in the research project. The UNO and UKON networks consist of 32 care organisations. 7 were not invited because they were already involved in other research projects. 13 organisations did not respond, whereas 12 did. To gain enough participants, convenient sampling was used to recruit 8 other nursing homes.

Of the twenty organisations that responded, four organisations eventually decided not to take part, because of organisational changes in the nearby future (3), or because of involvement in another new approach for management of behavioural problems (1). The participating organisations were free in selecting one of their DSCUs for participation, although DSCUs for special groups (e.g. Korsakov, Young Onset Dementia) were excluded. Of the participating DSCUs, nine were located in the densely populated Randstad area of the Netherlands, the other eight were situated in less densely populated areas (Noord-Brabant, Gelderland and Friesland) (Figure 4). All DSCUs were split up in several shared living rooms in which a group of residents had their regular place. The mean size of the DSCU was 29 residents [min 18 max 43] and a mean number of 11 [min 6 max 19] residents resided in one living room. One DSCU dropped out after T4 because it moved to another location. All other units participated in the study from T0 until T5. Randomisation took place using random allocation software²³ in November 2010. To avoid contamination, block randomisation was used for two DSCUs which were part of one larger organisation (the two units were entered as one in the software). All the 15 other DSCUs stemmed from separate organisations.



Figure 4: Map of the distribution of participating DSCUs amongst The Netherlands

Reach

Legal representatives of the residents were informed about the research project and the possibility to object to the use of observational data of the resident through a folder and a letter from the DSCU leader. This resulted a participation rate of minimum 89% (42/47), maximum 100% . All residents were included in the implementation of the care programme, for the care programme was implemented on unit level rather than on resident level.

Before the start of the intervention, the contact person of the DSCU provided a list of all care staff working at the DSCU. All staff was invited to the training, which was made compulsory by the DSCU leader. Care staff received a certificate when he or she had participated in both the trainings session, or when they had made up for their absence during one of the trainings sessions by reading the education material and gaining information through co-workers. In other words, when the researchers were convinced a staff member had obtained enough training to understand the background of the care programme and to be able to use the care programme in care practice, a certificate was granted. The participation rate was calculated by comparing the amount of invitations for the trainings sessions to the amount of certificates granted, this resulted in a mean rate of care staff of 81 % (SD 14, Range 34%-97%). With regards to the psychologists and physicians, all but three psychologists attended both trainings sessions, three psychologists attended one of the two sessions. All but five physicians attended both trainings sessions, four physicians attended one of two trainings sessions and one physician received information about the care programme in an individual session.

The main reasons for not participating were being on leave and illness.

Intervention quality

Relevance

Q1 had a response of 60% (9/15) on T1 and 56% (23/41) on T2. In response to the question 'What do you think of the structure of care programme?' one responder (3%) answered 'not good', 26 (81 %) responded with 'good' and five responders (16 %) answered 'very good'. The overall score for the confidence in the programme being able to diminish challenging behaviour on the DSCU was 6,6 (SD 0.9).

The response of Q2 was 85% (41/48 questionnaires, 35% telephonic interview, 65 % digital questionnaire, of which 1 person did not fill in the open questions about barriers and facilitators). The 15% that did not respond were either no longer working on the DSCU or they had only recently started working on the DSCU. Of each participating DSCU, at least two out of three 'key figures' (physician/psychologist/team leader) responded. On the question on satisfaction with the content of the care programme (0 = not satisfied, 1 = hardly satisfied, 2= slightly satisfied, 3 = satisfied, 4 = very satisfied), the most common answer was 'satisfied'(e.g median = 2).

Feasibility

Most responders of Q2 (27/41) stated that the care programme could be used in the currently available time. Some of the advantages about working with the care programme

that were mentioned were 'the process is more clear, there is more structure', 'better analysis of behaviour' and 'earlier detection, more attention for behaviour'. The most frequently mentioned disadvantage (23/41) was 'too many forms'. Some responders (12) also answered 'big time investment'. All but one responder would recommend the use of the programme to colleagues, although three responders stated that they would only advise on the use of some parts of the programme.

Extent to which the programme was performed

In Q2, responders were asked whether the forms of each step of the care programme were being used, and whether they used the care programme in all cases of challenging behaviour. This question (which % of all cases of challenging behaviour is treated according to the care programme?) was asked with regard to the analysis forms in step 2, the treatment form in step 3 and the evaluation form in step 4. The analysis form for care staff was best implemented, the treatment and evaluation forms were the least used form (table1).

Table 1: Use of the Forms of the Care Programme in case of Challenging Behaviour per DSCU (16 DSCUs, 41 respondents). (% of the residents with challenging behaviour, pre-arranged answer categories, answers derived from more than one key person on the DSCU).

	Never	<25%	25-50%	51-75%	>75%
Analysis care staff form	0	0	3	8	5
Analysis physician/psychologist form	0	2	2	10	2
Treatment form	2	6	4	4	0
Evaluation form	1	8	5	2	0

Second order process data

Implementation components

At the start of the intervention, two training sessions were held. In the first session information was given about causes and mechanisms of challenging behaviour and the use of the care programme was explained. The second session was held approximately two weeks after the first session. During these two weeks care staff had practiced using the care programme. In the second session, feedback about the use of the care programme was discussed.

To further facilitate the implementation, one of the researchers (SZ) arranged evaluation sessions with the involved care staff, DSCU leader, psychologist or physician. In these evaluation sessions, barriers and facilitators in implementing the care programme were discussed and tailored communication was used to improve implementation on the DSCU ²⁴.

Every DSCU was visited at least one time for an evaluation session, the follow up of this session could be either by phone, email, or with another evaluation session, depending on the degree to which the implementation was already successful. In total, 45 evaluation sessions with tailored communication were held (min. 1 max. 5 per DSCU).

Also, one of the researchers (SZ) could be contacted via phone or email if there were any questions with regards to the care programme. This option was rarely used; two psychologists and one team leader took the initiative in asking a question regarding the content of the care programme via email. Phone and email were mostly used for requests to send more forms.

Barriers and facilitators for implementation

From the answers on open questions in Q2, several categories of barriers and facilitators emerged, which were confirmed in the analysis of the transcripts of the interviews. The categories can be divided in three themes: organisational aspects, culture DSCU and the lay-out of the care programme.

Organisational aspects

Staff turnover

It became apparent from the interviews that staff turnover rates could influence the implementation process. Staff turnover sometimes resulted in situations in which only a part of the team was truly well informed about the care programme. Although attempts were made to train new staff members, the situation remained suboptimal. While the turnover of nursing staff had adverse consequences, the change of DSCU leader, psychologist or physician was even more detrimental, for they had a leading role in implementing the care programme. When these key stakeholders were absent for a period, there was often a drop in attention for implementing the care programme. When key stakeholders were then replaced, the new person would often need time to really get acquainted with the use of the care programme as well as all other methods used on the DSCU, which greatly slowed down the implementation. Overall, there were no DSCUs without change in key stakeholders. There was an overturn of 2.64 in key persons (range 1-6) per DSCU. Absence or change of these key persons was a real barrier in implementing the care programme, as this psychologist points out in one of the interviews:

Psychologist:

Well, for example, I drew up a plan for this lady. And in my absence, a physician, a new physician, just crossed right through it.

High workload

High workload and time being scarce was often mentioned as one of the barriers in implementing the care programme. Although opinions differed on the amount of time the care programme would really cost once implemented, it was obvious that having to learn to work according to the care programme would cost some time, which was, in the eyes of care personnel, not always available.

Nurse:

But we work under a constant lack of time and staff shortage. And these kinds of things are the first to slip through then.

Psychologist:

Yes, well, really the time pressure, yeah that's it. And then also my own involvement... I realise I'm not at the unit very often and I kind of feel like, please don't use it [the care programme], because I can't handle anything extra at the moment. And well, I think that is alarming, because that is a very ambiguous signal that you are sending

Concurrent and former projects

It appeared that implementation of the care programme was easier on DSCUs that rarely initiated new projects. Key persons of these DSCUs stated that being cautious not to adapt too many new projects helped in keeping care staff motivated when a new project was proposed. In contrast, some DSCUs were involved in several new projects, like implementing electronic health records for all residents or using new forms for quality improvement on the DSCU. This seemed to interfere with implementing the care programme, for time is already scarce. Also, some of the staff members of those DSCUs expressed skepticism about new projects. They had seen many new projects come and go during the last years, many of which did not cause relevant improvement to daily care.

Psychologist:

Yeah, well, it makes a difference that we are not, well, this is a fairly new location, where they have not started up all kind of new projects, which does make a difference you know.

Multidisciplinary meetings

For the care programme to work properly there has to be a structure in which physician, psychologist and care staff meet each other regularly. Although this happens during the (obligatory) multidisciplinary care meetings, it was a precondition for implementing the care programme that there would be extra time in which the forms of the care programme would be discussed. In reality, this precondition was not always met. The working hours

of the physician or psychologist did not always correspond with each other or with the care staff that filled in the form. Because of the lack of contact between disciplines, it sometimes occurred that disciplines were simultaneously treating one resident without knowing this from each other and with one of the disciplines not using the care programme. Also sometimes, when care staff filled in an analysis form, it took many weeks before a psychologist or physician was able to respond to it, which was not stimulating for care staff to fill in more forms in the future.

Organisational changes

During the implementation of the care programme, some of the DSCUs encountered minor or major organisational changes. For example, on one of the DSCUs there were plans at hand that would change the position several staff members had. Another organisation changed their management structure, which caused changes in responsibilities and duties of DSCU leaders. Such changes cause turmoil on DSCUs which interfere with the implementation of the care programme.

4

Culture of the organisation/DSCU

Support of key persons

For a rapid and solid implementation process it was important that key persons like physicians, psychologists and DSCU leaders functioned as 'team champions' in supporting the use of the care programme²⁵. These team champions could support the implementation by embracing the care programme and emphasising filling in the forms when care staff reports challenging behaviour, by reporting back on the forms or helping filling in the forms when care staff found it difficult. Without one or more key persons taking the lead on implementation and on stimulating the care staff to use the forms, it was very difficult to keep everyone focused on using the care programme. Also, support of higher management of the organisation, for example by calculating in extra time, facilitated the implementation, because more time and understanding was available during implementation.

Attitude towards change

In the individual interviews, some respondents stated that their team was very open to a new method in managing behavioural problems. These teams often seemed to be motivated to start working with the Grip on Challenging Behaviour care programme. On other DSCUs, respondents observed there was more reluctance in changing current routines and procedures. This was also noticed by DSCU managers and sometimes by psychologists and physicians.

Certified nurse assistant:

People are often stuck in the old system. They do not always want to try out new things. But if you save time later on, that affects the resident I think.

Aspects of the care programme

The care programme was not digitally available

Some of the organisations of which the DSCUs were part had recently transferred to using electronic health records. Part of this transfer was to eliminate all paper files and forms, as to create one method of working. Because the digital systems are different for almost each nursing home, it was not possible to provide one general digital version of the care programme and it was therefore only provided in a paper version. For those DSCUs that only had a digital administration systems, the paper forms of the care programme became easily forgotten. Also, the work method of using forms did not fit in with the normal working methods, which was a barrier for the implementation.

Many forms

The care programme consists of eight different forms (detection tool, three analysis forms (nursing staff, psychologist, physician), an extra analysis tool for the psychologist, a treatment form, an evaluation form and one agenda form to overview the process). Although the use of the forms was separated by different disciplines and time periods, many respondents complained that at first sight, the amount of forms was overwhelming and that this made it tempting to discuss behaviour informally or via email instead of starting filling in an analysis form. When asked, however, respondents often stated that almost all forms were useful and filling in the forms did not take much extra time after all. Even so, merely the first impression and the prospect of having to fill in the forms did hinder the implementation.

Teamleader:

The only thing that does not really work as an advantage, although you do really need all, is the number of forms. And I think that when you just put it out there, like 'these are the forms...' that that can scare people off.

Discussion

The aim of this paper was to describe the process of implementing the Grip on Challenging Behaviour care programme in 17 dementia special care units (DSCUs). The model of Leontjevas et al.⁶ was used to evaluate both first order and second order process data.

First order process evaluation

Data on the sampling quality show that the participation rate of residents and the rate of staff receiving training sessions was over 80%. The 17 participating nursing homes were not randomly selected, but the variance in size and location allow for generalisation of the study effects²⁶.

The respondents considered the structure of the care programme to be good and they generally believed the care programme could diminish challenging behaviour on their DSCU. The actual degree of implementation was not optimal; in only a small percentage of the DSCUs, all forms of the care programme were used and none of the DSCUs used all forms in all cases of challenging behaviour. Obviously, the later steps in the process are the first to be omitted, as earlier research on a stepwise approach to depression also confirmed⁶. In contrast, all DSCUs used at least the first two steps of the care programme, detection and analysis, which probably still resulted in adjustment in the individual care plan although the treatment form was not used.

The degree of implementation should be considered in the analysis. If possible, analysis should be corrected for degree of implementation or subgroup analysis should be performed to analyse differences in effects for different degrees of implementation.

Second order process evaluation

The Grip on Challenging Behaviour care programme was developed as a practical tool that meets the needs of those working with challenging behaviour in nursing home care. Although education theory emphasises that professionals are more prone to adapt innovation when it is based on problems they encounter in actual practice²⁷, the implementation of the care programme was not optimal. Despite the use of several implementation strategies (training, tailored communication, phone and email support), analysis of the second order process data identified various barriers in implementing the care programme.

Organisational aspects influenced the ease with which the care programme was embraced on a DSCU. Staff turnover, high workload, concurrent projects, cancelled meetings and organisational changes were described as barriers for implementing the care programme. It is not the first time these organisational factors were found to be of influence on the implementation of an intervention in nursing home care⁷. It seems that, although the extent of the project and the time investment is explained before the start of the project, the decision to participate in a project is often made by managers, without consultation of team

members of the DSCU. This top-down decision making process might lead to an imbalance between the admittance of the care programme in the policy of an organisation and the possibilities of actual implementation on a specific DSCU. For example, most DSCU leaders know the turnover rates and the amount of care staff working on temporary or flexible contracts on their DSCU. The absence of a permanent care staff team makes it almost impossible to implement any changes in the nursing home setting. It thus seems of great importance to consult not only the management team of an organisation, but also the DSCU team that is involved in the implementation of the care programme in the decision making process. Although it is impossible to be ahead of all future organisational changes, the DSCU team can assess the possibility that organisational aspects like staff turnover and concurrent projects will form barriers in implementation.

Organisational aspects thus sometimes appeared to be a barrier in implementing the care programme. The culture on the DSCU and organisational aspects like staff turnover, organisational changes and involvement in concurrent projects strongly interact. Not surprisingly, the interviews showed that DSCU culture could also form a barrier as well as a facilitator in the implementation process. The way in which care staff dealt with the introduction of the care programme can be explained through the four cultural orientations that can be distinguished from the competing values framework^{28;29}. The first, group culture, is characterised by strong social relations and an internal focus. This type of culture might be linked to the reluctance to change found in some DSCUs, since DSCUs with a group culture are focused on the internal organisation of the team rather than on improving and changing working methods by adapting an external method²⁹. The DSCU teams that were enthusiastic to start working with the care programme seem to have a more open attitude towards change and welcomed external input, which is characteristic for the second cultural orientation, developmental culture. Rational culture is control oriented and focuses on productivity and achievement. There were no DSCUs characterised by this orientation, which might be only logical in a non-profit organisation. Finally, hierarchical culture emphasises stability and is characterised by uniformity, internal efficacy and a close adherence to rules and regulations. For DSCUs with this orientation, the attitude of the key persons in implementing the care programme is crucial. Earlier research on implementation of a multifaceted intervention in nursing homes also showed that having a team champion, e.g. someone who is passionate about the use of the care programme, has a substantial impact on the effectiveness of a team to adapt innovation⁹. Implementation indeed seemed to be facilitated when an enthusiastic key person was willing to commit to the care programme and that absence or departure of such a team champion seriously impacted the implementation process.

Finally, two aspects of the care programme formed a barrier in the implementing the care programme. The number of forms to be filled in scared some people off. Also, a digital version of the care programme would have been more appropriate for some DSCUs. For future implementation of the care programme, a reduced number of forms (i.e. merging some forms together) and digitalising of the forms should be considered.

Conclusion

The first order process data allow analysis of the effects of the care programme, although the degree of implementation should be considered. With regard to the second order data, the barriers in implementing the care programme can partly be overcome by reshaping some components of the care programme, but the major implementation issues consider the organisational culture of the DSCUs. Future projects that involve implementation should involve leaders of care teams in the decision to participate. It would also be well-advised to perform a diagnostic analysis²⁷ of organisational aspects and organisational culture before the start of the project, as to better adapt to the specific needs and possibilities within an organisation.

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Chapter 5

Coming to grips with challenging behaviour:
A cluster randomised controlled trial on the
effects of a multidisciplinary care programme for
challenging behaviour in dementia.

