EFFECTIVENESS AND COSTS OF DEMENTIA CARE MAPPING INTERVENTION IN DUTCH NURSING HOMES

GEERTJE VAN DE VEN

Lieve pap,
ik draag dit proefschrift aan jou op.

Effectiveness and costs of Dementia Care Mapping intervention in Dutch nursing homes

For reasons of consistency within this thesis, some terms have been standardized throughout the text. As a consequence the text may differ in this respect from the articles that have been published.

The studies presented in this thesis have been performed at the Department of Primary and Community Care and the Scientific Institute for Quality of Healthcare (IQ healthcare). These are part of the Radboud Institute Health Science (RIHS), one of the approved research institutes of the Radboud University Nijmegen Medical Centre.

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Chapter 1

General introduction

"The next time you communicate with someone who is not at his or her cognitive best, remind yourself of this: This interaction is not about me. This interaction is about someone who is seeking connection on terms that may not advance the interests or needs of my ego. I am going to go where your needs are taking you. I am going to be with you in that place, wherever and however it is. I am going to let my ego disappear now. I am going to love you in your image instead of trying to re-create you in mine."

Michael Verde, President,
Memory Bridge, Chicago, Illinois

INTRODUCTION

In our ageing society, dementia is a growing concern. Dementia influences the quality of life of those affected by the disease, and increases utilization of care resources.[1] To illustrate the extent of the problem, the prevalence of dementia in the population of Dutch nursing home residents (65.000 people) is 53%.[2,3] A specific and highly pervasive problem in this group of residents is the presence of neuropsychiatric symptoms. In addition to directly affecting the residents' quality of life, these symptoms represent a serious challenge for the professional caregivers. Although in recent decades, various forms of person-centered dementia care were shown to be effective in reduction or secondary prevention of neuropsychiatric symptoms,[4] what is missing is a method to systematically implement it in all facets of nursing home dementia care. Dementia Care Mapping (DCM)-intervention offers a set of methods to this aim. DCM aims at reducing both neuropsychiatric symptoms in people with dementia and staff problems in nursing homes. It is a person-centered intervention, rooted in psychosocial theory of personhood in dementia and it consists of cycles of systematic observation, feedback to the staff, and action plans. Important distinctions with other methods are: 1) staff (rather than physicians, psychologists, etc.) are directly involved in the creation of improvement actions; 2) DCM allows for timely initiation of tailor made interventions and 3) it allows for adaptations to patients needs on many different levels in the organization. The main objective of this thesis is to study (cost)effectiveness of DCM in nursing home dementia care.

This introduction provides a general background on problems in dementia care in (Dutch) nursing homes and on interventions addressing these problems. A rationale is provided for choosing to study (cost)effectiveness of the DCM intervention in alleviating resident

and staff problems. Finally, the aim and research questions addressed in this thesis are outlined.

RESIDENT PROBLEMS: HIGH PREVALENCE OF NEUROPSYCHIATRIC SYMPTOMS

Due to personality and emotional changes, decreasing cognitive capabilities and loss of meaningful social interaction with others, dementia often manifests itself as a sustaining decline on personhood, comfort, and dignity. As dementia often takes away control over thoughts and actions, symptoms like anxiety and agitation may emerge. These symptoms are referred to as neuropsychiatric symptoms and are very common in people with dementia.[5,6] The prevalence of neuropsychiatric symptoms including psychosis, agitation/aggression, depression and apathy, among institutionalised people with dementia is about 80%.[3] These symptoms are burdensome, they directly affect the residents' quality of life[7] and are often 'treated' with psychotropic medication[8] and physical restraints.[9] However, these treatment approaches to neuropsychiatric symptoms are mostly inadequate, harmful, and have limited effectiveness.[10]

STAFF PROBLEMS: JOB DISSATISFACTION AND HIGH ILLNESS AND TURNOVER RATES

Besides affecting the resident's quality of life, neuropsychiatric symptoms represent a serious challenge for the professional caregivers. Qualitative research indicates that care staff experience difficulty and feelings of guilt and distress in coping with symptoms of challenging behavior. Without a proper staff support, these difficulties often lead to job dissatisfaction.[11,12] Staff job dissatisfaction in nursing homes is frequent and is accompanied by high illness absenteeism and turnover rates, which ultimately lead to staff shortages.[13] This is not only a problem for the staff and organizations (high costs); a strong relationship has been found between high staff turnover and poor resident outcomes such as diminished quality of life, use of psychotropic drugs, and drug-induced hospital admissions due to serious adverse events.[14-16]

ORGANIZATIONAL PROBLEMS: SUBOPTIMAL QUALITY OF CARE

Unlike in many other countries, in Dutch nursing homes there are separate units for the residents with physical disabilities and for those with dementia. Another characteristic of Dutch nursing homes is that they employ care staff, nurses, specially trained elderly care physicians, physical therapists, occupational therapists, speech therapists, dieticians, and psychologists.[17-19] Besides these common characteristics, there is a substantial variation in the way care is provided in Dutch nursing homes. First, there is

a variation in care forms and living conditions, depending on preferences and visions of care organizations. Some residents live in small-scale housing and homelike groups of 5 to 12 people,[20] while others live in (closed) dementia special care units, mainly in larger groups. Also, there is a variation in staff/patient ratio in Dutch nursing homes.[21] Staff/patient ratio is defined as the number of staff at each unit engaged in direct patient care divided by the number of patients in the unit. Also, there are major differences in workload, multidisciplinary cooperation, level of education of professional caregivers and team managers, and job satisfaction.[22] These variations are reflected in quality of care. For instance, research shows that staff/patient ratio is related to adverse patient outcomes.[23] In 2008, of the 229 nursing homes with a dementia special care unit that were visited by the Health Inspectorate, 32 (14%) received a warning due to risky situations and high staff illness.[24] The 'Visible Care' report stresses the need for urgent action to reduce falls and neuropsychiatric symptoms. These facts suggest that the current efforts put into dementia care leave room for improvement in quality, effectiveness, and cost-effectiveness.[25] In the next section, approaches to address these problems will be discussed.

IMPROVING DEMENTIA CARE THROUGH PERSON-CENTERED CARE

The traditional focus of nursing on biological aspects of health and well-being has been derived from the biomedical model of acute care. At the same time, the neglect of psychosocial needs results in many people with dementia spending long hours alone and emotionally distressed in residential care.[26] In recent decades, person-centered dementia care has been developed as a method to improve the quality of care in nursing homes. Person-centered care has emerged as a response to a culture of care which reduced dementia to a strictly biomedical phenomenon, was task-driven and relied on control techniques such as physical restraints. Person-centered care is the kind of care that is respectful of and responsive to individual patient preferences, needs, and values, and that ensures that patient values guide clinical decisions.[27] It is developed to fit the predominantly psychosocial needs of dementia residents, as well as the needs of the staff caring for dementia residents. It is assumed to improve the quality of dementia care and reduce neuropsychiatric symptoms.[4] Implementation of the principles of person-centered care insures closer contact and better interaction between the residents and the staff. This way, the staff is able to signal problem behaviors before they escalate. Therefore, person-centered care has been praised as important for the well-being of residents with dementia.[26,28] Recently, evidence is increasing that it might also be beneficial for the well-being of the staff.[16]

A variety of person-centered interventions are available for people with dementia, such as physical activity, environmental adaptations and sensory stimulation.[29] While temporary effective, many person-centered interventions, such as person-centered bed-side bathing[30,31] have a limited scope. They often focus on residents or staff alone, or on a single caregiving situation and are often imposed on the staff. Since these interventions do not include systematic adaptations in management style and organizational climate, their effects are often limited and short-lived. What is missing is a method to systematically implement the principles of person-centered care in all aspects of nursing home dementia care. While guidelines and protocols are necessary, they are too abstract to serve the purpose of application of person-centered care in daily practice together with the necessary staff development.[32,33] DCM intervention offers a set of methods to these aims.

RATIONALE FOR THE USE OF DEMENTIA CARE MAPPING INTERVENTION

Dementia Care Mapping intervention has been developed by the members of the Bradford Dementia Group[34] and is based on the principles of person-centered care developed by prof. Tom Kitwood.[15] Kitwood suggested the need for a new culture of care that would preserve personhood in the course of dementia. In his final book, Dementia Reconsidered, Kitwood (1997) described DCM as "a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill".[35] Later, Brooker specified the following central components of person-centered care: valuing people with dementia; using an individual approach that recognizes the uniqueness of the person; making an effort to understand the world from the perspective of the person; and providing a supportive social environment.[26] Additionally to the work of Kitwood and Brooker, McCormack and McCance developed a framework for person-centered nursing, comprising four components: prerequisites, such as the skills of the nursing staff; the care environment, such as interior and sounds; person-centered care processes like showering; and patient and staff outcomes, such as quality of life and job satisfaction.[36,37] These theories of personhood and person-centered care form the backbone of the DCM intervention. DCM implements person-centered care underpinned by the psychosocial theory of personhood in dementia.[38] Systematic observations of expressions of well-being in people with dementia help staff to think about the degree to which the care they provide benefits the residents.

THE DEMENTIA CARE MAPPING INTERVENTION: PERSON-CENTERED CARE IN ACTION

DCM is an observational tool that has been used in formal dementia care settings since 1992. However, DCM can be used both as an instrument for developing person-centered care practice, and as a tool in evaluative research.[30,39] Regarding the residents, DCM uses systematic observations of the actual care, as it takes place in formal settings such as nursing homes and day care centers. Based on these observations, the care staff receives personalized feedback that stimulates drawing of tailor made action plans, geared towards improved residents' outcomes. Action plans are tools for the staff to implement person-centered care in daily practice. An important distinction with other person-centered interventions is that in DCM, staff creates better care by themselves rather than implementing action plans developed by others. This implies their empowerment, which entails more satisfaction and less work-related stress. In addition, it allows for timely signaling of problems to the other members of the multidisciplinary care teams in nursing homes, and for timely initiation of tailor made psychological/ social or other interventions,[31] which is very important in ensuring long-term positive effects on residents. Furthermore, unlike other person-centered care methods, DCM allows for changes on many different levels: individual (residents and caregivers), group (professional development, team climate), dementia special care units, multidisciplinary teams, management, and organizations. This way, the improvement actions can become well-coordinated and sufficiently tailored to individuals, groups and organizations.

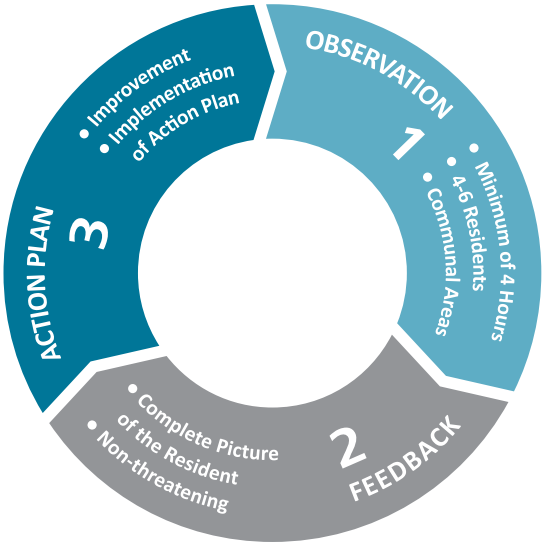

Figure 1. Single cycle of Dementia Care Mapping

A single DCM cycle (Figure 1) consists of:

1. Observation

   An observer (mapper) continuously observes an average of five (four to six) residents with dementia for a representative period (a minimum of four hours a day) in communal areas (living rooms or common rooms) of care facilities. After each 5-min period (a time frame) a coding protocol is used to record what has happened to each participant and what the behavior of the staff was. DCM employs behavioral category codes (BCCs), well/ill-being (WIB) values, personal detractions (PDs), and personal enhancers (PEs) to code the different kinds of behavior. Because PDs and PEs are staff behaviors that have the potential to undermine or enhance the personhood of those with dementia, PDs and PEs are often related to the WIB values in the interpretation of observations.

2. Feedback

   The results of the observation are fed back to the staff. A positive communication style of the feedback is meant to enable the staff to interpret it in the context of the residents' lives rather than relating it to themselves in a negative way. The purpose of the feedback is to enable the staff to form a more complete picture of the residents, see what works good for the residents (higher WIB's) and what not, thereby preventing resistance to feedback or unwillingness to change their personal style of care.

3. Action plans

   The staff draw up action plans for care improvements at an individual and group level on the basis of feedback discussions. Action plans are tools for implementing the principles of person-centered care in daily practice. Examples of action plans are:

"Try and see if Miss Rose will benefit from helping with the household tasks on the unit."

"Positive interactions can be further improved. For instance, when glancing over a magazine together with a resident, other residents can be invited to join in. Hereby, the caregiver may find it useful to choose a place to sit which offers the possibility to survey the level of engagement among the residents."

"Discuss in a multidisciplinary team the similarities and differences in care needs of the day care group and the residents. Depending on the actual care needs, assessments allow for the day care persons to participate in the residents activities and vice versa."

EVIDENCE

DCM has been extensively used to improve the quality of care in nursing homes. An Australian pilot study established a decrease in neuropsychiatric symptoms, as well as improvement in staff interactions with residents with increase in positive care, and positive social interactions and decrease in neutral, negative protective, and negative restrictive interactions,[40] and an Australian randomized controlled trial found less agitation in residents in units providing person-centered care and DCM than in task focused care.[41] In the first Dutch pilot study, positive effects were obtained for patient well-being (WIB-scores), anxiety, agitation, positive staff-resident interactions (PEs), and staff satisfaction with contacts with clients.[42] However, no randomized controlled trial to study the (cost)effectiveness of DCM in Dutch nursing homes has been performed yet. The main objective of the present study is to evaluate (cost)effectiveness of DCM in Dutch nursing home dementia care by performing a large scale randomized controlled trial.

Research questions and outline of the thesis

The aim of this thesis is to investigate the (cost)effectiveness of the DCM intervention in nursing home settings. The design and methods of the DCM study are described in *chapter 2*.

The following research questions are addressed:

1. *Is the DCM intervention effective in alleviating resident and staff problems in nursing home dementia care?*
   In this chapter we describe to what extent the DCM intervention is effective in reducing dementia residents' agitation (primary), reducing dementia residents' neuropsychiatric symptoms and improving dementia residents' quality of life (secondary) and improving staff job satisfaction and reducing stress-related symptoms and absenteeism (secondary). *(chapter 3)*

2. *Is the DCM intervention cost-effective?*
   Economic considerations are important in the implementation of new interventions. In order to find out whether the DCM intervention affects the costs and as presented

in chapter 1 effects of care, we investigated the efficiency of DCM compared to usual care in a cost minimization analysis as effects turned out to be equal. Outcome measures were health care consumption, number of falls, and psychotropic drug use at the resident level; and absenteeism at the staff level. *(chapter 4)*

3. *What is the feasibility and usability of web-based data collection in nursing homes?*
   While web-based research data collection is increasingly used, it is still much more common to use the paper-and-pencil method in nursing homes. Because of the high workload of the nursing staff, we decided to use the less time consuming method of web-based data collection in our study. In this study we systematically implemented web-based data collection in nursing homes and evaluated its feasibility and usability. *(chapter 5)*

4. *To what extent is the DCM intervention implemented according to the protocol and what are the barriers and facilitators for the implementation and for compliance to the intervention protocol?*
   Chapter 6 describes the results of a process analysis in which we studied to what extent the intervention was implemented according to the protocol (quantitative). We also explored the underlying mechanisms in the implementation of DCM by identifying barriers and facilitators for compliance to the intervention protocol (qualitative). *(chapter 6)*

Finally, *Chapter 7: General discussion* presents and discusses the main findings in their broader theoretical and practical context. We also discuss methodological considerations in this kind of research. Finally, we reflect on implications of our findings for practice and future research.

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Chapter 2

Improving person-centered care in nursing homes through Dementia Care Mapping: design of a cluster-randomized controlled trial

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ABSTRACT

Background: The effectiveness and efficiency of nursing home dementia care are suboptimal: there are high rates of neuropsychiatric symptoms among the residents and work-related stress among the staff. Dementia Care Mapping is a person-centered care method that may alleviate both the resident and the staff problems. The main objective of this study is to evaluate the effectiveness and cost-effectiveness of Dementia Care Mapping in nursing home dementia care.

Methods/Design: The study is a cluster-randomized controlled trial, with nursing homes grouped in clusters. Studywise minimization is the allocation method. Nursing homes in the intervention group will receive a dementia-care-mapping intervention, while the control group will receive usual care. The primary outcome measure is resident agitation, to be assessed with the Cohen-Mansfield Agitation Inventory. The secondary outcomes are resident neuropsychiatric symptoms, assessed with the Neuropsychiatric Inventory – Nursing Homes and quality of life, assessed with Qualidem and the EQ-5D. The staff outcomes are stress reactions, job satisfaction and job-stress-related absenteeism, and staff turnover rate, assessed with the Questionnaire about Experience and Assessment of Work, the General Health Questionnaire-12, and the Maastricht Job Satisfaction Scale for Health Care, respectively. We will collect the data from the questionnaires and electronic registration systems. We will employ linear mixed-effect models and cost-effectiveness analyses to evaluate the outcomes. We will use structural equation modelling in the secondary analysis to evaluate the plausibility of a theoretical model regarding the effectiveness of the Dementia Care Mapping intervention. We will set up process analyses, including focus groups with staff, to determine the relevant facilitators of and barriers to implementing Dementia Care Mapping broadly.

Discussion: A novelty of Dementia Care Mapping is that it offers an integral person-centered approach to dementia care in nursing homes. The major strengths of the study design are the large sample size, the cluster randomization, and the one-year follow-up. The generalizability of the implementation strategies may be questionable because the motivation for person-centered care in both the intervention and control nursing homes is above average. The results of this study may be useful in improving the quality of care and are relevant for policymakers.

BACKGROUND

The prevalence of neuropsychiatric symptoms among nursing home residents with dementia is about 80%.[1-4] In addition to directly affecting the residents' quality of life, these symptoms represent a serious challenge to professional caregivers.[5,6] Staff job dissatisfaction results in high illness absenteeism (5.4%) and turnover rates, which ultimately leads to staff shortages.[7-13] A strong relationship has been found between high staff turnover and poor resident outcomes such as quality of care deficiencies, quality of life deficiencies, use of psychoactive drugs, and drug-induced hospital admission due to serious adverse events.[6,8,14,15] These facts suggest that the current efforts put into dementia care leave room for improvement in quality and cost-effectiveness of care. In order to provide optimal dementia care, the staff often needs additional training.[13,16-18] Dementia Care Mapping (DCM) is a multicomponent intervention, which was developed by the Dementia Research Group at Bradford University, UK, in 1992, and is based on Kitwood's social-psychological theory of personhood in dementia.[19] This theory posits that much of the ill-being that people with dementia experience is due to negative environmental influences, including staff attitudes and care practices. Dementia Care Mapping assists staff in identifying the triggers causing the well-being and ill-being of people with dementia.[20]

Dementia Care Mapping offers an integral, person-centered approach to dementia care. Many other interventions based on person-centered care, such as multimodal sensory stimulation (snoezelen)[14,21] and person-centered bathing[22,23] have a more limited scope. These interventions aim either at residents or at staff alone, and while they are very valuable in their own right, they are limited to psychosocial aspects of care or they apply in a single caregiving situation such as bathing. These interventions often do not include systematic adaptations in management style and organizational climate. We can expect that single-scope interventions, usually aimed either at staff, residents, management style, or organizational climate alone, need to operate synergistically if we are to sustainably improve effectiveness, efficiency, and quality of dementia care in nursing homes. Dementia care experts recommend using a range of interventions that address the needs of both residents and staff.[24] The aims of this study are to reduce the frequency and intensity of neuropsychiatric symptoms, improve the quality of life of dementia patients, improve staff-resident interactions and staff job satisfaction, and reduce job-related stress by means of the introduction of the DCM method in dementia care. We will use a cost-effectiveness analysis to determine whether the intervention positively affects the efficiency of care.

METHODS/DESIGN

Study design and setting

The study is a cluster-randomized, controlled trial (Figure 1). We will evaluate the DCM intervention in Dutch nursing homes, which will be clustered. We will use cluster-randomization in order to avoid contamination with the effects of possible exchange of information within a cluster. We will use a studywise minimization method[25] to allocate the clusters (units) to either the intervention group or the control group. Nursing homes in the intervention group will receive DCM training and a DCM organizational briefing day.

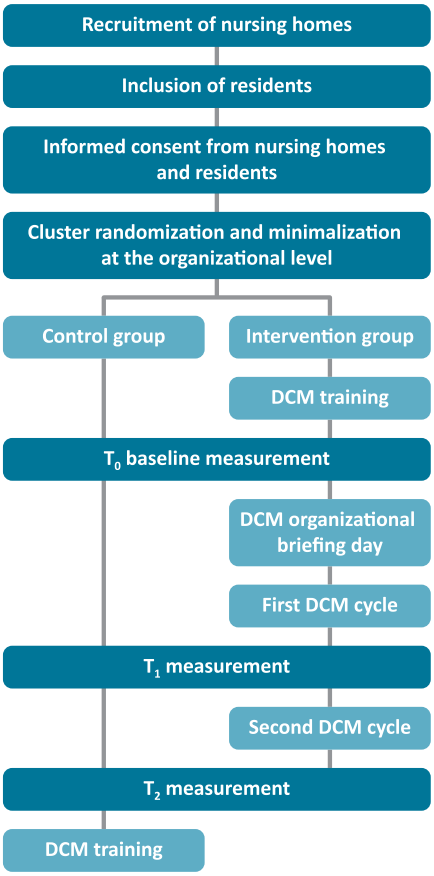

Figure 1. Study design

Care will be evaluated in two DCM cycles of observation, feedback, and action plans. Quantitative methods will be used to study effectiveness and efficiency, and qualitative methods will be used to conduct a process analysis and to study facilitators of and barriers to broader implementation of DCM in daily practice. The ethical committee Arnhem-Nijmegen waived approval for this study (registration number 2010/147).

Study sample

The study sample will consist of residents with dementia from nursing home dementia special care units (DSCUs) and their formal caregivers. Now, at the time of writing, the nursing homes have been recruited. This was done in several ways: e.g. advertising on the Dutch DCM website http://dcmnederland.nl/, the VENVN website (the website of a Dutch professional organization for nursing personnel), and invitational letters to nursing homes with information about the project.

We recruited 34 DSCUs from 11 nursing home organizations. The participating nursing homes serve several regions in the Netherlands. A DSCU is defined as a residential unit with common areas and staff. This can be a group in a small group residential facility or a DSCU in a nursing home. The number of patients in a DSCU can range from 3 to 32. The participating DSCUs will provide residence for at least 250 people. The inclusion criteria for the residents are as follows:

- Age of 65 years or more
- Dementia diagnosed by an elderly care physician according to the Diagnostic and statistical manual of mental disorders-IV criteria for dementia[26]
- Approval of the elderly care physician for inclusion
- At least one of the following neuropsychiatric symptoms: aggression, motor or verbal agitation, psychosis, depression, and apathy
- Informed consent given by the residents themselves, their families, or their legal guardians
- The resident must use the common areas, such as the shared living room, at least 4 hours a day.

