Towards a person-centred approach for older people with intellectual disabilities

The use and effect of Dementia Care Mapping

Feija Schaap

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Colophon

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Veerle Vroon

… Ik zag je toen en ik wist in te zien
dat in mijn leven zoveel is gezien
zonder dat ik het ooit eerder zag:
dat kijken zoveel liefs vermag.

Joost Zwagerman

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General introduction

CHAPTER 1

The main objective of this thesis was to examine the use and effects of Dementia Care Mapping in care for older people with intellectual disabilities. The increased life-expectancy of people with intellectual disabilities is giving rise to increasing rates of dementia and related behavioural changes. This has its impact on the provision of care by professional care staff and creates a need for new knowledge and skills. Dementia Care Mapping is a promising method to support ID-care staff in their daily work with ageing clients with intellectual disabilities. This first chapter describes the background, key concepts, objectives of the study, and introduces the research questions, a brief study design, and the outline of the further thesis.

Psychosocial consequences of ageing for people with intellectual disabilities

In the past few decades the lifespan of people with intellectual disabilities has greatly increased.[1-3] Intellectual disability (ID) can be defined as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits; it is characterised by significant limitations both in intellectual functioning and in adaptive behaviour, as expressed in conceptual, social, and practical adaptive skills.[4-6] European usage commonly categorises ID into four levels: mild, moderate, severe and profound.[5,6] This categorisation indicates the wide range of intellectual disabilities, and the associated range of intensity of need for support and care. This wide range of need for support and care increases even more with the ageing of people with ID, due to the increasing likelihood of age-related cognitive, social, psychological and biological conditions.[7-9] Many of these age-related conditions occur more frequently and usually earlier in people with ID than in the general population.[10,11]

One of these age-related conditions is dementia. Dementia is a clinical syndrome, or a combination of various clinically recognizable signs and symptoms. In general, these symptoms can be divided into three clusters: decline in cognitive abilities, decline in non-cognitive abilities and decline in activities of daily living (ADL).[5,6] As defined, this increasing loss of function in multiple cognitive domains from a previously higher level interferes with daily life and does not occur in the context of delirium or another mental disorder.[5,6] Dementia may be caused by various underlying diseases, including Alzheimer's disease, vascular

dementia, Lewy body dementia, frontotemporal dementia and Parkinson's disease.[12] Dementia involves a wide range of changes: in memory, functional capacity, communication, personality, and behaviour. These consequences can result in behaviour like agitation, resistance, depression and apathy.[13-16] They pose behavioural and care concerns such as wandering, sleep disturbance and incontinence, and may present with auditory and visual hallucinations.[2,17,18]

Dementia strongly impacts the lives of those who have ID, as well as their house-mates and care staff.[1,19,20] In contemporary care for older people with ID, it is recognized as a major challenge.[12,21] It is important to distinguish intellectual disability from dementia: intellectual disability refers to an individual's baseline level of functioning, whereas dementia is a significant decline from that level.[21] Although the diagnosis of dementia in people with ID is complex due to pre-existing deficits and different presentation, its prevalence is estimated to be 18% at the age of 65.[21,22] This prevalence is even higher among people with Down's syndrome, 68-80% of whom have developed dementia by the age of 65.[23,24] In fact, in this group the average age of onset of dementia is the early 50s, much younger than in the general population.[25,26]

People with ID generally age in the residential care organisation where they have lived throughout their lives, either in their current group home or in a group home specialised in ageing people with ID.[27-29] Many older people with ID have not lived independently, have not married or had children, and have very limited informal support networks as their parents age and die.[28] This underlines the importance of long term relationships with care staff, because the way of expressing wishes is not always understandable for people less experienced with people with ID.[18,30-32] Staff who provide long-term care to the same clients may recognise changes in their actual needs as a result of their experience with and knowledge of clients' behaviour, habits, personality and life histories. Nevertheless, age related changes imply changes in the nature and intensity of support, involving consequences for the nature of care provided by staff for older people with ID.[33]

Consequences for the job contents of staff providing care to ageing people with intellectual disabilities

Formal care staff are key in supporting older people with ID,[32,34] but can encounter difficulties in dealing with the changing psychosocial, age-related conditions of their clients, especially in cases of dementia.[35,36] In ID-care services, many employees have built long term, staff-client caring relationships with their clients, which distinguishes this setting from many other healthcare settings.[37] Care staff describe their work with people with ID as increasingly time consuming and increasingly stressful as their clients grow older. Moreover, the nature of support and care changes with the ageing of clients; more time is spent in supporting individuals in their activities of daily living (ADL) and in nursing, especially as dementia advances.[17,34] For example, the nature and task of providing support and care becomes contrastingly different in mid- and end- stage dementia: for people with mid-stage dementia, ADL and daily support take the greatest amount of time, but for people with end-stage dementia the emphasis shifts to ADL and nursing care, combined with comforting and symptom relief.[17,31,38,39] Care staff also perceive dealing with behaviour of clients with dementia as challenging, as it takes extensive time and effort.[17,18] For example: supporting clients who wander; ensuring that clients do not get lost or injure themselves; supporting and comforting clients who are sad, restless, agitated or anxious; and intervening when clients cause friction with housemates by being noisy and physically or verbally aggressive.[17,18] This complexity of issues experienced by care staff can lead to a loss of focus and a tendency to react to separate deficiencies, instead of to the person as a whole and his or her needs and wishes.[7]

Increasing attention is currently being paid to ageing in place, i.e. keeping older clients in their current residence, even when they have an increasing need for care and support because of life changes or declining health.[7,40] Care staff are strongly committed and motivated to keep older clients with dementia in their own homes, and to care for their clients in their own environment, up to the very end.[38,41,42] However, staff often lack the knowledge and skills to adapt to clients' changes in needs and dependency.[32,43-45] They often experience difficulties and feelings of guilt and distress in coping with what they perceive as challenging behaviour; this in turn decreases their self-esteem, which can influence the staff–client relationship.[46-51] The high commitment of ID-care staff to ageing in place often makes them

unaware of possible obstacles to provision of quality care.[28,45,52-54] Furthermore, the lack of knowledge and skills can lead to low job satisfaction, stress, and burnout on the part of staff, and a reduced quality of life for clients.[46-49,55,56] Therefore, care staff urgently need psychosocial methods to support them in addressing their ageing clients' changing needs and behaviour so as to provide them with good care and a dignified life situation.[36,44,45,57]

A new paradigm in intellectual disability care due to ageing: an overview

In the Netherlands, older people with ID usually live and grow older in group homes where they receive residential care. In each group home live a small number (between 4 and 12) of people with ID in need of care and support.[58] This care and support includes all aspects of day-to-day life, including activities of daily living (ADL) and day care activities. Support is provided by ID-care professionals, mostly social workers (68%), followed by nurses (20%) and certified nursing assistants (8%), most of them (85%) trained at vocational level, and some (8%) having a bachelor degree.[31,59-61] The nature of ID-care and support changes as the clients age in place.

Traditionally, ID-care places a major emphasis on the empowerment of clients, on promoting the acquisition of skills, and on helping them to reach individual independence. Also important is realisation of the highest possible level of community participation.[38] These concepts remain important components of ID-care. Yet, this 'activating' approach is less practical when trying to help persons with ID to cope with ageing, increasing disability and decline, as well as the increasing need for 'caring' and symptom relief.[31,38] These needs call for new types of care.[34,45] ID-care organisations are willing to train their care staff in this changing type of care.[36] Such training must include an evidence-based method, enabling professionals to effectively upgrade their knowledge and skills to support their ageing clients.[13,43,45,53]

ID-care employs a wide variety of methods and approaches for providing care to people with ID. The choice of a certain method, training or approach depends mainly on staff's own demands.[62-65] However, the methods used often lack either a theoretical or methodical base, and are seldom evidence-based.[66] Of the myriad methods used in the Netherlands, only six have been found to be evidence-based,[66] only three of which are suitable for care of older people with ID:[67] Education and Support Program (aimed at people with profound intellectual

and multiple disabilities; PIMD),[68] Triple C (aimed at people with ID in combination with behavioural and psychological problems),[69,70] and Gentle Teaching (aimed at people with behavioural problems, whether or not with ID).[71] None of these methods are aimed at people with ID and dementia.