Abstract

Objectives

The Grip on Challenging Behaviour care programme was developed using the current guidelines and models on managing challenging behaviour in dementia in nursing homes. It was hypothesised that the use of the care programme would lead to a decrease in challenging behaviour and in the prescription of psychoactive drugs without increase in use of restraints.

Design

A randomised controlled trial was undertaken using a stepped-wedge design to implement the care programme and to evaluate the effects. An assessment of challenging behaviour and psychoactive medication was undertaken every four months on all participating units followed by the introduction of the care programme in a group of three to four units. A total of six-time assessments took place over 20 months.

Setting

17 dementia special care units of different nursing homes.

Participants

659 residents of dementia special care units. All residents with dementia on the unit were included. Units were assigned by random allocation software to one of five groups with different starting points for the implementation of the care programme.

Intervention

A care programme consisting of various assessment procedures and tools which ensure a multidisciplinary approach and which structure the process of managing challenging behaviour in dementia.

Measurements

Challenging behaviour was measured using the Cohen-Mansfield Agitation Inventory (CMAI) and the Neuropsychiatric Inventory (NPI). Research assistants (blinded for intervention status of the unit) interviewed nurses on the units about challenging behaviour. Data on psychoactive drugs and restraints were retrieved from resident charts.

Results

A total of 2292 assessments took place involving 659 residents (1126 control measurements, 1166 intervention measurements). The group of residents who remained in the intervention condition compared to the group in the control condition differed significantly in the CMAI change scores between successive assessments (-2.4 CMAI points, 95%CI -4.3 to -0.6). No significant effects were found for the control-to-intervention group compared to the group who remained in the control group (0.0 CMAI points, 95%CI -2.3 to 2.4). Significant effects were found on five of the twelve NPI items and on the use of antipsychotics (OR 0.54, 95% CI 0.37 to 0.80) and antidepressants (OR 0.65, 95%CI 0.44 to 0.94). No effect on use of restraints was observed.

Conclusion

The Grip on Challenging behaviour programme was able to diminish some forms of challenging behaviour and the use of psychoactive drugs.

Background

Challenging behaviour is very common in nursing homes; over 80% of nursing home residents with dementia show one or more forms of challenging behaviour¹. The presence of challenging behaviour in nursing homes diminishes quality of life of residents, is associated with the use of physical restraints, and results in higher costs²⁻⁴.

Although several effective psychosocial interventions have been developed⁵⁻⁷, the prescription of psychoactive drugs currently predominates the treatment of challenging behaviour^{8:9}. The effects of drugs on behaviour, however, are limited¹⁰. What is more, the adverse effects of this type of interventions can be very serious¹¹⁻¹⁴, which underlines the need for other, more effective and less harmful methods of managing challenging behaviour.

While prescribing psychoactive drugs or using restraints to control challenging behaviour is a relatively straightforward treatment, many current models emphasise that the management of challenging behaviour requires an analysis of the meaning of behaviour. In line with the work of Kitwood¹⁵ on the concept of person-centered care, Cohen-Mansfield proposed the model of unmet needs to explain the challenging behaviour of people with dementia¹⁶. A thorough analysis of those needs (which may have various causes such as physical illness, cognitive impairments, psychological needs or personality features) is needed to understand and diminish challenging behaviour. Other models place more emphasis on the influence of (environmental) stimuli. In the model of progressive lowered stress threshold, for example, it is assumed that people with dementia have more difficulty with processing environmental stimuli than healthy people, which makes them experience more stress than healthy elderly. When there are too much environmental stimuli, the stress threshold is exceeded and symptoms of challenging behaviour may appear. To prevent challenging behaviour, the amount of stimuli should therefore be adjusted to the processing capabilities of the person with dementia¹⁷. There has also been attention for explaining challenging behaviour as a result of the way in which people with dementia cope with the complex changes in life they experience¹⁸⁻²¹.

Understanding challenging behaviour as a symptom of underlying problems implies analysis and treatment should be focused on the biological, psychological or social factors that can help explain the challenging behaviour, rather than on the behaviour itself²². To achieve this, several professional disciplines (i.e. physician, psychologist, nursing staff, recreational therapist) should work together in determining the type of treatment needed and the goals to be reached, based on the underlying causes of the behaviour or on better techniques for care staff to cope with the behaviour. Current international and Dutch guidelines follow this view and state that the management of challenging behaviour in nursing homes should be undertaken as a multidisciplinary venture by using an individually tailored care plan that is based on thorough analyses of the behaviour and that consists of one or more psychosocial interventions combined with limited and non-permanent use of psychoactive drugs when indicated²³⁻²⁸.

The Grip on Challenging Behaviour care programme was developed using the current guidelines and models on challenging behaviour in dementia²⁶⁻²⁸. It structures the process of detection, analysis, treatment and evaluation of the treatment of challenging behaviour and pre-arranges multidisciplinary consultation. The care programme provides tools for multidisciplinary care teams that helps them in taking the right steps and asking the right questions to identify and, if possible, treat the underlying problem of the challenging behaviour²⁹. The aim of this study was to determine the effects of the Grip on Challenging Behaviour care programme. This paper reports on the effects that using the care programme has on challenging behaviour and on the use of psychoactive drugs and restraints.

Methods

Ethics

The full trial protocol has been published elsewhere²⁹. The study protocol is in accordance with the declaration of Helsinki, with the Dutch legislation on medical research and it is in agreement with the Conduct Health Research of the Dutch federation of Biomedical Scientific Societies. The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Centre. The committee stated that, in accordance with Dutch legislation, the study can be performed without a review procedure by the committee because in the study, only observational data gathered by nursing staff as part of their daily work were used.

Setting

In the Netherlands, nursing home care is divided into units for people with predominantly physical disorders (somatic units) and units for people with dementia (dementia special care units, DSCUs). For this study, only DSCUs were included. On these units a psychologist and an elderly care physician usually have a permanent position and work with care staff in a multidisciplinary team.

The care programme was introduced on 17 DSCUs of 17 different nursing homes in the Netherlands. The main hypothesis was that the use of the care programme would diminish challenging behaviour and the use of antipsychotics without a concomitant increase in the use of other psychoactive drugs and restraints. The study was registered in The Netherlands National Trial register, under number NTR 2141.

Design

A stepped-wedge design was used, which is considered appropriate when an intervention will probably do more good than harm and when there are practical and logistic constraints to implementing the intervention simultaneously to all participants³⁰, which is applicable to the Grip on Challenging Behaviour care programme. Practical and logistic considerations

(training and support of implementation of the units on different time points instead of all at once) also influenced the decision, but more important, the stepped-wedge design is far more efficient in terms of sample size than a traditional parallel analysis of covariance (ANCOVA) design³¹.

The participating care units were randomly divided into five groups by using random allocation software³². Challenging behaviour was assessed every four months for 20 months (February 2010-October 2012), resulting in six-time assessments. The first group was trained in using the care programme after the baseline assessment. The second group was trained after the next assessment point, and so on, resulting in all care units using the care programme at the time of the last assessment.

Sample size

The following assumptions were used in calculating the sample size. DSCUs house 20 residents on average, the prevalence of challenging behaviour is 80% and the mean CMAI score is 47.7¹. It was expected that 5% of the residents' (legal) representatives would not agree with the resident being enrolled in the research project. In the event a resident died or moved away from the unit, the new resident who was admitted instead was enrolled in the study so no further attrition was expected.

The Cohen-Mansfield Agitation Inventory (CMAI)³³, as the primary outcome, was used to calculate the sample size. Based on an earlier study of Chenoweth in which training and support on person-centered care was compared to dementia care mapping and usual care, it was expected that the Grip on Challenging Behaviour care programme would lead to a 10 point decrease on the CMAI³⁴. Based on a recent Dutch study in nursing home residents³⁵, a mean intra-class correlation coefficient of 0.1 was assumed for clustering of challenging behaviour within a DSCU.

Based on these assumptions and a significance level (α) of 0.05 (two-sided) and a power (β) of 0.80, at least 14 dementia DSCUs with six-time measurements were needed in a stepped-wedge design. Recruiting more than 14 DSCUs was preferred as the timeframe of the project (20 months) might have led to some DSCUs dropping out due to unforeseen circumstances, such as staffing problems or renovations.

Intervention

Grip on Challenging behaviour is an evidence- and practice-based care programme that consists of 4 steps: detection, analysis, treatment and evaluation (Figure 1). The most recent scientific knowledge and evidence-based guidelines were incorporated into the care programme. Expert meetings with nurses, psychologists and elderly care physicians were held to ensure fit between science and practice. Representatives of the professional

associations of nurses, psychologists and elderly care physicians were consulted in the development process of the care programme³⁶.

In principle, care staff detected challenging behaviour in daily care after which they commenced using the structured analysis form (as described below). To ensure that no signs of challenging behaviour were missed during daily observations, every six months (prior to the standard multidisciplinary meeting about the resident, which is compulsory in the Netherlands) the units' care staff filled in a screening tool to detect signs of challenging behaviour that they did not already address spontaneously. If signs of challenging behaviour were detected (either in daily care or by using the screening tool), a structured analysis form was used by the care staff. This form could also be used whenever signs of challenging behaviour were detected in daily care. Following this, the unit psychologist or the unit elderly care physician was called in to undertake further analysis. Both the physician and the psychologist had their own analysis form, based on and structured by the explanatory models of challenging behaviour and national guidelines. After the analysis was completed, the treatment goal, the outline of the treatment plan and an evaluation date - all defined in a multidisciplinary meeting with the involved disciplines - were filled-in on the treatment form. At the predetermined evaluation date, a multidisciplinary evaluation took place by using a flowchart on the evaluation form.

A full day of training was organised on the unit before the Grip on Challenging Behaviour care programme was implemented on a DSCU. The training was split-up into two sessions: one kick-off meeting in which the care programme was introduced and one follow-up meeting two weeks after the care programme was implemented on the unit. In the training session, several models regarding challenging behaviour were discussed and used to explain different forms of behaviour, such as the unmet-needs model, the model of progressive lowered stress threshold and the adaptation-coping model. Care teams were encouraged to think about their own residents and the behaviour of their residents in light of these models. Part of the training was also focused on the negative consequences of using psychoactive medication and on the alternatives to medication, in particular psychosocial interventions.

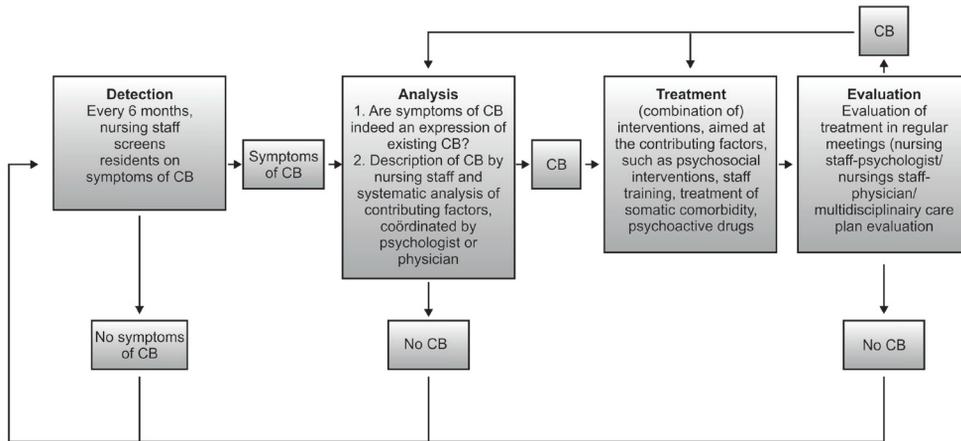


Figure 1: Outline of the care programme. CB = Challenging Behaviour

Participating DSCUs

Care organisations were approached by the University Network of Organisations for Care for the Elderly of the VU University Medical Center (UNO-VUmc) and the University Nursing Home network (UKON) of the Radboud University Medical Centre to allow one of their DSCUs to take part in the study. In addition, convenient sampling was used by one of the researchers (MS) to further invite nursing homes that were not affiliated with universities. The participating organisations were free to select which one of their DSCUs would take part in the research project, however units for special target groups (Korsakov patients, Huntington patients, etc.) were excluded. All residents with a diagnosis of dementia were included in the study.

Measurements

Primary outcome

The primary outcome for this study was challenging behaviour. There are different ways to define and measure challenging behaviour, but for this research project, every form of behaviour that may challenge the person with dementia or the people living with and/or caring for the person with dementia is considered 'challenging behaviour'²⁶. This means that both externalised behaviour like aggression or calling out as well as more silent behaviour like apathetic or depressive behaviour was considered as challenging behaviour.

As agitation and agitation-related behaviours are the most prevalent and persistent form of challenging behaviour³⁷, causing diminished quality of life and high caregiver burden^{38;39}, an instrument specifically focused on these behaviours was used, i.e. the Cohen-Mansfield

Agitation Inventory (CMAI)³³. The CMAI is a questionnaire containing 29 items regarding agitated behaviour. Each item may be scored from 1 (this behaviour never occurs) to 7 (behaviour occurring multiple times per hour).

To determine effects on other forms of challenging behaviour than agitation the Neuropsychiatric Inventory for nursing homes (NPI-NH)^{40;41} was used. The NPI-NH is a structured interview concerning 12 different domains of challenging behaviour. For each domain the severity and the frequency of the behaviour can be scored. The total score is the product of the severity and frequency score and ranges from 0-12. A total score of at least 4 is considered clinically relevant^{1;42}.

Both the CMAI and the NPI-NH have been translated into Dutch and have been found to be reliable and valid in Dutch settings^{41;43}.

The questionnaires were administered by interviewing the care staff member who was most involved in the daily care of the resident. The research assistants conducting the interviews were trained in administering the CMAI and NPI-NH questionnaires. The interview assistants were blinded for intervention or control status of the DSCUs. Neither the care staff members nor the psychologist or physician were informed about the CMAI and NPI-NH scores.

Secondary outcomes

Data on psychoactive drug use were retrieved from patient charts and classified according to the Anatomical Therapeutic Chemical (ATC) classification system⁴⁴. The drugs were categorised into antipsychotics (ATC code N05A), antidepressants (ATC code N06A), anxiolytics/hypnotics (ATC code N05B and N05C), anti-epileptics (ATC code N03) and anti-dementia drugs (ATC code N06D). The interview assistant also collected an up-to-date overview of (physical) restraints that were used on the unit. For analyses, the restraints were divided into four categories: bedrails, other night-time restraints (belts in bed, restraining blanket), daytime restraints (table-top, fixation in chair or wheelchair, geriatric chair, separation). Because of the ongoing debate on the ethical, legal and practical aspects of using surveillance technology in long term dementia care, the use of surveillance technology (movement sensor, bed exit alarm, chips in clothing) was also analysed as a separate 'restraints' category.

Other measurements

Characteristics of the residents (sex, age, and time of institutionalisation) were retrieved from the patient's charts. The units' elderly care physicians classified the type of dementia according to the DSM-IV⁴⁵ and they determined the severity of the dementia, using the Global Deterioration Scale (GDS)⁴⁶. This is a seven-point scale that describes seven stages from 'no global impairment' (1) to 'very severe global impairment' (7).

After the last assessment, a questionnaire about the degree of implementation of the care programme was distributed amongst the unit leader, the psychologist and the physician of the DSCUs. These key persons rated the percentage of cases with challenging behaviour they were currently treating by means of the care programme. The questionnaire contained four questions: in which percentage of the cases concerning challenging behaviour is: (1) the analysis form for care staff used, (2) the analysis form for psychologist or physician used, (3) the treatment form used and (4) the evaluation form used? Response categories were: never, <25 %, 25-50%, 50-75%, 75-100%. A score for the degree of implementation of the care programme was assigned to each DSCUs based on the questionnaire. When a DSCU consistently scored above average compared to the other DSCUs, they were categorised as 'good implementation (score = 3)', when a DSCU consistently scored below average they were categorised as 'poor implementation (score =1)'. DSCUs scoring variably were categorised as 'moderate implementation (score = 2)'.

The interviewed care staff were obviously aware whether their DSCU was in the intervention condition, which could potentially introduce information bias. It was assumed that determining whether the attitude towards the care programme is associated with CMAI scoring and determining whether the effect of participation in the training about the care programme is associated with CMAI scoring, could both provide an indication of the importance of this bias.

To determine whether the attitude towards the care programme is associated with CMAI scoring, the attitudes of staff members were investigated in the first two intervention groups at T1 and T2. The interviewed care staff member of the DSCU in the intervention group received a questionnaire containing 3 items:

- 1) Do you think the introduction of a care programme for managing challenging behaviour is necessary on your unit? (not at all necessary, hardly necessary, necessary, very necessary)
- 2) What do you think of the way the care programme has been set up (bad, not good, good, very good)?'
- 3) How much faith do you have in the care programme being able to decrease challenging behaviour on your unit (rating 1 to 10).

To determine whether the effect of participation in the training about the care programme is associated with CMAI scoring, differences between the CMAI scoring of the same residents scored by a care staff member who participated in the training session and was actively involved in the care programme versus care staff members who did not participate in the training were investigated.