Residents with an estimated life expectancy of 6 weeks or less, or those who are physically unable to spend time in common areas of the facility, will not be included in the study. If residents withdraw their consent for any reason or develop a life-threatening disease, they will be excluded from the study. Evidence shows that the attrition rate is relatively high in this kind of population, so, to allow for intention-to-treat analysis, we will replace any participants lost to follow-up with new participants.

Bias control and randomization

Randomization will take place after the study sample has been recruited and informed consent has been given, but before the DCM training, the DCM organizational briefing day, and the start of the intervention. The clusters will be randomized to avoid contamination by the effects of possible exchange of information within a nursing home. The dementia care mappers will be recruited from DSCUs other than those where the DCM cycles will take place. The reason for this is that the DCM observations and feedback should not be influenced by professional or personal relationships. The minimization method will be used for randomization[25] to assure an equal distribution of baseline characteristics to the intervention and control groups. This means that nursing homes will be randomized with the aid of adaptive weights based on the sizes of the nursing homes, DSCU sizes and the formal caregiver-to-resident ratios. Nursing homes will be randomly allocated to one of two conditions: the DCM intervention and usual care. A person who has no knowledge of and no relationship to the study will do the randomization with appropriate software to assure allocation concealment.

Because of the DCM training and intervention, the study cannot be blinded with respect to nursing homes, residents, and their caregivers. The researcher (GV), the research assistant (FB), and the DCM trainer (AP) will not be blinded to this information.

Intervention

The Bradford Dementia Group[27] developed the DCM method, which is based on the principles of person-centered care.[28,29] The DCM method is an observational tool that has been used in formal dementia care settings since 1992, both as an instrument for developing person-centered care practice, and as a tool in evaluative research.[20,30,31] DCM is a method in which care improvement plans (action plans) are based on systematic observations of the actual care as it takes place in formal settings such as nursing homes and day care. The feedback to the staff is expected to raise their awareness regarding the interdependency of their own behavior and that of the residents. The feedback occurs in a nonthreatening way and does not serve as staff-evaluation tool. The fact that not only 'negative' but also 'positive' events are recorded and brought to light motivates staff to improve their competences and performance. DCM offers a set of tools for personal and organizational development. Through DCM, the staff may attain an important signalling role towards the members of the multidisciplinary care teams in nursing homes (which include psychologists, elderly care physicians, regular physicians, physiotherapists, and occupational therapists). This allows for the timely initiation of tailor made psychological or other interventions,[32] which is very important in ensuring long-term positive effects of DCM. Furthermore, it is important to emphasize that the DCM method acts as a channel

for the timely implementation of various kinds of improvements for individuals (residents and caregivers) groups (professional development needs), DSCUs, multidisciplinary teams, management, and organizations. This way, the improvement actions become well coordinated and sufficiently individually tailored.

Intervention components of Dementia Care Mapping

Phase 1: training in Dementia Care Mapping

Staff members of intervention nursing homes will receive DCM training. A basic DCM user needs a 4-day course of basic concepts and skills. A basic user can participate in a DCM team under the supervision of an advanced user. To become an advanced user, a staff member must also take a 3-day course about the background and theory of DCM. Advanced users can map care, report observations, lead a DCM team, give feedback to the staff, and instruct and support them in drawing up action plans. At least one staff member in each organization will become an advanced user.

Phase 2: organizational briefing day for Dementia Care Mapping

At the end of the DCM training, intervention nursing homes will be visited and will receive a one-day training course. This course provides organization-wide basic understanding of the DCM method to ensure endorsement of DCM goals and methods and to aid its implementation in an organization or setting.

Phase 3: two Dementia Care Mapping cycles: observations-feedback-action plan

After completing the DCM training and the DCM organizational briefing day, the intervention nursing homes will carry out two DCM cycles. A single DCM cycle (Figure 2) consists of:

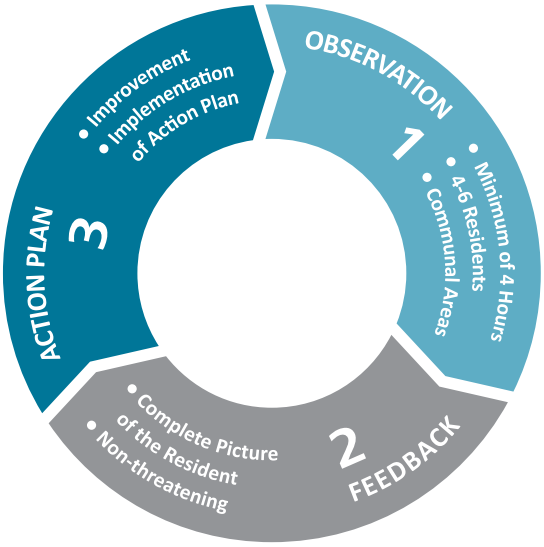

Figure 2. Single cycle of Dementia Care Mapping

1. *Observation.* An observer (mapper) continuously observes an average of five (four to six) residents with dementia for a representative period (a minimum of 4 h/day) in communal areas (living rooms or common rooms) of care facilities. After each 5-min period (a time frame) a coding protocol will be used to record what has happened to each participant and what the behavior of the staff was.[20,30] DCM employs behavioral category codes (BCCs), well/ill-being (WIB) values, personal detractions (PDs), and personal enhancers (PEs) to code this behavior (Figure 3).
2. *Feedback.* The results of the observation are fed back to the staff. The positive communication style of the feedback enables them to interpret it in the context of the residents' lives rather than relating it to themselves in a negative way. The feedback style enables the staff to form a more complete picture of the residents and prevents resistance to negative feedback or unwillingness to change their personal style of care.
3. *Action plans.* The staff draw up action plans for care improvements at an individual level and a group level on the basis of feedback discussions. Action plans are tools for implementing the principles of person-centered care in daily practice.

Behavioral category codes (BCCs)

The BCCs describe 24 domains of participant behavior that has occurred, with operationalized rules for assignment.[5,31,36] Examples of behavioral category codes are:

Articulation	**(interaction with other people)**
Coming and going	**(autonomously walking, standing, or moving)**
Intellectual activity	**(an activity with the accent on intellectual skills)**
Nodding	**(sleeping, dozing, or nodding off)**

Well/ill-being (WIB) values

WIB values are rated on a six-point scale ranging from extreme ill-being (-5) to extreme well-being (+5). Well/ill-being is a global state that cannot be determined with just one 5-min period. Therefore, the 5-min observation (formerly WIB value) has been renamed the ME (mood/engagement) value. The ME values can be averaged to arrive at a WIB score. This provides an index of relative well-being for a particular period for an individual or a group.

Personal detractors (PDs) and personal enhancers (PEs)

PDs and PEs are staff behaviors, and they are recorded whenever they occur. The PDs are behaviors that potentially undermine personhood; examples are neglect, humiliation, and punishment of the person with dementia.[8,47] These are described and coded according to type and severity. The PE structure is parallel to that of the PD; they both build on the description of positive person work, such as validation, support, and kindness towards the person with dementia. The PEs and PDs are further categorized according to the degree to which they support or undermine the five psychological needs that Kitwood describes: comfort, identity, attachment, occupation, and inclusion.[8,9]

Figure 3. Explanation of BCC, WIB, PD, and PE

Control group

Caregivers in the control group will receive neither the DCM training nor the DCM organizational briefing day. The control group residents will continue to receive usual care during the trial. To motivate these nursing homes to complete the measurements, a researcher will visit each control nursing home at the start of the trial, and the control nursing homes will receive the DCM training after the trial.

Measurements

The study outcome variables will be measured at the resident and staff levels. The primary outcome measure is resident agitation, to be assessed with the Cohen-Mansfield Agitation Inventory (CMAI). This questionnaire consists of 29 items about agitation and aggression in residents with dementia, and it has been validated for use in the Netherlands.[33,34] The secondary outcome measures are the residents' other neuropsychiatric symptoms, to be assessed with the Neuropsychiatric Inventory- Nursing Homes (NPI-NH), a comprehensive neuropsychiatric rating scale including the following symptoms: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy,

disinhibition, irritability, aberrant motor behavior, night-time disturbances and eating change.[35] The residents' quality of life will be measured with Qualidem[36] and EQ-5D.[37] We will use the Global Deterioration Scale (GDS) to obtain information about dementia severity.[38] Such information will include fall incidents, physical restraints, and the amount of care delivered, which is recorded in the nursing home administration system. A questionnaire about the resident demographics at baseline has been developed for our study, and it includes the following variables: age, sex, marital status, highest completed education, country of origin, longest former profession, and co-morbidity.

The following staff outcome measures will be collected: stress-related symptoms, job experience, job satisfaction, job-stress-related absenteeism, and employee turnover. We will use the General Health Questionnaire (GHQ-12) to measure stress-related symptoms. This validated instrument consists of 12 questions, and it is sensitive for measuring changes in general health.[39,40] We will also use two validated Dutch questionnaires: the Questionnaire about Experience and Assessment of Work (QEAW) and the Maastricht Job Satisfaction Scale for Healthcare (MJSS-HC).[41,42] The questionnaire about staff demographics at baseline was developed for the present study and consists of the following variables: age, sex, marital status, highest completed education, country of origin, and experience with person-centered care.

All staff members of the participating units will be asked to fill in questionnaires about themselves (MJSSHC, QEAW, and GHQ-12). Any staff member who is the caregiver primarily responsible for a particular resident will also be asked to fill in questionnaires about the resident (CMAI, NPI-NH, Qualidem, EQ-5D and GDS; Table 1). The staff will use an internet application with a personal user name and password to fill in these questionnaires. All the variables will be measured at baseline (T0), after the first DCM cycle (T1), and after the second DCM cycle (T2).

Quantitative and qualitative methods will be used in process analyses. Quantitative process analyses will help account for the possible differences in intervention 'dosage' that might moderate the effects of the DCM. Qualitative process analyses will be used to determine relevant facilitators of and barriers to further implementation.

Economic data

The cost-effectiveness of the intervention will be calculated and compared to usual practice. Table 1 shows the various data sources for the assessment of resource use, direct costs and staff productivity losses. We ask all organizations and residents (or their family or legal guardian) permission to extract data from the nursing home administration system. Intervention costs, including costs for the DCM training, will be

estimated. Study-specific costs, which would not occur in routine application, will not be considered.

Table 1. Data sources for measurements of residents and staff

Variable	Instrument/source	Type of variable
Residents		
Demographic variables	Self-developed questionnaire	Control variables
Dementia severity	Global Deterioration Scale[37]	Control variable
Care needs	Weight of Care Package: nursing home administration	Control variable
Agitation	Cohen-Mansfield Agitation Inventory[32,33]	Primary outcome/ICER
Neuropsychiatric symptoms	Neuropsychiatric Inventory – Nursing Homes[34]	Secondary outcome
Quality of life	Qualidem[35] and EQ-5D[36]	Secondary outcome/ICER
Fall incidents	Nursing home administration	Secondary outcome/ICER
Physical restraints	Nursing home administration	Secondary outcome/ICER
Amount of care delivered and medication use	Nursing home administration	Secondary outcome /ICER
Staff		
Demographic variables	Self-developed questionnaire	Control variables
Stress-related symptoms	General Health Questionnaire-12[38]	Secondary outcome/ICER
Job experience and job assessment	Questionnaire about Experience and Assessment of Work[41]	Secondary outcome/ICER
Job satisfaction	Maastricht Job Satisfaction Scale for Health Care[40]	Secondary outcome/ICER
Stress-related absenteeism	Nursing home administration	Secondary outcome/ICER
Employee turnover	Nursing home administration	Secondary outcome/ICER

Sample size calculations

The calculation of the sample size calculation includes two steps:

1. Chenoweth et al.[43] report that the treatment-control difference was 10.9 in their recent cluster-randomized controlled trial, which had with five units in the control group and five in the DCM group, a 20% attrition rate in 8 months, and an average of 14 evaluable patients at follow-up. As the 95% confidence interval of the mean difference was 0.7-21.1, the standard error of the difference was approximately (21.1-0.7)/4 = 5.1. Therefore, a study with a similar attrition rate, standard deviation, cluster (unit) sizes, interclass correlation coefficient (ICC), analysis method and design, but with nine clusters per arm, would have a standard error of difference of approximately $5.1\sqrt{(5/9)} = 3.8$. For a true difference between the treatments of 10.9, the power of such a study would be 80% (two-sided testing at alpha = 0.05).
2. In our study, we plan to include at least five organizations in the control group and at least five organizations in the intervention group, with an average of three units in each organization. Due to the correlation, the 'effective' sample size for each arm will be

$$\frac{\textit{number of units per arm}}{[1 + (\textit{number of units per organization} - 1) \times (\textit{correlation of units within organization})]}$$

Allowing the correlation between units within a organization to be 0.3 at most (which is a safe margin), we would need 15 units/arm to have an 'effective' sample size of 9 units/arm. Using step 1, we conclude that, with at least 15 units/arm, along with an attrition rate, standard deviation, cluster (or unit) size, and an ICC (for patients within a unit) similar to those of Chenoweth et al.[43], we would have 80% power to detect a true difference of 10.9 between the treatment group and the control group.

Statistical analyses

The effects on the primary outcome will be evaluated by means of linear mixed-effect models with treatment, baseline measures, and control variables (used in the sequential balancing minimization procedure)[25] as covariates and the DSCU as a random effect, to correct for dependencies within DSCUs. We use intention-to-treat analysis and subgroup analysis were we compare the observed patients with the control group. We will use structural equation modelling in the secondary analysis to evaluate the plausibility of a theoretical model including a number of mediator variables (WIB and PE/PD). We will use quantitative methods to study the effectiveness, efficiency, and factors that can influence the implementation of DCM in the organization. We intend to evaluate focus groups and determine relevant facilitators of and barriers to implementation by means of qualitative methods.

Economic evaluation

The cost-effectiveness analyses focus on the addition of the DCM intervention to nursing homes and comparing it to usual care from a societal perspective. On the basis of the above-mentioned outcomes, two different incremental cost-effectiveness ratios (ICERs) will be computed: costs per quality-adjusted life year gained (by residents) and costs per increase in scores on staff job satisfaction measure (MJSS-HC). Other outcome measures such as neuropsychiatric symptoms and volumes of care, work stress, stress-related absenteeism and staff turnover will be financially valued and included in the ICER on the cost side. Cost-effectiveness will be analyzed in a Bayesian fashion, i.e. we will derive an acceptability curve that can evaluate efficiency in a set of increasing thresholds for the denominators of the ICERs. Furthermore, cost-effectiveness analysis will be accompanied by the value of the information analysis.

DISCUSSION

A strength of DCM is that it offers an integral person-centered approach to dementia care in nursing home settings. In addition to psychosocial interventions (action plans) focusing on individual staff members and residents, DCM also induces systematic adaptations in management style and organization climate. We can expect that all these conditions need to operate synergistically if we are to sustainably improve effectiveness, efficiency, and quality of dementia care in nursing homes.

The major strengths of the study design are the large sample size, cluster randomization, and a follow-up of 1 year. We will randomize clusters after recruiting the study sample and seeking informed consent from the residents. In this way, we can control for potential selection bias in the control and intervention groups. We will use the minimization method for randomization to assure an equal distribution of baseline characteristics. However, it is possible that both the intervention and the control nursing homes in our study are more than averagely motivated to implement person-centered care. Any implementation strategies developed on the basis of our findings may therefore have suboptimal generalizability. However, in this respect, no differences are to be expected between the intervention and the control groups. The effect of the DCM intervention could perhaps be underestimated because nursing home organizations in the control group may already have a more positive attitude towards person-centered care than the average nursing home organization in the Netherlands. We will collect data from previous person-centered-care track records for all nursing homes in the study.

In this study, we will first train the staff from the intervention nursing homes before taking baseline measurements. The purpose of this is to minimize the attrition rate; the period from the start of the training and the end of the first DCM cycle is 9 months. Due to the decision to train the staff before the baseline measurement, it is conceivable that training might affect the behavior of the trained staff member in that he or she may already start applying the principles of person-centered care in daily practice. Obviously, this could influence caregiving in the intervention nursing homes before the baseline measurement. In order to attenuate contamination, the staff will be instructed not to disclose or try to implement the DCM method or person-centered care until the organizational briefing day has taken place. Possible baseline differences will be accounted for by their inclusion in the analyses.

From a public health perspective, this study should provide evidence regarding the effectiveness of non-pharmacological support for dementia patients in nursing homes in the Netherlands. It is necessary for policymakers to make their decisions about

financing new services on the basis of strong evidence regarding the acceptance of new interventions and their cost-effectiveness.

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Chapter 3

Effects of Dementia Care Mapping on residents and staff of care homes: a pragmatic cluster-randomized controlled trial

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ABSTRACT

Background: The effectiveness of Dementia Care Mapping (DCM) for institutionalized people with dementia has been demonstrated in an explanatory cluster-randomized controlled trial (cRCT) with two DCM researchers carrying out the DCM intervention. In order to be able to inform daily practice, we studied DCM effectiveness in a pragmatic cRCT involving a wide range of care homes with trained nursing staff carrying out the intervention.

Methods: Dementia special care units were randomly assigned to DCM or usual care. Nurses from the intervention care homes received DCM training and conducted the 4-months DCM intervention twice during the study. The primary outcome was agitation, measured with the Cohen-Mansfield Agitation Inventory (CMAI). The secondary outcomes included residents' neuropsychiatric symptoms (NPSs) and quality of life, and staff stress and job satisfaction. The nursing staff made all measurements at baseline and two follow-ups at 4-month intervals. We used linear mixed-effect models to test treatment and time effects.

Results: 34 units from 11 care homes, including 434 residents and 382 nursing staff members, were randomly assigned. Ten nurses from the intervention units completed the basic and advanced DCM training. Intention-to-treat analysis showed no statistically significant effect on the CMAI (mean difference between groups 2.4, 95% CI 22.7 to 7.6; p=0.34). More NPSs were reported in the intervention group than in usual care (p=0.02). Intervention staff reported fewer negative and more positive emotional reactions during work (p=0.02). There were no other significant effects.

Conclusions: Our pragmatic findings did not confirm the effect on the primary outcome of agitation in the explanatory study. Perhaps the variability of the extent of implementation of DCM may explain the lack of effect.

INTRODUCTION

The prevalence of neuropsychiatric symptoms (NPSs) such as anxiety, apathy, and hallucinations among institutionalized people with dementia is about 80%.[1] These symptoms directly affect the residents' quality of life and represent a serious challenge to professional caregivers. Staff job dissatisfaction in care homes is frequent and results in high illness absenteeism and turnover rates, which ultimately lead to staff shortages.[2] A strong relationship has been found between high staff turnover and poor resident outcomes such as quality of life. These findings underline the need for interventions to alleviate resident and staff distress.[3]

Person-centered care (PCC) is an alternative to conventional task-focused care practices. Evidence suggests that different types of PCC improve both resident and staff outcomes.[4–6] Dementia Care Mapping (DCM) is a person-centered, multicomponent intervention developed by the Dementia Research Group at Bradford University in the UK and is based on Kitwood's social-psychological theory of personhood in dementia.[5] This theory states that much of the ill-being that people with dementia experience is due to negative environmental influences, including staff attitudes and care practices.

DCM is a cyclic intervention consisting of three components: systematic observation, feedback to the staff, and action plans. The action plans are based on the observed actual needs of the resident. This method allows for timely initiation of tailor made interventions at the individual level (residents and caregivers) and the group level (nursing teams), as well as at the levels of multidisciplinary teams, management, and organizations. In short, DCM is a multi-component intervention aiming at synergistically implementing diverse person-centered interventions to improve the quality and effectiveness of care.[7]

Chenoweth and colleagues' cluster-randomized controlled trial (cRCT)[8] compared the effectiveness of PCC training sessions, DCM, and usual, task-focused care. They found that there was less agitation [measured with the Cohen-Mansfield Agitation Inventory (CMAI)] in units providing PCC (mean difference 13.6) and DCM (mean difference 10.9) than in task-focused care. Importantly, this trial demonstrates the effectiveness of DCM in near ideal conditions. Two researchers carried out the intervention, the setting was well-resourced and tightly controlled, and the care homes were specifically selected for their approaches to care: this renders Chenoweth and colleagues' study explanatory in character.[9–11] Our present study is of a pragmatic nature. Pragmatic studies are intended to maintain the internal validity of RCTs while they are designed and implemented in ways that would better address the demand for evidence about real-world risks. Their purpose is to provide information for making decisions about daily practice. The

care homes in this study were not stringently selected so that they would be broadly representative. The nursing staff rather than the researchers were trained to carry out the DCM intervention. This pragmatic cRCT investigated the effectiveness of DCM on resident and staff outcomes.

METHODS

Participants

We recruited care homes via letters of invitation and by approaching care homes that had already had contact with DCM Netherlands. Care for people with dementia in the Netherlands is generally provided in dementia special care units, where residents generally live in small groups of 5 to 12 people. Staff in Dutch care homes includes nurses, specially trained elderly care physicians,[12] physical therapists, occupational therapists, speech therapists, dieticians, and psychologists, all of whom the care home employs.[13]
The study sample consisted of residents with dementia and their formal caregivers. The inclusion criteria for the residents required dementia diagnosed by an elderly care physician according to the Diagnostic and statistical manual of mental disorders-IV criteria for dementia,[14] approval of the elderly care physician for inclusion, age of 65 years or more, at least one NPS, informed consent from the family of the resident, and the ability of the resident to use the common areas, such as the shared living room, for at least 4 hours a day. Residents with an estimated life expectancy of 6 weeks or less and those who were physically unable to spend time in common areas of the unit were not included in the study.
We used cluster randomization to avoid contamination through exchange of information within a care home. We used the minimization method in the randomization:[15] we randomized care homes using adaptive weights based on the sizes of the care homes, the sizes of the units (or clusters), and the formal caregiver-to-resident ratios. The study statistician (RD), who was unaware of the identity of the units, used SPSS, version 18 (SPSS, Chicago, Ill.) to randomly allocate them to either the intervention group or the usual care group (allocation ratio 1:1).
We needed 15 units per arm at baseline to achieve an 80% chance of detecting a true difference of 10.9 for our primary outcome of agitation measured with the CMAI. For this purpose, we also needed an attrition rate, standard deviation, cluster size, and an intraclass correlation coefficient (for patients in a unit) similar to Chenoweth and colleagues, with a maximum correlation of 0.3 between an organization's units. We replaced participants lost to follow-up with new participants throughout the study. The details of the methods are reported in the published protocol.[16] The trial is registered

with the Dutch Trials Registry, number NTR2314 (http://www.trialregister.nl/ trialreg/admin/rctview.asp?TC = 2314).

Ethical Statement

Written informed consent was obtained from the family of the residents. In those cases in which the resident signed the informed consent form, also the family or legal representative provided a signature for consent. The Committee on Research Involving Human Subjects in the Arnhem-Nijmegen Region approved the study participation.

Procedures

The managers of the units of care homes allocated to the intervention selected staff members who were competent and interested in becoming certified dementia care mappers. DCM Netherlands provided a guideline specifying the required competences. Ten staff members, two from each intervention care home, attended the basic and advanced training given by DCM Netherlands and became certified dementia care mappers.[16] Advanced users are able to observe, report, provide feedback to the staff, and instruct and support them in drawing up action plans. After the training, a member of DCM Netherlands and the researchers (AP and GV) gave the intervention care homes a DCM organizational briefing day. After completing the DCM training and attending the organizational briefing day, the trained mappers were to carry out at least two DCM cycles. Each DCM cycle consists of observation, feedback, and action plans.