Person-centred care as promising option to improve care for older people with ID and dementia

Person-centred care is especially promising in care for older people with ID and dementia.[7,34,72] 'Person-centred care' evolved from the field of dementia care, and in recent years the term has been closely linked to the concept of 'good-quality care'.[73,74] Person-centred care is strongly connected to Tom Kitwood's concept of personhood in dementia, developed in response to the biomedical reductionist view of persons with dementia.[75,76] Personhood refers to the relational aspects of being human, and the importance of being in an inclusive psychosocial environment where people recognise you as a person with a unique personality and life history.[73-75,77,78] Kitwood's view model highlights the relational components of personhood, engaging both the 'cared for' and the 'carer' in its construction and maintenance.[76]

Kitwood proposes that fulfilment of five psychological needs is essential if the person with dementia is to experience well-being: the need for attachment, comfort, identity, inclusion and occupation; these come together in the central need for love (Figure 1).[79] According to Kitwood, meeting the whole cluster of needs enables a person to experience well-being.[80] On top of recognising psychological needs as central to well-being, the person-centred approach underscores how difficult it can be for people with dementia to meet their own psychological needs.[81] Kitwood stressed that this is because of the nature of cognitive and functional impairments associated with dementia (e.g. language and executive function) makes it difficult for people with dementia to meet their own needs.[77,79,81] To meet these psychological needs, person-centred care provided by professional staff should comply with four major elements summarised in Brooker's VIPS-framework: (1) a base that asserts the absolute value of all human lives, regardless of age or cognitive ability; (2) an individualised approach, recognising the uniqueness of the person; (3) understanding the world from the

perspective of the person; (4) positive social psychology, allowing the person to experience relative well-being.[78,82,83]

Figure 1. Kitwood's flower of psychological needs of people living with dementia[79]

Several studies have shown that professionals and experts advise the use of person-centred care as a guiding principle in providing quality of care for older people with ID.[7,32,34,54,84,85] Person-centred methods are associated with psychosocial benefits for both people with dementia and their care staff, but also for people with ID (whether or not with dementia) and their care staff.[72,86] The methods of person-centred care enable staff to tailor care to the needs of individual clients, which may in turn yield more productive interactions between the clients and their care professionals.[72,87,88] Furthermore, person-centred care involves a collaborative approach of staff to coordination of care.[74,89] Studies focused on staff caring for older people with ID showed training to be satisfactory and supportive when it was consistent with the principles of person-centred care, when it was tailored to people with ID, and when supported in solving problem issues in practice, e.g. by a manager or behavioural specialist.[34,90] Such methods can be derived partly from residential geriatric dementia care.[84,85,91] However, most person-centred methods used in ID-care are derived directly from

routine dementia care and have not been specifically adapted to ID-care, and they are often used in an unsystematic way,[66] which limits their effectiveness.[45] A person-centred method to support staff in the care of older people with ID is currently lacking.

Dementia Care Mapping as good practice in routine dementia care; also for people with intellectual disabilities?

Dementia Care Mapping (DCM), a person-centred intervention originally designed to support dementia-care staff working in psychogeriatric nursing homes, is promising as a support to staff caring for older people with ID and dementia. It might improve their knowledge and skills in providing daily care. DCM is rooted in Kitwood's psychosocial theory of personhood in dementia, as described above. DCM is an person-centred observational tool to increase the quality and effectiveness of care for people with dementia from a person-centred approach, aiming at higher job satisfaction of staff and quality of life of residents.[77,92] Studies on DCM applied in psychogeriatric nursing homes found that it reduced negative affective behaviour as well as physical and verbal agitation in people with dementia.[93,94] Use of DCM also decreased stress and risk of burnout on the part of staff, and increased their job satisfaction.[93,95,96]

DCM consists of repeated cycles of systematic observation, feedback to staff, and development of action plans (see Box 1 and Figure 2). A full cycle includes the following steps: first, the DCM-mappers (observers) systematically observe four clients for 4 to 6 consecutive hours in communal areas in a group home. The results of the observations are analysed and reported to the staff, to help them understand clients' behaviour in the context of their lives and their care.[97] The feedback is intended to increase the insights and awareness of staff as to their own and clients' behaviour, and enhance staff-client interactions.[92] Based on the feedback, the staff make action plans at individual and group levels, directly applicable in daily care. These action plans lead to improved competences, performance and interactions on the part of staff. More detailed information on the DCM procedure is provided in Box 1.

Box 1. Dementia Care Mapping: person-centred care in action

Dementia Care Mapping (DCM) is an intervention developed by the Dementia Research Group at Bradford University to improve the quality and effectiveness of care from the perspective of people with dementia [97]. It is based on Kitwood's social-psychological theory of personhood in dementia.[77] DCM was designed as observational tool to develop person-centred care for people with dementia in nursing homes.[92] Person-centred dementia care can be specified as: valuing people with dementia (V); using an individual approach that recognises the uniqueness of the person (I); making an effort to understand the world from the perspective of the person (P); and providing a supportive social environment (S) [78]. DCM has three main components:

A: Mappers' training in DCM
A staff member receives training to become a certified DCM mapper. A basic DCM mapping course includes four days of basic concepts and skills. To participate in research a mapper must achieve the level of advanced mapper. Required for this is a three-day course focused on the background and theory of DCM, and person-centred care. An advanced DCM mapper can observe (map) care with an inter-reliability score of ≥0.8, report the observation, provide feedback, and instruct staff in drawing up action plans.[92]

B: Organisational introductory briefing
Before the mapping (systematic observation of the actual care) takes place, the basic principles of DCM and person-centred care are explained to the complete staff of a group home, to ensure endorsement and appropriate implementation [92].

C: DCM cycle: observations-feedback-action plan
The introductory DCM organisational briefing day is followed by a DCM-cycle, consisting of:

1. *Observation, analysis and report.* A mapper observes four to six residents in communal areas for 4 to 6 hours. For each 5-minute time frame a code is noted to record what happened with each resident and the associated behaviour of the staff. The DCM coding protocol contains 23 behavioural category codes (BCCs), well/ill-being (WIB) values of clients, and personal detractions (PDs) and personal enhancers (PEs) in staff-client interactions.[97] PDs and PEs refer to staff behaviour and are often related to the WIB values in the interpretation of observations. After analysis the observations are included in a report.

2. *Feedback.* The results of the mapping are communicated verbally to the staff. The purpose of this feedback is to discuss and gain insight into residents' behaviour in the context of both their lives and the care.[97] The feedback is complemented with knowledge of dementia and person-centred care. Feedback is presented in a non-threatening way and is intended to enhance staff awareness of their own and residents' behaviour and of staff-resident interactions, thereby motivating them to improve their competencies, performance and interactions.[92] The feedback is supported by the written report.

3. *Action plans.* Based on observation and feedback, the staff draw up action plans to improve care at individual and group levels. Action plans are tools to implement theoretical knowledge of dementia and the principles of person-centred care in daily practice, and to increase uniformity of care.