Analyses

SPSS 20.0 was used for the descriptive analyses. For all other analyses, MLwin, version 2.26 was used. Mixed models were used to adjust for dependency of the repeated measures

over time within the individual residents and for dependency of the residents within the DSCU when necessary (e.g. when inter-correlations were significant; $p < 0.05$). No missing CMAI or NPI data were imputed.

Although the stepped wedge design has advantages in practical and logistic ways which were crucial for the realisation of the implementation of the care programme on 17 DSCUs, there are several viewpoints on the correct way to analyse data from stepped wedge designs^{47,48}. For the current study, differences in changes of CMAI scores were analysed between three different groups: 1) the change in CMAI score when remaining in the control condition 2) the change in CMAI score after changing from control to intervention 3) the change in CMAI score when remaining in the intervention condition. The difference in change of CMAI scores were analysed using linear mixed models. Because change scores might be influenced by the initial baseline score of the CMAI (higher baseline scores increase the probability of finding larger change scores), it was tested whether the baseline CMAI scores of the five separate intervention groups differed from the baseline score to the rest of the group, using independent T-tests.

Because the NPI-NH measures quite heterogeneous areas of behaviour, the twelve individual symptoms were dichotomised into clinically relevant symptoms (NPI-NH score per item ≥ 4)^{1,49}. Analyses were undertaken on the total amount of clinically relevant symptoms (range 0-12) and on the presence of each individual symptom before and after the intervention. The NPI-NH analyses were undertaken using binomial logistic mixed models with a second order PQL estimation procedure⁵⁰.

Medication data and data on (physical) restraints were dichotomised for each category (antipsychotics, anxiolytics, antidepressants, anti-epileptics, anti-dementia drugs; bedrails, other night-time physical restraints, daytime physical restraints, surveillance technology) and analysed with binomial logistic mixed models using a second order PQL estimation procedure⁵⁰. Data were dichotomised because almost none of the residents were prescribed more than one restraint or drug of one category. Because of logistic reasons, for one DSCU data on antidepressants and anxiolytics was not available for the first measurement. Data were imputed from the second measurement for these 32 residents, as this unit was still in the control group during the second assessment.

Next to the initial analyses, adjusted analyses were performed correcting for the confounding variables age, sex, GDS stage, type of dementia and length of stay on DSCUs. Finally, if prevalence rates allowed it, interaction of the intervention with these variables and with degree of implementation and duration of the intervention were performed.

For the analyses on information bias, an independent t-test was performed between the CMAI scores of care staff that trusted the care programme to be beneficial and the CMAI scores of care staff that did not think the care programme would make a difference.

The difference between CMAI scores obtained from the care staff member actively involved in the care programme and from the care staff member who did not participate in the training on the care programme was analysed by paired t-tests and by calculating Pearson correlation coefficients.

For all analyses, a cut off score of $p < 0.05$ was used for statistical significance.

Results

Of the 20 organisations that originally showed interest in participation, four decided not to take part. Three of these organisations declined because of organisational changes in the nearby future, one organisation had planned to introduce their own new approach for the management of behavioural problems. One of the participating organisations selected two DSCUs on separate independent locations to participate in the study. One unit that did participate moved to another location after T3. Only data from T0-T3 were used in this study for this DSCU.

Of the 17 participating DSCUs, nine were affiliated with one of the university networks. Nine of the participating units were located in the densely populated Randstad area of the Netherlands, the other eight were situated in less densely populated areas (Noord-Brabant, Gelderland and Friesland). All units were organised into several shared living rooms in which a set group of residents resided. The mean size of the unit was 29 residents (range 18-43) and a mean number of 11 (range 6-19) residents resided in one living room.

In total, 659 unique residents participated in this study, with a mean age of 84 (SD 7.3) and 69.7 % was female (Table 1). 178 residents participated in all assessments, other residents either enrolled at a later moment or they had died, been discharged or moved away to another unit before the end of the study (see figure 2). The prevalence rates of challenging behaviour and the use of psychoactive medications are shown in table 2.

Five of the units consistently scored above average on the implementation questionnaire (good implementation; score = 3). Eight units scored moderately on the implementation (score = 2). Three units scored consistently below average (bad implementation; score = 1). The unit which moved to another location after T3 had not as yet implemented the care programme.

Table 1: Characteristics of the residents enrolled in the study

Unique residents	659
Mean age	84 (SD 7.3)
Sex (% female)	69.7
Duration of institutionalisation (months)	Median 20 (Range 0-203)
Mean Global Deterioration Score (GDS)	5.67 (SD 0.76)
GDS Unknown	1.3%
GDS <=3	0.4%
GDS 4	6.6%
GDS 5	27.8 %
GDS 6	53.9%
GDS 7	10.0 %
Type of Dementia	
Alzheimer's	49.0 %
Vascular	15.6%
Mixed Alzheimer/Vascular	16.3 %
Lewy Body/Parkinson	2.5%
Fronto temporal	2.5%
Other/unknown	14.0%

Table 2: Overview of the measurement data.

	T0	T1	T2	T3	T4	T5
Mean CMAI (SD) C	51 (18)	55 (19)	53 (20)	53 (20)	56 (22)	-
Mean CMAI (SD) I	-	47 (18)	52 (19)	51 (18)	50 (17)	51 (19)
Mean clin.rel. NPI (SD) C	2,7 (2,2)	3,0 (2,5)	3,0 (2,5)	2,3 (2,3)	3,3 (2,8)	-
Mean clin.rel. NPI (SD) I		1,9 (2,2)	2,4 (2,2)	2,4 (2,3)	2,4 (2,3)	2,4 (2,4)
% Antip. C	27,9	28,1	27,4	26,0	20,0	-
% Antip. I	-	23,3	25,9	24,3	23,0	22,6
% Anxi. C	23,5	21,3	25,1	27,6	26,2	-
%Anxi. I	-	21,7	17,3	17,6	18,4	21,2
% Antid. C	32,3	33,5	33,0	30,1	27,7	-
% Antid. I	-	28,3	29,5	27,0	25,7	28,5

For each intervention condition (C=control, I=intervention), data are presented about mean total CMAI scores, mean amount of clinically relevant NPI symptoms, percentages of residents using antipsychotics, anxiolytics and antidepressants. SD= standard deviation. Note that the stepped wedge design causes the group sizes of the control and intervention condition to change. Every intervention group contains residents that were in the control group on the previous measurement.

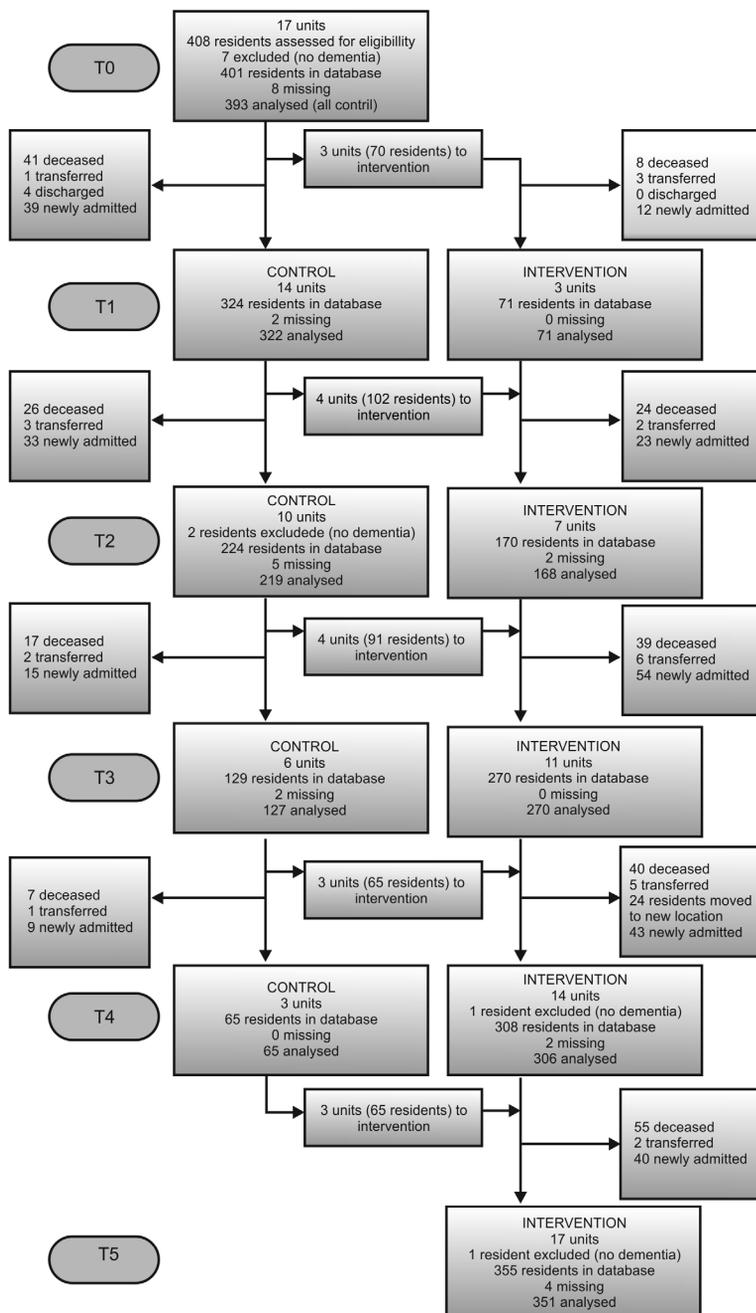


Figure 2: Flowchart for the primary outcome analysis.

A total of 2292 measurements of the total CMAI score were conducted on 659 unique residents. Data were missing when one or more CMAI items was missing or a resident was absent (e.g. admission into hospital). Residents without dementia were excluded. Residents could drop out of the study because of dying, discharge to home, transfer to another unit or nursing home.

Primary outcome

None of the analyses showed significant differences in CMAI scores at baseline.

Table 3 shows the results of the analyses of the changes in CMAI score between subsequent measurements. These analyses yielded significant effects in the group that maintained in the intervention condition compared to the group that maintained in the control condition (-2.4, 95%CI -4.3 to -0.6). The analyses were corrected for age, sex, severity of dementia, type of dementia, length of stay on the DSCU and for prescription of psychoactive medication. The effect of the degree of implementation was examined by analysing the interaction between the intervention and the degree of implementation. The effect of the programme on the differences of CMAI scores was -3.2 (95%CI -6.4 to 0.0) between the intervention-intervention and the control-control group when implementation was good.

Table 3: Effects of the care programme on CMAI scores.

	Regression coefficient (SE)	95 % confidence interval	P
Control-control (reference category)			
Control-intervention	-0.1 (1.1)	-2.3 to 2.2	0.96
Control-intervention*	0.0 (1.2)	-2.3 to 2.4	0.99
Intervention-intervention	-2.2 (0.9)	-3.9 to -0.4	0.02
Intervention-intervention*	-2.4 (0.9)	-4.3 to -0.6	0.01

*Results of the analyses of the differences between two measurements. The control-control group is the reference category, which means a score of e.g. -0.01 is the contrast of the difference between two subsequent measurements of the control-control group and the control-intervention group. * corrected for age, sex, type of dementia, GDS stage, length of stay on DSCU and prescription of psychoactive drugs. All analyses were adjusted for significant influences of inter-correlation of repeated measures and clustering on the unit.*

Figure 3 shows the results of the analyses of the number of clinically relevant neuropsychiatric symptoms in the measurements before and after the implementation of the care programme. An odds ratio of 0.83 (95%CI 0.67 to 1.04) was found between the control and intervention measurements.

The analysis of the number of clinically relevant NPI-NH symptoms revealed an interaction effect for severity of dementia (GDS stage). No effects were found for less severe stages of dementia (GDS < 6) (OR 0.99; 95%CI 0.77 to 1.26), whereas significant effects were found (OR 0.79; 95%CI 0.63 to 0.99) for the severe stages of dementia (GDS ≥ 6). An interaction effect was also found for degree of implementation. When the implementation of the care programme was good, the odds ratio for the number of clinically relevant NPI-NH symptoms was 0.59 (95%CI 0.42-0.83).

Figure 3 and table 4 show the results of the analyses of the twelve separate symptoms of the NPI-NH. A significant decrease in clinically relevant symptoms of delusions, depression, apathy, disinhibition and aberrant motor behaviour was found. A trend towards a decrease of the prevalence of clinically relevant symptoms was found for all other symptoms except for irritability. Because of the prevalence rates of the symptoms, these analyses were undertaken with smaller group sizes. As a consequence, models for adjusted analyses did not converge so only the initial analyses can be reported.

Table 4: Effects of the care programme on individual clinically relevant NPI-NH symptoms.

	Odds ratio	95%CI	P
Delusions	0.67	0.47-0.96	0.03
Hallucinations	DNC	-	-
Agitation	0.82	0.48-1.39	0.47
Depression	0.42	0.29-0.60	<0.01
Anxiety	0.81	0.50-1.32	0.41
Euphoria	DNC	-	-
Apathy	0.76	0.60-0.97	0.03
Disinhibition	0.63	0.45-0.89	0.01
Irritability	1.03	0.59-1.83	0.91
Aberrant motor behaviour	0.65	0.48-0.86	<0.01
Night-time beh. disturbance	0.91	0.68-1.24	0.57
Eating abnormalities	0.76	0.54-1.06	0.10

Results of mixed model analyses on the prevalence of clinically relevant NPI-NH symptoms. Models for hallucinations and euphoria did not converge (DNC), because of low prevalence rates. All analyses were adjusted for significant influences of inter-correlation of repeated measures and clustering on the unit.

Secondary outcomes

Figure 3 also shows the effects of the care programme on the prescription of psychoactive drugs. Analyses on anti-epileptic drugs and anti-dementia drugs could not be performed because of low prevalence rates (resp. 5.1 % and 9.6 %). For the other categories except anxiolytics, the odds of being prescribed psychoactive drugs were significantly lower after the introduction of the care programme (antipsychotics: OR 0.54; 95% CI 0.37-0.80 ; antidepressants: OR 0.65; 95% CI 0.44-0.94). Models for adjusted analyses did not converge because of low prevalence rates.

No significant effects were found in any of the restraint categories (bedrails, night-time restraints, daytime restraints and surveillance technology). Both before and after the introduction of the care programme, 31.7 % of the residents were being restrained or monitored by surveillance technology. Most of these residents had bedrails ($\pm 85\%$).

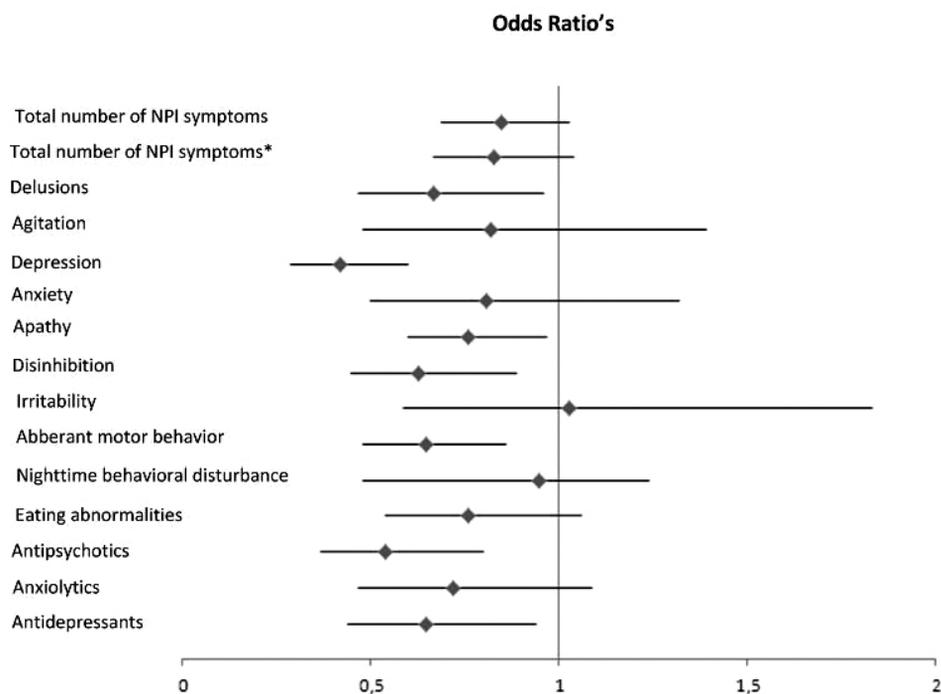


Figure 3: Forest plot of the Odds Ratio's for NPI symptoms and psychoactive medication

Analyses of information bias

All but one care staff member (N=16) believed the introduction of the care programme was necessary and judged the design of the care programme to be good, and therefore no analyses were possible on these data. There were differences in the care staff rating as to whether they believed the care programme would be able to decrease challenging behaviour on the unit. Twelve care staff members scored a rate of six or higher on this question (range 1-10; 12 care staff members scoring the CMAI of 45 residents) and four care staff members rated five or lower (4 care staff members scoring the CMAI of 22 residents). No significant differences were found in the CMAI scoring between these two groups (mean difference= 3 points, $t(65) = 0.55$, $p = 0.59$).