The control group residents received usual care during the trial. We defined usual care as the continuation of daily care practices without implementation of DCM. The control care homes were offered the DCM training after the trial.[16]

Outcomes

The study outcome measures were assessed at the resident and staff levels. The primary outcome measure at the resident level was agitation, assessed with the CMAI. This assessment instrument consists of 29 items about agitation and aggression and has been validated for use in care homes in the Netherlands.[17] The CMAI measures the frequency (on a seven-point scale from never to several times an hour) of agitation during the preceding 2 weeks (total score range: 29–203). We also assessed NPSs and quality of life as secondary outcome measures. We assessed the NPSs with the Neuropsychiatric Inventory – Nursing Home (NPI-NH) version, a comprehensive assessment scale including the following symptoms: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, night-time disturbances, and eating change.[18] The frequency (F) is rated on a four-point (1–4) Likert

scale and the severity (S) is rated on a three-point (1–3) Likert scale, yielding an F times S score. When a symptom is not present, the F and S scores are both zero. The F times S score thus contains information about prevalence, frequency, and severity (range: 0–12 for each symptom). We used the Global Deterioration Scale (GDS) to assess the severity of dementia.[19] The residents' quality of life was measured with the Qualidem[20] and the EuroQol 5D.[21] The Qualidem includes 37 items and is a multidimensional scale specifically designed for institutionalized residents with dementia. The authors of the Qualidem state that, in case of severe dementia (GDS 7), 18 instead of 37 items can be applied. Therefore, patients in GDS 7 and those in GDS 1–6 are frequently analyzed separately.[22] We decided to use only the subscales that were applicable to patients in all stages of dementia. Because not all items were applicable to patients with GDS 7, the maximum score would differ on some subscales for patients in GDS 7 and patients in GDS 1–6. Therefore, we determined the maximum scores for both groups with the applicable items, and converted the original scores into percentages of the maximum score (scale 0–100). This way, we could analyze the data for both groups together. Furthermore, we collected the following demographic data at baseline: age, gender, marital status, and country of birth.

We used the General Health Questionnaire (GHQ)-12 as the primary outcome measure at the staff level to measure stress related symptoms.[23,24] We also assessed job experience and job satisfaction as secondary outcome measures using two validated Dutch questionnaires: the Questionnaire about Experience and Assessment of Work (QEAW)[25] and the Maastricht Job Satisfaction Scale for Healthcare (MJSS-HC).[26] The following staff demographics were collected: age, gender, marital status, country of birth, and previous experience with person-centered care.

All nursing staff of the participating units were asked to fill in questionnaires MJSS-HC, QEAW, and GHQ-12. Any staff member who was primarily responsible for a particular resident was also asked to fill in the resident assessment instruments (CMAI, NPI-NH, Qualidem, EuroQol 5D, and GDS). The staff used an internet application (with a personal username and password) to fill in these questionnaires. All the variables were measured at baseline (T0), after the first DCM cycle (T1), and after the second DCM cycle (T2) with intervals of 4 months between measurements and a time window of 2 months for completion. The study started in October 2010 and lasted till April 2012.

Statistical analyses

Analyses were based on the principle of intention-to-treat; all questionnaires were analyzed according to their randomized condition. The analyses included all initially and newly included residents and staff members from whom we received at least one completed assessment. The effects were evaluated by means of linear mixed-effect models for longitudinal data, with control variables used in the studywise minimization procedure[15] as covariates and the unit as a random effect, to correct for dependencies within units. To correct for dependencies caused by repeated measurements, we assumed a heterogeneous structure for the residuals. The following effects were estimated for the outcome variables: the main effect of the intervention, the main effect of time (at three points) and the interaction between the group and time. Two-sided values of $p<0.05$ were deemed statistically significant. Additionally, we imputed missing data for resident questionnaires that were not completed. Missing data were imputed under the missing-at-random assumption and were based on characteristics extracted from the residential files. Because we did not have any other information about the staff, we did not impute missing data for missing staff questionnaires. We used SPSS, version 18 (SPSS, Chicago, Ill.) for statistical analyses.

RESULTS

Participants

Across 34 units, 434 residents were eligible (Figure 1). The elderly care physician excluded 31 (7.1%) of these residents, 72 (16.6%) did not give informed consent, and 63 (14.5%) dropped out before or during the baseline measurement. The 268 (61.8%) residents with informed consent (their own or that of their legal representatives) were included in the study. Ninety-three residents did not complete the study: 87 of them died and 6 moved to another unit or care home. None of the reallocated patients reentered the study. During the study period, 81 new residents with informed consent were included. From the same 34 units, 376 nursing staff members were enrolled and 319 (84.8%) of them remained throughout the study. During the study, 53 new staff members were included.

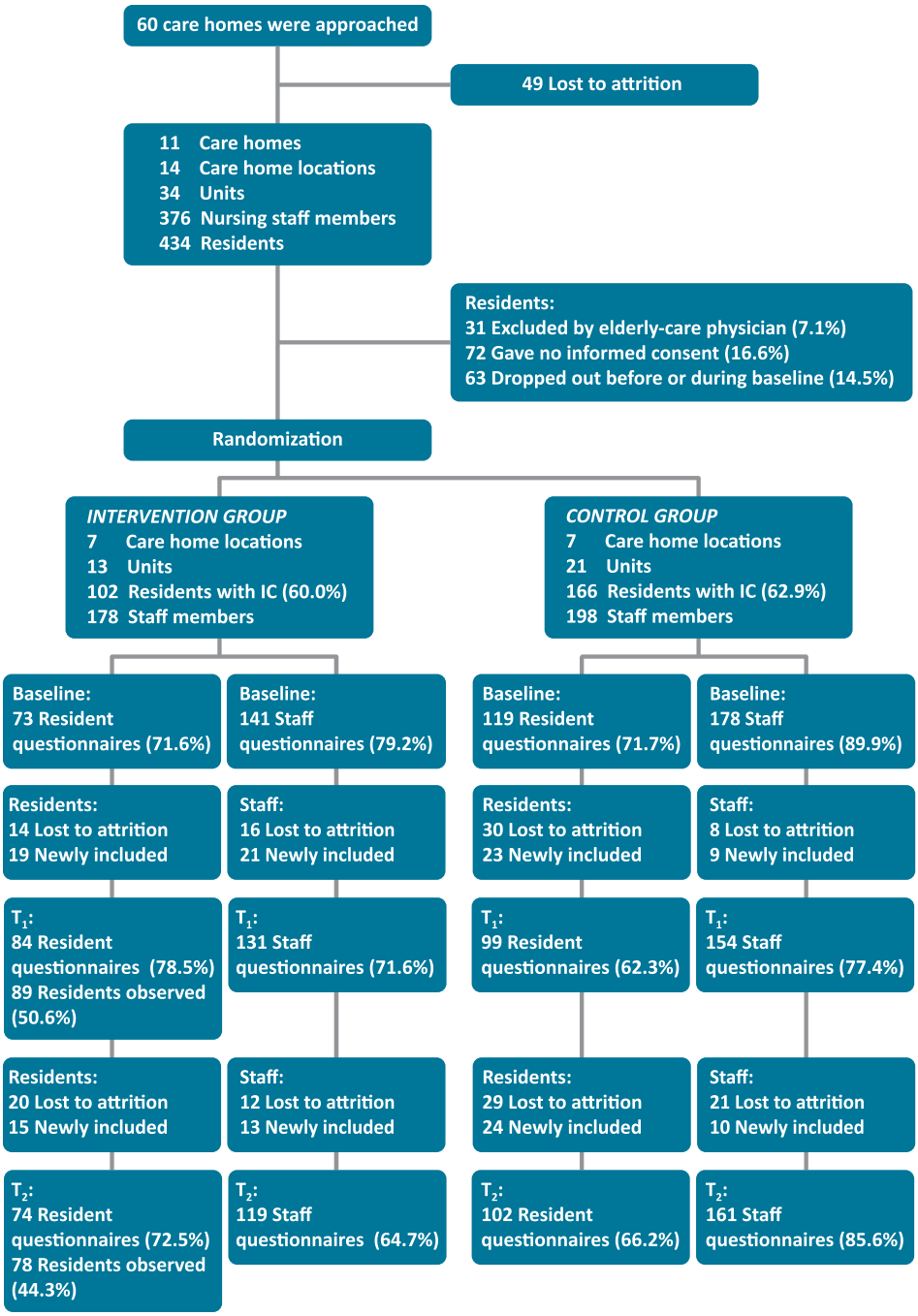

Figure 1. Flowchart detailing numbers of residents and staff

Table 1 shows baseline characteristics of the residents and staff. The mean age of the participating residents was 84.0 (SD 6.3) years and 75.1% were women. Most of the participating staff members were women (98.4%), and their mean age was 43.0 (SD 10.9) years. More than half of them had a previous interest in or experience with person-centered care (56.0% in the intervention group and 55.6% in the control group). The intervention and control groups differed in terms of the proportions of staff in permanent positions. There were no other statistically significant differences in the demographic characteristics at baseline between the intervention and control groups (Table 1).

Table 1. Baseline characteristics of residents and staff

	DCM group	Control group	
Residents	**n=73**	**n=119**	**p**
Mean age in years (SD)	84·6 (6.1)	83·5 (6.6)	0·36
Women	75·1%	73·9%	0·87
Born in the Netherlands	97·5%	97·5%	0·91
Staff	**n=141**	**n=178**	**p**
Mean age in years (SD)	43·6 (10.4)	42·6 (11·3)	0·32
Women	98·6%	98·3%	0·85
Born in the Netherlands	91·5%	89·9%	0·74
Management position	2·1%	2·2%	0·94
Permanent position	98·5%	91·3%	0·01
Mean years working in the current position (SD)	10·3 (8·3)	10·0 (8·6)	0·45
Mean years working in the organization (SD)	12·8 (8·1)	10·1 (7·9)	0·43
Mean number of hours a week according to contract (SD)	23·7 (6·7)	22·6 (7·2)	0·92
Previous interest in or experience with person-centered care	56·0%	55·6%	0·94

Effects of Dementia Care Mapping on residents and staff

Table 2 shows the results of the primary analysis of the outcome measures. The web appendix provides table S1 and S2, in which the mean scores and standard errors (SE) of all outcome measures can be found.

We found no significant effect of the DCM intervention on our primary outcome measure, agitation, as measured by the CMAI. The mean difference between groups was 2.4 with a 95% CI of 22.7 to 7.6 and p = 0.34.

There was a significant interaction effect of group and time (p=0.02) for NPSs in dementia, measured with the NPI-NH. The total F times S score dropped in the control group over time, which means fewer NPSs, but this was not the case in the intervention group. The symptom ‘delusions’ in the NPI-NH also showed a significant interaction effect between time and group; fewer delusions were reported over time in the control group than in the intervention group (p=0.01).

Table 2. Effects of Dementia Care Mapping on residents and staff based on intention-to-treat analysis

Residents	Baseline (n=192)	T_1 (n=182)	T_2 (n=175)
	Mean score (SE)	Mean score (SE)	Mean score (SE)
CMAI: total score		**p_g=0·340 p_t=0·704 p_{gt}=0·473**	
DCM	46·61 (1·91)	47·86 (1·88)	48·18 (2·30)
Control group	45·29 (1·56)	44·32 (1·63)	45·81 (1·97)
NPI-NH: total FxS score		**p_g=0.226 p_t=0·616 p_{gt}=0·022**	
DCM	5·35 (0·94)	7·19 (0·95)	6·28 (0·92)
Control group	6·28 (0·88)	4·45 (0·88)	4·13 (0·86)
Qualidem: total score		**p_g=0.521 p_t=0.014 p_{gt}=0.995**	
DCM	64·52 (2·06)	61·88 (2·10)	62·45 (2·19)
Control group	66·31 (1·71)	63·72 (1·81)	64·11 (1·88)
EuroQol 5D: tariff score		**p_g=0.158 p_t=0.001 p_{gt}=0.087**	
DCM	0·39 (0·03)	0·34 (0·03)	0·35 (0·03)
Control group	0·44 (0·02)	0·41 (0·02)	0·36 (0·02)
Staff	**Baseline (n=318)**	**T_1 (n=284)**	**T_2 (n=279)**
	Mean score (SE)	Mean score (SE)	Mean score (SE)
GHQ-12: total score		**p_g= 0·122 p_t=0·000 p_{gt}=0·432**	
DCM	17·48(0·33)	15·72 (0·38)	14·57 (0·37)
Control group	16·67 (0·29)	14·89 (0·34)	14·42 (0·32)
MJSS-HC: total score		**p_g= 0·560 p_t= 0·005 p_{gt}=0·069**	
DCM	76·98 (1·36)	76·40 (1·34)	78·08 (1·40)
Control group	77·29 (1·44)	75·10 (1·43)	75·58 (1·46)
QEAW: subscale of emotional reactions		**p_g= 0·719 p_t= 0·000 p_{gt}=0·015**	
DCM	13·69 (1·51)	23·38 (1·67)	53·28 (1·20)
Control group	9·48 (1·40)	25·97 (1·59)	53·09 (1·12)

SE= standard error; p_g = main effect of the intervention; p_t = main effect of time (at three times)
p_{gt} = interaction between group and time; CMAI= Cohen-Mansfield Agitation Inventory
NPI-NH= Neuropsychiatric Inventory – Nursing Home version; GHQ-12= General Health Questionnaire; MJSS-HC= Maastricht Job Satisfaction Scale for Healthcare; QEAW= Questionnaire about Experience and Assessment of Work

The quality of life measured with Qualidem showed a significant overall time effect (p=0.01); poorer quality of life was reported over time in both groups. The subscale 'social relations' in the Qualidem showed a significant interaction between group and time (p=0.03). The score in the control group decreased between baseline and T1, while between T1 and T2, the intervention group showed a decrease in quality of social relations.

Measuring the quality of life in the EuroQol 5D resulted in significantly decreased values, irrespective of the group (p<0.01 for time effect). There were no other statistically significant results at the resident level.

At the staff level, the GHQ-12 showed a significant overall time effect, and fewer stress-related symptoms were reported over time in both groups (p<0.001). There were significant differences between all times: T1 compared to baseline (mean difference -1.8, 95% CI -2.3 to -1.2; p<0.001), T2 compared to T1 (mean difference -0.8, 95% CI -1.4 to -0.2; p=0.01) and T2 compared to baseline (mean difference -2.6, 95% CI -3.2 to

-2.0; p<0.001). We found no significant intervention effects in the MJSS-HC. The group by time effect in the QEAW was significant for the subscales 'autonomy' (p=0.04) and 'work pleasure' (p=0.03), but these differences were not straightforwardly in favor of the intervention group or the control group.

On the subscale 'emotional reactions', staff in the intervention group reported significantly fewer negative emotional reactions (such as being hurried or nervous) and more positive emotional reactions (such as being optimistic and relaxed) over time than staff in the control group did (interaction effect p=0.03). There were no other statistically significant results at the staff level.

In total, 40.9% of all resident questionnaires that should have been filled in by the nursing staff were completely missing (47.6% in the intervention group and 34.6% in the control group). We used multiple imputation in SPSS with the missing-at-random assumption. In this procedure, known relationships that are based on the valid values in the sample, are used to help estimate the missing data. Valid values from the same or from other cases, for example of the CMAI baseline score, unit, or age, were used to create a model for predicting missing values. Analysis with imputed missing data yielded the same results as the linear mixed-effect models analysis. Since there were no differences, we chose to report the findings based on the original data.

DISCUSSION

The findings of this pragmatic trial did not confirm the effect on the primary outcome of agitation, Chenoweth and colleagues found in their explanatory study.[8] The intervention units reported more NPSs in residents over time than the control group. It could be that, due to the DCM intervention, staff members in the intervention group developed keener observation skills. Additionally, compared to usual care, work-related emotional reactions of the staff developed into more positive ones. This corresponds with the staff outcomes in Jeon and colleagues' study,[27] in which emotional exhaustion scores declined over time in the intervention group but not in the control group. However, considering the sizes of these two effects, their clinical relevance may be limited.

Our lack of evidence for the effect of DCM on agitation seems to contradict the earlier findings of Chenoweth et al.[8] However, their explanatory trial and our pragmatic trial cannot be compared straightforwardly because of the differences in the study designs.[11] We trained ten nursing staff members from the care homes to perform the DCM intervention without extra support from the research team or DCM Netherlands. This contrasts with Chenoweth's study,[8] in which two research-allied DCM experts performed the DCM intervention in all participating units, thereby minimizing the variation of

intervention implementation between the units.[8,27,28] A Dutch pilot study has found effects of DCM on affective behavior and verbal agitation. In this study with a before-and-after design, the mappers were from the same highly committed care home.[29] Our results are based on intention-to-treat analysis, which means that all questionnaires were analyzed according to their randomized condition, regardless of the actual adherence to the intervention. The variation in adherence across care homes may have masked possible effects of the intervention.

Chenoweth and colleagues[8] selected the care homes for their study because they had task-focused, not person-centered, care systems. In contrast, we used no criteria for the selection of care homes. Indeed, at the start of our study, all care homes claimed to be working with person-centered care systems. It could be that our control group was more like the PCC group than the control group with task-centered care. It is possible that this has attenuated any intervention-induced differences between the intervention and control groups.

The main strengths of this study are the large sample size, and a follow-up of 1 year. We randomized clusters after recruiting the study sample and seeking informed consent from the residents. This way, we controlled for potential selection bias in the control and intervention groups. We used the minimization method in randomization to optimize the distribution of baseline characteristics .

This study has several limitations. First, we were unable to blind participating staff to the intervention, given the necessity for staff to be trained in DCM. Second, we cannot guarantee that the units were representative of Dutch care homes – they agreed to participate in this study because they were at least interested in PCC and DCM. While the RCT is the gold standard for testing the effectiveness of an intervention, complex psychosocial interventions such as DCM require process analysis so that we can determine, at least to some extent, the 'dose-response' relationship.[30]

As already discussed, this trial emulates the real-life situation: the intervention care homes differed in commitment, and nursing staff were trained to map the dementia care. In order to provide information for daily practice, we need to explore the relationship between the extent of the implementation and the effectiveness of DCM.

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Table S1. Effects of Dementia Care Mapping on residents based on intention-to-treat analysis

	Baseline (n=192)	T_1 (n=182)	T_2 (n=175)
	Mean score (SE)	Mean score (SE)	Mean score (SE)
CMAI: total score			**p_g=0·340 p_t=0·704 p_{gt}=0·473**
DCM	46·61 (1·91)	47·86 (1·88)	48·18 (2·30)
Control group	45·29 (1·56)	44·32 (1·63)	45·81 (1·97)
CMAI: subscale of physically aggressive behaviour			**p_g=0·949 p_t=0·615 p_{gt}=0·943**
DCM	11·96 (0·71)	11·79 (0·64)	12·00 (0·79)
Control group	12·06 (0·57)	11·71 (0·55)	12·14 (0·67)
CMAI: subscale of physically non-aggressive behaviour			**p_g=0·480 p_t=0·413 p_{gt}=0·198**
DCM	12·38 (0·86)	13·62 (0·87)	13·45 (0·95)
Control group	12·33 (0·71)	12·05 (0·76)	12·70 (0·82)
CMAI: subscale of verbally agitated behaviour			**p_g=0·138 p_t=0·068 p_{gt}=0·364**
DCM	9·96 (0·77)	10·11 (0·79)	9·77 (0·76)
Control group	8·77 (0·64)	8·89 (0·69)	7·61 (0·76)
NPI-NH: total severity score (FxS)			**p_g=0·226 p_t=0·616 p_{gt}=0·022**
DCM	5·35 (0·94)	7·19 (0·95)	6·28 (0·92)
Control group	6·28 (0·88)	4·45 (0·88)	4·13 (0·86)
NPI-NH: total workload score			**p_g=0·396 p_t=0·455 p_{gt}=0·393**
DCM	2·31 (0·40)	2·34 (0·38)	2·33 (0·43)
Control group	2·27 (0·38)	1·60 (0·36)	1·78 (0·40)
NPI-NH: severity score (FxS) for the subscale of delusions			**p_g=0·143 p_t=0·618 p_{gt}=0·014**
DCM	0·24 (0·12)	0·60 (0·12)	0·51 (0·11)
Control group	0·40 (0·11)	0·22 (0·11)	0·17 (0·11)
NPI-NH: severity score (FxS) for the subscale of hallucinations			**p_g=0·882 p_t=0·550 p_{gt}=0·527**
DCM	0·10 (0·08)	0·22 (0·11)	0·19 (0·09)
Control group	0·16 (0·07)	0·19 (0·10)	0·12 (0·08)
NPI-NH: severity score (FxS) for the subscale of agitation/agression			**p_g=0·862 p_t=0·501 p_{gt}=0·552**
DCM	0·63 (0·17)	0·62 (0·17)	0·52 (0·17)
Control group	0·77 (0·16)	0·49 (0·16)	0·60 (0·16)
NPI-NH: severity score (FxS) for the subscale of depressed mood			**p_g=0·901 p_t=0·630 p_{gt}=0·494**
DCM	0·40 (0·15)	0·61 (0·17)	0·40 (0·14)
Control group	0·55 (0·14)	0·47 (0·15)	0·45 (0·13)
NPI-NH: severity score (FxS) for the subscale of anxiety			**p_g=0·095 p_t=0·256 p_{gt}=0·085**
DCM	0·57 (0·18)	0·97 (0·20)	0·93 (0·19)
Control group	0·47 (0·17)	0·43 (0·18)	0·35 (0·18)
NPI-NH: severity score (FxS) for the subscale of euphoria			**p_g=0·595 p_t=0·003 p_{gt}=0·303**
DCM	0·14 (0·08)	0·11 (0·06)	0·06 (0·03)
Control group	0·27 (0·07)	0·21 (0·05)	0·02 (0·03)
NPI-NH: severity score (FxS) for the subscale of apathy			**p_g=0·579 p_t=0·853 p_{gt}=0·307**
DCM	0·82 (0·27)	0·97 (0·27)	0·99 (0·27)
Control group	0·93 (0·25)	0·70 (0·26)	0·57 (0·26)
NPI-NH: severity score (FxS) for the subscale of disinhibition			**p_g=0·175 p_t=0·675 p_{gt}=0·916**
DCM	0·53 (0·15)	0·52 (0·15)	0·48 (0·14)
Control group	0·34 (0·14)	0·24 (0·14)	0·21 (0·14)
NPI-NH: severity score (FxS) for the subscale of irritability			**p_g=0·537 p_t=0·450 p_{gt}=0·215**
DCM	0·68 (0·16)	0·81 (0·16)	0·59 (0·15)
Control group	0·76 (0·14)	0·49 (0·15)	0·51 (0·14)