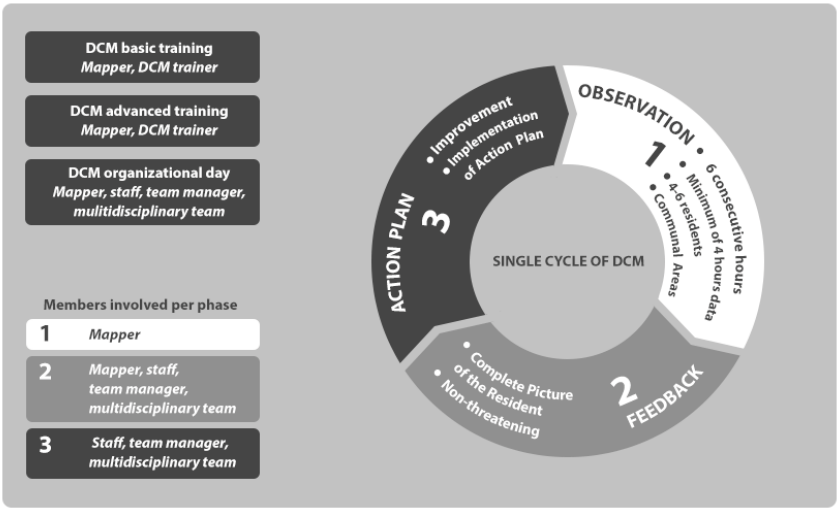

Figure 2. Dementia Care Mapping intervention components and cycle (based on: Van de Ven (2013))[92]

DCM has a number of characteristics that are promising to support ID-care staff in their daily work with ageing people with ID: it is a structured psychosocial, cyclic method based on the principles of person-centred care, and makes use of structured direct observations.[98-100] Furthermore, staff are directly involved in the development of improvement actions (in cooperation with, rather than directed by, physicians, psychologists, behavioural specialists); DCM supports timely initiation of tailor made interventions and allows for adaptations to clients' needs, at various levels in the organisation.[101] The use of DCM in care for people with ID is new; available studies on DCM in ID-care are few and small.[98-100] Research on the feasibility and effectiveness of DCM in ID-care is currently missing.

Objective of the thesis and research questions

The main objective of this thesis was to examine the use and effects of DCM in care for older people with ID and dementia. This resulted in the following research questions:

1. Is Dementia Care Mapping feasible in care for older people with intellectual disabilities and dementia?
2. What is the effect of Dementia Care Mapping on job satisfaction and caring skills of ID-care staff?
3. What is the effect of Dementia Care Mapping on the quality of life and wellbeing of older people with intellectual disabilities?
4. What are the reach, efficacy, adoption, implementation, and maintenance of the first use of Dementia Care Mapping in care for older people with intellectual disabilities?
5. What are the experiences regarding the use of Dementia Care Mapping in ID-care from a professional perspective?

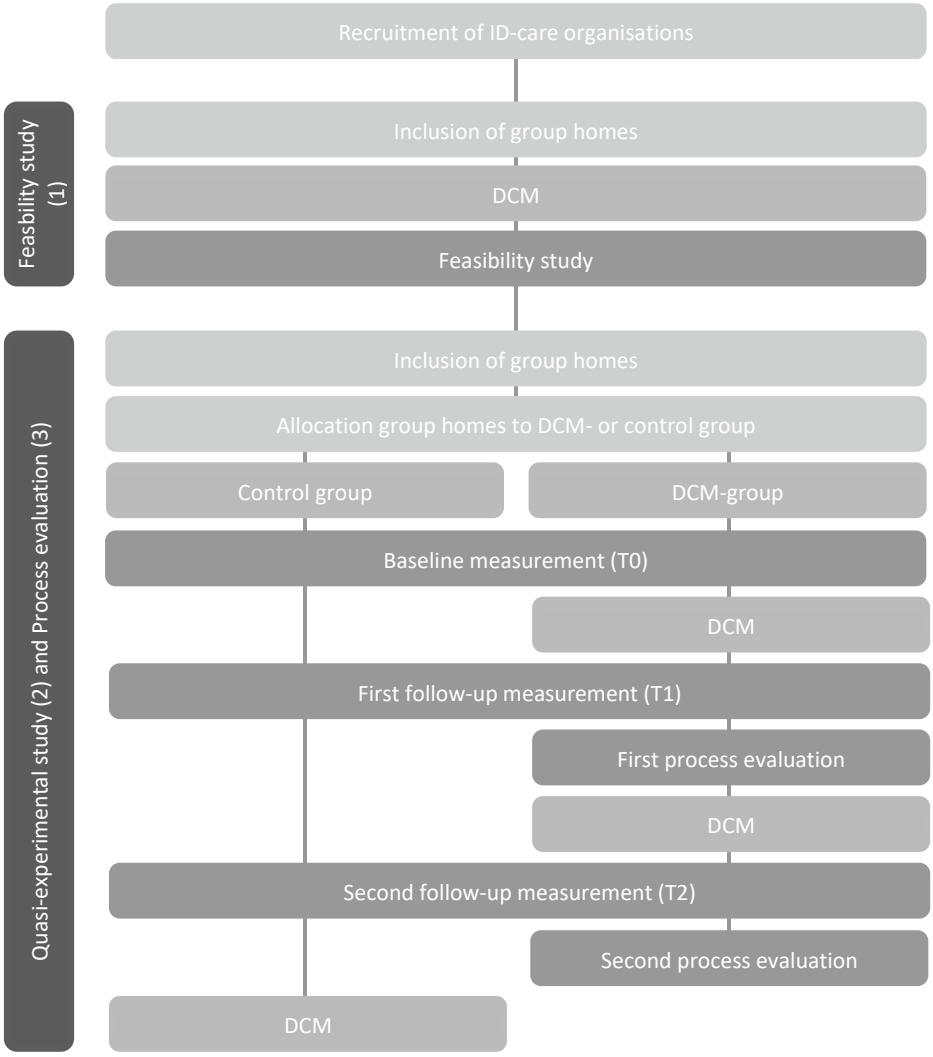

Figure 3. Design of three studies on 'Dementia Care Mapping in the care for older people with ID', as included in this thesis

Design of the study

The thesis is based on three studies regarding DCM: a feasibility study, a quasi-experimental study on effectiveness in professionals and clients, and a process evaluation (Figure 3). We first set up a study to assess the feasibility of DCM in care for older people with dementia (research question 1). We then recruited ID-care organisations aimed at older people and located in the north of the Netherlands, to assess the feasibility of using DCM among staff, using focus groups in two group homes (N=15), and using semi-structured, face-to-face interviews with group home managers (N=2), DCM-mappers (N=2) and DCM-trainers (N=2). We consulted experts from DCM-Netherlands, and DCM-UK (Bradford University), and other experts on DCM, dementia and ID-research to validate our conclusions on the feasibility of DCM in the care for older people with ID and dementia.

Second, we performed a quasi-experimental study comparing DCM with care as usual, using a baseline measurement and follow-up measurements in 23 group homes for older people with ID (research questions 2 and 3). From all care staff involved we collected data on self-reported job satisfaction, person-centred care-skills and quality of dementia care (N=227). Staff were involved in the direct provision of care in these homes, i.e. supporting clients in all aspects of day-to-day life, including activities of daily living (ADL) and day care activities. Moreover, we collected data on all clients living in the group homes (N=224), with or without dementia, regarding their quality of life (QoL) as reported by direct care staff and a close relative.

Third, we set up a process evaluation both to gain insight into the use and implementation of DCM and to examine the experiences of professionals with DCM in ID-care (research questions 4 and 5). We obtained detailed in-depth data from all professional users (N=55), using focus group discussions and face-to-face interviews after each application of the DCM cycle in twelve group homes. We also used these data to report on the experiences of professionals in using DCM in daily care for older people with ID. Moreover, using open and closed questions in the follow up questionnaires in the quasi-experimental study, we collected quantitative data regarding the opinion of staff members on DCM (N=136).

Outline

Chapter 2 describes the results of the feasibility study of DCM in care for older people with ID and dementia (research question 1). Chapters 3 and 4 present the results of the quasi-experimental trial, aimed respectively at the job satisfaction of staff (research question 2) and at the quality of life of older people with ID (research question 3). Chapter 5 describes the process analysis of the first use of DCM in ID-care according to the RE-AIM framework (research question 4). Chapter 6 presents the results of the mixed-method study on the experiences and (dis)advantages of staff and managers with DCM in ID-care (research question 5). Chapter 7 summarises and discusses the main results of the thesis in their broader theoretical and practical context. We also discuss a number of more general methodological considerations for this kind of research. Finally, we reflect on the implications of our findings for practice and for future research.