The analyses of CMAI scoring by staff care members actively involved in the care programme and by care staff members who did not participate in the training of the care programme, (N=240 residents; 56 actively involved care staff members, 33 care staff members not involved) showed high correlation between raters ($r > 0.70$) and on both time points a non-significant difference of 1 point between raters ($t(69) = -0.446$, $p = 0.657$, on T1 and $t(169) = 1.213$, $p = 0.227$ on T2).

Discussion

The aim of this study was to determine the effect of using the Grip on Challenging Behaviour care programme on the prevalence of challenging behaviour and on the use of psychoactive medication and restraints. The care programme was implemented in 17 DSCUs and challenging behaviour and the use of psychoactive medication and restraints was measured over a 20-month period. A significant decrease of challenging behaviour, measured as differences in total CMAI score between subsequent measurements, was found in the group of DSCUs that were using the care programme for over eight months compared to the control group, but this difference was smaller than expected. No significant effects were found on differences in CMAI score on the first assessment, four months after the care programme was introduced. The frequency of the use of the detection tool, which was administered half annually, might have resulted in this delayed effect. A decrease of the odds for several individual NPI items was found but for the total number of clinically relevant neuropsychiatric symptoms a decrease was only found for residents with severe dementia. For the secondary outcomes, a decrease in prescribed psychoactive drugs (antipsychotics and antidepressants) was found after the care programme was introduced. Although it is regularly supposed that a decrease in use of psycho-active drugs might lead to an increase in use of restraints (and vice versa)⁵¹, no such effect was found in our study.

Even though not all effects were statistically significant, analyses of individual clinically relevant behavioural symptoms consistently show the benefit of the use of the care programme. A significant decrease of delusions, depression, apathy, disinhibition and aberrant motor behaviour was found. The significant effects on depression and apathy are promising, as these 'quiet' symptoms are easily overlooked^{52;53}. Care staff have to be really vigilant for signs of depression and apathy, particularly in the more severe stages of dementia, as they are more difficult to detect than in the less severe stages. The introduction of a detection tool and the emphasis in the training sessions on detecting these symptoms probably raised more awareness about these symptoms, including in the more severe stages of dementia. The interaction effect that was found for severity of dementia on the effect on total number of clinically relevant NPI symptoms might be explained by the additional attentiveness to depression and apathy in severe stages of dementia.

In spite of growing awareness regarding negative side effects and limited effectiveness, the prescription rates of psychoactive drugs remain high^{54;55}. It is quite remarkable that up until now, medication has had such a significant place in the approach to challenging behaviour. Although in general, the focus in care-giving for people with dementia has gradually evolved from a pure disease-oriented view to a more person-centered and tailored approach, it seems that the treatment of challenging behaviour has not fully benefitted from this progression. In Dutch nursing homes, every resident has his/her own individual care plan, there are protocols for pressure ulcers, feeding problems, the use of antibiotics and so on. In contrast, there is no protocol which assures a structured and tailored

approach when challenging behaviour occurs. Cornegé-Blokland et al. concluded in earlier research that better implementation of guidelines would help bringing down inappropriate prescription rates and that as long as alternative approaches to challenging behaviour are not adequately implemented, physicians will more often feel that they have run out of other options and prescribe psychoactive drugs⁵⁶. However, a structure of communication and collaboration between different disciplines is necessary to apply the guidelines.

The evident effects on prescription of psychoactive drugs, especially on antipsychotics, are thus an important finding of this study. The Grip on Challenging behaviour care programme provides a tool which structures the multidisciplinary process of analysing behaviour and developing a treatment plan. It is likely that the structured analysis and the more explicit involvement of a psychologist has led to the use of more psychosocial treatments. Furthermore, the trainings sessions and the use of the care programme probably made care staff and clinicians reflect on the negative side effects of psychoactive drugs use and gave physicians a feeling of support in trying other treatment options and not revert to medication. Hence, the care programme had more effects on (prescribing) behaviour of clinicians and care staff than on the actual challenging behaviour of the residents, in particular agitation, on which only small effects were found. While the assessment of agitation with one NPI-NH item might have been too broad and unspecified to measure subtle changes, the CMAI was especially developed to measure several aspects of agitation. The effects that were found on the CMAI are, however, relatively small. It is, of course, no surprise that behaviour of clinicians is more easily influenced than the behaviour of residents with dementia. It might be that more fundamental changes in (the environment of) long term dementia care are needed to diminish agitation in dementia residents. More research into the effects of, for example, small scale living and home-like facilities would therefore be very welcome⁵⁷.

Nevertheless, the effects on challenging behaviour found in this study are also smaller than those of earlier multidisciplinary interventions^{34;58;59}. However, there are significant differences between these studies and ours that can explain these discrepancies. Most of these studies made a preselection of residents with severe forms of challenging behaviour, either selected by facility managers³⁴ or by a cut off score for frequency of the behaviour^{58;59}. The Grip on Challenging Behaviour care programme, on the other hand, does not use a cut off score for inclusion. This means that all of the residents of the DSCU were included in (analysis of) the care programme, including residents without challenging behaviour, which mutes the effect size of the study. The only study known to us that did analyse all residents is the study of Fossey et al., in which the effects of a training and support package for managing agitated behaviour in dementia were analysed⁶⁰. Similar to the current study, Fossey et al. found effects on the use of psychoactive drugs, but in their study no effects on challenging behaviour were found.

Additionally, in the Grip on Challenging Behaviour study, the DSCUs stemmed from 17 different care organisations, which all had their own care system and culture, whereas other studies limited the inclusion of residents to one facility⁵⁸ or to multiple facilities with

the same care and management structure³⁴. Although including several different kinds of organisations does improve generalisability of the results, it also meant that the way in which the care programme was implemented had to be adjusted to the daily routine of each separate DSCU which increased the risk of implementation problems. Problems with implementation indeed did arise during the study and adjusted analyses for CMAI scores showed larger effects for the DSCUs in which implementation was good, which supports the idea that larger effects would have been possible with better implementation.

Finally, one of the strengths of the Grip on Challenging Behaviour study is the fact that once the care programme is implemented, the team of the DSCU is able to use it without involvement of external parties. In contrast, earlier studies involved an external expert team which carried out the intervention⁵⁸⁻⁶⁰. The effects that were measured in the Grip on Challenging Behaviour study, however, cannot be attributed to extra staffing or availability of extra expertise on a unit. Furthermore, the effects found in the Grip on Challenging Behaviour study can be obtained without the investment of external parties once the training sessions are finished, which is of great relevance to nursing home practice.

There are some limitations to this study which should be considered when interpreting the results. First, the participating nursing homes were not randomly selected and half of them were part of university networks of long term care. Although the variety in participating nursing homes represents the Dutch situation, the nursing homes that were part of university networks are obviously eager to participate in scientific research projects and are more used to research circumstances, which by definition distinguishes them from nursing homes which do not collaborate with universities. The participating units from these nursing homes, however, did not differ in implementation rates from the other involved DSCUs. Secondly, the care programme is aimed at improving the structure and multidisciplinary of the process of managing challenging behaviour. Therefore, outcomes of working according to the care programme instead of measuring the effects of different interventions that were used were measured. The success rate of different intervention methods could nevertheless be important for the overall effects. Further research into the effectiveness of the separate parts of the care programme and the use of different (psychosocial) interventions in the treatment phase would therefore be useful. Finally, the Grip on Challenging Behaviour care programme was developed for use in Dutch nursing home care practice, which has unique characteristics like the availability of a specialised physician and a psychologist. To transfer the results to long term care in other countries, adaptations are probably needed.

There are also some methodological considerations. First, the choice for using a stepped wedge design was based on both practical and statistical benefits. By using this design, the research team was able to guide the implementation on all units. Also, less participants are needed to achieve enough power over a limited period of time, which makes it a particularly strong design that is very suitable for this specific type of complex intervention studies. Because this is a relatively new design, however, there is no consensus yet over how to analyse the data. Moreover, because of clustering on unit level and switching from control to intervention status at different time points, and because of possible collinearity between

time of intervention and unit, the analysis for this specific study was very complicated and the best possible solution, in our view, was to analyse change scores. Nevertheless, the interpretation of the effects on change scores is not as straightforward as one might hope. Secondly, the interviewed nursing staff were obviously not blinded for the intervention, although the interview assistants were. When performing intervention research in a population of people in the more severe stages of dementia living in long term care facilities, nursing staff are an essential source of information. In this type of intervention study they are however also usually the people who perform (parts of) the intervention, which could potentially introduce information bias. Therefore, a bias analysis was conducted in this study, which, as reported in the results section, did not show any signs of influence of information bias. In our view, this is the best way to deal with the area of tension between conducting complex intervention studies in nursing home care and performing methodologically sound research.

Conclusion

A small but significant decrease in prevalence of challenging behaviour was found after implementation of the Grip on Challenging Behaviour programme. The programme considerably diminished the use of psychoactive drugs, especially antipsychotics and antidepressants, while no difference in restraint use was found.

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Chapter 6

Nurses in distress? An explorative study into the relation between distress and individual neuropsychiatric symptoms of people with dementia in nursing homes.

Abstract

Objectives

To optimize care and interventions to improve care, and to reduce staff burden, it is important to have knowledge of the relation between individual neuropsychiatric symptoms and distress of care staff. We therefore explored the relation between frequency and severity of individual neuropsychiatric symptoms and distress of care staff.

Design

This is an explorative study with a cross-sectional design.

Participants and setting

Care staff was interviewed regarding 432 residents of 17 nursing homes for people with dementia.

Measurements

Behavioural problems were assessed using the Nursing Home version of the Neuropsychiatric Inventory (NPI-NH) questionnaire. The distress scale of the NPI-NH was used to determine the distress of care staff.

Results

Agitation/aggression had the highest mean distress score and was also the most prevalent symptom. Disinhibition and irritability/lability also had high mean distress scores, whereas euphoria/elation, hallucinations and apathy had the lowest mean distress score. The symptom severity of each symptom strongly predicted the distress score, whereas the frequency of the symptoms was a less important factor.

Conclusion

Although some of these findings are in accordance with studies among informal caregivers, there are also notable differences. Apathy caused little distress among care staff. Therefore, care staff might not feel the urgency to explore the causes of this symptom. The findings of this study emphasize the importance of supporting care staff in the management of behavioural problems, especially aggression and apathy.

Background

During the course of their illness, most people diagnosed with dementia develop neuropsychiatric like apathy, depression, delusions or aberrant motor behaviour¹. As a result, neuropsychiatric symptoms are very common in both people with dementia dwelling in a community and people with dementia living in nursing homes.

Next to the obvious effect they have on (the quality of life of) people with dementia themselves, neuropsychiatric symptoms place a burden on the people caring for them. Indeed, several researchers found that the presence of neuropsychiatric symptoms is associated with distress of informal caregivers². For instance, the presence of apathy is associated with a deterioration of the relationship between informal caregivers and the person with dementia, and angry behaviour is associated with caregiver depression^{3,4}. Consequently, neuropsychiatric symptoms are a common reason for institutionalization of people with dementia, largely due to the caregiver burden associated with it⁵⁻⁷. As a result, the prevalence of neuropsychiatric symptoms is very high in nursing home units for people with dementia⁸⁻¹⁰.

It seems likely that the caregiver burden associated with neuropsychiatric symptoms is not just reserved for informal caregivers. Qualitative research indeed indicates that care staff experience difficulty and feelings of guilt and distress in coping with problems like aberrant thoughts or vocally disruptive behaviour^{11,12}. Recent research of Morgan et al.¹³ showed, by using a diary instrument, that incidents of combative behaviour are often distressing for care staff.

While research shows a relation between neuropsychiatric symptoms as a whole and distress of care staff, it remains unclear which of the individual symptoms are most distressing and whether severity or frequency of symptoms is important for the amount of distress experienced. Up until now, only the relation between the individual symptom of combative behaviour and distress of long-term care staff has been quantified^{13,14}. There is a fair amount of research that explores the relation between individual neuropsychiatric symptoms and distress for the informal care-giving situation¹⁵⁻¹⁸, but it is quite possible that the difference in the relation that formal and informal caregivers have with the person with dementia is crucial in the experience of distress. To optimize long-term care for people with dementia and to optimize interventions to improve care and to reduce staff burden, it is important to have knowledge on which symptoms are related to higher caregiver distress and which symptoms do not cause much caregiver distress. Both sides of this spectrum of distress are important, for high caregiver distress implies high caregiver burden and increased risk at burn out, whereas low caregiver distress might cause diminished attention for the symptom and less eagerness to act quickly. In the current study, we therefore explored the relation of individual neuropsychiatric symptoms and their severity and frequency, with the amount of experienced distress of care staff.

Methods

Subjects and study design

This is an explorative study with a cross-sectional design. We used baseline data of a study into the effects of the care programme 'Grip on Challenging Behaviour'¹⁹. A total of 432 patients of 17 dementia special care units were included. Most of the 17 recruited special care units for dementia are part of nursing homes within the regional collaboration with the VU Medical Center (Amsterdam) and with the Radboud University Nijmegen Medical Centre. We included patients who were diagnosed with dementia according to the DSM-IV criteria²⁰. The diagnosis and the type of dementia were retrieved from patient records by the elderly care physician of the participating units.

The data collection took place from February 2011 to June 2011.

Measurements

Baseline characteristics of the residents (sex, age and date of institutionalisation) were retrieved from the patient charts. The severity of dementia was determined by the elderly care physicians, using the Global Deterioration Scale (GDS)²¹. This is a seven-point scale that describes seven stages from 'no global impairment' (1) to 'very severe global impairment' (7).

In the Netherlands, most care staff has received training in care-giving for 2 years or longer. These 'enrolled nurses' can receive training on different levels. In this study, we have interviewed the enrolled nurses who were most involved in the direct daily care for a resident about the neuropsychiatric symptoms of that resident and the distress these symptoms bring about. These nurses have received training on one of the higher levels (level 3 or 4), meaning 3 or 4 years of professional training. The characteristics of the level 3 and 4 enrolled nurses of the 17 participating units were retrieved from a questionnaire that was part of the larger 'Grip on Challenging Behaviour Study'.

The patient's neuropsychiatric symptoms were assessed by a trained research assistant using the Nursing Home version of the Neuropsychiatric Inventory (NPI-NH), which was developed for rating by care staff within institutions²²⁻²⁴. The Dutch version proved to be valid and reliable²⁵. The NPI-NH evaluates 12 neuropsychiatric symptom domains that are common in dementia: delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, nighttime behavioural disturbances, and appetite and eating abnormalities. The frequency (F) of a symptom domain is rated on a four-point scale (1 = sometimes to 4 = very often), and the severity (S) is rated on a three-point scale (1 = mild to 3 = severe). The NPI-NH score for each symptom domain is the product of frequency and severity subscores (F × S), which ranges from 0 (symptom was absent) to 12. The total possible NPI-NH score per patient ranges from 0 to 144 (12 × 12).

Caregiver burden associated with the neuropsychiatric symptoms was evaluated with the distress scale of the NPI-NH. This scale provides a quantitative measurement of the distress experienced by the nursing staff caused by each neuropsychiatric symptom expressed by the resident and consists of six levels: 'not at all distressing' (0), 'minimally distressing' (1), 'mildly distressing' (2), 'moderately distressing' (3), 'severely distressing' (4) and 'extremely distressing' (5). Total caregiver distress was calculated as the sum of the distress scores of each of the 12 domains, with a range of 0 to 60. The mean distress score per symptom was calculated on the number of patients who exhibit the symptom.

Statistical analysis

Data entry and analysis were performed using SPSS version 20.0²⁶. We explored the relation between distress of caregivers, and the severity of symptoms, frequency of symptoms and the F × S score using proportional odds ratios. Analyses were adjusted for nosological type of dementia (Alzheimer's vs other) and severity of dementia (GDS 3–5 vs GDS 6–7), and the interaction of the odds ratios with these variables was examined. In addition, separate odds ratios were calculated for the F × S score taking severity and frequency into account. This way, the separate influence of both severity and frequency on the relation between distress and F × S score could be determined. All significance tests were two tailed, and for all analyses, a p value of <0.05 was the criterion for significance.

Ethics

The Medical Ethics Review Committee of the VU Medical Center approved the study.

Results

Demographics

Table 1 shows the demographics of the included residents. Of the 432 included residents residing at dementia special care units of 17 Dutch nursing homes, 302 (69.9%) were female. The age ranged from 49 to 102 years, with a mean age of 83.3 years (SD = 7.6). The average time of institutionalization was 25 months, ranging from 1 to 152 months (SD = 25). The predominant nosological type of dementia was Alzheimer's disease (47.7%). The vast majority (62%) of the residents were in a moderately severe clinical stage of dementia (GDS score of 6).

Almost all (96.8%) of the responding level 3 and 4 enrolled nurses in the participating units were female. The mean working experience of his group is 17.6 (SD = 10.8) years, and they are on average 41 (SD = 12) years of age.