	Baseline (n=192)	T_1 (n=182)	T_2 (n=175)
	Mean score (SE)	Mean score (SE)	Mean score (SE)
NPI-NH: severity score (FxS) for the subscale of aberrant motor behaviour			**p_g=0·149 p_t=0·119 p_{gt}=0·073**
DCM	0·30 (0·12)	0·80 (0·17)	0·61 (0·16)
Control group	0·34 (0·11)	0·26 (0·15)	0·50 (0·15)
NPI-NH: severity score (FxS) for the subscale of night-time behaviour			**p_g=0·870 p_t=0·458 p_{gt}=0·986**
DCM	0·31 (0·12)	0·43 (0·15)	0·38 (0·13)
Control group	0·34 (0·11)	0·47 (0·13)	0·38 (0·12)
NPI-NH: severity score (FxS) for the subscale of eating change			**p_g=0·938 p_t=0·067 p_{gt}=0·069**
DCM	0·58 (0·22)	0·52 (0·18)	0·62 (0·18)
Control group	0·99 (0·21)	0·39 (0·17)	0·29 (0·17)
Qualidem: total score			**p_g=0·521 p_t=0·014 p_{gt}=0·995**
DCM	64·52 (2·06)	61·88 (2·10)	62·45 (2·19)
Control group	66·31 (1·71)	63·72 (1·81)	64·11 (1·88)
Qualidem: subscale of care relationship			**p_g=0·509 p_t=0·500 p_{gt}=0·757**
DCM	68·79 (2·61)	69·36 (2·35)	70·87 (2·64)
Control group	70·50 (2·07)	71·37 (2·00)	72·07 (2·24)
Qualidem: subscale of positive affect			**p_g=0·963 p_t=0·000 p_{gt}=0·292**
DCM	73·15 (3·13)	67·02 (3·31)	69·83 (3·40)
Control group	73·57 (2·65)	68·57 (2·88)	67·25 (2·94)
Qualidem: subscale of negative affect			**p_g=0·385 p_t=0·274 p_{gt}=0·911**
DCM	63·36 (3·03)	61·10 (3·19)	61·03 (3·15)
Control group	66·55 (2·64)	63·97 (2·74)	65·22 (2·69)
Qualidem: subscale of restless, tense behaviour			**p_g=0·167 p_t=0·468 p_{gt}=0·385**
DCM	48·27 (3·82)	44·04 (3·89)	47·43 (4·07)
Control group	53·77 (3·17)	53·81 (3·39)	53·28 (3·51)
Qualidem: subscale of social relations			**p_g=0·819 p_t=0·036 p_{gt}=0·029**
DCM	58·97 (2·96)	58·70 (2·97)	54·65 (3·02)
Control group	59·79 (2·46)	54·05 (2·58)	55·84 (2·61)
Qualidem: subscale of social isolation			**p_g=0·241 p_t=0·379 p_{gt}=0·310**
DCM	66·05 (2·84)	63·67 (3·04)	61·77 (3·21)
Control group	68·55 (2·26)	66·49 (2·61)	69·63 (2·73)
EuroQol 5D: tariff score			**p_g=0·158 p_t=0·001 p_{gt}=0·087**
DCM	0·39 (0·03)	0·34 (0·03)	0·35 (0·03)
Control group	0·44 (0·02)	0·41 (0·02)	0·36 (0·02)
EuroQol 5D: VAS score			**p_g=0·475 p_t=0·200 p_{gt}=0·336**
DCM	57·41 (2·95)	53·85 (2·98)	57·58 (3·00)
Control group	59·57 (2·48)	58·78 (2·62)	58·73 (2·61)
Severity of dementia: GDS			**p_g=0·722 p_t=0·208 p_{gt}=0·945**
DCM	5·46 (0·18)	5·54 (0·17)	5·61 (0·17)
Control group	5·37 (0·15)	5·44 (0·15)	5·56 (0·14)

SE= standard error
p_g = main effect of the intervention
p_t = main effect of time (at three times)
p_{gt} = interaction between group and time
CMAI= Cohen-Mansfield Agitation Inventory
NPI-NH= Neuropsychiatric Inventory – Nursing Home version
VAS= Visual Analogue Scale
GDS= Global Deterioration Scale

Table S2. Effects of Dementia Care Mapping on nursing staff based on intention-to-treat analysis

	Baseline (n=318)	T_1 (n=284)	T_2 (n=279)
	Mean score(SE)	Mean score(SE)	Mean score(SE)
GHQ-12: total score			p_g= 0·122 p_t=0·000 p_{gt}=0·432
DCM	17·48 (0·33)	15·72 (0·38)	14·57 (0·37)
Control group	16·67 (0·29)	14·89 (0·34)	14·42 (0·32)
MJSS-HC: total score			p_g= 0·560 p_t= 0·005 p_{gt}=0·069
DCM	76·98 (1·36)	76·40 (1·34)	78·08 (1·40)
Control group	77·29 (1·44)	75·10 (1·43)	75·58 (1·46)
MJSS-HC: subscale of satisfaction with the manager			p_g= 0·083 p_t= 0·925 p_{gt}=0·072
DCM	11·09 (0·39)	11·32 (0·39)	11·34 (0·40)
Control group	10·42 (0·42)	10·13 (0·42)	10·06 (0·43)
MJSS-HC: subscale of promotion			p_g= 0· 644 p_t= 0·039 p_{gt}=0·051
DCM	9·95 (0·25)	9·80 (0·26)	10·21 (0·27)
Control group	10·08 (0·26)	9·70 (0·27)	9·67 (0·27)
MJSS-HC: subscale of quality of care			p_g= 0·654 p_t= 0·000 p_{gt}=0·069
DCM	9·50 (0·34)	9·19 (0·34)	9·88 (0·35)
Control group	10·07 (0·37)	9·43 (0·37)	9·76 (0·37)
MJSS-HC: subscale of opportunity to grow			p_g= 0·911 p_t= 0·503 p_{gt}=0·108
DCM	10·90 (0·24)	10·83 (0·23)	11·15 (0·24)
Control group	11·05 (0·24)	10·91 (0·24)	10·81 (0·24)
MJSS-HC: subscale of contact with colleagues			p_g= 0·943 p_t= 0·087 p_{gt}=0·675
DCM	12·15 (0·19)	12·04 (0·20)	12·15 (0·21)
Control group	12·25 (0·20)	11·98 (0·20)	12·16 (0·21)
MJSS-HC: subscale of contact with patients			p_g= 0·674 p_t= 0·402 p_{gt}=0·567
DCM	12·17 (0·14)	12·14 (0·14)	12·21 (0·15)
Control group	12·36 (0·13)	12·14 (0·14)	12·23 (0·14)
MJSS-HC: subscale of clarity of task			p_g= 0·725 p_t= 0·066 p_{gt}=0·806
DCM	11·10 (0·19)	10·94 (0·19)	11·02 (0·20)
Control group	11·08 (0·20)	10·81 (0·20)	10·89 (0·20)
QEAW: subscale of autonomy			p_g= 0·387 p_t= 0·009 p_{gt}=0·037
DCM	44·37 (1·60)	45·89 (1·55)	43·86 (1·59)
Control group	40·59 (1·55)	43·41 (1·52)	44·51 (1·53)
QEAW: subscale of problems with task			p_g= 0·881 p_t= 0·001 p_{gt}=0·770
DCM	17·83 (1·32)	19·90 (1·33)	19·55 (1·38)
Control group	17·84 (1·33)	19·87 (1·35)	20·40 (1·36)
QEAW: subscale of work pleasure			p_g= 0·335 p_t= 0·343 p_{gt}=0·030
DCM	11·05 (1·98)	9·69 (2·00)	10·28 (2·02)
Control group	7·26 (2·03)	9·30 (2·05)	6·22 (2·05)
QEAW: subscale of job change			p_g= 0·603 p_t= 0·092 p_{gt}=0·703
DCM	16·51 (3·17)	18·27 (3·25)	16·58 (3·34)
Control group	17·33 (3·15)	21·37 (3·24)	19·64 (3·25)
QEAW: subscale of emotional reactions			p_g= 0·719 p_t= 0·000 p_{gt}=0·015
DCM	13·69 (1·51)	23·38 (1·67)	53·28 (1·20)
Control group	9·48 (1·40)	25·97 (1·59)	53·09 (1·12)

SE= standard error
p_g = main effect of the intervention
p_t = main effect of time (at three times)
p_{gt} = interaction between group and time
GHQ-12= General Health Questionnaire
MJSS-HC= Maastricht Job Satisfaction Scale for Healthcare
QEAW= Questionnaire about Experience and Assessment of Work

Chapter 4

The economics of Dementia Care Mapping in nursing homes: a cluster-randomized controlled trial

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ABSTRACT

Background: Dementia Care Mapping (DCM) is a cyclic intervention aiming at reducing neuropsychiatric symptoms in people with dementia in nursing homes. Alongside an 18-month cluster-randomized controlled trial in which we studied the effectiveness of DCM on residents and staff outcomes, we investigated differences in costs of care between DCM and usual care in nursing homes.

Methods: Dementia special care units were randomly assigned to DCM or usual care. Nurses from the intervention care homes received DCM training, a DCM organizational briefing day and conducted the 4-months DCM intervention twice during the study. A single DCM cycle consists of observation, feedback to the staff, and action plans for the residents. We measured costs related to health care consumption, falls and psychotropic drug use at the resident level and absenteeism at the staff level. Data were extracted from resident files and the nursing home records. Prizes were determined using the Dutch manual of health care cost and the cost prices delivered by a pharmacy and a nursing home. Total costs were evaluated by means of linear mixed-effect models for longitudinal data, with the unit as a random effect to correct for dependencies within units.

Results: 34 units from 11 nursing homes, including 318 residents and 376 nursing staff members participated in the cost analyses. Analyses showed no difference in total costs. However certain changes within costs could be noticed. The intervention group showed lower costs associated with outpatient hospital appointments over time ($p=0.05$) than the control group. In both groups, the number of falls, costs associated with the elderly care physician and nurse practitioner increased equally during the study ($p=0.02$).

Conclusions: DCM is a cost-neutral intervention. It effectively reduces outpatient hospital appointments compared to usual care. Other considerations than costs, such as nursing homes' preferences, may determine whether they adopt the DCM method.

INTRODUCTION

Care for the elderly with dementia is expensive. In 2005, 4.7% of the total health care costs in the Netherlands were spend on dementia, which is US $425.000.000.[1] Healthcare costs associated with dementia are predicted to rise with the increasing prevalence.[2] The most prevalent resident and staff problem in nursing home dementia care is neuropsychiatric symptoms (NPSs), which 80-90% of the nursing home residents with dementia have.[3] The high prevalence of NPSs is associated with increased demands on staff resources, job-related stress, burnout, and staff turnover.[4] Managing the high health care expenditures related to NPSs, without compromising the quality of care is not a trivial task.

Evidence suggests that different types of person-centered care (PCC) may reduce NPSs and improve both resident and staff outcomes.[5–7] There are examples of PCC interventions for nursing home residents with dementia that have been shown to lower the rate of NPSs, falls, and the use of psychotropic drugs.[8,9] Dementia Care Mapping (DCM) is a person-centered, multicomponent intervention developed by the Bradford Dementia Group at the University of Bradford in the UK and is based on Kitwood's social-psychological theory of personhood in dementia.[10] This theory states that much of the ill-being that people with dementia experience is due to negative environmental influences, including staff attitudes and care practices. DCM is a cyclic intervention consisting of three components: systematic observation, feedback to the staff, and action plans. The action plans are developed by the nursing staff and are based on the observation of the actual needs of the residents. This method allows for timely initiation of tailor made interventions at the individual level (residents and caregivers) and the group level (nursing teams and multi-disciplinary teams), as well as at the levels of management and organization. In short, DCM is a multi-component intervention aiming at synergistically implementing diverse single-scope interventions to sustainably improve the quality and effectiveness of care.[11]

We started a cluster-randomized controlled trial evaluating the effectiveness of DCM in Dutch nursing homes in 2010. The design and the results of this trial on resident and staff outcomes are published earlier.[12,13] Because of the importance of economic considerations in the implementation of new interventions, we also performed a cost analysis. Since we found no effect in our trial on our primary outcome of agitation, we used a cost minimization analysis to investigate the differences in costs of care.

METHODS

Participants

The design of the trial has been published previously.[13] We recruited nursing homes by sending invitational letters and approaching nursing homes that already had contact with DCM Netherlands. Care for people with dementia in the Netherlands is generally provided in dementia special care units. Staff in Dutch nursing homes includes nurses, elderly care physicians, physical therapists, occupational therapists, dietitians, and psychologists, all of whom are employed by the nursing home. Staff in Dutch nursing homes receive a fixed salary based on the number of hours they work, independent of the services they provide.[14,15] The study sample consisted of residents with dementia and their formal caregivers. Inclusion criteria for the residents required a diagnosis of dementia established by elderly care physicians according to the dementia criteria of the Diagnostic and statistical manual of mental disorders IV,[16] approval of the elderly care physicians for inclusion, age of 65 years or more, at least 1 neuropsychiatric symptom in the last 2 weeks as assessed with the Neuropsychiatric Inventory – Nursing Home, informed consent of the resident or his/her family, and the ability of the resident to use the common areas, such as the shared living room, for at least 4 hours a day. Residents with an estimated life expectancy of 6 weeks or less and those who were physically unable to spend time in common areas of the unit were not included in the study. Participants lost to follow-up were replaced by new participants throughout the study. The trial is registered with the Dutch Trials Registry, number NTR2314 (http://www.trialregister.nl/trialreg/admin/rctview.asp?TC = 2314).

Ethical Statement

Written informed consent was obtained from the family of the residents. In those cases in which the resident signed the informed consent form, also the family or legal representative provided a signature for consent. The Committee on Research Involving Human Subjects in the Arnhem-Nijmegen Region approved the study participation.

DCM intervention

The managers at the intervention nursing homes selected staff members who were interested in becoming certified DCM mappers and who met the competency requirements set by DCM Netherlands. A total of 10 staff members, 2 from each intervention nursing home, attended the DCM basic and advanced training provided by DCM Netherlands and became certified DCM mappers. An advanced level certification means that the mapper is qualified to conduct and report structured DCM observations, provide feedback to the staff, and instruct and support them in drawing up action plans

for the residents. At the end of the DCM training, a member of DCM Netherlands and a researcher (AP and GV) provided a DCM organizational briefing day for the intervention nursing homes. After completing the training and the organizational briefing day, the trained mappers had to complete at least 2 DCM cycles. A single DCM cycle consists of observation, feedback, and action plans. The control group residents received usual care during the trial. The control nursing homes were offered the DCM training, to take place after the trial. The study period started in October 2010 and lasted until April 2012.

Costs of the DCM intervention

For the purpose of calculating the costs of the DCM intervention, we included the following activities: DCM basic and advanced training, mapping exercise, inter-rater reliability test, observation, preparing the DCM reports, and feedback sessions.

Ten staff members (2 from each intervention nursing home) attended the DCM basic training (US $979.99 per attendee) and the DCM advanced training (US $1371.98 per attendee) provided by DCM Netherlands. We also included the nursing staff hourly wages (32 hours for the basic training and 32 hours for the advanced training). Additionally, we included the hourly wages of all the hours spend on DCM by the mappers. Every mapper did a mapping exercise (6 hours) and an inter-rater reliability test (1.5 hours). The actual hours spent in observation were extracted from the raw data sheets in the DCM reports. The feedback sessions (2 hours each) and the preparation of DCM reports (8 hours each) were standardized. The costs of the hourly wages were covered by a representative nursing home (US $27.68). We used the exchange rate of EUR 1.00=US $1.318.

We calculated the implementation costs per unit based on the invested hours in implementation activities during the trial. To calculate the mean unit costs per resident per day, we divided the total costs of implementing the DCM intervention by the number of residents in the unit and the days of the study period (549). The mean unit costs per resident per day were taken into account for a baseline period of 6 months (T0), 6 months following the first DCM cycle (T1) and 6 months following the second DCM cycle (T2).

Outcome measures

We analyzed the costs from a health care perspective. We used the following outcome measures, based on the aim of DCM to reduce these: health care consumption, number of falls, and psychotropic drug use at the resident level; and absenteeism at the staff level. Data for the economic analysis were collected over a period of 18 months, divided into three periods of 6 months: T0, T1 and T2.

A research assistant and/or a researcher (FB, EH, and GV) visited all nursing homes at the end of the trial to obtain information about all outcome measures. The number of contacts with the nursing home's health care professionals (elderly care physician, nurse practitioner, psychologist, social worker, occupational therapist, and dietitian) and the hospitals were extracted from the resident files. The calculation of costs for these contacts was based on a manual for health care cost analysis,[17] and the hourly wages of the nursing home's health care professionals were covered by a nursing home. The number of falls was obtained from the nursing home records at the unit level. While the costs of falls are included in the other outcome measures, such as outpatient hospital appointments, we only present the frequency of falls. Information about the residents' psychotropic drug use (antipsychotics, antidepressants, hypnotics, anxiolytics, anticonvulsants, and antidementia drugs) was collected at three times, set in the middle of each study period. Data about the use of all psychotropic drugs were collected and detailed to the drug, the dosage, and the regularity of use. Psychotropic drug prescriptions for incidental use were discarded. The pharmacy of the Medical Center of the Radboud University of Nijmegen provided the prices for the products. We used the pharmaceutical prices of generic products, since the DCM intervention is not likely to affect the choice of generic products or brand names. Outcome measures were calculated for each study period per resident, per day.

Data about staff absenteeism was collected at the unit level from the nursing home record system. The costs of absenteeism were based on the hourly wages of the nursing staff, and were provided by a nursing home.

Table 1 details the key unit costs, together with their sources. The baseline characteristics of residents were extracted from the available resident files, whereas staff baseline characteristics were acquired from a survey.

Table 1. Key unit costs in US dollars used to value resource use measured in the trial (2010-2012)

	Costs in Dollars	Source of Costs
Hospital		
• Outpatient clinic		
- University hospital	170.01/contact	1
- Regular hospital	84.35/contact	1
- Unknown hospital	94.89/contact	1
• Inpatient		
- University hospital	757.80/day	1
- Regular hospital	573.29/day	1
- Unknown hospital	734.07/day	1
• Emergency department	199/contact	1
• Ambulance	436.23/ride	1
Drugs		
• Psychotropic drugs	Various	2
Nursing home's health care professionals		
• Elderly care physician	47.08/contact	3
• Nurse practitioner	25.70/contact	3
• Psychologist	77.11/contact	3
• Social worker	32.76/contact	3
• Physical therapist	28.73/contact	3
• Occupational therapist	28.73/contact	3
• Dietitian	26.25/contact	3
• Nursing staff	27.68/hour	3

Sources:
1. Hakkaart-van Oijen et al. 2010
2. Unit costs at Radboud University Hospital 2012
3. Professionals contacted for an indication of gross costs in 2012

Statistical analysis

Analyses were based on the principle of intention-to-treat; all data were analyzed in their randomized condition. The analyses included all randomized and newly included residents and staff members, of whom we had information for at least 1 period. We used the following outcome measures: health care consumption, number of falls, and psychotropic drug use at the resident level; and absenteeism at the staff level. The effects of DCM on costs were evaluated by means of linear mixed-effect models for longitudinal data, with the unit as a random effect to correct for dependencies within units. We did not account for dependencies within nursing homes, because not all nursing homes participated in the study with more than one unit. The control variables used in the studywise minimization[18] were treated as covariates: the size of the nursing home, number of residents per unit, and ratio of formal caregivers to residents. We assumed an AR1 correlation structure with heterogeneous covariance for the residuals to correct for dependencies caused by repeated measurements. The effects estimated for the outcome variables were the main effect of the groups (intervention and control), the main effect of time (T0, T1, and T2), and the interaction between group

and time. The DCM implementation costs were included in the total costs. Health care consumption and psychotropic drug use were analyzed at the resident level, whereas falls, absenteeism, total resident-based costs (health care consumption and drug use) and total costs (health care consumption and drug use, absenteeism, and intervention costs) were analyzed at the unit level. Outcomes analyzed at the unit level were corrected for the numbers of residents and staff members per unit. Two-sided values of $p<0.05$ were deemed statistically significant. Statistical analyses were carried out with SPSS version 18 (SPSS, Chicago, Ill.).

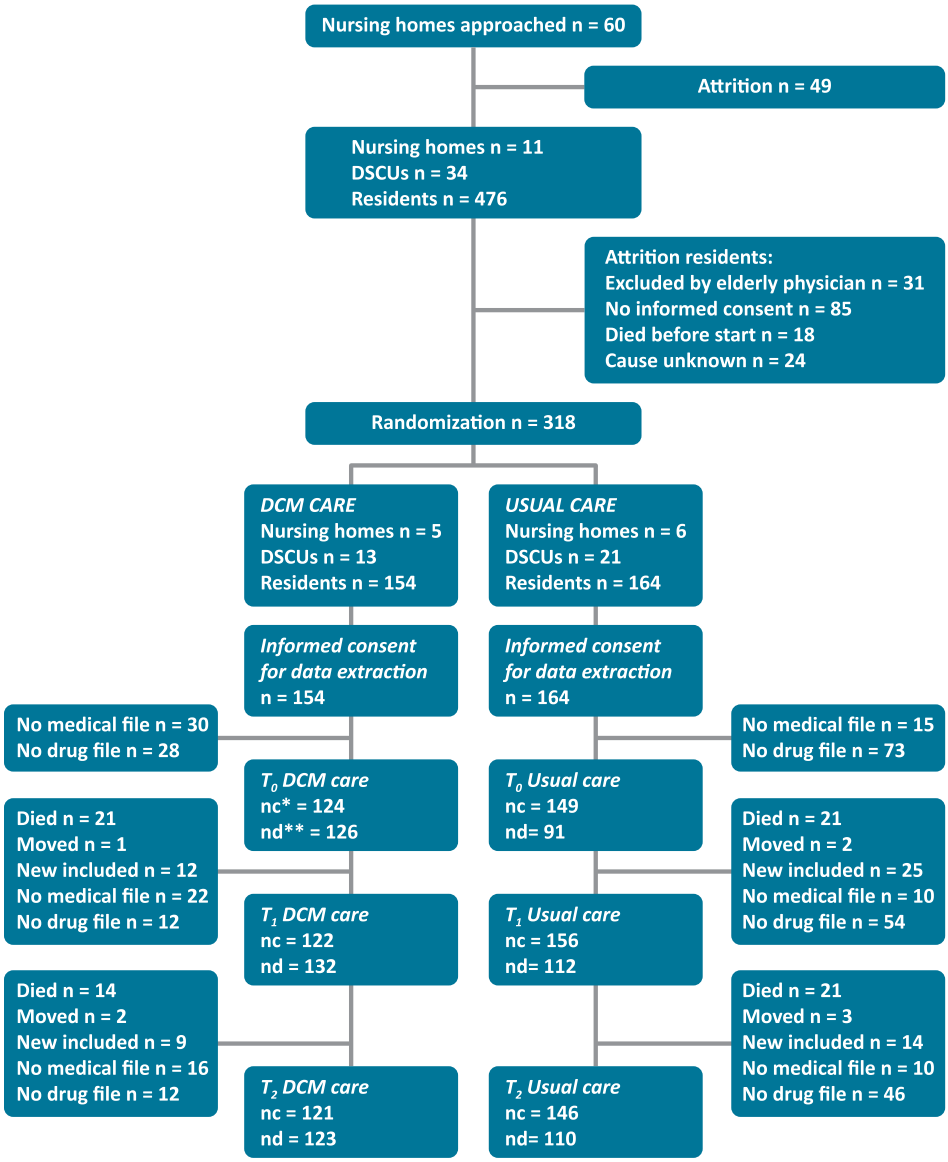
RESULTS

Trial participants

Thirty-four units from 11 nursing home organizations in different regions in the Netherlands were recruited for participation (Figure 1). The number of residents per unit ranged from 3 to 32. Table 2 shows the baseline characteristics of residents and staff. Staff baseline characteristics were taken from a survey completed by 319 staff members (84.8%). The intervention and control groups differed in terms of the proportions of staff in permanent positions. There were no other statistically significant differences at baseline between the intervention and control groups.