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Dementia Care Mapping to support staff in the care of people with intellectual disability and dementia: a feasibility study

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CHAPTER 2

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Abstract

Background The number of people with intellectual disability (ID) and dementia increases; this combination causes behavioural changes. Dementia Care Mapping (DCM) supports staff in dementia care in nursing homes, and may be useful in intellectual disability care. This qualitative study examines the feasibility of DCM for older people with ID and dementia.

Method We obtained data in focus groups and interviews with professional users, and analysed using a framework for feasibility studies. With experts in dementia and ID-research, we determined the overall feasibility.

Results DCM was found to be feasible in intellectual disability care, regarding five domains of feasibility. Staff reported DCM to be useful and valuable, and addresses to their demand for skills and knowledge. All professional users found DCM feasible in intellectual disability care, which was confirmed by experts.

Conclusion DCM is feasible in intellectual disability care. When fully tailored to intellectual disability care, DCM is useful, and provides opportunities to assess its effectiveness.

Introduction

The number of people with intellectual disability (ID) and dementia is growing as the life expectancy of people with ID increases. This has a large impact on the lives of people with ID and dementia, their housemates and on their care staff.[1-5] The combination of ID and dementia causes behavioural, emotional and psychological changes and can lead to challenging behaviour like agitation, depression or apathic behaviour, and mannerisms that are hard to grasp.[6-10] ID-care staff expresses a need for knowledge and skills to address the changing behaviour and needs to provide good care and to create a dignified life situation for their residents with dementia;[6,9,11-14] they tend to use an *ad hoc* approach.[11,12,15-17] Therefore, an evidence-based method that provides insights, knowledge and skills for professionals in the care of older residents with ID and dementia is urgently needed, but not yet available.

Dementia Care Mapping (DCM) is a widely used method to support staff working in dementia care in psychogeriatric nursing homes.[18-23] It is promising for staff working with older people with ID, and has a number of characteristics that are innovative for this field: it is a relatively structured psychosocial method, it is based on principles of person-centred care, and it is specifically aiming at people with dementia.[24-27] It is a structured, person-centred, multi-component intervention, designed to improve the quality and effectiveness of care from the perspective of people with dementia.[21,28,29] DCM is an observational tool, based on the social-psychological theory of personhood in dementia of Kitwood,[30] to increase person-centred care of people with dementia, which is explained further in Box 1 (p. 20). DCM aims at different levels: at the individual (residents and caregivers), at the group (care giving teams), and at multi-disciplinary teams and management.[29] Furthermore, person-centred methods, like DCM, are associated with (psychosocial) benefits for both people with dementia (whether or not with ID) and their care staff, by improving the quality of care.[31-35]

Available studies on DCM among people with ID are few and small, but those available yielded promising results. Finnamore and Lord (2007) applied DCM to eight people with both ID and dementia, Persaud (2001) and Jaycock et.al. (2006) studied DCM in 14 people with severe or profound ID but without dementia.[24-26] These studies indicated that those who provide DCM (DCM-mappers) found DCM to be acceptable and practical in ID-care. The authors recommended further use and assessment of DCM in the care of older people with ID, with or without dementia. This recommendation requires confirmation of the feasibility of

DCM in ID-care from a broader perspective, that is, from all professionals involved, being: mappers, staff and management.

The aim of this study is a piloting of DCM to examine whether this method is feasible in the care of older people with ID and dementia in group homes in the Netherlands. In this study feasible means: meeting a five-domain framework derived from the key areas of focus for feasibility studies of Bowen et al. (2009): demand, implementation, acceptability, practicality and adaptation (see Table 1).[36] We assessed DCM's feasibility from different perspectives: from the receivers of DCM (staff and group home managers) as well as from DCM-providers (DCM-mappers and -trainers). Findings were next further attuned to care for people with ID and dementia, based on advice of experts on DCM- and ID- and dementia research.

Methods

Design

We set up a qualitative study to assess the feasibility of DCM in the care of older people with ID living in a small-scaled group home. First, DCM was applied in two group homes for older people with ID, with or without dementia. Next, we evaluated the application of DCM with staff in focus groups and with group home managers, DCM-mappers and DCM-trainers using semi-structured, face-to-face interviews. We consulted experts from DCM-Netherlands, and DCM-UK (Bradford University), and other experts on DCM, dementia and ID-research regarding the design of the study and the interpretation of the results. DCM is an intervention aimed at staff, therefore we focussed in this feasibility study solely on those who provide and receive DCM and not on the residents.

Sample

We collected data from receivers of DCM, being staff and managers, and providers of DCM, being DCM-mappers and DCM-trainers, in two small-scale, residential group homes for older people with ID, randomly selected out of 25 homes. All homes met the criteria to carry out DCM (e.g. to observe four residents simultaneously in communal areas, of whom at least two people with dementia). In each group home eight older residents with ID, of whom three had dementia, were living together, supported in all aspects of day-to-day life, including activities

of daily living (ADL) and day care activities, by vocational trained professionals. All staff working in the group homes participated in the intervention and were invited to participate in a focus group, in each home one focus group. In one home, eight out of 12 staff members, and in the other home seven out of 12, attended the focus group. Staff not participating in the focus groups were absent because of illness or having their work shift at the same time. We also interviewed the managers of both group homes individually, as we did the two DCM-mappers, and the two DCM-trainers involved. In total, we conducted two focus groups and six face-to-face interviews.

Intervention

The intervention in our study consisted of a cycle of DCM in each group home (Box 1, Figure 1; p. 20). First, in each home we trained a staff member to become a certified, advanced, DCM-mapper. We selected a staff member who had the required competences: *e.g.* experienced with older people with ID with and without dementia, having at least a bachelors' degree, and basic knowledge of person-centred care. Next, to maintain independency, these mappers carried out DCM in each other's organisations. The mapping was applied at three different moments to cover all major daily situations: during day-care activities, on a regular midweek afternoon and evening, and on a quiet weekend day. In each mapping session four older residents, of whom three had dementia, were mapped simultaneously. After the mapping, the mapper presented the results in a report and a feedback session to the staff and manager, whereupon staff were able to draw up action plans.

Measures and Procedure

We conducted both focus group discussions with staff, and the face-to-face interviews with group home managers, DCM-mappers and DCM-trainers to ascertain their experience with and opinions of the mapping process and the feasibility and potential of DCM in ID-settings. We set up the design and the contents of the study, and the feasibility based on advice of experts on DCM- and ID- and dementia research, as we did in determining the overall feasibility. The focus group discussions took place within a month and the face-to-face interviews within two months after the application of a full cycle of DCM (see Box 1 and Figure 1). The focus group discussions and interviews were carried out in a semi-structured way,

guided by a topic list, led by a researcher [FDS, GJD] assisted by a researcher taking notes [FDS, ASF, GJD]. The focus groups and interviews all had a length of approximately 1.5 hours, were audio recorded, and next transcribed in full. The topic list was developed by the researchers, a.o. based on observations of a researcher (e.g. about implementation procedure, involvement of team) [FDS] during the introductory briefings and feedback sessions, and points of interest raised by the expert group. The topics addressed the experiences of the users of DCM concerning the demand for DCM, its implementation, acceptability practicality and adaptation (see Table 1). The design, analysis and reporting of the focus group discussions and interviews were performed according to the checklist: Consolidated Criteria for Reporting Qualitative Research (COREQ).[37]

Data Analysis and reporting

First, we assessed and described the background characteristics of staff and the older residents in the group homes where DCM was applied (f.e. educational level, experience). Next, we assessed feasibility using *key areas of focus for feasibility studies* of Bowen et.al (2009),[36] as presented in Table 1. We followed a stepwise procedure: we transcribed verbatim the interviews and contents of the focus groups and analysed them following the principles of conventional content analysis;[38] we used Atlas.ti computer software (version 7.5) (Atlas.ti Scientific Software Development GmbH, Germany). One interviewer [FDS] reviewed the transcripts for completeness and accuracy. Next, the transcripts were forwarded to the DCM-mappers and -trainers involved to check them for completeness. After approval of the contents by the mappers and trainers, two researchers [FDS, ASF] independently read all transcriptions to elicit key topics and the relationships between them. The first author [FDS] set up a concept codebook and discussed it with the second author. Third, both researchers [FDS, ASF] coded three transcripts and compared the coded transcriptions. Based on the outcomes of this comparison we refined, relabelled and regrouped the initial codes until reaching consensus. Then we calculated the Kappa coefficient to check on the inter-observer agreement. According to the criteria of Viera,[39] agreement was substantial (78%. Finally, after coding all transcripts, we identified themes based on several key areas of focus of Bowen et.al (2009) (Table 1). We collected main findings for each theme, separately for DCM-trainers and

mappers (providers), and the staff and their managers (receivers). We reported the results using the areas of focus for feasibility studies, mentioned in Table 1.