Table 1. Demographics of the 432 nursing home patients with dementia

Mean age \pm SD (years)	83,3 \pm 7,6
Sex (% female)	69,9
Mean duration of institutionalization \pm SD (months)	25 \pm 25
Mean Global Deterioration Scale (GDS) score	5,8 \pm 0,7
GDS score: \leq 3	1 %
GDS score: 4	4 %
GDS score: 5	21 %
GDS score: 6	62 %
GDS score: 7	12 %
Nosological types of dementia	
Alzheimer's	47,7 %
Vascular	19,0 %
Mixed Vascular/Alzheimer's	15,5 %
Lewy Body	3,7 %
Frontotemporal	2,5 %
Others	8,6 %

Caregiver distress related to individual neuropsychiatric symptoms

Table 2 shows the means of the two NPI-NH component scores, frequency (F) and severity (S), the product of the component scores ($F \times S$) and the distress scores. It also shows the odds ratios for distress between the lowest and highest scores of the three categories (severity, frequency and frequency \times severity). Of the residents, 89% had shown at least one neuropsychiatric symptom in the previous 4 weeks. The most common symptom was agitation/aggression (57%), followed by irritability/lability (53%) and anxiety (44%). Hallucinations, appetite and eating abnormalities, and euphoria/elation had the lowest prevalence (15–16%). Agitation/aggression had the highest mean distress score (2.3 ± 1.4), followed by disinhibition (2.1 ± 1.5) and irritability/lability (2.0 ± 1.4). Euphoria/elation had the lowest mean distress score (0.8 ± 1.2), followed by hallucinations (1.1 ± 1.4) and apathy (1.4 ± 1.3). All proportional odds ratios calculated between mild and severe symptoms show that the odds of being distressed are significantly higher when the symptoms are more severe. The odds ratios range from 13.6 for apathy to 82.3 for nighttime disturbance. The odds for being more distressed when the symptoms are more frequent are much lower (range 2.1 for hallucinations to 21.0 for appetite and eating abnormalities), although this relation is also significant for all symptoms. The odds ratios between the highest and lowest $F \times S$ scores are all significant. Further analyses, however, show that when these ratios are corrected for severity, the odds are much smaller, and most of these associations are no longer significant. Correcting the $F \times S$ analyses for frequency does not result in significantly

Table 2: Mean NPI-NH distress, frequency, severity and (frequency x severity) scores and the Proportional Odds Ratios for distress between the highest and lowest score on the category.

	N (%)	Distress Mean \pm SD	Severity Mean \pm SD	OR Severity [95% CI]	Frequency Mean \pm SD	OR Frequency [95% CI]	FxS Mean \pm SD	OR FxS (95% CI)
delusions	100 (23)	1.8 \pm 1.4	1.9 \pm 0.8	61.2* [18.3-204.7]	3.0 \pm 0.9	13.6*[2.7-67.3]	5.83	213.6*[26.2-1742.5]
hallucinations	63 (15)	1.1 \pm 1.4	1.5 \pm 0.8	72.6* \wedge [12.7-414.8]	2.5 \pm 1.1	2.1[0.5-9.1]	4.00	18.7*[2.1-163.9]
agitation/aggression	247 (57)	2.3 \pm 1.4	2.0 \pm 0.8	62.9* \wedge [28.0-141.2]	3.1 \pm 0.8	13.6*[4.4-41.8]	6.38	266.8*[61.1-1164.1]
dysphoria/ depression	142 (33)	1.8 \pm 1.3	1.8 \pm 0.8	35.2* \wedge [13.0-95.3]	2.9 \pm 1.0	7.1* \wedge [2.6-19.5]	5.32	48.0*[12.4-186.2]
anxiety	191 (44)	1.7 \pm 1.3	1.7 \pm 0.8	23.8* \wedge [10.2-55.4]	3.2 \pm 0.9	7.9* \wedge [2.4-25.6]	5.82	40.6*[10.4-158.0]
euphoria/elation	70 (16)	0.8 \pm 1.2	1.6 \pm 0.7	19.4* [3.9-97.0]	2.7 \pm 0.9	7.5*[1.3-42.4]	4.63	47.3*[4.7-472.7]
apathy/indifference	152 (35)	1.4 \pm 1.3	1.9 \pm 0.7	13.6* \wedge [5.6-35.3]	3.3 \pm 0.9	7.2 \wedge [1.6-33.3]	6.48	16.1*[3.1-83.5]
disinhibition	128 (30)	2.1 \pm 1.5	2.1 \pm 0.8	28.1* [10.7-74.1]	3.1 \pm 0.9	3.0 \wedge [0.9-9.7]	6.76	32.9*[6.3-170.4]
irritability/labiality	229 (53)	2.0 \pm 1.4	1.9 \pm 0.8	49.3* [22.2-109.5]	3.1 \pm 0.9	10.6* \wedge [3.3-33.5]	6.25	86.5*[21.7-344.9]
aberrant motor behaviour	134 (31)	1.8 \pm 1.5	2.1 \pm 0.7	80.8* [25.1-259.7]	3.7 \pm 0.7	8.9 \wedge [1.0-79.7]	7.74	19.2 \S *[2.6-141.5]
nighttime behaviour dist.	129 (30)	1.8 \pm 1.5	1.8 \pm 0.8	82.3* [26.1-259.1]	2.9 \pm 0.9	3.5 \wedge [1.0-12.2]	5.62	77.4*[13.0-462.0]
appetite/ eating abnor.	65 (15)	1.6 \pm 1.5	2.0 \pm 0.8	37.6* [8.8-159.9]	3.2 \pm 0.9	21.0* \wedge [2.2-199.1]	6.32	34.9 \S *[3.9-308.6]

FxS = frequency x severity. * = $P < 0.05$. \wedge = proportional odds assumption was not met. \S = reference FxS score was 2 instead of 1. OR = odds ratio between the highest and the lowest score on a category for scoring 1 point more on the distress scale. Example: the odds of scoring 1 point higher on the distress score when a resident had severe anxiety opposed to mild anxiety is 23.80. All ORs are adjusted for stage and type of dementia.

lower odds ratios. Subgroup analyses for nosological type of dementia and severity of dementia did not yield any structural differences in the relation between NPI-NH scores and distress scores.

Discussion

The aim of this study was to explore the relation between individual neuropsychiatric symptoms of residents and the degree of distress experienced by care staff of Dutch nursing homes. The neuropsychiatric symptoms were measured with the neuropsychiatric inventory for nursing homes, the NPI-NH.

First of all, the very strong relation of the total NPI scores ($F \times S$) with the distress scores implies that the presence of behavioural symptoms is a strong predictor of distress of care staff. Furthermore, the symptom agitation/aggression does not only have the highest mean distress score but is also the most prevalent symptom. The symptom euphoria/elation has the lowest mean distress score. These findings are in accordance with former studies among community-dwelling dementia patients and their informal caregivers¹⁵⁻¹⁷.

Although one study among informal caregivers indicated the relation between distress and symptoms may not be similar for different types of dementia (frontotemporal vs Alzheimer's)²⁷, subgroup analysis in our study did not show structural differences between nosological types of dementia. In the earlier study, though, the relation between symptoms and distress was only significantly different for one symptom (disinhibition), which was only shown by 4 people with Alzheimer's versus 18 with frontotemporal dementia (FTD). Differences in caregiver distress that are often found between FTD and Alzheimer's are more likely the result of the high prevalence and the clustering of several co-occurring symptoms in people with FTD²⁸. For even though the NPI-NH measures separate items, these items are probably not independent from each other (e.g. apathy and depression, and agitation and disinhibition). The distress these combination of symptoms causes may be more than the sum of its parts, and further research may be able to determine the distress caused by different 'profiles' of clustered neuropsychiatric symptoms.

The second notable difference is the degree of distress that is caused by the symptom apathy/ indifference, which was relatively higher in the studies among informal caregivers. An explanation for this can be that apathetic residents are not likely to disturb care staff in their daily duties and cause little inconvenience towards other residents in the nursing home. Possibly, apathy is interpreted by nursing staff as a sign of contentment of the resident so that care staff does not find it distressing. Also, in the presence of more obvious behaviour like calling out or excessively asking for attention, it is likely that the silent, apathetic resident causes less distress. For close relatives, on the other hand, the indifference signals an important loss in social interaction and in the quality of their relationship⁴.

The fact that apathy hardly causes distress could lead to nursing staff not feeling the urgency to explore this symptom further or to call in a physician or psychologist. Although there is research describing that apathy may not be related to quality of life²⁹, other research shows that apathy is associated with depression and pain^{30;31}. It is therefore very important to analyse the cause of apathy whenever it is present.

We also investigated the relation between caregiver distress and symptom frequency, symptom severity, and the combination of these two. Our results show a strong relation between the symptom severity and caregiver distress scores for all individual neuropsychiatric symptoms. The frequency of a symptom did not seem to have such a strong relation with caregiver distress. Although distress of nursing staff is not the only factor in determining clinical relevance, this finding is important for the concept of clinically relevant neuropsychiatric symptoms. Generally, a symptom total score of 4 or higher is considered a clinically relevant symptom¹⁰. Because this score is a product of the frequency and severity score of a symptom, there are several ways to achieve a score of 4 or higher. If, however, the total score is predominantly high because of a high frequency score (e.g. very frequent (4) × mild (1)), this might mean that in practice, the symptom does not cause distress in nursing staff, which makes the cut-off score for clinical relevance somewhat questionable. Indeed, when the odds ratios of $F \times S$ scores were corrected for the influence of either severity or frequency of the symptoms, we saw that the severity of symptoms was of much more influence than the frequency of the symptom. Interestingly, Kaufer et al.³² developed a shortened version of the NPI that does not include the frequency scale. Our findings imply that this version, the NPI-Q, might be a more useful tool to use in nursing home practice than the NPI-NH, for it saves time and still includes the most important features of the NPI, namely the severity of a symptom and the distress it causes. However, further research is necessary to validate the use of this scale without the frequency score in nursing home practice.

Some remarks have to be made with regard to the limitations of this study. First, we did not measure the characteristics of the individual care staff, like coping style or years of amount of working hours. Although Morgan et al.¹³ did not find an influence of such characteristics on report and attribution of combative behaviour, other research found that coping style and number of weekly working hours do influence the way in which behaviour impacts care staff^{14;33}.

Second, the trained interviewers reported that emotional distress was not a familiar concept for most interviewed caregivers. Some of the caregivers found it hard to discuss this concept, as if feeling distress would make them less professional. This could have resulted in underreporting of distress. Also, because this is a cross-sectional study and one caregiver was interviewed about both the severity and the frequency of the symptoms and the distress the symptom causes, it is possible that the distress caregivers experience has influenced their assessment of the severity and the frequency of the symptoms. This could have led to overreporting of (frequency or severity of) symptoms when nurses are distressed. The

use of trained research assistants who had clear descriptions on how to judge the severity, frequency and the distress of a symptom has probably reduced this influence to a minimum. Finally, as several researchers point out, behaviour, especially combative behaviour—described as agitation/aggression in the NPI-NH, is most likely an interplay between the person with dementia and the professional caregiver^{13;34}. Therefore, many items on the NPI-NH possibly measure rejection of care and other types of interpersonal (mis)communication. The explorative character of this study is not suitable for deeper analysis of these interpersonal effects and the causal relationship between neuropsychiatric symptoms and distress. It is, however, a very important topic for further research, as Orstein and Gaugler² pointed out earlier. So far, both qualitative and quantitative approaches have led us to the current knowledge on the relation between neuropsychiatric symptoms. For further research, it seems appropriate to combine both methods in a mixed methods design, to be able to both measure and interpret the data in a more holistic way.

Conclusion

Despite the limitations mentioned earlier, this study is unique in its focus on measuring distress of care staff in a long-term care setting in relation to specific neuropsychiatric symptoms of dementia. The current study confirms former studies in that neuropsychiatric symptoms are very common among dementia patients and that there is a strong relation between the presence of neuropsychiatric symptoms and distress among caregivers^{10;15;17;18}. Our findings emphasise the importance of supporting care staff in coping with neuropsychiatric symptoms of dementia patients in nursing homes. For instance, it seems prudent to train care staff in the importance of acknowledging symptoms that do not cause much distress, like apathy, as clinically relevant symptoms. Furthermore, management of combative behaviour and training on the effects of interpersonal effects on this behaviour should be a priority, for it is not only the most distressing type of behaviour but also the most prevalent.

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Chapter 7

Coming to grips with challenging behaviour: a cluster randomised controlled trial on the effects of a new care programme for challenging behaviour on burnout, job satisfaction and job demands of care staff on dementia special care units.

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Abstract

Background

Caring for people with dementia on dementia special care units is a demanding job. Challenging behaviour is one of the factors influencing job satisfaction and burnout of care staff. A care programme for challenging behaviour of nursing home residents with dementia might, next to diminishing challenging behaviour of residents, improve job satisfaction and reduce feelings of burnout of care staff.

Objectives

To determine the effects of a care programme for challenging behaviour of nursing home residents with dementia on burnout, job satisfaction and job demands of care staff.

Design

The care programme was implemented according to a stepped wedge design in which care units were randomly divided over five groups with different time points of starting with implementation.

Setting

17 Dutch dementia special care units.

Participants

Care staff members of the 17 units.

Intervention

The care programme consists of an education package and of various structured assessment tools that guide professionals through multidisciplinary detection, analysis, treatment and evaluation of treatment of challenging behaviour.

Methods

Burnout, job satisfaction and job demands were measured before implementation, half-way through the implementation process and after all care units had implemented the care programme. Burnout was measured with the Dutch version of the Maslach burnout inventory (UBOS-C, three subscales); job satisfaction and job demands were measured with subscales of the Leiden Quality of Work Questionnaire. Mixed model analyses were used to determine effects. Care staff could not be blinded for the intervention.

Results

Of the 1441 questionnaires, 645 were returned (response 45%, 318 control measurements, 327 intervention measurements) by 380 unique care staff members. Significant effects were found on job satisfaction (0.93, 95% CI 0.48 to 1.38). On the other outcomes, no significant changes in scores were found.

Conclusion

Positive effects of using the Grip on Challenging behaviour care programme were found on job satisfaction, without an increase in job demands.

Background

Working in long term care facilities for people with dementia is a demanding job due to work environment related factors such as caring climate, understaffing and time pressure^{1;2}, but also because of resident related factors such as challenging behaviour^{3;4}.

To support care workers in their daily tasks, several guidelines and protocols have been developed on various topics. In case of challenging behaviour in dementia, multiple guidelines are available, for example from the National Institute for Health and Care Excellence⁵, the International Psychogeriatric Association⁶ and the American Medical Directors Association⁷. Yet, the use of and adherence to the guidelines in actual practice seems to be low⁸, and the prevalence rates of challenging behaviour and use of psychoactive medication are still high⁹⁻¹².

The complexity of guidelines is often a barrier to implementation. Especially with multidisciplinary guidelines, it is important to develop recommendations that are understandable and usable for health care professionals with different educational backgrounds. Involving the end-users of the guidelines in the development, using different implementation strategies and attuning implementation to the local organisational structure could facilitate the implementation process^{13;14}.

The Grip on Challenging Behaviour care programme (GRIP) is a newly developed care programme that is based on the current evidence-based guidelines and integrates the use of guidelines within the organisational structure and processes of daily nursing home care¹⁵. In developing GRIP, representatives of all involved disciplines (care staff, psychologists, physicians) were consulted. GRIP contains education, multidisciplinary consultation and guidance by means of several structured forms, each of which are adapted to the education levels of the different users. The education sessions are aimed at improving staff knowledge and the use of the structured forms enlarges the insight into the actions undertaken by each discipline, which can improve support amongst different disciplines. Also, the clear description of the procedures and the availability of various tools to structure the process of managing challenging behaviour can improve feelings of control over the situation.

Using GRIP could potentially lead to a reduction of burnout, because staff knowledge, feelings of control and feelings of support are important factors in developing burnout^{2;16;17}. Burnout can be predicted by the combination of feelings of personal accomplishment, emotional exhaustion and depersonalisation regarding residents¹⁸. The content of GRIP might influence these predictors by increasing feelings of personal accomplishment (because of the increased knowledge and feelings of control) decreasing emotional exhaustion (because of increased responsibilities) and decreasing depersonalisation (because analysing behaviour requires more involvement in the lives of residents). Next to this, while the implementation of GRIP could (temporarily) increase job demands, the feelings of control and support could improve job satisfaction¹⁹.

As a result of the rapidly ageing society and the increasing complexity of care, the appeal on care staff will probably increase immensely during the next decades. It is therefore of the utmost importance to develop ways in which job satisfaction can be improved and burnout

can be minimised. As described above, it is possible that GRIP increases job demands, but it might also have a positive effect on feelings of burnout and job satisfaction. Therefore, this study is focused on the effects of GRIP on burnout, job satisfaction and job demands of care staff.

Methods

Setting

This study took place in the Netherlands in 17 dementia special care units (DSCU) that were part of larger care organisations. Psychologists and “elderly care physicians”²⁰ are usually employed by the care organisation and they are part of the care team on the DSCU. The participating units were located throughout the country. Nine of the participating units were located in the densely populated Randstad area of the Netherlands, the other eight were located in less densely populated areas (Noord-Brabant, Gelderland and Friesland).