Table 2. Baseline characteristics

Nursing Homes	**Intervention Group (n=5)**	**Usual Care Group (n=6)**
Number of nursing homes	5	6
Number of units	13	21
Number of residents per unit (mean and SD)	13·5 (8·2)	8·80 (4·47)
Number of staff members per unit (mean and SD)	14·0 (7·4)	9·28 (6·61)
Number of staff per resident (mean and SD)	0·17 (0·04)	0·18 (0·01)
Residents	**Intervention Group (n=154)**	**Usual Care Group (n=164)**
Mean age in years (SD)	84·8 (6·0)	84·59 (6·6)
Women	118 (76·6%)	121 (73·8%)
Staff	**Intervention Group (n=141)**	**Usual Care Group (n=178)**
Mean age in years (SD)	43·6 (10·4)	42·6 (11·3)
Women	139 (98·6%)	175 (98·3%)
Born in the Netherlands	129 (91·5%)	160 (89·9%)
Years working in the current position (mean and SD)	10·3 (8·3)	10·0 (8·6)
Years working in the organization (mean and SD)	12·8 (8·1)	10·1 (7·9)
Permanent employment contract	139 (98·5%)	163 (91·6%)
Number of hours a week by contract (mean and SD)	23·7 (6·7)	22·6 (7·2)
Previous interest in or experience with person-centered care	79 (56·0%)	99 (55·6%)



*nc = number of residents for study of health care consumption
**nd = number of residents for study of psychotropic drug use

Figure 1. Flowchart of nursing homes and residents

Costs

Analyses showed no effect of the intervention on total costs (p=0.60). The total costs included residents' health care consumption and drug use, staff absenteeism, and the costs of the DCM intervention. Figure 2 shows the mean total costs per resident per day. There were no differences between the intervention and control groups for the total residents' costs (health care consumption and drug use). On the staff level, there was no significant difference between the intervention and control group for costs associated with absenteeism. In both groups, the number of falls, costs of care provided by the elderly care physicians and nurse practitioners, increased over time (p<0.02), but no significant interaction between group and time was found.

Compared to the control group, the intervention group showed a decrease in costs associated with outpatient hospital appointments over time (p=0.05). The use of psychotropic drugs decreased over time in both groups (p=0.01 for time effect). We found a significant interaction for the psychotropic drug use. However, the interaction pattern did not clearly favor either the intervention group or the control group.

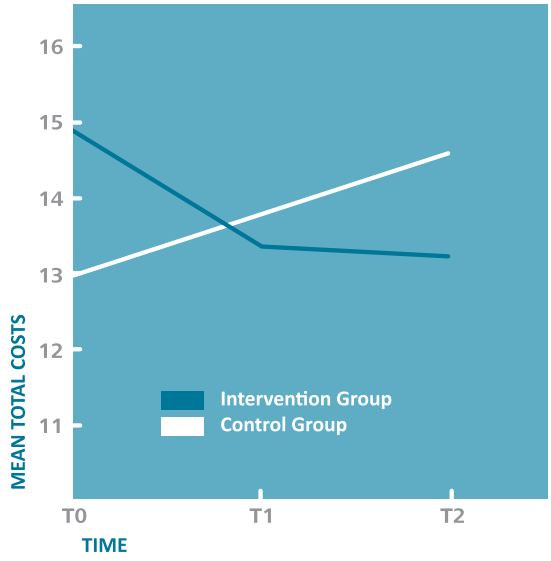


Figure 2. Mean total costs per resident per day in US dollars

The mean DCM implementation costs per resident per day were US $0.63 (SD $0.23) (see Table 3). The findings just outlined were not affected by the exclusion of the DCM implementation costs from the model.

Table 3. Intervention costs

	Hours invested per unit (mean and SD)	Mean costs hours invested (hourly wages $27.68)	Training costs
DCM basic training	32 hours (0·00)	$885·76	$979·99
DCM advanced training	32 hours (0·00)	$885·76	$1371·98
Mapping exercise	6 hours (0·00)	$166·08	
Inter-rater reliability test	1·5 hour (0·00)	$41·52	
Observation	20·85 hours (11·20)	$577·13	
Preparing DCM reports	28.43 hours (15·03)	$786·94	
Feedback sessions	6·89 hours (4·14)	$190·72	
Total intervention costs per unit (mean and SD)	$2856·81 ($365·86)		
Costs per resident per day (mean and SD)	$0·63 ($0·23)		

Table 4 shows the means and SEs for the intervention and control groups for all outcome measures.

Table 4. Results (costs) for residents and staff

	Intervention Group			Usual Care Group				
Residents	**T0 n=154**	**T1 n=144**	**T2 n=137**	**T0 n=164**	**T1 n=166**	**T2 n=156**	**Baseline ICC**	**Significance**
Mean annual number and SE of falls per resident								
Falls	2·78 (0·63)	3·13 (0·40)	3·33 (0·39)	1·41 (0·64)	1·48 (0·41)	1·81 (0·39)	0.03	$p_{g=}$0·11 $p_{t=}$0·023 $p_{gt=}$0·799
Mean costs of health care consumption per resident per day in US dollars and SE								
Elderly care physician and nurse practitioner	2·52 (0·34)	2·60 (0·45)	2·84 (0·40)	2·83 (0·32)	4·05 (0·41)	3·73 (0·36)	0.08	$p_{g=}$0·07 $p_{t=}$0·011 $p_{gt=}$0·067
Psychologist	1·03 (0·17)	0·93 (0·15)	0·74 (0·14)	0·88 (0·18)	1·25 (0·15)	1·23 (0·15)	0.00	$p_{g=}$0·12 $p_{t=}$0·636 $p_{gt=}$0·126
Paramedical professionals	0·74 (0·12)	0·68 (0·13)	0·72 (0·13)	0.55 (0·11)	0·75 (0·12)	0·76 (0·16)	0.06	$p_{g=}$0·84 $p_{t=}$0·506 $p_{gt=}$0·189
Outpatient hospital contacts	1·00 (0·14)	0·87 (0·12)	0·65 (0·16)	0·91 (0·15)	0·71 (0·12)	1·04 (0·14)	0.18	$p_{g=}$0·78 $p_{t=}$0·313 $p_{gt=}$0·050
Hospital Admissions	0·70 (0·26)	0·53 (0·28)	0·86 (0·30)	0·45 (0·24)	0·54 (0·25)	0·11 (0·27)	0.01	$p_{g=}$0·23 $p_{t=}$0·939 $p_{gt=}$0·322
Total health care consumption	3·28 (0·42)	2·92 (0·39)	3·50 (0·46)	3·10 (0·39)	3·19 (0·36)	3·23 (0·43)	0.08	$p_{g=}$0·90 $p_{t=}$0·545 $p_{gt=}$0·541
Psychotropic drug use	0·20 (0·07)	0·32 (0·08)	0·13 (0·06)	0·36 (0·07)	0·28 (0·08)	0·25 (0·06)	0.03	$p_{g=}$0·40 $p_{t=}$0·011 $p_{gt=}$0·032

Total resident-based costs: health care consumption and drug use	4·16 (0·62)	3·83 (0·66)	4·25 (0·59)	4·02 (0·62)	3·83 (0·66)	4·40 (0·57)	0.04	$p_{g=}$0·59 $p_{t=}$0·514 $p_{gt=}$0·193
	Intervention Group			**Usual Care Group**				
Staff	**T0 n=178**	**T1 n=183**	**T2 n=184**	**T0 n=198**	**T1 n=199**	**T2 n=188**		**Signifi-cance**
Mean costs per unit per day in US dollars and SE								
Absenteeism	9·55 (2·23)	8·79 (1·59)	8·57 (1·69)	7·25 (2·78)	7·53 (2·04)	9·92 (2·17)	0.05	$p_{g=}$0·42 $p_{t=}$0·793 $p_{gt=}$0·249
	Intervention Group			**Usual Care Group**				
Total costs including DCM intervention	**T0**	**T1**	**T2**	**T0**	**T1**	**T2**		**Signifi-cance**
Mean costs per resident per day in US dollars and SE								
Total costs Health care consumption, drug use, absenteeism, and intervention costs	14·91 (2·29)	13·36 (1·65)	13·20 (1·92)	12·97 (3·12)	13·76 (2·11)	14·64 (2·44)	0.02	$p_{g=}$0·93 $p_{t=}$0·991 $p_{gt=}$0·604

DCM = Dementia Care Mapping, SE = standard error, P_g = main effect of the groups, P_t = main effect of time, P_{gt} = interaction between group and time

DISCUSSION

Overall, DCM turned out to be a cost-neutral intervention, sustaining affordability of institutionalized dementia care. The intervention group did show lower costs associated with outpatient hospital appointments than the control group during the evaluation period. The relationship between this cost saving effect and the DCM intervention is not clear. The effects on costs did not change when the DCM implementation costs were eliminated from the model, which means that these costs are negligible compared to the costs associated with daily care.

The average number of falls corresponds with the numbers found in previous studies in Dutch nursing homes.[19] In contrast to Chenoweth and colleagues' study,[20] we found no reduction in falls. Chenoweth et al. calculated the proportion of residents who did fall, whereas in this study we collected the registered number of falls at the unit level. This was done for practical reasons concerning the registration of falls in the nursing home records. There is no reason to believe that this difference in approach influenced the results. Importantly, in long term care facilities like nursing homes, it seems to be difficult to reduce the number of falls, even when, unlike DCM, an intervention focuses on preventing falls.[21]

The use of psychotropic drugs decreased in both groups over time. Chenoweth and colleagues[20] found no significant effect of DCM on drug use. Despite the reluctance of physicians to change their pharmaceutical prescribing habits,[22] the decrease in psychotropic drug use can be explained as a result of a steady change in the policy of elderly care physicians to decrease the prescription of inappropriate psychotropic drugs.
The main strengths of this study are the large sample size, cluster randomization, and the relatively long study period of 18 months. We cluster-randomized the units after recruiting the residents and seeking informed consent. This way, we controlled for selection bias in the control- and intervention groups. We used the minimization method in randomization to optimize distribution of baseline characteristics across the intervention and control groups.
This study has several limitations. First, we were unable to blind participating staff to the intervention, given the necessity of staff training in DCM. Second, we cannot guarantee that the units were representative of Dutch nursing homes – they agreed to participate in this study because they were at least interested in PCC and DCM. Furthermore, the nursing home data and hospital care appointments were extracted from residents' medical files. There is variation in the way health care professionals register their contacts with the residents. Some nursing homes had structured electronic files, while others had paper files that made it difficult to extract all the necessary information. In both cases, there may be some under-registration. Particularly the drug files for the residents who had died or relocated were often unavailable. However, there is no reason to believe that the rates of under-registration differ between the intervention and control groups. Finally, we did not measure the time nurses spent on different tasks or residents. Because the nurses work a fixed number by contract, it was difficult to recover the data for differences in time spent on the actual care delivery. If anything, we would expect that the DCM intervention increased the proportion of time spent on tailored care.
We find that DCM is a cost-neutral intervention for nursing home residents with dementia that has an advantage over usual care when it comes to the costs of outpatient hospital appointments. Since DCM has shown positive effects on resident outcome measures such as depression, agitation and quality of life,[20,23] considerations other than costs may determine whether or not a nursing home will adopt this method.

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Chapter 5

Web-based data collection in nursing homes: the future?

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ABSTRACT

Background/Objectives: While web-based research data collection is increasingly used in nursing homes, it is still much more common to use the paper-and-pencil method. In this study we systematically implemented web-based data collection in nursing homes. This study explores feasibility of web-based data collection based on response rates and evaluates its usability.

Design: Survey within a cluster-randomized controlled trial.

Setting: 34 Dementia special care units (DSCUs) from 14 nursing homes in the Netherlands.

Participants: In addition to taking part in a cluster-randomized controlled trial on the (cost)effectiveness of Dementia Care Mapping intervention, 372 nursing staff members were also approached to participate in the usability survey regarding web-based data collection.

Measurements: Response rates in the main trial were registered at baseline, T1 and T2 with 4 months between each measurement and a time window for completion of 2 months. Usability of the web-based data collection was evaluated at T2 in nursing staff using a self-developed questionnaire.

Results: The average response rate using web-based data collection was 73.9%. 280 (75.3%) nursing staff members completed the questionnaire about usability of the web-based data collection. Nursing staff members in this study were positive about the clarity of the instruction letter and webpage and the safety of the web-based questionnaires. The majority of the staff preferred web-based questionnaires over the paper-and-pencil method.

Conclusion: Web-based data collection in nursing homes is feasible with response rates comparable with the paper-and-pencil method. Nursing staff members in this study were very positive about the web-based method and the majority preferred web-based over the paper-and-pencil method. Given a carefully designed implementation procedure, web-based data collection can be an efficient way to collect research data in settings like nursing homes.

INTRODUCTION

Data collection in research usually costs a lot of time, effort and money. Researchers are often facing the challenge of collecting a large amount of data in limited time and with limited budget. Recent findings suggest that web-based data collection might have many advantages over the paper-and-pencil method in terms of efficacy i.e., substantial savings in time and money.[1,2] While this data collection technique is used more and more, in nursing homes it is still much more common to use paper-and-pencil questionnaires.[3-10] There may be several reasons why web-based data collection has not often been used in this settings. It is generally thought that staff in nursing homes have a low familiarity with computer and internet applications and therefore prefer paper-and-pencil questionnaires.[11-13] Because of this, most researchers fear a decrease in response rate when using web-based questionnaires. However, considering the potential advantages of web-based data collection, we decided to implement this method systematically in our intervention study.[14] This study explores the feasibility of web-based data collection based on response rates in our main trial. Furthermore, the web-based data collection is evaluated by means of an usability survey.

METHODS

Participants

Participants were the nursing staff members from 34 dementia special care units (DSCUs) from 14 nursing homes. In addition to taking part in a cluster-randomized controlled trial on the (cost)effectiveness of Dementia Care Mapping intervention,[14-16] the nursing staff members (n=362) were also approached to participate in an usability survey regarding web-based data collection.

Procedure

Main trial

To evaluate the (cost)effectiveness of Dementia Care Mapping, all nursing staff members of the participating nursing homes filled in several questionnaires at baseline, T1 and T2. The time between each measurement was 4 months with a time window for completion of 2 months. All nursing staff members were asked to complete a questionnaire about their job experience, which took approximately 10 minutes to complete. Nursing staff members who were the primarily responsible caregiver of a particular resident, were also asked to complete one or more resident questionnaires. The amount of questionnaires depended on the number of residents for which they were primarily

responsible for (range 0-11). The time to complete a questionnaire about one resident was approximately 30 minutes.

Implementing web-based data collection

The main goals of the web-based data collection were fast and easy data collection with response rates comparable to the paper-and-pencil method. We systematically implemented the web-based data collection[17] which consists of the following: at the start of the main trial, the researcher made a telephone call to the managers of the participating DSCUs to discuss the feasibility of the internet application in the respective nursing homes and the use of the computer at work during work time to complete the questionnaires. After the telephone call, the researcher visited the nursing homes. At least the managers, and in most cases also the nursing staff members, were informed about the study and the questionnaires. During this visits it appeared that not everyone was familiar with this kind of computer applications. Nursing homes were therefore requested to provide (technical) assistance for the care team when needed. The research team also made a helpdesk available with a research assistant accessible by email or telephone. To increase the response rates, reminder letters were sent to the non-responders after three and six weeks. At the same time, an email with a list of non-responders was sent to the managers so they could remind the nursing staff personally.

Internet application for the web-based data collection

For the purpose of data collection we developed a website to be used by the nursing staff of the nursing homes. The website consisted of a login page, and a secured page with the actual questionnaires that were made in LimeSurvey, an open source online survey application.[18] This application made it possible to make questions compulsory, automatically validate data (for example age of nurses have to be between 15-80) and to skip questions that are not applicable.

After logging in with a personal username and password, a page was loaded on which the participants could click one or more buttons, depending on the number of residents they were asked to complete questionnaires about. Upon completing a questionnaire, nursing staff members were automatically redirected to the start page of the website, triggering a database update which resulted in the deactivation of the button associated with the completed questionnaire. This immediate update made it clear for nursing staff which questionnaires still had to be completed.

To control both the website's content as well as changes in information about nursing staff and residents, we developed an Access database application. This application allowed for all mutations to be automatically communicated to the website through an open

database connection. For example, in case a resident was reported as deceased, the button for the respective questionnaire was automatically removed from the website. The data from completed questionnaires were imported into our data analysis program.

Usability survey

Based on literature, we developed a questionnaire to assess the usability of web-based data collection.[19-21] We measured the following aspects: (1) Experience with internet/web-based data collection, (2) Instruction/lay-out, (3) Possible problems, (4) Accessibility, (5) Privacy, (6) Helpdesk and (7) Preferences. Two types of scales were used: 5 point Likert type scales (1 – completely disagree, 5 – completely agree). Where this was not possible, e.g., asking about the frequency of internet usage, ordinal type scales were used.

RESULTS

Response rates DCM study using web-based data collection

The response rates for the staff and resident questionnaires at the different measurement points are shown in Table 1. The average response rate in this study was 73,9%.

Table 1. Response rates of the three points of measurement in the DCM study

Point of measurement	Staff questionnaires	Resident questionnaires
T0	319 / 376 (84.8%)	192 / 268 (71.6%)
T1	285 / 382 (74.6%)	183 / 266 (68.8%)
T2	280 / 372 (75.3%)	176 / 256 (68.8%)
Average response rate = 73.9%		

Usability

Usability was evaluated in 280 nursing staff members (75.3%), immediately upon completing T2 measurement. The results of the usability questionnaire are shown in Table 2. 78.1% of the nursing staff use a computer or internet almost every day and 77.1% of them did ever complete a web-based questionnaire before. There was a computer available at work for the purpose of filling in the questionnaires for this study for almost all nursing staff (90.7%). Most of the nursing staff (62.4%) was also able to fill in the questionnaires for this study during work time without interference with their care tasks. 94.3% of the nursing staff did not experience problems with the computer or internet when completing the questionnaires. Nursing staff judged it more safe to complete questionnaires web-based than with the paper-and-pencil method. Only 7.2% preferred completing questionnaires using paper-and-pencil.

Table 2. Usability of web-based data collection DCM study (n=280)

1. Experience internet/web-based data collection	
How often do you use a computer or internet?	78.1 % almost every day 14.0 % about once a week 7.9 % less than once a week
Apart from this study, did you ever complete a web-based questionnaire before?	77.1 % yes
	Mean and SD*
Filling in the questionnaires electronically is a pleasant experience.	3.68 (SD 0.97)
2. Instruction/lay-out	
The invitational letter containing instruction is understandable.	4.12 (SD 0.61)
I find it hard to understand how the website works.	1.93 (SD 0.88)
I think that the website looks orderly.	3.91 (SD 0.69)
3. Possible problems	
I experienced problems with the computer or internet when completing the questionnaires.	94.3 % no 5.0 % yes, little problems 0.7 % yes, big problems
4. Accessibility	
A computer was readily available at work for the purpose of filling in the questionnaires for this study.	90.7 % yes
I was able to fill in the questionnaires for this study during work time without interference with my care tasks.	62.4 % yes
5. Privacy	
	Mean and SD
I think it is a safe procedure to fill in the questionnaires for this project using the internet.	3.59 (SD 0.80)
I think it would be a safe procedure to fill in the questionnaires for this project using paper-and-pencil.	2.34 (SD 0.86)
6. Helpdesk	
I made use of the helpdesk.	2.2 % yes
	Mean and SD
If yes, the use of the helpdesk was satisfactory.	3.00 (SD 1.10)
If not, what were the reasons for not contacting the helpdesk? (several answers possible)	
I didn't have questions/problems	93.6 %
I didn't have the time	2.1 %
I didn't feel like it	0.0 %
The helpdesk was not clear to me	1.4 %
Other reasons	2.4 %
7. Preference	
Regarding the DCM study, I prefer completing questionnaires:	75.6 % web-based 7.2 % paper-and-pencil 17.2% no preference

*1=completely disagree; 2=disagree; 3=neutral; 4=agree; 5=completely agree

DISCUSSION

The average response rate achieved by means of web-based data collection 73.9% (SD = 6.0), showed that this method is feasible for the nursing homes. The response rates from comparable studies on non-pharmacological interventions in nursing homes using

paper-and-pencil method ranged from 55-95%, with a mean response rate of 75.5% (SD= 15.7).[3-10] While it is debatable to compare response rates from different studies because of their heterogeneity in study design and instruments, response rates in our study seem to be comparable with studies using paper-and-pencil technique.

The results of the usability survey show that most nursing staff members are familiar with the computer or internet. They are positive about the web-based method of data collection and a large majority prefers web-based over the paper-and-pencil method. The high response rates might have been enhanced by the systematic implementation method we used: personal contact with at least the nursing home managers and as far as possible also with the responders and firm agreements on availability of computers and allocation of time to the staff to fill in the questionnaires.

The advantages of web-based data collection are (1) the potential to collect a large amount of data in a relatively short amount of time, (2) the elimination of the necessity for researchers to enter or process the data manually, which has a high error risk, (3) decrease in costs (paper, postage, mail out, data collection and data entry), (4) the possibility to automatically validate data, (5) the possibility to make questions compulsory so that missing values are reduced, (6) questions that are not applicable are automatically skipped, (7) response (rate) data are available directly upon the completion of questionnaires, and (8) data from web-based surveys can be easily imported into statistical analysis programmes.

When considering to use this method of data collection, we advice to take the specific constraints of the setting into account, such as familiarity of staff with the computer and the allocation of time to the staff to fill in the questionnaires. In nursing homes where the computer is located outside the resident's common living area, the use of a portable computer system, such as a tablet, could be a solution.

CONCLUSION

This study shows that web-based data collection is feasible in nursing homes. Response rates are comparable with studies using paper-and-pencil technique. Nursing staff members in this study were very positive about the web-based method and the majority preferred web-based over the paper-and-pencil method. When implementing web-based data collection, researchers need to ensure that the necessary infrastructure is provided. Given a carefully designed implementation procedure, web-based data collection can be an efficient way to collect research data in settings like nursing homes.

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Chapter 6

Dementia Care Mapping in nursing homes: a process analysis

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ABSTRACT

Objectives: To perform a quantitative and qualitative process analysis of the DCM intervention trial.

Design/measurements: We used a survey method and analyses of the intervention documentation in a quantitative analysis to determine the degree of adherence to the intervention protocol. We used focus group discussions in the qualitative part to determine barriers to and facilitators for implementation.

Setting/participants: Thirteen units and 10 DCM mappers participated in the quantitative part of the process analysis. Three focus group meetings were held: one with the three team managers, one with the four nursing staff members, and one with the four mappers.