Ethical Assessment

The Medical Ethical Committee of the University Medical Centre Groningen did not consider approval necessary for this study (decision M13.146536), because DCM is an intervention aiming at staff. We obtained written informed consent from the legal representatives (i.e., a relative or an administrative person) of the people with ID involved in the study for participating in DCM.

Table 1. Key area of focus for feasibility studies, adapted to this study

Area of focus	*Sample outcomes of interest*	*Participants (N=21)*[1]
Demand	• Perceived demand • Expressed interest or intention to use	Staff Managers DCM-mappers
Implementation	• Degree of execution • Amount, type of resources, and preconditions needed to implement • Factors affecting implementation ease or difficulty • Fit within organisational culture and vision	Staff Managers DCM-mappers DCM-trainers
Acceptability	• Perceived appropriateness • Perceived applicability • Perceived positive or negative effects on organisation	Staff Managers DCM-mappers DCM-trainers
Practicality	• Perceived usability of each component • Positive/negative effects on target participants	Staff Managers DCM-mappers DCM-trainers
Adaptation	• Satisfaction • Perceived added value • Intention to continue use • Suggestions for improvement	Staff Managers DCM-mappers

[1] Staff: n=15, Managers: n=2, DCM-mappers: n=2, DCM-trainers: n=2.
Note. Adapted from "How we design feasibility studies: by: Bowen et al. (2009)[36]

Results

Background

Table 2 presents the background of the staff and residents of both group homes. In both, staff had worked, on average, for more than 10 years together in the same group home. Staff in both homes reported that some of them incidentally received a training in caring for older people with ID, but that most of their current knowledge was practice-based. In each home lived eight older people with ID, of whom three had dementia. The residents had been living together for many years in the same home, some for more than 40 years. In both homes complex care was provided*;* the residents had moderate to severe levels of ID; and had multiple problems, such as syndromes (e.g. Down's, Rett, Prader-Willy), autism, psychiatric diseases (e.g. anxiety disorder, delusional disorder) and/or problems linked to ageing (e.g. dementia, hearing and sight impairment, internal conditions, cancer).

Table 2. Characteristics of participants in the study

		Team 1	Team 2
Staff	Team size	12	12
	Gender (female)	100%	92%
	Educational level (intermediate vocational)	92%	92%
	Experience with target group (years; mean)	20 years	20 years
	Involvement with current residents (years; mean)	15 years	15 years
	Knowledge on people with ID and dementia	Experience based	Most experience based
	Currently used method(s) in group home	Method Urlings[1]	None[2]
	Personalised care[3]	Yes	Yes
Residents	Group size	8	8
	Gender (female)	63%	38%
	Persons with dementia (diagnosed or suspected)	3	3
	Complex care[4]	Yes	Yes

[1] Urlings (2014)[40]

[2] Staff attended several courses on older residents and complex care; no specific method was used in group home

[3] Personalised care: care is adapted to the residents' (physical) needs

[4] Complex care occurs due to low level of functioning (IQ ≤ 50) and multiple problems as a syndrome, autism, psychiatric diseases and/or problems linked to ageing.

Feasibility

Demand

Staff, managers and mappers found DCM useful to address their need for professional competences (insights, knowledge and skills) on dementia and person-centred care. They described their work as increasingly difficult, and mentioned often feeling unable to provide good care to their residents because of the problems associated with ageing. Along with more insights into the behaviour of individual older people with ID and dementia, DCM gave professionals new skills and greater knowledge to deal with dementia and to provide person-centred care.

> *At first we thought he was just being stubborn. (...) For example when someone is much more cooperative and easy going in the afternoon than in the morning. Back then we were like: whether you like it or not, we take showers in the morning. Hoopla. And after DCM we all were like: oh, yeah, ooh. We should not have done this and not have done that… (Staff 1.1)*
>
> *The way of living. Not wanting any medicine. Always struggling with him. When he didn't want to put on his clothes and he lay down naked under the desk. Or chasing him with the shower nozzle. I really will never do that again. (Staff 1.2)*
>
> *Looking back I think, ooh, we should have done things very differently. It was all lack of knowledge. (Staff 1.4)*

Implementation

Both teams applied DCM according to the DCM-implementation protocol,[41] and were strictly monitored and supported by the DCM-trainers. This protocol included descriptions of the DCM-preconditions and every step for applying DCM, which ascertains a similar implementation in both homes.

Carrying out consecutive six-hour mappings of four people in communal areas, as prescribed in the DCM-protocol, was found to be not possible because *residents* had free access to their own apartments and some of them had external day-care activities. After consultation with DCM Netherlands and DCM UK, we decided that for optimal results the mappings should comprise six hours, albeit in two or three parts, with a minimum duration of two hours.

Maybe to restrict it a bit. (…) Cutting [the observation – FDS] into pieces would be an idea. But on the other hand, then you would not observe the unfilled moments. Those also yield a lot of information (...) So I think both. That you observe different things, like an activity, an eating situation, but also an empty moment when nothing is happening. (Mapper 2)

Preconditions

As a part of the implementation, we discussed with DCM Netherlands the degree to which mappers, staff, managers and organisation realised DCM-preconditions,[41] as presented in Table 3. The required preconditions on the mappers' educational level (bachelor) were realised in both group homes. At the level of the teams, one group home had realised more preconditions than the other. For example, regarding the level of commitment to DCM one team was eager to participate for more knowledge, the other team appeared to be hesitant. Commitment by the team and the manager was found decisive for success by the DCM-mappers and -trainers (see Table 3). Furthermore, in one location not all staff members were included in the team's introductory briefing; this caused irritation during the mapping and the feedback session, due to lack of clarity about the intervention. Safety and stability within the teams proved necessary for openness to feedback. One team appeared stable and mutual supportive, but the other team was slightly unstable due to a forthcoming reorganization.

If you want to achieve maximum results from DCM, you should look carefully at the team. People should feel safe. (Manager 2)

At the management level, one group home had realised more preconditions than the other one (see Table 3). One team manager was firmly committed to DCM and took a coordinating role; the other manager was less involved in the team, and let a coordinating staff member manage the implementation of DCM. As both organisations had a vison and/or worked with a method related to person-centred care, no conflicting underlying visions interfered with the implementation of DCM.

The team manager also has a crucial role in this. Manager Y, of course, is very enthusiastic and contributes substantively to the discussion, but you don't see manager X doing that. I thought that was a shame. (Mapper 2)

Table 3. Preconditions to be fulfilled during implementation DCM

Level	Precondition	Fulfilled in group home 1	Fulfilled in group home 2
Mappers	Educational level: ≥ bachelors' degree	✓[1]	✓
	Experienced with older people with ID and dementia	✓	~
	Advanced trained in DCM-method (Inter-reliability in coding ≥ 0.8)	✓	✓
	Met DCM-mapper requirements	✓	✓
	Advanced in Person-Centred Care	~	✓
Staff/Team	Positive attitude towards DCM	~	✓
	Inclusion of all staff members in all sessions (briefing/feedback)	-	✓
	Experience with person-centred care practice	~	~
	Safe and stable team	~	✓
	Open for change in own care behaviour	~	✓
	Trust in team management	-	✓
Management	Firm commitment to DCM	-	✓
	Provision of time and resources to implement DCM	~	✓
	Team manager active and present in team	~	✓
	Team manager coordinating DCM in organisation	~	-
Organisation	Current procedures connect with Person-Centred Care	✓	✓

[1] ✓ = yes, n = no, ~ = partially

Acceptability

Overall, the DCM-mappers and -trainers found DCM acceptable in the care for older people with ID and dementia. They found no major adaptations necessary for its use in ID-care, although the character of ID-care differs from the routine care in nursing homes where DCM normally is applied. For example, unlike in nursing home settings, older residents with ID have during their entire lives been dependent on care, have free access to their own apartments and often have external day-care activities.