Care programme

Details of GRIP are described elsewhere¹⁵. In the training sessions that are part of GRIP, the use of structured forms was explained and care staff was educated on how to detect and reflect on signs of challenging behaviour. GRIP consists of four steps; detection, analysis, treatment and evaluation. In addition to the day-to-day observations of resident behaviour by care staff, a detection tool was introduced which is to be filled in half-annually for every resident. When challenging behaviour is detected, care staff initiates the analysis by filling in an analysis form for care staff with one or more co-workers. This form consists of questions to reflect on the behaviour and on the situation and environment in which the behaviour took place. After filling in the form, either the physician or the psychologist is consulted. Both disciplines have their own analysis form which consists of various diagnostic options, such as a checklist to determine or rule out physical causes of the behaviour (analysis form physician) and a section in which a functional analysis of the behaviour can be made (analysis form psychologist). The analysis ends with a conclusion on the possible causes of the behaviour. Next, in a multidisciplinary meeting, the conclusion of the analysis is discussed and a treatment plan is made. On the treatment form, a clear goal should be described, the severity of the current situation should be scored on a 10-point scale and an evaluation date should be planned. Finally, on the prearranged date, the evaluation takes place, guided by a flow chart of possible treatment outcomes and interventions on the evaluation form.

Design

GRIP was implemented on the 17 DSCUs according to a stepped wedge design (Table 1). According to this design, the 17 participating units were randomly divided over five groups using random allocation software²¹. Every four months a new group of DSCUs received

training and started to use GRIP. The implementation began in February 2011 and was completed in June 2012.

Data collection

Assessment took place at three time points, before the start of the implementation (T0, February 2011), midway through the implementation process (T3, February 2012, 6 control units, 11 intervention units) and after the implementation process (T5, October 2012). A questionnaire was distributed amongst all care staff employed on the unit. Care staff could fill in the questionnaire and return it by means of a stamped addressed envelope.

Table 1: The stepped wedge design of implementing GRIP.

Group	T0	T1	T2	T3	T4	T5
1 (3 units)	0	1	1	1	1	1
2 (4 units)	0	0	1	1	1	1
3 (4 units)	0	0	0	1	1	1
4 (3 units)	0	0	0	0	1	1
5 (3 units)	0	0	0	0	0	1

Time periods are four months apart. The assessment of job satisfaction and job strain took place on T0, T3 and T5.

Sampling

The amount of participating DSCUs needed was determined with regard to the resident related outcomes of the research project, which resulted in 17 participating units (sample size calculation and full trial protocol are published elsewhere²²). The unit leader of a DSCU would provide a list of all the care staff currently working on the unit. No selection was made with regard to education, working experience or working hours. All care staff working on the DSCUs received the questionnaire on the three time points described above.

Outcome Measurements

Burnout was measured using the Dutch version of the Maslach Burnout Inventory (MBI)¹⁸, the Utrechtse Burnout Scale – C. The original MBI consisted of 22 items divided over three subscales, but a confirmatory factor analysis showed that although the original factor

structure could be retained, two items should be omitted from the UBOS-C. The adapted version proved to be valid and reliable in determining burnout²³. The UBOS-C consists of 20 items, divided over three dimensions: emotional exhaustion (being emotionally worn out, 8 items, range 0-48), depersonalisation (feeling emotionally distant towards residents, 5 items, range 0-30) and personal accomplishment (feelings of professional failure, 7 items, range 0-42). All items can be scored from never (0 points) to every day (6 points) and are summed into a total score per subscale. For interpretation, some items are recoded so that a higher score on each subscale means a higher risk for burnout.

Job satisfaction and job demands were measured using two subscales (“Job Satisfaction” and “Work and Time Pressure”) of the Leiden Quality of Work Questionnaire, a reliable and valid questionnaire measuring several separate job characteristics²⁴. The Job Satisfaction scale contains six items (range 6-24) and the Work and Time Pressure scale contains five items (range 5-20) that are summed into a total score for both scales, each reaching from totally disagree (1 point) to totally agree (4 points).

Other measurements

Because job satisfaction and burnout can be influenced by various variables such as age, working experience and attitude²⁵, these variables were measured and included in the analyses. The questionnaire therefore contained questions about age, sex, years of working experience, occupation and education level of care staff. In addition, the Approaches to Dementia Questionnaire (ADQ)²⁶ was used to measure attitude of care staff. The ADQ is a questionnaire on the attitude of care staff with regards to dementia and dementia care. The questionnaire contains various statements about dementia care on which respondents can rate their agreement (from totally agree to totally disagree). The ADQ measures attitude towards dementia on two scales, hopefulness (8 items) and person-centeredness (11 items).

Analysis

SPSS 20.0 was used for the descriptive analyses. For all other analyses, MLwin, version 2.28 was used²⁷. Mixed models were used to adjust for dependency of the repeated measures over time within the individual care staff members and for dependency of the care staff within the DSCU. No missing data were imputed. Because the distribution of the scores on the UBOS depersonalisation scale was not normal and could not be transformed into a normal distribution, the scores were dichotomised into low (<2) and high (>2). Hence, for the analyses of the UBOS depersonalisation scores binomial logistic mixed models with a second order PQL estimation procedure were used.

Next to the initial analyses, adjusted analyses were performed correcting for sex, age, years of working experience and the influence of job demands. In addition, interaction of the intervention with education level of care staff (these analyses were only performed in the subgroup of certified care staff), with occupation (nurses and nurse assistants, recreational

therapists, uncertified nursing assistants, other), with years of working experience and with attitude was analysed.

For all analyses, a cut off score of $p < 0.05$ was used for statistical significance.

Results

In total, 1441 questionnaires were distributed amongst the care staff, of which 645 questionnaires were returned (response rate 45%; 318 control measurements, 327 intervention measurements) by 380 unique care staff members. Of the responding care staff members, 368 (97%) were female and the mean age was 42 years (SD 12). The mean time of working experience was 16 years (SD 12). Further, 77% of the respondents were certified care staff, 5 % were recreational therapists, 12% were uncertified nurse assistants and 6 % had another profession (such as team leader, spiritual counsellor) (Table 2).

Table 2: Characteristics of responders

Unique respondents	380
Sex (% female)	97%
Mean Age (years)	42 (SD 12)
Working Experience (years)	16 (SD 12)
Occupation: Care staff	80 %
< 3 years training	15 %
3 years training	72 %
>3 years training	14 %
Recreational therapist	4 %
Uncertified nurse assistant	11 %
Other/missing	4 %

The mean scores on the subscales of the UBOS-C questionnaire for burnout were relatively low (25 out of the possible 120 points) before the start of the intervention, which indicates the responders were not at high risk for burnout. The mean job demands scores were average before implementation (12, scale range 5-20) and the mean scores on job satisfaction were above average (18, scale range 6-24) (Table 3). Significant positive effects were found on job satisfaction (0.93, 95% CI 0.48 to 1.38; a relative change of 5%). No significant changes in scores for emotional exhaustion, personal accomplishment, depersonalisation or job demands were found (Table 3).

Table 3: Effects of the GRIP on burnout and Job satisfaction

	Mean (range)	B (95% CI)	B adjusted (95% CI)
Emotional Exhaustion	11 (0-48)	1.37 (0.00 to 2.74)	0.507 (-0.20 to 1.21)
Depersonalisation	3 (0-30)	OR 1.42 (0.96 to 2.11)	OR 1.28 (0.83 to 1.96)
Personal Accomplishment	11 (0-42)	0.57 (-0.10 to 1.25)	0.65 (-0.05 to 1.35)
Job Demands	12 (5-20)	-0.22 (-0.45 to 0.09)	-0.20 (-0.52 to 0.12)
Job Satisfaction	18 (6-24)	0.89 (0.44 to 1.34)*	0.93 (0.48 to 1.38)*

For each scale, the range of the scale and the mean score of the study population before intervention are given. B adjusted= analysis corrected for age, sex, job demands and working experience (analysis on job demands were corrected for age, sex and working experience). * = $p < 0.05$

No interaction effects were found for attitude measured with the ADQ. For the education level of care staff, an interaction effect was found for two subscales of the UBOS. Care staff with a higher education level scored higher on emotional exhaustion but lower on depersonalisation when using GRIP, whilst no effects were found for the lower education levels. In other words, higher educated care staff felt more exhausted but less detached from residents when GRIP was used. An interaction effect was also found for occupation. Recreational therapists scored lower on the depersonalisation scale of the UBOS when using GRIP.

Discussion

The aim of this paper was to describe the effects of using the Grip on Challenging Behaviour care programme (GRIP) on burnout, job satisfaction and job demands of care staff. Burnout was measured on three dimensions; feelings of personal accomplishment, feelings of emotional exhaustion and depersonalisation.

The scores on the burnout dimensions were low, indicating that the care staff was not at high risk for burnout, which is in line with earlier studies^{28;29}. Before implementation, job satisfaction of care staff was above average and job demands were reported as average, which is also comparable to earlier studies in Dutch nursing homes^{17;29}. Job satisfaction was significantly higher when GRIP was used, while the measured job demands did not change. This is an important finding, for extra workload and time pressure (higher job demands) are often proposed as a barrier to implementation of interventions^{30;31}. It might be that the improvements in decision authority and the (multidisciplinary) support in managing challenging behaviour that are offered by GRIP have buffered for the effects that job demands can have on care staff, resulting in heightened job satisfaction while the job demands did not change. Indeed, in the job demand-control-support model¹⁶, it is assumed that these variables are interconnected. It is also known that staff knowledge

and the opportunity to reflect on difficulties at work influence job satisfaction². It is likely that GRIP has increased staff knowledge through the training sessions and has supported decision making and reflection with co-workers by the structure and the forms it offers.

No effects were found on the burnout subscales in the total group of responders. However, an interaction effect was found between occupation and using GRIP on the depersonalisation subscale. When GRIP was used, an effect on depersonalisation was found only for recreational therapists. The fact that recreational therapists had less feelings of depersonalisation when GRIP was used could be inherent to their job; making contact and being aware of the personal preferences of residents, is a specific goal in recreational therapy and GRIP might have helped them to attune to the preferences of the residents even more. Another explanation might be that recreational therapists do not spend as much time with the residents as the rest of the care staff. Since they only interact with the resident during activities, it might be easier to fully engage and sympathise with the residents.

An interaction effect was also found for education level; care staff with higher education levels had more feelings of emotional exhaustion but less feelings of depersonalisation when using GRIP. These two dimensions are probably interconnected; less depersonalised feelings might lead to getting more emotionally exhausted (after all, less depersonalisation means being more emotionally involved), and this might also coincide with more job satisfaction²⁵. Thorough analysis of the behaviour of the residents means interpreting their behaviour, getting to know their feelings, past experiences and personal preferences. Hence it is not surprising when staff gets less depersonalised from residents when GRIP, which emphasises thorough analysis, is used. It is, however, interesting to see that GRIP did not cause the same effect in the care staff with lower education. In this group, the use of GRIP did not lead to more emotional exhaustion nor did they become less depersonalised from their work. The absence of changes in emotional exhaustion and depersonalisation in the lower educated care staff members may mean that lower educated staff did not always use GRIP to its full extent. The feelings of emotional exhaustion in the higher educated group of care staff might also be a result of the responsibilities they have in the implementation process and the quality of care. Possibly as a result of the decreasing amount of team managers available^{32,33}, the higher educated care staff often function as a senior care giver³⁴, which means they have the main responsibility for maintaining or improving good quality of care and implementing innovations on the unit.

The results on burnout and job satisfaction are not conclusive. This could be explained by the fact that job satisfaction and burnout are predicted by many other factors than challenging behaviour. The effects could, however, also be muted by the implementation rate of GRIP, which was suboptimal. Although care staff members almost unanimously stated that there was a need for a structured care programme for challenging behaviour prior to the implementation period, and GRIP itself was rated as feasible and applicable, the actual implementation proved to be a challenge. It seemed that, although GRIP offered a clear structure, it was hard to adapt the structure to the mostly unstructured daily work routines. When there was no clear authority figure that encouraged and supervised the

use of GRIP, implementation was very difficult, which is in line with other research on implementation in long term care^{13;33}. These findings might be interpreted as a need for a more structured approach and more support in the organisation of long term care as a whole rather than just on the topic of challenging behaviour.

There are some limitations in this study that should be taken into consideration. Feelings of burnout, job satisfaction and job demands are influenced by many other things than the management of challenging behaviour alone. The sample size of this study may have been too small to determine the subtle effects of using GRIP on a multicomponent concept such as job satisfaction. The use of a questionnaire specifically aimed at these variables in relation to challenging behaviour might have been more suitable for our research aim. To the best of our knowledge, no such questionnaire is available. Furthermore, the mean years of working experience in the respondent group was relatively high, which might have led to a respondent group that is more conscientious and less prone to experience burnout than the whole population. Lastly, the care staff members were not blinded for the intervention. Although this is inherent to this type of research (improving burnout, job satisfaction and job demands by an intervention implies involving people in both the intervention and the measurements), this could have influenced the results.

Despite these limitations, the positive effects that were found in absence of increases in job demands are promising. The effects of GRIP were measured repeatedly over a prolonged period of time, which increases the validity of our results. In conclusion, the Grip on Challenging Behaviour care programme could be a step forward in making care for people with dementia less challenging for care staff and thus could be a contribution to the preservation of care staff in dementia long term care.

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Chapter 8

Summary and General Discussion

Introduction

The main goal of the research project described in this thesis was to develop and study the effects of a care programme that would be able to guide care teams in managing challenging behaviour. By structuring the management of challenging behaviour and prearranging multidisciplinary involvement it was expected that the care programme would be able to diminish challenging behaviour-related outcome measures. This chapter summarises and discusses the main findings of this project. It also addresses the methodological issues and the implications for clinical practice and health care policy. Finally, the implications for further research are discussed.

Summary of the main findings

Chapter 2 and 3, study protocol and development of Grip on Challenging Behaviour (GRIP). In chapter 2, the design of the GRIP project is described. A stepped wedge design was chosen, in which different clusters of Dementia Special Care Units (DSCUs) cross over from control to intervention condition over time. Resident outcomes were planned to be measured on six separate occasions, and care staff outcomes were planned to be measured over three separate occasions. In total, a 20-month period was chosen to implement GRIP and study the effects.

In chapter 3, the development process of GRIP is described.

GRIP was based on the national and international guidelines for the management of challenging behaviour. Several expert meetings were organised to further develop the structure of GRIP and the accompanying forms. In the expert meetings, discussions regarding the goal, content, and feasibility of GRIP were held with representatives from different disciplines engaged in long-term care for people with dementia. This development process resulted in a structure for the multidisciplinary management of challenging behaviour that can be used by the several involved disciplines (e.g. care staff, psychologist, physician). The structure of GRIP consists of four steps, which are detection, analysis, treatment, and evaluation. Detection can be performed by care staff either in daily care or by a detection tool which is administered every six months. After challenging behaviour is detected, the care staff fills in an analysis form and consults either the psychologist or physician. Both clinicians can use their own analysis form, which is based on the discipline-specific guidelines. After the analysis, a treatment plan is formed based on the results of the analysis. Finally, by using a flow chart, the evaluation takes place. The structure of GRIP, individual steps and forms, and underlying principles of GRIP are all explained through two training sessions at the start of the implementation.

Chapter 4, process evaluation of the implementation of GRIP.

To evaluate the validity of the results of the effect study on GRIP, as well as to evaluate the barriers and facilitators to implementing GRIP for future implementation purposes, a process evaluation of the implementation of GRIP was undertaken. In chapter 4, the results of the process evaluation are described. The first order process data show that the preconditions for implementation and interpreting the effects of implementation are met; e.g. the recruitment and reach both allow for the generalisation of the results and GRIP was judged to be feasible and relevant to long-term dementia care.

The initial reaction of the care teams to the implementation of GRIP was positive. People were confident that GRIP could reduce challenging behaviour and they were contented with the structure GRIP could bring to the way challenging behaviour is managed. Through interviews and questionnaires, facilitators and barriers for implementing GRIP could be determined.

First, there were organisational aspects that hindered the implementation. Although in the preparation of the project, the management of the participating organisations was thoroughly informed about the (time) investment the project would cost, factors such as high workload, staff turnover, concurrent projects, insufficient time for multidisciplinary consultation, and organisational changes hindered the implementation in some of the DSCUs. In some cases there seemed to be a gap between the management, which judged the implementation of GRIP to be possible and desirable for their organisation, and actual daily care practice. These findings demonstrate the value of conducting a process evaluation, as these factors can be reckoned with in future implementations, for instance by involving more care staff members and clinicians in the decision making process on participating in the implementation of GRIP.

Next, the culture of the organisation could form either a barrier or a facilitator for implementing GRIP. The support of a key person who was enthusiastic about using GRIP made an obvious difference in the implementation rate, and accordingly, when a key person resigned, it was very difficult to maintain enough attention for the use of GRIP. In addition, in the project there were units with a culture open to change and innovations, whereas there were other units that were more focused on keeping things the way they were.