Results: The process analysis showed a substantial variation across the units in adherence to the intervention protocol. Despite the DCM mappers passing the DCM basic and advanced training tests and the inter-rater agreement test, the mean number of implemented intervention components was relatively low (mean: 53.9%, range: 0–74.2%). The qualitative analysis resulted in the following hypothesis: Important conditions for successful implementation are: 1) experience of nursing homes with person-centered care practice, 2) firm commitment of the team manager to DCM, and 3) additional training and support for the mappers, especially in the matter of providing feedback to the staff.

Conclusions: Adherence to the intervention protocol varied considerably across the units, and there were some serious barriers to the implementation of the DCM intervention. The findings of the process analysis can be useful in improving both the intervention and the protocol adherence and in developing effective implementation strategies.

INTRODUCTION

While a randomized controlled trial (RCT) design is the golden standard for determining the effectiveness of an intervention,[1] the use of an RCT design in complex psychosocial interventions can be troublesome because such interventions are often unblinded and multi-component by nature. As a result, different results can appear in different trials, settings, or countries with one and the same intervention. Additional information about the process of the implementation (e.g., sampling quality and intervention quality) is crucial to understanding why an intervention is effective in one setting and not in another.[2] Evaluations of both the sampling quality and the intervention quality are essential.[3,4] In other words, the effectiveness of an intervention is not only determined by its internal quality, but also by the way it is implemented and by the participants' experiences, beliefs, attitudes, and behavior.[5]

Dementia Care Mapping (DCM) is a complex, multi-component, psychosocial intervention that aims to reduce neuropsychiatric symptoms (NPSs) in people with dementia in nursing homes.[6] It consists of cycles of systematic observation, feedback to the staff, and action plans (Figure 1). The nursing staff develop the action plans, which are based on the observation of the actual needs of the residents. This kind of close observation stimulates timely initiation of tailor made interventions at the individual level (residents and caregivers) and the group level (dementia special care units, nursing teams, and multidisciplinary teams), as well as at the levels of management and organizations. Dementia Care Mapping is based on the principles of person-centered care and posits that much of the ill-being that people with dementia experience is due to negative environmental influences, including staff attitudes and care practices.[6-8] Currently, DCM is being used in more than 26 countries, and its popularity is still growing. Chenoweth and colleagues conducted a cluster RCT (cRCT) design in 2009 and found that there was less agitation in DCM units than in units using task-focused care.[9] In 2010, we started a trial of the effectiveness and costs of DCM in dementia special care (DSC) units in nursing homes.[10] Unlike Chenoweth and colleagues, we did not find an effect of DCM on agitation.[11]

While the two trials are both cRCTs studying the same intervention, the results are different. If we take a closer look at these trials, we see some differences in study design and implementation. In the Chenoweth et al. trial[9], the same two researchers carried out the intervention across all units, and the setting was well-resourced and tightly controlled. The nursing homes in the intervention group and the control group differed with respect to their approaches to care (person-centered vs. task-focused). Being tightly controlled, this trial is explanatory in character.[12-14] The nursing homes in our trial were not stringently selected for the type of care they provide, which makes them highly

representative. The nursing staff, rather than the researchers, were trained to carry out the DCM intervention, which introduced the possibility of inter-individual variability in skills. Our cRCT is therefore more pragmatic; it maintains the internal validity of an RCT while it is designed and implemented to mimic real-life implementation.

The contribution of this paper lies in exploring factors affecting the implementation of the DCM intervention in daily practice. We studied the extent to which the intervention was implemented according to the protocol and identified barriers to and facilitators for adherence to the intervention protocol.

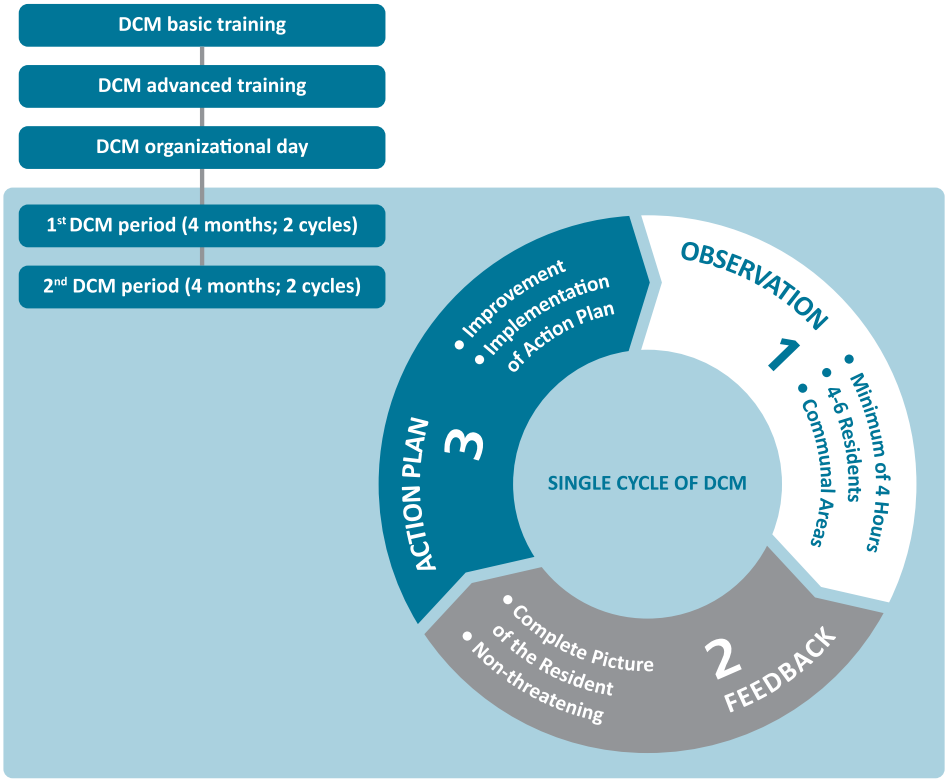

Figure 1. Dementia Care Mapping intervention components and components of a DCM cycle

METHODS

Design

The design of the DCM trial has been published elsewhere.[10] The studies of the effects of DCM on resident and staff outcomes and on costs have also been published elsewhere.[11,15] Briefly, DSC units from the recruited nursing homes were randomly assigned to DCM or the usual care condition. The team managers at the intervention nursing homes

selected staff members who were motivated to become certified DCM mappers and who met the competency requirements set by DCM Netherlands. The selected staff members attended basic user and advanced user training courses provided by DCM Netherlands. They used a standardized assessment kit developed by Bradford University in their examination. Supplementary to these exams, we used inter-rater agreement to test the observation skills of the mappers; the requirement was to achieve a minimum of 80% agreement with the DCM trainer (experienced DCM observer). An advanced user certification means that a mapper is capable of conducting and reporting structured observations of residents and resident–caregiver interactions, providing feedback to the staff, and instructing and supporting them in drawing up action plans to fit the care to the residents' needs.

Implementation of the actual DCM intervention started with the organizational briefing day and continued with two DCM cycles, each consisting of observation, feedback, and action plans. Figure 1 depicts the components of the intervention. The control group residents continued with their usual care during the trial.

Setting and participants

Five nursing homes consisting of 13 DSC units participated in the intervention group. These 13 units consisted of 178 nursing staff members and 170 residents. An unit was defined as a residential unit with common staff and shared areas. This was either a group in a small-scale housing facility or a DSC unit in a nursing home. The number of residents in these units ranged from 5 to 25. A total of 10 staff members, 2 from each nursing home, became certified DCM mappers. The participants in this process analysis consisted of the mappers, the team managers, and the nursing staff recruited from these 13 units.

Ethical approval

We obtained written informed consent from the family of each resident. For cases in which a resident signed an informed consent form, the family or a legal representative also signed for consent. The Committee on Research Involving Human Subjects in the Arnhem-Nijmegen Region approved the study participation.

Data collection and analysis

We designed our process analysis using Baranowsky and Stables' theoretical framework.[16,17] In this model, the process analysis components are: 'fidelity' (the quality and integrity of the intervention), 'dose delivered' (the extent to which participants are actively engaged in the intervention), 'dose received' (the number of participants), and

'context' (the factors that potentially affect either the implementation or the outcomes of the intervention). The components of the DCM intervention were compared and fitted into the components of the Baranowsky and Stables' model. Based on this, we defined and operationalized 14 quantitative variables and 1 qualitative variable for the process analysis (Table 1).

Quantitative process analysis

We collected data for the quantitative part of the process analysis using a short self-developed questionnaire for the mappers to measure the following variables: the attendance rate at the feedback sessions, the time that elapsed between the end of the feedback sessions and the drawing of action plans, the frequency with which the team manager used the DCM concepts in daily practice, and the frequency of contact of the mapper with the mapped unit. Table 1 shows the scales used for these variables. From the DCM observational reports we extracted the data about the number of observational reports, hours of observation, and the proportion of the residents observed. We divided the number observed by the number of residents per unit to calculate the proportion of the residents who were observed. Although the intervention protocol did not require the observation of a minimum proportion of the residents (only a minimum of 8 hours of observation per resident, per cycle), we used this variable in the process analysis because it indicates the 'reach' of the intervention. Because the action plans are a crucial element in the intervention, we evaluated the quality of the action plans using the following SMART criteria: 'specific' (is the action plan concrete?), 'measurable' (is the described behavior observable?), 'acceptable' (is the action plan reasonable for the population?), 'realistic' (is the action plan attainable?), and 'time bound' (is it clear when or how often the action should be executed?). We added the criterion 'person-centered' i.e., formulated with appreciation of and respect for the people with dementia and their specific needs. The action plans were anonymized, and two members of the research team rated each action plan independently (0 = action plan does not meet the criteria, 0.5 = action plan partially meets the criteria, 1 = action plan meets the criteria). Since we used six SMART criteria, the score for an action plan could range from 0 to 6. The percentage of the maximum score was calculated for each unit. Eventual differences in the rating were resolved by consensus. All quantitative variables were measured per DCM cycle, at unit level. Means and ranges were calculated for all variables.

Qualitative process analysis

Data for the qualitative process analysis were collected via three focus group meetings: one with the team managers, one with the nursing staff, and one with the mappers

from the participating intervention units. All of the 12 team managers and all of the 10 mappers were invited to participate in the focus groups. Additionally, three nursing staff members, selected at random from each of the five nursing homes, were invited to participate. We used the same topic guide for all focus groups (Box 1). The focus groups lasted 2 hours each. An independent, experienced moderator led the focus group discussions. All data were recorded and transcribed. The respondents were contacted for a member check; they read the transcripts and confirmed that they were accurate. The focus group data were analyzed on the basis of a grounded theory approach: a constant comparative analysis to identify common themes and issues.[18] The first step in data analysis was coding the raw transcripts. Coding is an analytic interpretive process in which conceptual labels are given to the data. The purpose is to attain new insights by breaking through standard ways of thinking about phenomena reflected in the data. The codes pertained as closely as possible to the transcribed fragments. Each transcript was coded by one member of the research team (ID, FB, or GV). Subsequently, the codes were mutually compared and discussed until consensus was reached (ID, FB, and GV).

1. **What do you think about DCM?**
2. **What were your expectations of DCM?**
3. **What changes did you notice after starting DCM? (for yourself, your colleagues and the residents?)**
4. **What went right?**
5. **What could be improved?**
6. **If you were the manager of the organization, what actions would you take to establish succesful implementation of DCM?**

Box 1. Topic guide for the focus groups

Using the same method, we grouped codes referring to the same phenomenon in categories, and categories in themes.[19] The themes were the basis for the creation of a hypothesis. In the second stage of our analysis, we slightly modified the grounded theory approach by using a general implementation framework to classify the factors found into four categories, namely: individual, social, organizational, and societal.[20] The use of this kind of framework helps identify the level(s) at which the problems arise and can therefore serve to guide the improvements as well as further research.

RESULTS

Quantitative process analysis

Fidelity

All mappers passed the DCM basic and advanced training tests and achieved a satisfactory inter-rater agreement of at least 80%.

We assessed 190 action plans according to the SMART criteria. The score agreement of the two members of the research team was 927 out of 1140 (81.3%). The greatest agreement was for the criterion 'acceptable' (90.0%), and the lowest, for the criterion 'measurable' (71.1%). Almost all action plans fully met the criterion 'person-centered' (95.8%). The percentage of the maximum score was calculated for each unit; the mean score was 53.9% (range 0–74.2%).

Dose delivered

Observation. The hours spent observing varied considerably across the units (range: 0 to 35.8 hours). The number of completed DCM reports and action plans also varied greatly (Table 1).

Feedback. The staff attendance at the feedback sessions varied between no attendance (0) and everybody or almost everybody present (4). We found the dichotomy in this variable across the units noteworthy. They consistently fell into two categories over time: high attendance (score >2) and low attendance (score ≤ 2) at all feedback sessions.

Action plans. The mean number of action plans per unit was 20.2. Some units drew the action plans within 4 weeks after the feedback sessions, while other units had already completed the task during the feedback sessions.

The most frequent response (47.6%) for the variable 'team manager mentioned DCM' was 2 ('sometimes'), and the most frequent response (38.1%) for the variable 'mapper contact with staff or residents' was also 2 ('sometimes').

Dose received

The staff attendance at the organizational day varied between 6.7% and 96.8%. The mean for the representation of different levels of disciplines at the organizational day was 12.7. Most (>80%) of the attendees were nurses with different levels of qualifications. In most units, the psychologist, manager, dietician, dietary assistant, elderly care physician, team manager, occupational therapist, coordinator volunteer, and physiotherapist were also represented.

Table 1. Variables in the process analyses

Theoretical element	Variable	Source	Mean score per unit and range	Intervention protocol
Fidelity	Passing rate for DCM basic training	DCM Netherlands	100%	100%
	Passing rate for DCM advanced training	DCM Netherlands	100%	100%
	Passing rate of inter-rater agreement (minimum score = 80%)	DCM Netherlands	100%	100%
	Quality of action plans	Action plans	Mean 53.9% Range 0–74.2%	N.A.
Dose delivered	Hours of observation	DCM reports	Mean 17.1 Range 0–35.8	8
	Number of reports	DCM reports	Mean 3 Range 0–6	2
	Staff attendance at feedback session (0 = no attendance; 1 = very few/almost nobody; 2 = less than half of the team; 3 = half of the team or more; 4 = everybody or almost everybody)	Questionnaire mappers	0 = 23.8% 1 = 7.1% 2 = 45.2% 3 = 2.3% 4 = 21.4%	4
	Total number of action plans	Action plans	Mean 20.2 Range 0–78	N.A.
	Time in which action plans were formulated (0 = no action plans were formulated; 1 = after 4 weeks or later; 2 = within 4 weeks; 3 = within 2 weeks; 4 = action plans were formulated during the feedback session)	Questionnaire mappers	0 = 35.7% 1 = 4.8% 2 = 40.5% 3 = 9.5% 4 = 9.5%	4
	Team manager mentioned DCM (0 = never; 1 = seldom; 2 = sometimes; 3 = often; 4 = very often)	Questionnaire mappers	0 = 23.8% 1 = 19.0% 2 = 47.6% 3 = 9.5% 4 = 0.0%	4
	Contact mapper and mapped unit (0 = never; 1 = seldom; 2 = sometimes; 3 = often; 4 = very often)	Questionnaire mappers	0 = 23.8% 1 = 19.0% 2 = 38.1% 3 = 19.0% 4 = 0.0%	4
Dose received	Staff attendance at organizational day	Documented by researcher	Mean 64.8% Range 6.7–96.8%	100%
	Number of different levels of disciplines represented at organizational day	Documented by researcher	Mean 12.7 Range 6–22	N.A.
Reach	Proportion of residents observed	DCM reports	Mean 48.1% Range 0–92.9%	N.A.

DCM = Dementia Care Mapping; N.A. = not applicable

Reach

No unit observed all their residents. In 7 of the 13 units, the proportion of residents observed was less than 50%.

Outliers

Two of the units had extremely low adherence to the intervention protocol, namely 0%. Considering that the standard procedure of DCM Netherlands considers the possibility of low adherence (because DCM Netherlands does not standardly support the implementation of DCM), we decided to include these units in our analysis for representativeness and insight into realistic difficulties in implementation. Comparisons of means and medians showed that the mean values did not differ substantially from the central values (median).

Qualitative process analysis: context

Three focus group meetings were held to identify barriers to and facilitators for the DCM implementation: one with the three team managers, one with the four nursing staff members and one with the four mappers at the intervention nursing homes. All participants in the focus groups were female. All focus groups represented staff from three nursing homes (60% of the intervention nursing homes).

Everyone appreciated the organizational briefing day very much. The enthusiasm of the mapper and the team manager, the adequate information about DCM, and the earlier positive experiences with person-centered care all facilitated the DCM implementation. Two barriers to implementation were a top-down decision process regarding participation in the DCM trial and doubt about the motives of the organization (window-dressing; interest in participating in research in general instead of interest specifically in DCM). The organizational setup at the start of the study was named as a barrier (if staff in the nursing homes were frustrated about the staff policy), as well as a facilitator (if a person-centered vision of care delivery had already been adopted). Participants from all disciplines emphasized the importance of the 'right' personality and skills of the mapper, such as being empathic and having good communication skills. The perceived positive properties of the DCM intervention were objectivity, visible results, promotion of self-awareness, and the cyclic approach.

Some themes were common to all focus groups, while others were brought to light by only one of the three. For instance, only the nursing staff highlighted the importance of knowing about the content and process of DCM before the implementation. The mappers were all very positive about the DCM training, both regarding the content and the skills of the trainer. However, they noted that it was difficult to maintain this enthusiasm

when they faced barriers at work, such as high work pressure. All participants agreed that the motivation and support of the team manager are essential for the successful implementation of DCM. As Table 2 shows, the team managers noted some negative properties of DCM (intensity, complexity, lack of immediate visible results, and the impossibility of observing residents outside the living room), and so did the mappers (practical fuss, large investment in time or money for the mapper and the organization, lack of immediately visible results, and the impossibility of observing residents outside the living room).

Integrating the findings of the focus groups, we hypothesize that the following conditions are important for successful implementation: 1) experience of nursing homes with person-centered care practice, 2) a team manager with a firm commitment to DCM, and 3) additional training and support for the mappers, especially in the matter of providing feedback to the staff.

Table 2. Factors influencing the implementation of Dementia Care Mapping, positive (+) or negative (-)

Theme	Individual	Social	Organizational	Societal
DCM training	Enthused by the content of the training (+)	Enthused by the trainer (+)		
Characteristics of the mapper	DCM connects with the vision of the mapper (+) Mapper needs more support (-) Mapper needs to have the right skills and competencies (+ /-) Doubt about the objectivity of DCM (-) Mapper disappointed by the implementation process (-)	Insecurity of the mapper: contrast between training and daily practice is great (-) Mapper needs to have the right skills and competencies (+ /-)	Insecurity of the mapper: contrast between training and daily practice is great (-) Mapper needs more support (-) Mapper needs to have the right skills and competencies (+/-) There must be enough mappers (-)	
Introduction of DCM into the organization	Acquaintance of the mapper with DCM is suboptimal (-) Interest in the DCM method (+) Positive experiences with person-centered care (+)		Acquaintance of the mapper with DCM is suboptimal (-) Decision to start DCM was made top down (-) Inclusion of staff members in implementation of DCM is suboptimal (-)	
Organizational setup at the start			DCM connects with current procedures (+/-) Turbulence in organization (-) DCM connects with vision of the organization (+)	

Theme	Individual	Social	Organizational	Societal
Positive properties of DCM	Confidence in the DCM method (+) Positive experiences with DCM (+) Objectivity of DCM (+) or lack of it (-) Visible results through DCM (+) or lack of them (-) DCM increases job intensity (+) DCM increases self-awareness (+) DCM provides concrete handles for problem behavior (+) DCM is cyclic: the method returns (+)	Confidence in the DCM method (+) Visible results through DCM (+) or lack of them (-) DCM increases self-awareness (+) DCM provides concrete handles for problem behavior (+) DCM is cyclic: the method returns (+)	Confidence in the DCM method (+)	DCM increases self-awareness (+)
Negative properties of DCM	Logistical and practical fuss to implement DCM (-) Lack of visible results with DCM (-) Implementation of DCM requires an investment (-)	Logistical and practical fuss to implement DCM (-)	Logistical and practical fuss to implement DCM (-) The difficulty of observing residents in the hallway Complexity of the DCM method (-) Implementation of DCM requires an investment (-)	Implementation of DCM requires an investment (-)
Feedback meetings	An active role of staff members in formulating action plans (+) or the lack of it (-)	Feedback meetings were tough for mapper (-)	Low staff attendance at feedback sessions (-) Feedback meetings were tough for mapper (-)	
Daily practice	Attitude of staff members toward DCM (+/-)	Attitude of staff members toward DCM (+/-) Attitude of team leader regarding DCM (+/-)	High work pressure (-) Lapsing into old habits (-) Attitude of staff members toward DCM (+/-) Attitude of team leader toward DCM (+/-) A broad basis for DCM (+/-) Mapper needs more support (-)	
Resident's family	Skepticism of family (-) Family is positive about DCM (+)			
Turnover		Staff turnover (-)	Staff turnover (-) Resident turnover (-)	Resident turnover (-)

DISCUSSION

The results of the process analysis show a substantial variation across the units in adherence to the protocol. Despite the mappers fulfilling all the DCM basic and advanced level requirements, some of the units implemented as little as three of the ten intervention components that the intervention protocol requires. While the nursing home team managers used the DCM Netherlands list of competencies to select the mappers, personal communication revealed that the team managers sometimes based their selection on other criteria, such as: a particular staff member deserved the training or needed additional professional development. This may have introduced variability in the entry level competences among the trainees.

The results of the process analysis provide insight into barriers to and facilitators for optimal adherence to the DCM intervention protocol. Better adherence may improve the effectiveness of the intervention.[21] Comparison with a similar trial that Chenoweth et al. conducted in Australia[9,11] reveals that the nursing homes in our study were randomly selected so that they would be broadly representative, while the nursing homes in the Australian study were specifically selected for their approaches to care to maximize the differences between the intervention and the control groups. This may have reduced the room for improvement in our trial by introducing a ceiling effect. Furthermore, the nursing staff, rather than researchers, were trained to carry out the DCM intervention in our trial. Presumably, this introduced variability in the way the intervention was carried out. For example, as the qualitative analysis shows, some of the mappers felt insecure about providing feedback, which may have served as a barrier to full implementation of DCM in the organization. The implementation of DCM was also very dependent on the commitment of the different team leaders. Rokstad and colleagues found that, to successfully implement DCM, the leaders should be active role models, expound a clear vision, and include and empower all staff in the professional development process.[22]

Typically, most of our facilitators and barriers were categorized as individual and social; very few were societal. This is understandable, as DCM is an intervention aiming at improvements at the work floor level. However, successful interventions also encounter barriers and a few facilitators at the organizational and societal levels. In the case of the DCM intervention, the currently lacking societal link could be assigned a role in support (incentives) and promotion of person-centered dementia care.