> *As a mapper I found it very practical, also being there, talking with the clients, and also the contacts with the staff went very well. It was actually all very doable. (Mapper 1)*

The appropriateness and applicability of DCM in the care of older with ID and dementia was qualified as good. Mappers were able to apply the existing DCM-codes in the care of people with ID, no new codes were required. However, mappers and trainers found

slight differences in the use of DCM in ID-care, compared to the original DCM application. For example: people with ID showed more varying kinds of behaviour. Furthermore, some DCM-codes were used more frequently (i.e. more codes A *(articulation),* B *(borderline),* W (*withstanding*) and T (*timalation: sensory stimulation/interaction*), and some codes were used less (i.e. G *(going back: reminiscence)).* In Mood and Engagement (ME) scores, people with ID were found to be more engaged to objects. Some codes were interpreted differently: e.g. in the use of personal detractions or personal enhancers (PDs/PEs) the PD 'Infantilisation' was found to be easily confused with PE 'Validation' (recognize and support the reality of the resident). Therefore, mappers strongly recommended developing a DCM-manual with codes, case histories and examples from ID-settings. Subsequently, DCM-mappers and trainers reported that the mappers' training needed to include more attention to specific characteristics of care of people with ID.

> *That is also noticeable with hand-rubbing. (…) It is not timalation* [sensory stimulation/interaction -FDS] *and not a feeling. It is purely focused on themselves, the rubbing makes it a code W. This is not how it was described in the handbook, but we discussed with the mappers that it can be a code W, but we need to make that clear. (DCM Trainer 2)*

Practicality

The mappers were able to carry out mappings as intended, except for the six consecutive hours as mentioned above. According to the staff and mappers, the mappings influenced neither their own work nor the usual behaviour of the residents.

The feedback and actions developed based on the observations were perceived as useful and applicable by the staff. Both the staff in general and managers were positive about the use of DCM; it provided new insights into how their residents perceived care, and gave concrete cues for providing individual care, although most inability to provide good care exists during ADL. Moreover, staff indicated that they were surprised and often not being aware of their own caring behaviour, for example that they were speaking childish to their older residents (personal detraction (PD) Infantilisation)) or pushing a wheelchair without warning (PD objectification).

> *These actions can be used immediately. Very practical. (Staff 2.3)*

Yes, because you learn to look more from the client's perspective. What he or she needs. (Staff 2.2)

The points may not always be immediately useful, but you really learn to look in a different way. (Staff 2.6)

By the long observation you discover someone's possibilities. And if you focus solely on problem behaviour or on problems, you will miss that (...). DCM really does help with that. (Staff 1.6)

Adaptation

The receivers of DCM, staff and managers, found DCM adaptable to ID-care, they reported being satisfied and finding that it added value, and they intended to continue the use of DCM. Staff and managers reported that the mappings by an independent mapper were useful and eye-opening by trying to take the perspective of their residents. Beforehand, one team was sceptical about the outcomes, but nevertheless perceived the mapping and feedback as valuable.

I get stuck at times. When things don't go well during care. I noticed that I got new ideas from the DCM meetings, like: I can try again and do it that way. (Staff 2.3)

A bit of an eye-opener, there are still some ways to try that could work out better. I find that very positive. Look at situations differently. (Staff 2.5)

*DCM provides a practical dimension. My staff said: yes, we do work in a person-centred way, but how does that work in daily practice? And I know that staff are convinced that they do work like that. But now you show them whát they do, what they can do differently, and how they can do it. (*Manager 1)

Subsequently, the staff found DCM to have added value for all older residents, independently of whether they had dementia or not. They reported being surprised to see unexpected possibilities in their residents. Moreover, staff mentioned that DCM helped them to apply in practice knowledge gathered previously in courses, and to implement other (person-centred) methods in which they had previously been trained.

> *Previously, I worked with a group of children with severe learning disabilities, and with a PIMD-group. Those were people with very low levels of functioning, not people with dementia, but with a very low level of functioning. (...) If I now look back at the situation with those groups, I think DCM could also be very meaningful there. (Staff 2.6)*

Staff and managers considered the cyclic character of DCM useful and expressed an intention to apply this method in their routine work. Staff, managers and a mapper even suggested expanding the DCM method to include individual observations, so as to focus more on the problems in private areas, as during assisting individual residents in activities of daily life (ADL).

> *I thought it might be better to follow the clients individually. Because at that moment she* [the mapper – FDS] *was alone in the living room, and everything happening at the back of the hallway was impossible to observe. Or, for example, client J., the way she goes to her own room and does all kinds of things there. In there, she is much more on her own, doing things on her own. (Staff 1.6)*
>
> *I think that would add to [*the mapping - FDS*] of the behaviour of client J., because other things are happening there. (Staff 1.1)*

Discussion

We found that DCM is feasible in ID-care for older people with ID and dementia, from the perspective of receivers (staff, managers), providers (DCM-mappers, DCM-trainers) and experts in ID- and dementia research. DCM in ID-care settings was found to meet five aspects of feasibility: it met a demand, was implementable, acceptable, practical and adaptable in ID-care.

Our study showed that DCM is feasible for use in the care of older people with ID and dementia, without major adaptations. According to all professional users (receivers and providers), the method provides for a need, is non-invasive to the residents*;* the observations did not influence the usual behaviour of the residents and of staff, and the results were found of great value for daily care practices. This confirms and extends the findings of Finnamore and Lord (2007), Persaud (2001) and Jaycock et.al. (2006), who assessed DCM in ID-care from

the providers' perspectives only.[24-26] They concluded that DCM is acceptable and practical in ID-care for people with or without dementia.[25,26] They found the mappings to be accurate, although they used observation periods shorter than the prescribed six consecutive hours, and found slight differences in use of DCM-codes (i.e. more codes W (*withstanding*) and T (*timalation*)). Furthermore, our finding of a need for expansion of the mappings in private areas, to complete the picture of the (challenging) behaviour and wellbeing of the residents being mapped, was touched on by Jaycock et al. (2006) from the provider's perspective.[25]

Our observations on demand and preconditions support those of previous studies in different settings. The demand for a method to handle problems associated with the ageing of people with ID (as dementia) we found, is widely reflected in studies of experiences of staff in working with adults and older people with ID.[12,14,16,42-45] Several studies of DCM in nursing home settings reported difficulties similar to ours in fulfilling the DCM-preconditions. These studies concluded that to reach optimal effect of DCM, the implementation requires strong and accurate attention.[19,22,25,33,46-49] Increasing the number of realised preconditions is likely to increase the success of the implementation.[29,46,48] However, as DCM is a multi-component method for application in practice, realising all preconditions is hard to accomplish. Although the realisation of the preconditions was not perfect, this did not obstruct the implementation of DCM in the group homes concerned.

We found the framework of Bowen et.al. (2009) for assessing feasibility also to be applicable regarding ID-care; it confirmed findings of previous studies on health interventions in patients with advanced, incurable diseases and their caregivers, in older hospitalised patients, and in children with autism.[50-53] Moreover, we were able to apply all five aspects of Bowen's framework, whereas the previous studies usually addressed only some of them. Bowen's framework thus seems to be fully applicable to ID-care, leaving to be answered whether that also holds for various other types of care.