Lastly, there were specific aspects of GRIP that formed a barrier for implementation for some units. The amount of forms that were used put some people off and the fact that GRIP was not digitally available meant that for some units the working method of GRIP did not attune with other working methods in daily care. Again, these are factors which can be reckoned with in future implementations.

Chapter 5, effects on resident outcomes.

The effects of GRIP on challenging behaviour and the use of psychoactive drugs and restraints are described in chapter 5. The effects on the main outcome measurement, the Cohen Mansfield Agitation Inventory (CMAI)¹, were small. There were no effects on the total amount of clinically relevant neuropsychiatric symptoms measured with the neuropsychiatric

inventory (NPI-NH)², but significant positive effects on residents showing signs of delusions, depression, apathy, disinhibition, and aberrant motor behaviour were found. Furthermore, significant effects on the prescription of antipsychotics and antidepressants were found. No changes in restraint use were found. Adjusting analyses for the implementation rate shows that better implementation leads to larger effects of GRIP.

Chapter 6 and 7, the experience of challenging behaviour by care staff

Next to diminishing challenging behaviour and the use of psychoactive medication, the impact of challenging behaviour on care staff was also considered an important field of research. First of all, there seemed to be a lack in the literature about the relation between individual forms of challenging behaviour and the experience of distress of care staff. Therefore, in chapter 6, a closer look is taken at this relation. It became clear that agitation causes the most distress for care staff and that euphoria causes the least amount of distress. Furthermore, the severity of symptoms is a far more important predictor for the amount of distress experienced by care staff than the frequency of behaviour.

The results that were found differ from the research amongst informal carers. For example, delusions and apathy do not cause as much distress in formal care as in informal care. In case of delusions, this might be a sign of a positive professional attitude, in case of the latter, apathy, this might be a sign of professional indifference, which asks for more education and attention for the seriousness of this symptom.

Chapter 7 proceeds with the effects of the use of GRIP on professional carer outcomes. According to the demands-control-support (DCS) model, high-demand jobs with low decision authority and low work-related social support increase the risk for burnout and lowered job satisfaction. In the Grip on Challenging Behaviour study, no beneficial effects on burnout were measured, but job satisfaction improved when GRIP was used. The introduction of GRIP has probably led to an enhanced feeling of decision authority and social support, which, according to the DCS model, has led to higher job satisfaction while job demands stayed the same.

Methodological Issues

This section addresses the methodological issues that should be reckoned with when interpreting the results of the GRIP study.

Stepped wedge design

Because most people with dementia living in nursing homes are at the end of their lives, attrition rates are high in studies involving this population. During the 20 month follow up period, 659 residents were included, of whom only 178 were included in all of the

assessments. The stepped wedge design was chosen for the GRIP study, for it allows for the replacement of residents who have died or moved away from the unit during the study³. The use of the stepped wedge design had several other logistic and practical advantages. For example, by training a group of three or four units every four months instead of all of the units at once, it was possible to assign the monitoring of the initial implementation phase to one researcher who could keep the overview and compare different units in order to gradually improve the implementation strategies.

Because of several complicating factors, however, analysing the data from a trial with a stepped wedge design becomes an elaborate process. Next to the repeated measurements and the clustering of variables within a unit, which demand a mixed model approach, the control group and intervention group are continuously changing over measurements due to crossing over from control to intervention condition and the attrition of residents. This makes the interpretation of the effects more complex, as they consist of a 'between-subject effect' and a 'within-subject effect', and the proportion of the 'within-subject effect' varies depending on the attrition rate of the residents. There is an ongoing discussion about how to deal with this continuously changing composition⁴⁻⁶, and in the Grip on Challenging Behaviour trial, the usual analysis methods sometimes led to inconsistent or incalculable results. In these cases, a less than optimal analysis method like analysing change scores had to be used, which makes the interpretation of the effects more difficult.

To make the most of the stepped wedge design, more agreement about the statistical methods to be used would be helpful. Although the stepped wedge design has rather tempting practical advantages, without clarification on how to analyse the data, the design loses some of its appeal.

Blinding

Implementing an intervention in dementia care and concurrently determining the effects on the behaviour of residents inevitably means involving care staff in the measurements. After all, effects on the behaviour of residents can only be assessed by people who know the residents and who are able to observe the resident for a prolonged period of time. Involving care staff in the measurements on challenging behaviour does, however, increase the probability of bias; e.g. the tendency of people to report differences in behaviour because they believe GRIP to be beneficial. To find out the possible influence of the information bias, an interim analysis was performed, which is reported in chapter 5. These analyses did not suggest any significant influence of information bias.

Complex intervention research

The GRIP project is an example of complex intervention research in a complex system. GRIP is a complex intervention as it contains various interacting components⁷, like staff education, multidisciplinary involvement, and various tools to support the process of

managing challenging behaviour. Although positive effects of using GRIP were found, it is unclear which components of GRIP were the most important for the effects. Next to this, GRIP is implemented in a complex system, namely that of a dementia special care unit. In these units, many variables coexist and interact nonlinearly⁸. For example, in case of challenging behaviour, factors such as the prescribing behaviour of physicians and the personal characteristics of residents are likely to influence the outcome measurements. It is for that reason that these kinds of variables were incorporated in the mixed model analysis. It is very likely, however, that there are other 'hidden' influential variables⁸ that have an impact on behaviour. In fact, one of the 'challenging' parts of the behaviour is that the cause and influential factors of the behaviour are often unknown. Unit-bound factors like organisational culture, shifts of care staff, care incidents, etc. will also influence behaviour and behaviour related outcome measurements. In the GRIP study, these unit-bound factors led to variance in the degree of implementation, which influenced the effect size of the results. This finding stresses the importance of performing a process evaluation when conducting complex intervention research in a complex system. Still, for the interpretation of the effects, the indistinct causality⁸ (unclear direction and connection of causality) makes it difficult to determine what components of the intervention worked on which unit and why.

Selection of measurement instruments for challenging behaviour

The primary outcome for the effects of GRIP was challenging behaviour, measured with the Cohen Mansfield Agitation Inventory (CMAI)¹ and the Neuropsychiatric Inventory (NPI-NH)². It is, however, debateable as to whether these tools truly only measure behaviour that is 'challenging'. For example, the CMAI item 'hoarding' could mean that a resident regularly collects various items in his/her stroller and subsequently hides them behind his/her bed. Care staff may have knowledge of this behaviour and, therefore, collects the hoarded things from behind the bed every other day, which does not upset the resident. Because the situation is under control, interventions are not needed but the behaviour still scores a certain amount of points on the CMAI and hence it may cloud the results of GRIP on this measurement scale.

For the NPI-NH, a cut off point for clinical relevance was used to avoid the problem of every form of aberrant behaviour being immediately classified as challenging. The original NPI-NH instructions state that the subscores can be summed up to one 'challenging behaviour score', but because of the choice for a cut off point for clinical relevance, analysis on this total score was no longer possible. However, analysis of individual symptoms is more appropriate when looking at the content of GRIP because GRIP focuses on disentangling behaviour and making a clear treatment goal for distinct behavioural features, which is the opposite of interpreting behaviour in a total challenging behaviour score.

Implications for practice and health care policy

The start of the Grip on Challenging behaviour project was very promising. Both research^{9,10} and experience in practice suggested a considerable need for a better way to manage challenging behaviour, which was reflected in the ease with which the minimum number of participants for the study was reached. GRIP was carefully developed in accordance with evidence-based documents that described the way challenging behaviour should be managed¹¹⁻¹³.

Based on the results that were found in the effect study, implementing GRIP in Dutch nursing homes can be advised for diminishing challenging behaviour and the prescription of psychoactive medication. However, it was also found that better implementation results in larger effects and that implementation was far from optimal. The process evaluation revealed several barriers and facilitators to implementing GRIP. Before making GRIP available nationwide, small adjustments to the structure of GRIP should, therefore, be made and a better implementation strategy should be developed. The barriers for implementation that were found can be reckoned with in the future development of GRIP, but they also have implications for both daily care and health care policy. These implications will be described below.

A frequent consultative structure is essential

The Dutch situation in which several professions such as psychologists and physicians are part of the care team seems an outstanding starting point for providing optimally tailored care for residents. In some organisations, however, time pressure, fragmented employment contracts and limited coordination between various disciplines result in a multidisciplinary structure that is virtually non-existent apart from the obligated care plan meetings¹⁴. During the implementation of GRIP, a lack of communication between clinicians would sometimes lead to scenarios in which treatments did not attune or the effects of treatment would be unclear because multiple treatments were applied at the same time without consultation between the responsible disciplines. To be able to approach complex care issues methodologically (detecting problems, analysing, treating, and evaluating treatment), a frequent consultative structure between disciplines is needed¹⁵. Sticking to only the biannual care plan meetings seems a lost opportunity for the individual residents as well as for the professional field of psychogeriatric care as a whole. In a true multidisciplinary structure, clinicians should be able to consult each other and work together on a far more regular basis.

Improvement of the involvement of the psychologist

Between the participating care organisations, there were many differences with regards to the frequency and structure of psychologist consultations on a unit. For example, the hours a psychologist has available per unit differed greatly between organisations. Furthermore, on some of the participating units, the psychologist would wait for a request from the care staff to come into action, which would sometimes lead to an absence of visits from the psychologist for weeks. In contrast, in another unit, a weekly consultation with the psychologist was scheduled in which the psychologist made inquiries about any possible behavioural problems. As psychologists have a central role in the management of challenging behaviour, the latter, more proactive working method would seem more appropriate. Care organisations, however, will have to invest in time and education to improve the availability and quality of their psychological expertise.

Fewer changes in the working methods and more consistency in policy are needed

The working methods for care staff differed between the participating units and seemed to have gone through several changes in the last couple of years. For example, the method used for structuring the multidisciplinary care plan meetings differed per participating unit and was also subject to changes during the project. In addition, although the goal and content of digital filing systems are the same for each nursing home, every separate organisation was using a different system. Moreover, many care staff members did not know how to operate the system properly, the systems seemed unnecessarily complicated to care staff, and newly employed staff often had trouble adjusting to the filing system and many other working procedures.

The continuous changes in organisational aspects cause constant disturbance and commotion and in some cases they lead to a culture in which care staff develops their own set of unwritten rules and working methods which are not always beneficial for the residents. For instance, in one particular participating unit, the care staff could not see the wood for the trees with regard to the amount of different approaches to individualised care that had come and gone in recent years. Paradoxically, they had fully routinised the only care task that had been stable over the years; making sure that residents were washed and clothed in the morning. They made this task an, in their eyes, efficient and workable routine, in which they claimed there was no time for individualised approaches or preferences, which is obviously the opposite of the 'individualised care' that the organisation was so eagerly promoting.

The large amount of innovations that the care staff is presented with might also explain the lack of readiness to change that is sometimes found in this group. The care staff stated that they had extensive experience with the introduction of new working methods, but that these methods would just as easily fade into the background within weeks and that they did not feel that implementing GRIP would pass off any differently. Interestingly enough,

while most interventions should be integrated in the working methods of care staff, they themselves often complain of unsuccessful implementation. It seems that organisations might underestimate the investments that are necessary for implementation trajectories.

It is a pity that initiatives that are taken to improve care seem to turn out in less instead of more quality of care. To keep professional carers enthusiastic towards innovation and to increase the chance of innovations being successful, organisations might benefit from a more consistent policy on the organisation and improvement of care; clear decisions need to be made with regard to committing to one new project instead of being involved in every opportunity for innovation.

Development of one overlapping meta-structure

The remarks on the lack of clarity about the working methods and policies in dementia care described above also apply to the current state of research on interventions for dementia long-term care. Increasingly more complex interventions are being developed, for example to improve the attitudes of care staff^{16;17}, improve the quality of life of residents¹⁸ and, obviously, diminish challenging behaviour¹⁹⁻²¹. Although each of these topics is very important to improve the quality of care delivered, it seems impossible for care organisations to adapt a new care structure for each care challenge. What is more, many interventions seem to rely on the effects of structuring and clarifying the approach to a specific care challenge (often through working methodically) rather than offering one treatment option. It might, therefore, be worthwhile to examine the possibilities to provide one structured approach to improve the quality of dementia care as whole, which can be applied to various care challenges. To reach the optimal efficacy of such a 'meta-structure', current effective approaches should be examined for their effective components. In other words, the 'black box' of the interventions should be opened to determine which components should be a part of the meta-structure.

Upgrading the education of the care staff

Lastly, throughout the project, "teach us how to "solve" challenging behaviour" was a recurring theme amongst the care staff. Despite the training sessions and the background and content of GRIP, which all aim at analysing the behaviour and critical appraisal of the environment and the role of care staff, it was rather difficult to change the line of thought that there should be a cure, preferably one, for all challenging behaviour of all of the residents.

The ability of abstract thinking about behaviour, reflecting on oneself and placing oneself in the residents' position is essential for effectively managing challenging behaviour, but these competences did not always seem to be sufficiently developed in the nursing staff. This raises questions about the content of the education of nursing staff and the way their education prepares them for the complex reality in which they have to work. Education

which is specifically aimed at care for people with dementia seems an evident need in Dutch long-term care²². Moreover, one might ask to which amount it is fair to ask nurse assistants and practice licensed nurses (helpenden and verzorgenden niveau 3) to perform the complex task of interpreting behaviour without the on-the-job support of higher educated staff (for example, registered nurses).

The general tendency to postpone nursing home admittance until the situation becomes truly dangerous for the person with dementia or his/her environment leads to a high prevalence of challenging behaviour which results in nursing home care becoming more and more complex, resembling the complexity of those residing in psychiatric wards. However, the staffing of dementia special care units has certainly not grown in expertise accordingly. Despite the brochure of the Health Care Insurance Board (CVZ) mentioning that people with dementia in nursing homes will have 'a registered nurse (verpleegkundige) who takes special care of your health'²³, the staff of the dementia special care units almost always consists of nurse assistants (helpenden) and practice licensed nurses (verzorgenden)²⁴. Care organisations appreciate the benefits that the employment of registered nurses would have²⁵, but financial constraints make it difficult to put this in practice. It seems that, in government policies, the seriousness of the behavioural aspects of dementia is underestimated. While the (financial²⁶) resources on dementia special care units do not compare to psychiatric wards, the behaviour that is treated there surely does. The main difference seems to be that dementia is a disease of old-age, and the main thought seems to be that it justifies psychiatric care being valued over care for those people with dementia. This form of ageism is ethically untenable and should be countered²⁷.

Implications for further research

Local analysis for bottom up implementation

The idea that care staff should be better prepared for the complex reality of psychogeriatric care is far from new. Moreover, several projects and trainings have been developed to help nursing staff to improve the quality of care and to better handle challenging behaviour. These developments, however, have apparently not led to any large-scale changes in the approach to challenging behaviour. Moreover, several care teams stated during the Grip on Challenging Behaviour training that they already were familiar with concepts such as 'person-centred care', 'emotion oriented care', and 'behavioural analysis'. Even so, some carers stated that 'they knew about all of those fancy ideas, but it just does not work like that in practice'. The current available care models and methods have been developed to guide and support care staff, but apparently the implementation methods are ill adapted to the needs and perceptions of those having to work with them.

Although much literature can be found on implementation methods and barriers and facilitators for implementation^(e.g. 20;28;29), these influencing factors are all determined after the implementation of the intervention. As research on implementing guidelines suggests, it is more rational to make a local diagnostic analysis of the culture of an organisation and the local barriers and facilitators to implementation^{30;31}. In other words, before an intervention is even developed, researchers should explore the local needs, preferences, and culture. By doing this, custom-made interventions that fit with the local situation can be developed bottom-up instead of top-down³². In practice, this would mean a researcher should get the time and means to really submerge him or herself into the local culture and the needs for education and innovation that are felt by the care team. Only after such an analysis can an optimal implementation of interventions be expected.

Research on the explanatory models on challenging behaviour

Although raising the level of expertise and capacities of care staff could certainly improve the management of challenging behaviour, the call for more explicit tools and treatments for challenging behaviour might also stem from the lack of satisfactory models that can explain why people with dementia act the way they do.

In the development and training of GRIP, the models of unmet needs³³ and theories about coping³⁴ were used. These models represent the current way of thinking about the origin of challenging behaviour. They also reflect the current view on dementia care, which should consider the individual preferences and characteristics of the person with dementia.

Although these models are being used in practice, the scientific literature on the actual effects of (severe) dementia on, for example, personality, coping styles, or experiencing emotion is mostly lacking. Moreover, despite the current view being often proposed as a bio-psycho-social view on dementia (Figure 1), the biological side of dementia tends to be overlooked in the current models. For instance, the influences of physical functioning (for instance, delirium or inflammatory processes) on behaviour remain largely unknown. Next to that, the neuropsychological consequences of dementia on behaviour have not yet been researched.