A limitation of the quantitative part of our process analysis is that we could only obtain data from the units in the intervention group, due to the RCT methodology. Except for the calculated maximum scores based on our intervention protocol, there are no data from other studies and no golden standards to compare the scores with. Another limitation is a possible selection bias for the focus group participants. It is possible that

only the people who were actively involved in DCM, or the people with a strong opinion about DCM, participated in the focus groups. Further, there were not many participants in each focus group, which could have had a negative influence on the nature and range of interactions between the participants.

The assessment of the action plans lacks an essential component: the actual level of their implementation. It is very difficult to acquire reliable information about the implementation of action plans such as "more eye contact with client A" because of the low reliability of the socially desirable answers. While DCM measures would be suitable and reliable for evaluating the quality of interactions, DCM is our intervention under study, so it is not appropriate as an outcome measure. Chenoweth et al.[21] used the quality of interactions schedule (QUIS),[23] which measures the quality of interactions between care staff and residents, and quality of care. Although this would be a good alternative for measuring the quality of interactions, we did not use the QUIS because it is time consuming and requires extra observers. Since we found no effect of DCM on NPSs, while our qualitative analysis suggests that improvements in interactions did take place, we recommend using QUIS, or a comparable observation tool, in future research.

The major strength of this study is that we quantified the degree of implementation by operationalizing variables for as many components of the process analysis as possible. Another strength is that we conducted focus groups with representatives from the three major stakeholder groups (team managers, nursing staff members and mappers). The fact that we found stakeholder-specific themes as well as common themes underlines the need for tailor made implementation strategies, not only for each nursing home, but also for the different disciplines involved in implementing DCM.

CONCLUSIONS

The variability in adherence to the intervention protocol shows that there is room for improvement. Better adherence may improve the effectiveness of the intervention.[21] We recommend that nursing homes aspiring to implement DCM make clear agreements from the start in terms of the underlying organizational vision and the team manager's commitment. An assessment of the necessary organizational adjustments could be helpful. To ensure that mappers meet the requirements, we recommend that DCM Netherlands be involved in selecting the mappers and in supervising them throughout the critical phases of the implementation (such as the feedback sessions) until they feel confident in their performance. A staff member, preferably a team manager, should coordinate the DCM implementation. Since many nursing homes had difficulties with the attendance rates at feedback sessions, a specific implementation strategy may be

necessary to optimize the effectiveness of this essential intervention component. We also recommend that the DCM training module for feedback be enriched and extended to accommodate the individual differences between the mappers. The role of the team manager in the feedback sessions is to facilitate matters for the mapper and to ensure that enough staff members attend. In conclusion, strong organizational commitment, additional mapper training and support, and, if necessary, organizational adaptations to achieve readiness to internalize the valuable principles of the DCM intervention may all facilitate implementation.

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Chapter 7

General discussion

INTRODUCTION

In our ageing society, dementia is a growing concern. Dementia influences the quality of life of those affected by the disease, and increases utilization of care resources.[1] To illustrate the extent of the problem, the prevalence of dementia in the population of Dutch nursing home residents (65.000 people) is 53%.[2,3] A specific and highly pervasive problem in this group of residents is the presence of neuropsychiatric symptoms. In addition to directly affecting the residents' quality of life[4], these symptoms represent a serious challenge for the professional caregivers. Neuropsychiatric symptoms are often 'treated' with psychotropic medication[5] and physical restraints.[6] However, these treatment approaches are mostly inadequate, harmful, and have limited effectiveness.[7]

In recent decades, person-centered dementia care has been developed as a method to improve the quality of care, e.g. in nursing homes where task-focused care still prevails. Person-centered care is respectful of and responsive to individual patient preferences, needs, and values, and ensures that patient values guide clinical decisions.[8] Although evidence suggests that different types of person-centered care improve both resident and staff outcomes,[9-12] what is missing is a method to systematically implement it in all aspects of nursing home dementia care.

Dementia Care Mapping (DCM) intervention offers a set of methods to this aim. It is a person-centered intervention, rooted in psychosocial theory of personhood in dementia. DCM aims at reducing both neuropsychiatric symptoms in people with dementia and staff problems in nursing homes. The intervention consists of cycles of systematic observations, feedback to the staff, and action plans. Important distinctions with other methods are that in DCM, staff create better care through self-developed improvements rather than implementing action plans developed by others, it allows for timely initiation of tailor made interventions, and it allows for adaptations to patients needs on many different levels in the organization. The main objective of this thesis is to study (cost) effectiveness of DCM in nursing home dementia care.

In this chapter we summarize and discuss the main findings from the cluster-randomized controlled trial on (cost)effectiveness of the DCM intervention in Dutch nursing homes. We also discuss methodological considerations in this kind of research and reflect on implications of our findings for (clinical) practice and future research.

SUMMARY OF FINDINGS

Research questions (per chapter):

1. Is the DCM intervention effective in alleviating resident and staff problems in nursing home dementia care? (Chapter 3)
2. Is the DCM intervention cost-effective? (Chapter 4)
3. To what extent is the DCM intervention implemented according to the protocol and what barriers and facilitators are there for the implementation and for the compliance to the intervention protocol? **(**Chapter 6)

Contrary to our expectations, we found no statistically significant effect of the DCM intervention on agitation, our primary outcome measure at resident level (CMAI) (chapter 3). Significantly more neuropsychiatric symptoms were reported in the intervention group than in the control group. No effect was found on quality of life. At staff level, no effects were found on stress reactions, job satisfaction or absenteeism. Staff in the intervention group reported significantly fewer negative and more positive emotional reactions during work. There were no other statistically significant effects.

We calculated the total costs by summing up healthcare consumption and drug use of the residents, staff absenteeism, and the costs of the DCM intervention (chapter 4). We found no difference in total costs between the intervention and the control group. Overall, DCM is a cost-neutral intervention. The effects on costs did not change when the DCM intervention costs were eliminated from the model, which means that these costs are negligible compared to the costs associated with daily care. The mean DCM intervention costs per resident per day were US $0.63 (SD $0.23). More specific comparisons of costs showed that in the intervention group, the costs associated with outpatient hospital appointments were significantly lower than in the control group.

The lack of effect of DCM on our primary outcome measure was puzzling, and asked for further investigation into the possible interfering factors. We performed a quantitative and qualitative process analysis, which is described in detail in chapter 6. The aim of the process analysis was to find out to what extent the intervention protocol was adhered to (quantitative analysis), and to find out which facilitators and barriers are there for successful implementation of DCM in daily practice (qualitative analysis).
The quantitative part of the process analysis showed a substantial variation in adherence to the intervention protocol across the units. Despite the mappers fulfilling all the DCM basic and advanced level requirement, there was al considerable variation between the units in their adherence to the protocol. This suggests that the training alone is

not enough to guarantee equal adherence across the units. For example, the mean staff attendance at the organizational day was 64.8% (range 6.7 - 96.8%), while the intervention protocol prescribed that all staff members should be present.
The qualitative part of the process analyses showed that experience with person-centered care, commitment of the team manager and the right competencies and enthusiasm of the mapper, were important facilitators for the implementation of DCM. The main barriers were a top-down decision to participate, doubt of the staff members about the motives of the management and insufficient commitment of the team manager. Most of our facilitators and barriers were categorized as individual and social; very few were societal (such as compensations of health insurance companies).[13] In sum, we hypothesize that the following conditions are important for successful implementation: 1) experience of nursing homes with person-centered care, 2) a team manager with a firm commitment to DCM, and 3) additional training (also 'on-the-job') and support for the mappers, especially in providing feedback to the staff.

INTERPRETATION OF THE FINDINGS

Is optimal implementation feasible in daily practice?

DCM showed effectiveness in a trial conducted in tightly controlled conditions, while no effects are found in our pragmatic study. Results of the process analysis suggest that the lack of effect in our study is due to suboptimal adherence to the protocol. The first question that arises is: Is optimal implementation feasible in daily practice?

DCM is a complex, multicomponent intervention. It is multi-phased and, in each of the phases, different staff members are involved. As shown in figure 1, implementation of one cycle of DCM consists of: 1) DCM basic mapper training; 2) DCM advanced mapper training; 3) DCM organizational day; 4) DCM cycle: Observation, Feedback, Action plans. Obviously, tight adherence to the complex protocol of this intervention requires planning and coordination. For example, the team manager has to schedule the feedback session within two weeks after the observations. In these two weeks, the mapper needs to schedule time for writing a DCM report. This requires agenda priorities in busy daily practice. Furthermore, in each phase of the intervention, competencies, motivation, and actions of the involved staff members need to be optimal. For instance, the mapper has to be motivated for the DCM training and has to be well trained in the DCM observation method, which implies good recognition of behavioral categories and sufficient attention span to simultaneously observe several residents. The nursing staff need to actively translate the feedback based on systematic observation into person-

centered action plans, and deliver the care according to these action plans. The team manager must coordinate the different phases of the DCM intervention and take care of maximal attendance of the staff members at the organizational day and feedback sessions.

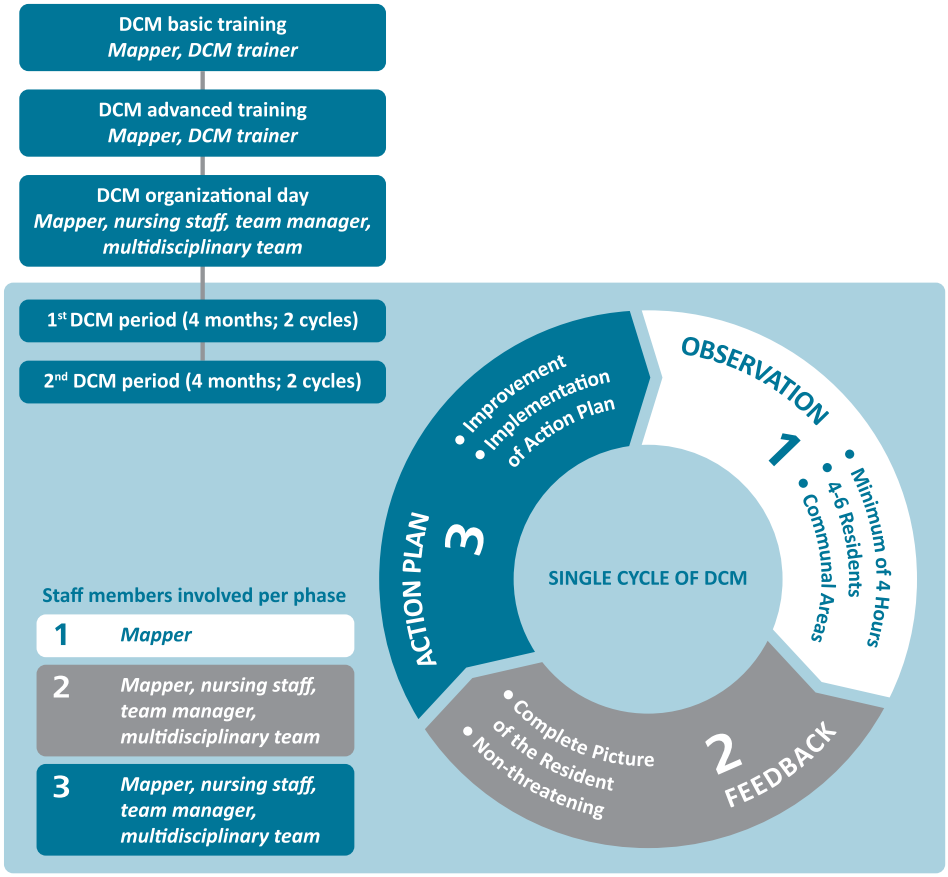

Figure 1. Staff members involved in the different phases of the DCM intervention

Each of our 13 participating units met a part of the requirements (such as maximal attendance of the staff at the feedback sessions or drawing up a sufficient amount of person-centered action plans), but none of them adhered completely to the protocol. Therefore, without using additional implementation strategies directed at the barriers we found (see critical factors for implementation), attaining of optimal effects in daily practice is very unlikely.

The strength of the DCM intervention - that it allows for changes at all levels in the nursing home organization - is at the same time also its weakness. Because of its multicomponent setup and the involvement of different kinds of nursing home staff, there are many potential weak links in the process. According to the findings of the qualitative process analysis, in addition to organizational factors, especially the mapper and the team manager are crucial for successful implementation of DCM.

Critical factors for implementation

Competencies of the mapper

The results of the qualitative study revealed that the mappers felt a strong need for additional DCM training and support on-the-job. All participants in the focus groups emphasized the importance of the 'right' personality and skills of the mapper for successful implementation of DCM, e.g. being empathic, having good communication skills, the ability to transcend the individual cases, and the ability to deal with group processes and resistance to feedback. Although we have clearly specified the profile for the candidate DCM mapper trainees, a substantial variation between the mappers was observed. For example, some freshly trained mappers were anxious about providing feedback to the team. This may have affected the quality of the feedback sessions, thereby significantly reducing the fidelity of the intervention.

Commitment of the team manager

The qualitative part of the process analyses showed that commitment of the team manager was crucial for successful implementation of DCM. The focus group data also showed that the team managers thought the DCM intervention was intense, complex, slow in showing results and they found it difficult to ensure continuity of observation due to the residents regularly leaving the living areas. These basically negative conceptualizations may have served as barriers in the implementation of DCM. Furthermore, we noticed a dichotomy in the way the nursing homes were included in our study. Some team managers, driven by enthusiasm about DCM, initiated participation in our study by themselves. Other team managers were instructed to take part in the DCM study by the director of their organization or by the Science Committee. Besides lacking internal motivation, some of the latter team managers doubted the motives of the organization which is not an optimal mindset for success. Research confirms the importance of the team manager for successful implementation of a new intervention.[14,15] The study of Rokstad and colleagues provides useful information about the influence of leadership in the implementation of DCM in nursing homes. According to Rokstad, leaders have a central role in drawing up clear and consistent professional visions, being continuously

supportive to the care staff and taking an active part in the care practice as role models. Leaders should be active role models, expound a clear vision and include all staff in the process of professional development and empowerment.[16]

Organizational factors

The focus groups revealed organizational factors that may have influenced the implementation of DCM, such as experienced work pressure, turbulence in the organization, staff- and resident turnover, and (lack of) a person-centered vision. For example, one participating organization was in the middle of an reorganization and did not have the required firm basis to start with a new complex intervention, such as DCM. Another example of an organizational barrier concerns a unit in which the nursing staff and team managers were convinced they already worked exclusively person-centered. In this organization it was very hard for the mapper to provide honest feedback about the occurrence of negative interactions with the residents (personal detractors), because the staff members were not open to receive feedback. While it is likely that organizational factors influenced the implementation of DCM, there is limited information available about practical approaches to working with barriers like mentioned above. Implementation strategies, such as improving staff motivation, and the corresponding skills to execute these strategies, represent a critical research and practice area.[17]

METHODOLOGICAL CONSIDERATIONS

DCM not effective or an implementation error?

Because of the variation in adherence to the intervention protocol in our study, the presence of an implementation error is very likely. Grol et al. described the phenomenon of an implementation error, which refers to low treatment fidelity, meaning the application of the intervention differs considerably from the original plan.[18] The variation in adherence across nursing homes may have masked possible effects of the intervention. The distinction between an implementation error and genuine ineffectiveness is crucial for the right interpretation of our results. Taking a closer look at our data, it became clear that none of the units implemented DCM completely according to the protocol. In other words: it is very plausible to assume that implementation of DCM was suboptimal in all participating units.

However, it is beyond the scope of our study, and our data and design are not suitable to address the crucial distinction between an implementation error and genuine ineffectiveness. Even if optimal implementation of DCM in daily practice is feasible, the

question that remained unanswered is: Is DCM effective in Dutch nursing homes when implemented completely according to the protocol?

Explanatory versus pragmatic

Our lack of (evidence for the) effect of DCM on agitation seems to contradict the findings of Chenoweth et al.[19] However, there are important differences between the Australian trial and our trial, which can explain the differences in findings. Importantly, the trial of Chenoweth demonstrates the effectiveness of DCM in near-ideal conditions. In Chenoweth's study, the setting was well-resourced and tightly controlled. Two research-allied DCM experts carried out the DCM intervention in all participating units, thereby positively affecting the fidelity of the intervention and intervention adherence. The nursing homes were specifically selected for their task-focused approaches to care to maximize the differences between the intervention and the control group. Also, the residents in Chenoweth's study were stringently selected: The residents were eligible when they were highly dependent (Residents Classification Scale (RCS) 1-3), had low cognitive functioning (levels C or D on question 8 of the RCS), and if they had need-driven dementia-compromised behaviors (questions 9-16 of the RCS). These characteristics renders Chenoweth and colleagues' study explanatory in character.[20-22]

Our present study is of a pragmatic nature. Pragmatic studies are intended to maintain the internal validity of RCTs, while being designed and implemented in ways that better address the demand for evidence about real-world factors. Their purpose is mainly to inform daily practice. Unlike in the trial of Chenoweth et al., we trained nursing home staff to perform the DCM intervention without extra support from the research team or DCM Netherlands. This may have produced variation in adherence across nursing homes and masked the possible effects of the intervention. The nursing homes in our study were not stringently selected so that they would be broadly representative of daily practice. Also, the residents in our study were less stringently selected i.e., with less need-driven behavior, than in the study of Chenoweth. This may have affected the possible differences with the control group since DCM is expected to be specifically effective in the subgroup of residents with need-driven behavior.

Sample selection

Despite our non-restrictive sampling strategy, our nursing home sample may not have been representative of the entire nursing home population in the Netherlands. Possibly, our sample (both intervention and control nursing homes) is more homogeneous regarding, at least, the nursing homes' interest in person-centered care and DCM. According to the researchers informal observation at the start of the study, all nursing

homes claimed to be working according the principles of person-centered care. If this is the case, than our control group could be more similar to the person-centered care group (intervention group) in the Chenoweth study, than to their control group.

Reliability web-based NPI-NH

There is a substantial discrepancy between the mean CMAI-score found in our study (46.35) and the mean FxE-score of the NPI-NH (5.61). Compared to other studies, the NPI-score in our study appears to be relatively low.[19,23] This relatively low score could possibly be an artifact of web-based administration of the NPI-NH questionnaire which is originally designed as an interview with the caregiver. When it comes to obtaining information about neuropsychiatric symptoms in patients with dementia, web-based administration might be less reliable than a face-to-face interview performed by a trained interviewer. For example, some of the issues in NPI can be construed as emotionally disturbing to formal caregivers. An interviewer can reassure the caregiver that they will discuss the problems in more detail after completion of the inventory while this is not possible in web-based administration. It is possible that our alternative data collection method has influenced the scores on the NPI-NH. However, this effect should be the same in both the intervention and the control group.

Possible improvement in interactions was not directly measured

DCM aims at improving the interactions between staff and residents. Although we did measure staff variables such as 'contact with patients', 'autonomy' and 'work pleasure', we did not directly measure the quality of interactions between staff and residents (the main focus of the DCM intervention). Furthermore, our process analyses did not include any variables regarding the actual degree of implementation of the action plans, which would have been a good measure of the degree of DCM implementation. The reason for this is that it is very difficult to acquire reliable information about the implementation of action plans, because of the high probability of obtaining socially desirable answers. DCM internal variables such as WIB-score would be a suitable and reliable measure of quality of interactions, but we could not use these outcome measures because it is not appropriate to expose the control group to the intervention under study. Chenoweth et al. used the quality of interactions schedule (QUIS),[24] which measures quality of interactions between care staff and residents, and quality of care.[19] Although this would have been appropriate instrument to measure the quality of interactions, we did not use the QUIS because these observations cost a lot of time and require independent trained observers which were not available. Since our qualitative analysis suggests that

some improvements in interactions did take place, we recommend using QUIS, or a comparable observation tool, in future research.

IMPLICATIONS FOR PRACTICE

The variability in adherence to the intervention protocol shows that there is room for improvement in the implementation of the DCM intervention. It is likely that with improved fidelity of the intervention, also its effectiveness would improve.[19,25,26] We recommend that nursing homes aspiring to implement DCM make clear agreements with all involved staff members from the start, in terms of underlying organizational vision and commitment of everyone involved. Also, the investments in time and money should be clear and agreed upon from the start. We advise against starting with DCM when an organization is in a turbulent period, such as a reorganization. The decision to start with DCM should not be taken top-down. The team manager has to agree on providing sufficient time for the mapper in the different stages of the intervention. An a priori checklist with the necessary organizational and budgetary adaptations could be helpful. To ensure that aspirant mappers meet the requirements, we recommend that a national DCM committee is involved in their recruitment. It is common that mappers only follow the DCM basic training. Since our study suggests that even the advanced training does not guaranty optimal implementation, it is even more important to recruit mappers with appropriate competencies. We also recommend that per organization, a staff member, preferably a motivated team manager, should be assigned the task of leading the DCM implementation. Since many nursing homes had difficulties with attendance rates at feedback sessions, an organization-specific implementation strategy may be necessary to optimize the effectiveness of this essential intervention component. Our last recommendation concerns the DCM training. The module for feedback should be enriched and extended to accommodate the individual differences between the trainees. Because of the essential role of the team manager, a training day specifically for the team managers is desirable. During this training day, the content and process of the DCM intervention and the role of the team manager in this process should be addressed. DCM Netherlands have already made adaptations in the training programme, based on these recommendations.

IMPLICATIONS FOR FURTHER RESEARCH

Potentially effective interventions, such as DCM, that may have positive impact on residents with dementia and their formal caregivers, can fail to show effectiveness due to their complexity in combination with practical and methodological issues.[27] The

current methods in the evaluation of complex interventions are weak in addressing the important distinction between an implementation error and genuine ineffectiveness. Vernooij-Dassen et al. (2014) outlines the rationale for a paradigm shift in methodology for evaluation of complex interventions in applied dementia care research.[28] Vernooij-Dassen et al. propose to plan a stepwise evaluation and implementation of potentially effective interventions, covering the whole continuum from highly controlled explanatory studies to implementation- and pragmatic studies. In this design, as a first step, effectiveness of an intervention is tested under highly controlled conditions. These explanatory trials can demonstrate efficacy or potential (in)effectiveness of an intervention. An example is the trial of Chenoweth et al. If effective, researchers can then proceed to the next stage of evaluation: an implementation study in which the complex psychosocial interventions is improved.[28,29] Unlike the explanatory studies, implementation- and pragmatic trials provide information about the effectiveness in daily practice and information useful in the actual implementation. Curran et al. (2012) propose a 'hybrid effectiveness-implementation' typology, with an a priori dual focus in assessing both clinical effectiveness and implementation. They suggest that an improved framework for the evaluation of complex interventions, would allow for a more rapid translational gains, more effective implementation strategies, and more useful information for decision makers.[30] Be it as it may, we may need different types of studies to gain a thorough insight in the working mechanisms of promising interventions and in suitable strategies for their implementation. While our pragmatic trial was preceded with a well-designed controlled explanatory trial (admittedly in another country),[19] the interpolation of an implementation study in between the two would have had the advantage of minimizing implementation errors by providing implementation methodology on time.[28] Also a blended design, in which an implementation strategy is tested while information is gathered on the clinical intervention's effectiveness, would be a good alternative.[30]

FINAL CONCLUSION

DCM showed to be effective in tightly controlled conditions in an explanatory trial,[19] but not in our pragmatic study. When implemented according to the intervention protocol, DCM is likely to be effective on resident and staff outcomes. To address the important distinction between an implementation error and genuine ineffectiveness of DCM, a stepwise evaluation and implementation or a blended design, is recommended for future research. We recommend nursing homes to start with DCM only if the barriers towards DCM are investigated and addressed. For instance, they have to be very motivated and capable of (approaching) optimal implementation.