Strengths and limitations

A key strength of this study is our use of a multi-informant design to examine the use of DCM in ID-care settings. Informants were receivers of DCM (staff and managers) and providers (DCM-mappers and -trainers), with confirmation by experts in dementia- and ID-research. Previous studies focussed mainly on the providers' perspective. Second, we used a

comprehensive framework for feasibility studies, which allowed us to examine the feasibility of DCM in ID-care in its broadest sense. Results of the previous studies of DCM in ID-care related mostly to the domains of acceptability and practicality. Third, we addressed the feasibility of DCM in routine ID-care practice, thereby enhancing the validity of our findings for routine practice.

Limitations of this study align with the pilot character of the study but should also be noted, the first being its small sample size and the full reliance on qualitative reports, which does not allow inferences on the effects of DCM. Second, each of the two randomly selected group homes had its own vision, culture, team characteristics, and habits in care. This provides a realistic representation of the implementation of DCM in actual ID-care practice, but generalisability to other settings remains to be investigated.

Implications

We found DCM to be feasible in the care of older people with ID and dementia, and allows for wider implementation of DCM in ID-care. It implies a next step to assess DCM's effects on the job satisfaction and quality of care of ID-care staff and its effects on the quality of life of older people with ID.[18,20,21,34,54] The method therefore needs to be tailored fully to ID-care: by means of small modifications in case histories, examples and behavioural category codes in the manual. Difficulties with fulfilling DCM-preconditions should be addressed, for example by fulfilling an agreed minimal number of conditions before implementing. In any case, we identified a demand of staff, mappers and managers, for a version of DCM with individual observations in private areas or during ADL; this should be considered, and if developed, followed up in a study. A major point of interest in this should be the adherence to the core values of DCM and person-centred care and the compliance of the adapted version to the prevailing ethical principles.

Conclusion

DCM is a feasible method in the care of older people with ID and dementia. It meets a strong demand for a method to support staff in caring for older people with ID, and was found to be implementable, acceptable, practical and adaptable in ID-care from different perspectives:

staff, managers, DCM-mappers and DCM-trainers. No major adaptations are needed to tailor DCM to ID-care settings; only small modifications in DCM-codes and examples and smaller observation periods are required, due to the different character of care in ID-settings. DCM can help care staff to provide adequate, person-centred, support for the growing group of older people with ID and dementia.

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Effects of Dementia Care Mapping on job satisfaction and caring skills of staff caring for older people with intellectual disability: a quasi-experimental study

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CHAPTER 3

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Abstract

Background The ageing of people with intellectual disability (ID), involving consequences like dementia, creates a need for methods to support care staff. One promising method is Dementia Care Mapping (DCM). This study examined the effect of DCM on job satisfaction and care skills of ID-care staff.

Methods We performed a quasi-experimental study in 23 group homes for older people with ID in the Netherlands. Among staff we assessed job satisfaction and care skills as primary outcomes, and work-experience measures as secondary outcomes (N=227).

Results DCM achieved no significantly better effect than care as usual (CAU) for primary outcomes on job-satisfaction (MWSS-HC) and working skills (P-CAT). Effect sizes varied from -0.18 to -0.66. We also found no differences for any of the secondary outcomes.

Conclusion DCM does not increase job satisfaction and care skills of staff caring for older people with intellectual disabilities. This result differs from previous findings and deserves further study.

Background

The ageing of the population with intellectual disability (ID) is accompanied by an increased risk of dementia, and creates a need for methods to support ID-care staff in their daily work.[1,2] Dementia leads to a wide range of changes in memory, functional capacity, communication, neurology, personality, and behaviour, and can result in agitation, resistance, depression and apathy.[3-6] These responses have a great impact on the lives of the people with ID, their housemates, and their care staff.[7-11] This a potential challenge to ID-care staff, who often lack the knowledge and skills to adapt to the changing behaviour, responses, and needs of their clients.[1,12-14] This lack can lead to low job satisfaction, stress, and burnout,[15-20] and creates a strong need for an evidence-based method to help professionals to appropriately support their ageing clients.[2,13,21,22] Such methods can be derived partly from standard geriatric and dementia care, as, for example, the use of person-centred approaches.[23-25]

Person-centred methods have been associated with improved quality of care, resulting in (psychosocial) benefits for both the people with dementia and their care staff.[26-31] Person-centred care includes valuing the person, using an individual approach that acknowledges the uniqueness of the person, making an effort to understand the world from the perspective of the person, and providing a supportive social environment (VIPS);[32] Organisations which perform well in person-centred care create more productive interactions between healthcare professionals and clients, leading to a decrease in negative responsive behaviour of clients.[33,34] Furthermore, person-centred methods have been shown to improve quality of care, thereby increasing the wellbeing of older people with ID, and contributing to job satisfaction of care staff.[6,28,33,35]

One such person-centred method is Dementia Care Mapping (DCM). This method supports dementia-care staff working in psychogeriatric nursing homes, to improve the quality and effectiveness of care for people with dementia (see Box 1; p. 20).[36] DCM is an intensive observational tool used within a cycle of practice development in care settings, and simultaneously an approach to achieve and embed person-centred care for people with dementia.[37] DCM prepares staff to take the perspective of the person with dementia in assessing the quality of the care the staff provide. It is designed to empower teams to engage in evidence-based critical reflection in order to improve quality of care at the individual level (clients and care staff), group level (staff and multidisciplinary teams), and management level,

claiming that such improvement leads to higher job satisfaction of care staff.[36,37] A number of studies on DCM in nursing home settings found that it leads to less agitation, affective problems and verbal agitation in people with dementia,[26,38] and that it benefits for staff by improving caring skills, leading to increased job satisfaction, which includes a direction of decreased stress and risk of burnout.[26,39,40] Barbosa et.al (2017) concluded in their review on the effects of DCM in dementia care that the method reduced stress and burnout among nursing home care staff.[40] Jeon (2013) and Van de Ven (2012) found over time a greater decline in stress and emotional exhaustion, fewer negative emotional reactions (such as nervousness), and more positive reactions (such as optimism), among staff in the DCM group than in the control group, although this was not a significant difference.[37,39] Van de Ven also found that, over time, staff in the DCM group were slightly more satisfied with their job than the control group, although this was not significant either.[37]

In ID-care DCM has as yet been little used, but has been found promising in providing good care for older people with ID - whether or not with dementia.[41-44] DCM was shown to be feasible for people with ID, with and without dementia, after tailoring case histories and examples to ID-care, but without altering the core DCM-principles and DCM-codes.[41,45] Nevertheless, evidence on its effectiveness is lacking.[41,45] The aim of this study is therefore to examine the effect of DCM on the job satisfaction and (person-centred) working skills of staff caring for older clients with ID.

Methods

Study design

Between November 2014 and April 2016 we performed a quasi-experimental study comparing DCM with care as usual, using a baseline measurement and follow-up measurements after 7 and 14 months.

Study setting and participants

We performed a two-stage sampling, first sampling ID-care organisations, and next assigning homes per organisation to either the DCM or the control condition. First, we approached six ID-care organisations with group homes for older clients in the north of the Netherlands; all

were willing to participate (100%). Second, each organization provided four group homes for the study. In a group home, a small number (range 4 to 12) of older people with ID live together and receive care, support, and supervision by care staff. In these group homes 55% of the clients had a diagnosis or strong suspicion of dementia. We collected data from all care staff involved in the direct care process in these homes, i.e. those who supported residents in all aspects of day-to-day life, including activities of daily living (ADL) and day care activities.

Inclusion criteria for the group homes regarded: the possibility to observe four people simultaneously in a public area for at least two consecutive hours, the presence of at least three older people with (a strong suspicion of) dementia, and a stable team without an anticipated reorganisation. We balanced the representation of organisations between the control and intervention groups by allocating, of the four group homes per organisation, two homes to the intervention group and two homes to the control group. Allocation of a group home to the intervention or control group depended on the geographical distance between the mapper and the home, as well as sufficient geographic distance between control and intervention group homes to prevent contamination.