Notwithstanding the obvious psychosocial influences on behavioural symptoms, dementia is a disease characterised by a degenerating brain. The current models about looking beyond challenging behaviour into the underlying reason all presume that we have some knowledge on the way people with dementia experience the world. Being able to find and resolve an

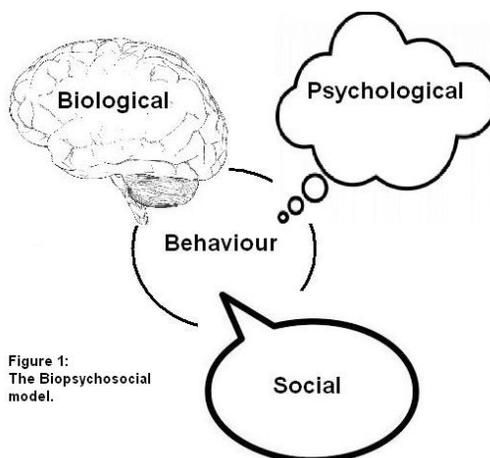


Figure 1:
The Biopsychosocial
model.

unmet need or to adapt to coping reactions in the right way requires an understanding about the perception a person with dementia has of his or her surroundings. Although the literature implies many forms of deteriorated perception for early stage dementia³⁵⁻³⁷, research in later stage dementia is lacking. Without a clearer idea about the way people with more severe dementia experience the world, a true bio-psycho-social model cannot be formed. Next to finding a scientific basis for the current psychosocial models, more research into the neuropsychological explanations of challenging behaviour in dementia is necessary to improve the available models and theories.

Concluding remarks

The current scientific literature and evidence-based guidelines emphasise the need for a structured approach to challenging behaviour in which several disciplines work together on detecting, analysing, treating, and evaluating the treatment of challenging behaviour. Up to now, very few interventions for managing challenging behaviour multidisciplinary and methodically have been scientifically studied. The GRIP project provided a carefully developed care programme that was implemented on 17 DSCUs. The degree of implementation on the units varied, which has both implications for the further development of GRIP as well as for care practice and health care policy. Nevertheless, the most important finding in this

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Chapter 9

Nederlandse Samenvatting

Grip op probleemgedrag

De ontwikkeling, implementatie en evaluatie van een zorgprogramma voor de aanpak van probleemgedrag bij dementie in het verpleeghuis.

Samenvatting

Probleemgedrag, zoals roepen, onrustig zijn of geagiteerd reageren, komt veel voor bij mensen met dementie. Vaak is probleemgedrag de reden waarom mensen worden opgenomen op een psychogeriatrische afdeling van een verpleeghuis, wat maakt dat de prevalentie van probleemgedrag op deze afdelingen hoog is.

De laatste jaren is er steeds meer aandacht voor de achterliggende oorzaken van het gedrag van mensen met dementie. De visie is hierbij dat mensen met dementie hun ongemak of onvrede communiceren door hun gedrag. Door bijvoorbeeld de omgevingsfactoren te onderzoeken, te kijken of er onvervulde behoeften zijn of na te gaan of er te veel of te weinig prikkels worden geboden, kan een oorzaak van het gedrag achterhaald en aangepakt worden. De richtlijnen over probleemgedrag stellen dan ook allemaal dat een grondige, multidisciplinaire analyse van het gedrag nodig is alvorens een behandelplan wordt gemaakt, en dat ingaan op de oorzaken van het gedrag door middel van psychosociale interventies de voorkeur heeft boven het gebruik van psychofarmaca als behandeling voor probleemgedrag.

De Nederlandse verpleeghuiszorg voor mensen met dementie kent een aantal unieke aspecten waarmee kwalitatief hoogwaardige zorg kan worden geboden. Zo wordt zorg multidisciplinair afgestemd tussen in ieder geval een specialist ouderengeneeskunde (die een 3 jarige specialisatie opleiding ouderenzorg heeft gevolgd), een psycholoog en de verzorgenden. Veel verpleeghuizen beschikken daarnaast nog over andere disciplines zoals een ergotherapeut, een fysiotherapeut, een diëtist, een logopedist, etc.. Daarnaast wordt in veel verpleeghuizen 'belevingsgerichte' of 'persoonsgerichte' zorg nagestreefd, waarbij de behoeften, wensen en voorkeuren van de bewoners zo veel mogelijk worden gevolgd. Hoewel de randvoorwaarden voor het leveren van optimale zorg dus aanwezig lijken, zien we dit niet terug in de prevalentiecijfers van probleemgedrag en psychofarmacagebruik. Het blijkt in de praktijk erg lastig te zijn om de richtlijnen te volgen en probleemgedrag gestructureerd te benaderen. Er is kennis nodig over hoe bijvoorbeeld signalen van probleemgedrag tijdig gesignaleerd kunnen worden en over hoe een multidisciplinair analyseproces vorm gegeven kan worden.

Dit proefschrift gaat over de ontwikkeling, implementatie en evaluatie van het zorgprogramma Grip op Probleemgedrag. Het zorgprogramma is gebaseerd op de bestaande nationale en internationale richtlijnen over probleemgedrag bij dementie en biedt educatie en begeleidend materiaal (zoals analyseformulieren, een evaluatieflowchart) voor een gestructureerde multidisciplinaire aanpak van probleemgedrag op psychogeriatrische afdelingen.

In **hoofdstuk 2** wordt het studieprotocol beschreven dat ontwikkeld werd om de effecten van het zorgprogramma te onderzoeken. Er is gekozen voor een 'stepped wedge design', waarbij verschillende groepen van psychogeriatrische afdelingen na een controle periode instromen in de interventie conditie. Uitkomsten op bewoners niveau werden zes keer

gedurende twintig maanden gemeten. Uitkomsten op het niveau van de werkbeleving van verzorgenden werden drie keer gemeten in dezelfde periode.

In **hoofdstuk 3** valt vervolgens te lezen welke stappen zijn ondernomen om het zorgprogramma te ontwikkelen. De projectgroep Grip op Probleemgedrag heeft de 'Richtlijn Probleemgedrag' van Verenso (beroepsvereniging Specialisten Ouderengeneeskunde), de 'Handreiking Psychologische Hulpverlening bij Gedragsproblemen bij Dementie' van het NIP (Nederlands Instituut van Psychologen) en de 'Richtlijn Omgaan met Gedragsproblemen bij Patiënten met Dementie' van V&VN (Verpleegkundigen & Verzorgenden Nederland) naast elkaar gelegd en onderzocht op overeenkomsten en verschillen. Alle richtlijnen volgen de stappen van het methodisch werken; signaleren -> analyseren -> behandelen -> evalueren. De stappen in het zorgprogramma zijn dus ook hierop gebaseerd. Vervolgens zijn discipline specifieke stukken uit de richtlijnen gebruikt om de analysestappen per discipline vorm te geven. De opzet van het zorgprogramma is in drie verschillende bijeenkomsten voorgelegd aan een groep van experts uit de praktijk. Naar aanleiding van hun commentaar is het zorgprogramma aangepast. Dit heeft uiteindelijk geleid tot een zorgprogramma dat bestaat uit 2 dagdelen educatie, een map met achtergrondinformatie en 8 ondersteunende werkbladen.

Grip op Probleemgedrag is geïmplementeerd op 17 psychogeriatrische afdelingen van verschillende zorginstellingen. Om de data die verzameld werd voor het effect onderzoek te kunnen duiden én om meer inzicht te krijgen in het implementatieproces voor toekomstige implementatiedoelstellingen werd een procesevaluatie uitgevoerd. De resultaten van deze procesevaluatie zijn terug te lezen in **hoofdstuk 4**. De procesevaluatie toonde aan dat werd voldaan aan de voorwaarden om de effectdata te kunnen interpreteren; de werving van deelnemers maakt generalisatie mogelijk en de opzet van het zorgprogramma werd door de gebruikers als passend en bruikbaar beoordeeld. Er werden echter ook verschillende factoren gevonden die de implementatie van het zorgprogramma beïnvloedden, waardoor de implementatie niet optimaal was.

Ten eerste waren er organisatorische factoren zoals personeelsverloop, onvoldoende multidisciplinaire samenwerking en organisatorische veranderingen die de implementatie nadelig beïnvloedden. Daarnaast was de afdelingscultuur en de betrokkenheid van een 'sleutelfiguur' op de afdeling van belang voor de mate van implementatie. Verder was het zorgprogramma niet digitaal beschikbaar terwijl sommige afdeling met digitale dossiers werkten. Tenslotte schrok de hoeveelheid werkbladen die bij het zorgprogramma hoorde sommige gebruikers aanvankelijk af, hoewel men ook aangaf alle bladen nodig te hebben voor een juiste aanpak van probleemgedrag.

In **hoofdstuk 5** worden de effecten van het gebruik van Grip op Probleemgedrag op probleemgedrag en psychofarmacagebruik beschreven. Hoewel de effecten op de primaire

uitkomstmaat, agitatie (CMAI), statistisch significant waren, is de grootte van het effect te klein om ook van klinische significantie te spreken (verschilscore tussen controle metingen versus interventiemeting: 2,4 punt op een schaal van 29-203). Op de individuele symptomen van probleemgedrag (NPI-NH) werden significante effecten gevonden op de prevalentie van wanen, depressie, apathie, ontremd gedrag en doelloos repetitief gedrag. Ook op het gebruik van antipsychotica en antidepressiva werden significante effecten gevonden. Er werden geen verschillen gevonden op vrijheidsbeperkende maatregelen. Wanneer de analyses aangepast werden voor de implementatiegraad werd duidelijk dat op de afdelingen waar het zorgprogramma beter geïmplementeerd werd, de effecten ook groter waren. Hoewel de effecten op de CMAI kleiner waren dan verwacht lijkt het zorgprogramma dus effectief in het verminderen van probleemgedrag en het gebruik van psychofarmaca. Eerdere onderzoeken toonden een groter effect op de CMAI aan, maar in deze onderzoeken werden alleen mensen met ernstig probleemgedrag geïnccludeerd, wat de kans op het vinden van een effect vergroot. Vanwege de preventie component van GRIP werden in dit onderzoek daarentegen gegevens van alle bewoners op een afdeling meegenomen, hetgeen de resultaten mogelijk verdunt heeft. Daarnaast worden vaak externe experts ingevlogen om probleemgedrag te verminderen, terwijl de kracht van Grip op Probleemgedrag o.a. ligt in het gebruik maken van de eigen expertise op de afdeling.

In **hoofdstuk 6 en 7** wordt dieper ingegaan op de beleving van professionele zorgverleners van mensen met dementie. Er bleek nog weinig bekend over de belasting die verzorgenden ervaren door specifieke vormen van probleemgedrag. In hoofdstuk 6 wordt daarom de relatie tussen twaalf symptomen van de NPI-NH en de mate van belasting van zorgverleners onderzocht. Met name de ernst van het gedrag, en minder de frequentie, blijkt de belasting te beïnvloeden. Agitatie wordt als meest belastend ervaren, euforie als minst belastend. Zorgverleners lijken minder dan mantelzorgers belasting te voelen van de symptomen wanen en apathie. Hoewel de mindere belasting door wanen wellicht een teken van professionaliteit is, zou de beperkte belasting door apathie kunnen betekenen dat dit symptoom ten onrechte als niet ernstig of passend bij dementie wordt ervaren. In hoofdstuk 7 wordt vervolgens het effect beschreven dat werken volgens Grip op Probleemgedrag heeft op de werkbeleving van zorgverleners. Op de vragenlijst die burn-out meet werd geen verschil gevonden en ook de ervaren werkdruk bleef gelijk. De werktevredenheid van zorgverleners nam toe nadat ze begonnen waren te werken volgens Grip op Probleemgedrag. Het gebruik van het zorgprogramma heeft waarschijnlijk geleid tot meer ervaren beslissingsbevoegdheid en sociale steun, factoren waarvan binnen het "demand-control-support model" aangenomen wordt dat ze de werkbeleving beïnvloeden.

Hoofdstuk 8 vat de bevindingen van de voorgaande hoofdstukken samen, presenteert de methodologische overwegingen en schetst enkele implicaties voor de praktijk en het onderzoek in de toekomst.

Methodologische overwegingen

Grip op probleemgedrag is een voorbeeld van een complexe interventie in een complexe setting. Anders gezegd: het zorgprogramma heeft verschillende componenten en er zijn talloze factoren die probleemgedrag op een afdeling kunnen beïnvloeden. Het is daarom lastig te duiden welke factoren precies de gevonden effecten hebben veroorzaakt. Daarnaast zijn er andere methodologische beperkingen waarmee in de interpretatie van de effecten rekening moet worden gehouden.

Zo maakt het gebruik van het stepped wedge design de interpretatie van de effecten complex. Verder is het voor een juiste beschrijving van het gedrag nodig gebruik te maken van de rapportages van de zorgverleners. Dit vergroot de kans op informatiebias (de neiging om niet bestaande verschillen te rapporteren omdat men gelooft in de werking van een interventie). Tenslotte zijn de analyses van het stepped wedge design complex en kan er gediscussieerd worden over de toepasselijkheid van een meetinstrument als de CMAI en van het wel of niet voorselecteren van bewoners met ernstig probleemgedrag.

Implicaties voor de praktijk

De implementatie van Grip op Probleemgedrag op de verschillende afdelingen verliep niet vlekkeloos. De bevindingen uit de proces evaluatie kunnen worden vertaald naar implicaties voor de klinische praktijk en gezondheidszorgbeleid. Ten eerste lijkt het gebrek aan constructief multidisciplinair overleg dat op sommige afdelingen werd vastgesteld een gemiste kans voor de psychogeriatrische zorg. Daarnaast werden er grote verschillen en continue veranderingen opgemerkt wat betreft beleid en werkmethoden binnen de verschillende organisaties. Een stabiel en eenduidiger beleid wat betreft organisatie en innovatie in de verpleeghuiszorg lijkt aangewezen. Verder zijn er inmiddels vele zorgprogramma's en andere complexe interventies ontwikkeld. Het is in de praktijk niet haalbaar voor elke zorgvraag een ander zorgprogramma te hanteren en het verdient dan ook aanbeveling één overkoepelende structuur te ontwikkelen waarmee kwalitatief hoogwaardige zorg kan worden geboden. Tenslotte wierpen de implementatieproblemen de vraag op of de huidige opleiding van helpenden niveau 2 en verzorgenden niveau 3 wel recht doet aan de complexiteit van de huidige psychogeriatrische verpleeghuiszorg. Het gedrag van mensen met dementie in het verpleeghuis is over de jaren heen qua complexiteit gestegen, hetgeen vraagt om een evenredige stijging van expertise en ondersteuning van personeel.

Implicaties voor toekomstig onderzoek

Vanuit de bevindingen uit het Grip op Probleemgedrag project kunnen ook aanbevelingen voor toekomstig onderzoek gedestilleerd worden. Huidige implementatietrajecten lijken niet altijd aan te sluiten bij de wensen, ideeën en de manier van leren en denken van zorgpersoneel.

Het lijkt daarom aangewezen meer aandacht te besteden aan het analyseren van de lokale situatie voorafgaand aan implementatie van interventies.

Verder ontbreekt het in de huidige bio-psycho-sociale verklaringsmodellen aan aandacht voor biologische/neuropsychologische factoren die probleemgedrag beïnvloeden. Zo lang niet duidelijk is hoe deze factoren het gedrag van mensen met dementie beïnvloeden blijft het onmogelijk een sluitend verklaringsmodel te ontwikkelen.

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Curriculum Vitea

Sandra Zwijsen is op 24 maart 1986 geboren in Harmelen. In 2004 behaalde ze haar gymnasium diploma aan het Kalsbeek College in Woerden. Tijdens haar middelbare school opleiding werkte ze als ongediplomeerde zorgmedewerker op een psychogeriatrische afdeling van verpleeghuis Heremalerhof (Harmelen). Het werken op deze afdeling inspireerde haar om de studie psychologie te volgen aan de Universiteit Utrecht. In 2007 behaalde zij daar haar Bachelor diploma Psychologie en in 2008 behaalde zij aan dezelfde universiteit haar Master diploma Psychologie, programma neuropsychologie. Na het behalen van haar Master diploma werkte ze als junior onderzoeker bij de afdeling Verpleeghuisgeneeskunde (thans Huisartsgeneeskunde & Ouderengeneeskunde) van het VUmc. Hier voerde zij tot 2010 onderzoek uit op het gebied van vrijheidsbeperkingen en domotica in de dementiezorg. In 2010 begon ze op dezelfde afdeling als promovendus aan het project Grip op Probleemgedrag. Tijdens haar promotiestudie heeft ze de post-academische Masteropleiding Epidemiologie met succes afgerond. Gedurende het promotietraject is ze tevens een korte periode bij het Trimbos instituut werkzaam geweest in het kader van het schrijven van een rapport over onbegrepen gedrag bij dementie in opdracht van de Inspectie voor de Gezondheidszorg. Momenteel is ze voor twee dagen in de week werkzaam als onderzoeker bij de afdeling Huisartsgeneeskunde & Ouderengeneeskunde van het VUmc waar ze onder andere betrokken is bij het vervolgttraject van Grip op Probleemgedrag en bij een project over de nieuw te vormen wet Zorg en Dwang in opdracht van het Ministerie voor Volksgezondheid, Welzijn en Sport. Daarnaast werkt ze drie dagen in de week als psycholoog bij ouderenzorgorganisatie QuaRijn.