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Summary

In our ageing society, dementia is a growing concern. To illustrate the extent of the problem, the prevalence of dementia in the population of Dutch nursing home residents (65.000 people) is 53%. Dementia influences the quality of life of those affected by the disease, and increases utilization of care resources. A specific and highly pervasive problem in this group of residents is the presence of neuropsychiatric symptoms. In addition to directly affecting the residents' quality of life, these symptoms represent a serious challenge for the professional caregivers. Neuropsychiatric symptoms are often 'treated' with psychotropic medication and physical restraints. However, these treatment approaches are mostly inadequate, harmful, and have limited effectiveness.

In recent decades, person-centered dementia care has been developed as a method to improve the quality of care, e.g. in nursing homes where task-focused care still prevails. Task-focused care is organized around care tasks, while person-centered care focuses on individual patient preferences, needs, and values. Although evidence suggests that different types of person-centered care improve both resident and staff outcomes, what is missing is a method to systematically implement it in all aspects of nursing home dementia care.

Dementia Care Mapping (DCM) intervention offers a set of methods to this aim. It is a person-centered intervention, rooted in psychosocial theory of personhood in dementia. DCM aims at reducing both neuropsychiatric symptoms in people with dementia and staff problems in nursing homes. The intervention consists of cycles of systematic observations, feedback to the staff, and action plans. Important distinctions with other methods are that in DCM, staff create better care through self-developed improvements rather than implementing action plans developed by others, it allows for timely initiation of tailor made interventions, and it allows for adaptations to patients needs on many different levels in the organization. The main objective of this thesis is to study (cost) effectiveness of DCM in nursing home dementia care.

CHAPTER 1: GENERAL INTRODUCTION

The introduction of this thesis provides a general background on problems in dementia care in Dutch nursing homes and on interventions addressing these problems. A rationale is provided for choosing to investigate (cost)effectiveness of the DCM intervention in alleviating resident and staff problems. Also, the aim and research questions addressed in the DCM trial are outlined in the general introduction.

CHAPTER 2: IMPROVING PERSON-CENTERED CARE IN NURSING HOMES THROUGH DEMENTIA CARE MAPPING: DESIGN OF A CLUSTER-RANDOMIZED CONTROLLED TRIAL

Chapter 2 describes the design of this study. The study is a cluster-randomized controlled trial, with nursing homes grouped in clusters. We used studywise minimization as the allocation method. Nursing homes in the intervention group received the DCM intervention, which consists of the DCM basic- and advanced training, an organizational briefing day, and at least two DCM cycles (each DCM cycle consists of observation, feedback, and action plans). The control group received usual care. The primary outcome measure was resident agitation, assessed with the Cohen-Mansfield Agitation Inventory (CMAI). The secondary outcomes were resident neuropsychiatric symptoms, quality of life, healthcare consumption and drug use. The staff outcomes were stress reactions, job satisfaction and absenteeism. We collected the data from questionnaires and electronic registration systems. We employed linear mixed-effect models and cost-effectiveness analyses to evaluate the outcomes. We set up process analyses, including focus groups with staff, to determine the relevant facilitators of and barriers to implementing DCM.

CHAPTER 3: IS THE DCM INTERVENTION EFFECTIVE IN ALLEVIATING RESIDENT AND STAFF PROBLEMS IN NURSING HOME DEMENTIA CARE?

In this study, 34 units from 11 nursing homes, including 434 residents and 382 nursing staff members, were randomly assigned. Ten nurses from the intervention units completed the basic and advanced DCM training and were to carry out at least two DCM cycles. Intention-to-treat analysis showed no statistically significant effect on our primary outcome agitation (CMAI). Significantly more neuropsychiatric symptoms were reported in the intervention group than in usual care. Staff in the intervention group reported significantly fewer negative and more positive emotional reactions during work. There were no other statistically significant effects. Our lack of evidence for the effect of DCM on agitation seems to contradict some earlier findings. These differences may be explained by differences in the study designs. It is plausible that the variability of the extent of implementation of DCM may explain the lack of effect.

CHAPTER 4: IS THE DCM INTERVENTION COST-EFFECTIVE?

We calculated the total costs by summing up residents' healthcare consumption and drug use, staff absenteeism, and the costs of the DCM intervention. Comparison of total costs made in the intervention and the control group showed no differences. Overall, DCM is a cost-neutral intervention. The results of the costs analyses did not change when the

DCM implementation costs were eliminated from the model, which means that these costs are negligible compared to the costs associated with daily care. The mean DCM implementation costs per resident per day were US $0.63 (SD $0.23). More specific comparisons of costs showed that in the intervention group, the costs associated with outpatient hospital appointments were significantly lower than in the control group. The relationship between this cost saving effect and the DCM intervention is not clear.

CHAPTER 5: WEB-BASED DATA COLLECTION IN NURSING HOMES: THE FUTURE?

While web-based research data collection is increasingly used, it is still much more common to use the paper-and-pencil method in nursing home research. Because of the high workload of the nursing staff, we decided to systematically implement the less time consuming method of web-based data collection in the participating nursing homes and evaluated its feasibility and usability. The average response rate using web-based data collection was 73.9%, which is comparable with the paper-and-pencil method. 280 (75.3%) Nursing staff members completed the questionnaire about usability of the web-based data collection. Nursing staff members in this study were very positive about the web-based method and the majority preferred web-based over the paper-and-pencil method. Given a carefully designed implementation procedure, web-based data collection can be an efficient way to collect research data in settings like nursing homes.

CHAPTER 6: TO WHAT EXTENT IS THE DCM INTERVENTION IMPLEMENTED ACCORDING TO THE PROTOCOL AND WHAT BARRIERS AND FACILITATORS ARE THERE FOR THE IMPLEMENTATION AND FOR THE COMPLIANCE TO THE INTERVENTION PROTOCOL?

The lack of effect of DCM on our primary outcome measure was puzzling, and asked for more insight into the possible interfering factors. The aim of the process analysis was to find out to what extent the intervention protocol was adhered to (quantitative analysis), and to find out which facilitators and barriers are there for successful implementation of DCM in daily practice (qualitative analysis).

The quantitative part of the process analysis showed a substantial variation in adherence to the intervention protocol across the units. Despite the mappers fulfilling all the DCM basic and advanced level requirements, there was a considerable variation between the units in their adherence to the protocol. For example, the mean staff attendance at the organizational day was 64.8% (range 6.7-96.8%), while the intervention protocol prescribed that all staff members should be present.

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CHAPTER 7: GENERAL DISCUSSION

In this chapter we present and discuss the main findings in their broader theoretical and practical context. We also discuss methodological considerations in this kind of research. In this chapter we conclude that DCM showed to be effective in tightly controlled conditions, but not in our pragmatic study. We recommend nursing homes to start with DCM only if the barriers towards DCM are investigated and addressed.

The main implications for practice and further research are:

- We recommend that nursing homes aspiring to implement DCM, make clear agreements with al involved staff members from the start, in terms of required time and costs, underlying organizational vision and the team manager's commitment.
- Because the commitment of the team manager and the motivation of the team are crucial for successful implementation, we advise against starting with DCM when the decision was taken top-down.
- To ensure that aspirant mappers meet the requirements, we recommend that a national DCM committee is involved in their recruitment.
- We recommend that per organization, a staff member, preferably a motivated team manager, should be assigned the task of DCM implementation.
- The training module for feedback should be enriched and extended to accommodate the individual differences between the trainees.
- Because of the essential role of the team manager, a training day specifically for the team managers is desirable.

- To address the important distinction between an implementation error and genuine ineffectiveness of DCM, a stepwise evaluation and implementation or a blended design, is recommended for future research.

Samenvatting

In onze vergrijzende samenleving is dementie een groeiend probleem. Om de omvang van het probleem te illustreren: de prevalentie van dementie bij patiënten in de Nederlandse verpleeghuizen (65.000 mensen) is 53%. Dementie heeft een negatief effect op de kwaliteit van leven en verhoogt het zorggebruik aanzienlijk. Een specifiek en ingrijpend probleem bij dementie is de hoge prevalentie van neuropsychiatrische symptomen, zoals agitatie en depressie. Deze symptomen hebben direct invloed op de kwaliteit van leven van de patiënten en vormen daarnaast een grote uitdaging voor de professionele zorgverleners. Neuropsychiatrische symptomen worden vaak 'behandeld' met psychotropische medicatie en vrijheidsbeperkende maatregelen. Deze behandelwijzen zijn echter veelal inadequaat, gevaarlijk en hebben beperkte effectiviteit.

In de afgelopen jaren is dementiezorg in verpleeghuizen steeds meer persoonsgericht geworden. Deze benadering is ontwikkeld als alternatief voor taakgerichte zorg. Terwijl taakgerichte zorg vooral georganiseerd wordt rondom zorgtaken, ligt de focus van persoonsgerichte zorg op de individuele voorkeuren, behoeften en waarden van de patiënt. Hoewel er bewijs is dat verschillende vormen van persoonsgerichte zorg bij zowel patiënten als medewerkers verbeteringen kunnen opleveren, zijn de meeste interventies op dit gebied incidenteel en kortstondig. Er ontbreekt een methode om persoonsgerichte zorg systematisch in alle aspecten van de zorg voor mensen met dementie in verpleeghuizen in te bouwen.

De Dementia Care Mapping (DCM) interventie is een methode die dit beoogt. DCM bestaat uit een set van methoden gericht op systematische implementatie van persoonsgerichte zorg. Deze interventie is geworteld in de psychosociale theorie van persoonlijkheid bij dementie. DCM poogt zowel de neuropsychiatrische symptomen van mensen met dementie als de medewerkersproblemen zoals werkstress in verpleeghuizen te verminderen. De interventie bestaat uit meerdere cycli van systematische observaties van medewerker-bewoner interacties, feedback naar de medewerkers en daaropvolgende actieplannen. Een belangrijke verschil met andere methoden is dat bij DCM de medewerkers zelf betere zorg ontwikkelen doordat zij zelf deze actieplannen opstellen. Door medewerkers inzicht te geven in zorgsituaties en mogelijke oorzaken van problemen en ze te betrekken bij het initiëren van verbeteringen, vermindert hun gevoel van onmacht. Daarnaast maakt DCM het mogelijk om tijdig en op maat te interveniëren, waarbij verschillende niveaus in de organisatie bij de verbeteringen betrokken kunnen worden. Op die manier kan men beter tegemoet komen aan de behoeften van patiënten. De hoofddoelstelling van dit proefschrift is om de (kosten)effectiviteit van DCM in de dementiezorg in Nederlandse verpleeghuizen te onderzoeken.

HOOFDSTUK 1: ALGEMENE INTRODUCTIE

In hoofdstuk 1 worden de achtergronden van de problemen in dementiezorg en de bestaande interventies die gericht zijn op het verminderen van deze problemen beschreven. Er wordt tevens een onderbouwing gegeven voor de keuze voor het onderzoek naar de (kosten)effectiviteit van de DCM interventie op relevante uitkomsten op patiënt- en medewerkerniveau. Het hoofdstuk eindigt met de beschrijving van de specifieke doelen en onderzoeksvragen.

HOOFDSTUK 2: HET VERBETEREN VAN PERSOONSGERICHTE ZORG IN VERPLEEGHUIZEN DOOR MIDDEL VAN DEMENTIA CARE MAPPING: DE OPZET VAN EEN CLUSTER- GERANDOMISEERDE GECONTROLEERDE STUDIE

Hoofdstuk 2 beschrijft de onderzoeksopzet. In dit onderzoek wordt gebruik gemaakt van een cluster-gerandomiseerd gecontroleerd opzet, met verpleeghuizen als clusters. Als randomisatiemethode is 'studywise minimisation' gebruikt. Verpleeghuizen in de interventiegroep ontvingen de DCM interventie, welke bestond uit de DCM basis en -gevorderden training, een organisatiedag en tenminste twee DCM cycli (elk bestaand uit observatie, feedback en actieplannen). De controlegroep ontving de gebruikelijke zorg. De primaire uitkomstmaat was de mate van agitatie bij de patiënten met dementie, gemeten met de Cohen-Mansfield Agitation Inventory (CMAI). De secondaire uitkomstmaten waren neuropsychiatrische symptomen, kwaliteit van leven, zorggebruik en medicatiegebruik van de patiënten met dementie. De uitkomstmaten bij medewerkers waren de aanwezigheid van stressreacties, arbeidstevredenheid en ziekteverzuim. We verzamelden de gegevens door middel van vragenlijsten en met behulp van de elektronische registratiesystemen in verpleeghuizen. Er werden lineaire mixed-effect modellen en kosteneffectiviteitsanalyses gebruikt om de effecten de evalueren. Daarnaast zijn kwantitatieve en kwalitatieve procesanalyses uitgevoerd om de mate van implementatie en belemmerende en bevorderende factoren voor de naleving van het interventieprotocol te onderzoeken.

HOOFDSTUK 3: IS DE DCM INTERVENTIE EFFECTIEF BIJ HET VERMINDEREN VAN PATIËNT- EN MEDEWERKERSPROBLEMEN IN DE DEMENTIEZORG IN VERPLEEGHUIZEN?

In dit onderzoek werden 34 afdelingen van 11 verpleeghuizen, met 434 patiënten en 382 medewerkers, geïncludeerd en via loting verdeeld over de interventie- en de controlegroep. Tien verzorgenden werkzaam bij de interventieafdelingen volgden de DCM training en voerden ten minste twee DCM cycli uit. Intention-to-treat analyse liet

geen statistisch significant effect zien op de mate van agitatie (primaire uitkomstmaat (CMAI)). In de interventiegroep werden significant meer neuropsychiatrische symptomen gerapporteerd dan in de controlegroep. Medewerkers in de interventiegroep rapporteerden minder negatieve en meer positieve emotionele reacties tijdens hun werk. Het gebrek aan bewijs voor het effect van DCM op de mate van agitatie bij patiënten spreekt enkele eerdere onderzoeksbevindingen tegen. Deze afwijkende bevinding komt mogelijk voort uit de verschillen in onderzoeksopzet. Het is tevens waarschijnlijk dat, vergeleken met eerder onderzoek, het gebrek aan effecten in ons onderzoek verklaard kan worden door een grote variatie in de mate van implementatie van DCM in de deelnemende verpleeghuizen.

HOOFDSTUK 4: IS DE DCM INTERVENTIE KOSTENEFFECTIEF?

De totale kosten werden berekend door de kosten van het zorggebruik, medicatiegebruik, ziekteverzuim en de kosten van de DCM interventie bij elkaar op te tellen. Er waren geen verschillen in totale kosten tussen de interventie- en de controlegroep: DCM blijkt een kostenneutrale interventie. De resultaten van de kostenanalyses veranderden niet wanneer de kosten van de DCM interventie niet meegenomen werden in de berekening. Dat betekent dat deze kosten verwaarloosbaar zijn vergeleken met de kosten voor de dagelijkse zorg. De gemiddelde DCM interventiekosten per patiënt per dag waren €0.48 (SD €0.17). Wel zagen we dat in de interventiegroep de kosten geassocieerd met polikliniekbezoeken significant lager waren dan in de controlegroep. De relatie tussen dit kostenbesparende effect en de DCM interventie is onduidelijk.

HOOFDSTUK 5: WEB-BASED DATAVERZAMELING IN VERPLEEGHUIZEN: DE TOEKOMST?

Hoewel onderzoekdata steeds vaker via internet wordt verzameld, is in verpleeghuisonderzoek de papier-en-pen-methode nog steeds veel gebruikelijker. Aangezien de werkdruk bij de verpleging en verzorging al hoog is, besloten we om de tijdbesparende web-based dataverzamelingsmethode systematisch te implementeren in de deelnemende verpleeghuizen en de uitvoerbaarheid en bruikbaarheid hiervan te evalueren. De gemiddelde respons bij de web-based dataverzameling in ons onderzoek was 73.9%, wat vergelijkbaar is met de papier-en-pen-methode. 280 (75.3%) verpleegkundigen en verzorgenden hebben de vragenlijst over de gebruikersvriendelijkheid van de web-based dataverzameling ingevuld. De verpleegkundigen en verzorgenden waren zeer positief over de web-based dataverzamelingsmethode en de meerderheid prefereerde deze methode boven de papier-en-pen methode. We concludeerden dat wanneer web-

based dataverzameling zorgvuldig wordt geïmplementeerd, dit een efficiënte manier is om onderzoeksdata te verzamelen in verpleeghuizen en vergelijkbare settings.

HOOFDSTUK 6: IN WELKE MATE IS DE DCM INTERVENTIE GEÏMPLEMENTEERD VOLGENS PROTOCOL EN WELKE FACTOREN WERKEN BELEMMEREND EN BEVORDEREND BIJ DE IMPLEMENTATIE EN DE NALEVING VAN HET INTERVENTIEPROTOCOL?

Het gebrek aan effect van de DCM interventie op onze primaire uitkomstmaat riep nieuwe vragen op over mogelijk interfererende factoren. Het doel van de procesanalyse was om te onderzoeken in welke mate het interventieprotocol werd nageleefd (kwantitatieve analyse) en welke factoren belemmerend en bevorderend werken bij de implementatie van DCM in de dagelijkse praktijk (kwalitatieve analyse).

Uit het kwantitatieve deel van de procesanalyse kwam een substantiële variatie tussen de verschillende afdelingen naar voren met betrekking tot de naleving van het interventieprotocol. Deze variatie bestond ondanks dat de mappers allemaal de DCM basis- en gevorderden training en de interbeoordelaarsbetrouwbaarheidstest hadden gehaald. De gemiddelde aanwezigheid van medewerkers tijdens de organisatiedag was bijvoorbeeld 64.8% (range 6.7 - 96.8%), terwijl het interventieprotocol voorschrijft dat alle medewerkers aanwezig moesten zijn.

Uit het kwalitatieve gedeelte van de procesanalyse kwam naar voren dat ervaring met persoonsgerichte zorg, betrokkenheid van de afdelingsmanager, de juiste competenties en enthousiasme van de mapper zeer belangrijke bevorderende factoren waren bij de implementatie van DCM. De belangrijkste belemmerende factoren waren een ‘top-down besluit tot deelname’, twijfel van de medewerkers over de motieven van het management en onvoldoende betrokkenheid van de afdelingsmanager. De meeste belemmerende en bevorderende factoren werden als individueel en sociaal gecategoriseerd; zeer weinig factoren waren maatschappelijk van aard (zoals compensaties van zorgverzekeraars). Samenvattend is onze hypothese dat de volgende voorwaarden belangrijk zijn voor een succesvolle implementatie van DCM: 1) ervaring van verpleeghuizen met persoonsgerichte zorg, 2) grote betrokkenheid van de afdelingsmanager bij DCM, en 3) aanvullende training (waaronder ‘on-the-job’) en steun voor de mappers, met name bij het geven van feedback aan de medewerkers.

HOOFDSTUK 7: ALGEMENE DISCUSSIE

In dit hoofdstuk presenteren en bediscussiëren we de belangrijkste bevindingen in hun bredere theoretische en praktische context. Daarnaast bediscussiëren we de methodologische overwegingen bij dit type onderzoek. Wij concluderen dat de DCM interventie effectief bleek te zijn in strikt gecontroleerde condities, maar niet in onze pragmatische studie. We bevelen aan om bij de implementatie van DCM rekening te houden met de mogelijke belemmerende factoren.

De belangrijkste implicaties voor de praktijk en verder onderzoek zijn:

- Voor een succesvolle implementatie van DCM is een goede planning essentieel. Er dienen duidelijke afspraken gemaakt te worden met alle betrokken medewerkers in termen van benodigde tijd en kosten, uitwerking van de onderliggende visie van de organisatie en betrokkenheid van de afdelingsmanager.
- Omdat de betrokkenheid van de afdelingsmanager en de inzet van het team op de werkvloer cruciaal zijn, raden we het af om de beslissing om DCM in te voeren vanuit de organisatietop te nemen.
- Vanwege het belang van de juiste vaardigheden van de mappers, raden we aan om DCM Nederland te betrekken bij hun werving.
- We adviseren dat er per organisatie een medewerker, bij voorkeur een gemotiveerde afdelingsmanager, de organisatorische taken van de DCM implementatie op zich neemt.
- Het onderdeel van de DCM training met betrekking tot het geven van feedback bereidt de mappers onvoldoende voor op deze complexe taak. Om individuele verschillen te verkleinen, raden we aan om de feedbackmodule in de DCM training uit te breiden, bijvoorbeeld met meer oefening in het geven van feedback.
- Ook voor de afdelingsmanagers is het wenselijk een specifieke DCM training te volgen, toegespitst op hun rol in de DCM implementatie.
- Om het belangrijke onderscheid te kunnen maken tussen een implementatiefout en daadwerkelijke ineffectiviteit van DCM, raden we een stapsgewijze evaluatie en implementatie of een gemengde onderzoeksopzet aan in verder onderzoek.

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Curriculum Vitae

Geertje van de Ven werd geboren op 28 januari 1982 als jongste dochter van Frans en Dorien van de Ven en zus van Lieke. Ze groeide op op het platteland van Ospel, waar ze de basisschool doorliep. In 1998 haalde ze haar havo-diploma aan de Philips van Horne Scholengemeenschap te Weert. Daarna studeerde ze Maatschappelijk Werk en Dienstverlening aan de Fontys Hogeschool Eindhoven. Gedurende deze studie verhuisde ze naar Helmond waar ze werkte als maatschappelijk werkster in dak- en thuislozenopvang Huize d'n Herd. Na het behalen van haar diploma Maatschappelijk Werk en Dienstverlening, startte ze met de opleiding Gezondheidswetenschappen aan de Universiteit Maastricht. Tijdens deze opleiding werkte ze als huishoudelijk medewerker in de Thuiszorg in Amsterdam en in het Elkerliek Ziekenhuis in Helmond. In het laatste jaar van deze studie verhuisde ze naar Nijmegen waar ze haar afstudeerscriptie schreef over depressie bij kinderen. In 2002 haalde zij met genoegen haar doctoraalexamen Geestelijke Gezondheidkunde, waarna ze ging werken op de afdeling IQ healthcare van het Radboudumc. Op deze afdeling werkte ze aan uiteenlopende onderzoeksprojecten met betrekking tot het verbeteren van de kwaliteit van zorg. Daarnaast zette ze zich in voor enkele afdelingsbrede verbeterprojecten, zoals intervisiebijeenkomsten voor onderzoekers. In 2010 startte ze haar promotieonderzoek aan de afdeling Eerstelijnsgeneeskunde van het Radboudumc. Tijdens haar promotieonderzoek naar de effectiviteit van Dementia Care Mapping werkte ze intensief samen met de deelnemende verpleeghuizen, DCM Nederland en de University of Bradford. Momenteel is ze werkzaam als onderzoeker bij functiewaarderings- en adviesbureau FWG in Utrecht, waar ze onder andere onderzoek doet naar trends en ontwikkelingen in de zorg. Sinds 2012 woont ze samen met haar vriend Ben Cox in Nijmegen, met wie ze na haar promotie naar Eindhoven verhuist.