Intervention

The intervention consisted of two applications of a full DCM-cycle (Box 1; p. 20) per group home, using the DCM-in-ID version, with an interval of six months. In this cycle the managers of each participating group home first selected a staff member with the required competences to become a "DCM-mapper" (i.e., a trained observer). DCM Netherlands trained these twelve staff members to an advanced DCM-level, meaning that they were able to carry out DCM: to observe (map) with an inter-rater reliability agreement of at least ≥0.8, report, provide feedback, and instruct and support in drawing up action plans.[37] Second, a DCM-trainer and a mapper jointly provided the DCM organisational introductory briefing in the group home. Third, the mappers carried out two full DCM-cycles, consisting of a 6-hour structured observation, feedback and action planning. A full cycle includes the following steps. First, the mappers observe four clients for 4 to 6 consecutive hours in communal areas in a group home. The results of the observation are reported to the staff, in order to help them understand clients' behaviour in the context of their lives and their care.[46] The feedback is intended to increase insights and awareness of staff as to their own and clients' behaviour, as well as staff-

client interactions.[37] A researcher observed the feedback sessions, for the evaluation of the process of DCM. Based on the feedback, the staff make action plans to improve care at individual and group levels, by improving their own competences, performance and interactions. The application of DCM was in close cooperation with the DCM-trainers, to guarantee accurate implementation; the DCM-trainers checked the reports and jointly provided the feedback with the DCM-in-ID mappers. The action plans were sent to the mappers and DCM Netherlands. To maintain independence and to avoid interpretation bias due to familiarity with habits, clients and colleagues, the mappers carried out DCM in each other's organisations. More detailed information on the DCM procedures is provided in Box 1 (p. 20).

The DCM-trainers strictly monitored the intervention and supported the newly trained mappers in carrying out DCM following the DCM-in-ID implementation protocol,[47] which includes a description of all DCM-preconditions and of every step needed to implement DCM in ID-care.[47] This protocol ensured that DCM was implemented and applied similarly in each group home and enabled a comparison of the group homes, even though these differed in (staff-team) size, number of residents, culture and approach.

Control condition

The control condition was care as usual (CAU): continuous care with use of regular services (support in all aspects of day-to-day life, including activities of daily living [ADL] and day care activities) but no DCM. After the study period the control group homes were offered a DCM-training day upon which DCM could be implemented.

Procedure

We collected data from all care staff at three time points: at baseline, and after 7 and 14 months (i.e. three months after each application of DCM in the intervention group). Staff could choose to fill in the questionnaire on-line or on paper. Personal details were anonymised by giving each staff member an identification number.

Outcome measures

Primary outcome measures were self-reported job satisfaction, person-centred care-skills and quality of dementia care. We measured job satisfaction of care staff with the *Maastricht Work Satisfaction Scale in Health Care* (MWSS-HC). This is a validated and reliable questionnaire which relates best to previous studies of care staff in various settings. It has also been used in studies of DCM in nursing home settings.[26,48] The MWSS-HC is a 21-item questionnaire using a five-point Likert scale response format, from 'very dissatisfied' (1) to 'very satisfied' (5). All items relate to the job satisfaction of health care workers, divided into seven subscales of three items each, regarding satisfaction with: the manager, promotion possibilities, quality of care, opportunity to grow, contact with colleagues, contact with clients, and clarity of the task. Scores are the mean of all items, with higher scores denoting greater job satisfaction. Table 1 provides further (psychometric) details on this questionnaire. We assessed person-centred care skills and quality of dementia care, first measuring the level of the provided person-centred care with the *Person-Centred Care Assessment Tool* (P-Cat);[49] and second, with the *Sense of Competence in Dementia Care Staff Scale* (SCIDS).[50] The P-CAT is an assessment scale whereby care staff can rate to what extent care is person-centred. It is a validated scale, consisting of 13 items formulated as statements about the presence of person-centredness in the group home (see Table 1). A five-point scale ranging from 1 (disagree completely) to 5 (agree completely) is used for scoring. Items 8–12 are negatively worded and the responses have to be reversed before analysis. The three subscales focused on personalising care (seven items), organisational support (four items), and environmental accessibility (two items). The scores are the means of all items; higher scores indicate more person-centred care in the group home. The SCIDS measures the sense of competence of care staff in dementia care. This is a validated questionnaire containing 17 items with a 4-point Likert-scale (see Table 1). All items are scored from 1 (not at all) to 4 very much). Higher scores denote a greater level of sense of confidence. Scores are added up for items from 1 to 17 for the overall SCIDS score; higher scores indicate a higher level of confidence in dementia care. Subscales include: professionalism (five items), building relationships (four items), care challenges (four items), and sustaining personhood (four items). We translated the SCIDS using a standard forward-backward method.[51,52] Two independent translations into Dutch (by two authors) were combined into a single version. A native English speaker, fluent in Dutch and with a medical

background, translated this provisional Dutch version back into English. In case of deviations from the original English version, the Dutch translation was revised. This occurred in only a few cases, as the back translation was found to be nearly identical to the source text.

Secondary outcome measures regarded possible explanatory variables for job satisfaction and care skills, being: self-reported self-esteem, professional efficacy, commitment to work, work perception and provision of person-centred care. We measured self-esteem with the *single-item self-esteem scale* (SISE), a single item on a 5-point Likert-scale.[53] The wording of the SISE is: "Please indicate to what extent the following statement applies to you: *I have high self-esteem".* In various studies, the SISE was shown to be a reliable and valid instrument for measuring global self-esteem.[54-57] The SISE was also translated according to the forward-backward method. We assessed commitment to work with the validated *Utrecht Commitment Scale* (UWES-9; see Table 1). Its items are scored on a 7-point-Likert scale ranging from 0 (never) to 6 (always). The subscales vitality, dedication, and absorption all contained three items. Scores are the mean of all items, and higher scores indicate a higher commitment to work. To gain deeper insight into the dedication of ID-care staff, we added two items from the *dedication* subscale of the UWES-15.[58] We assessed professional efficacy using the subscale 'professional efficacy' from the *Utrecht Burn Out Scale* (UBOS; the Dutch equivalent of the *Maslach Burnout Inventory*).[59,60] We chose to use this subscale exclusively because its contents fitted the objectives of DCM, in contrast to the other parts of this measure. Professional efficacy was measured using a 7-point-Likert scale from 0 (never) to 6 (always). Its score is the mean of all items, higher scores denoting a higher professional efficacy. We measured work perception with the Work Perception scale, which contained questions regarding pleasure, contentedness and feelings regarding work.[61] This is a three-item, five-point Likert-scale from 1 (disagree completely) to 5 (agree completely). The mean of the score indicates the work perception of the staff member, with higher scores indicating a more positive work perception (see also Table 1). Lastly, we measured provision of person-centred care provided by staff, using questions from the *Care fit for VIPS* assessment tool. This tool is based on principles for this type of care, as specified by Brooker,[62,63] aspects which were not covered by the other questionnaires. We selected questions to measure change in time regarding this care. These questions were translated following the forward-backward method.

Table 1. Properties of used outcome measures

Name	Internal consistency	Inter-rater reliability	Test–retest reliability	Mean (SD)	Validated for care staff	Nr questions/ answers	Separate use of sub-scales	Responsive to change	Previous use in DCM research	Domains/subscales
MWSS-HC[a,c]	$\alpha \geq 0.84$	$r \geq 0.50$	N/A	3.43 (0.39)	✓	21/5	✓	✓	✓	Job satisfaction *Subscales: satisfaction with* *- the manager* *- promotion possibilities* *- quality of care* *- opportunity to grow* *- contact with colleagues* *- contact with clients* *- clarity of task*
P-CAT[a,d]	$\alpha \geq 0.83$	$r \geq 0.82$	$r \geq 0.82$	2.53 (0.54)	✓	13/5	✓	✓	✓	Person-centred care *Subscales:* *- extent of personalizing care* *- amount of organizational support* *- degree of environmental accessibility*
SCIDS[b,e]	$\alpha \geq 0.91$	$r \geq 0.74$	$r \geq 0.73$	55.63 (7.48)	✓	17/4	✓	✓	✓	Sense of confidence in dementia care *Subscales:* *- professionalism* *- building relationships* *- care challenges* *- sustaining personhood*
SISE[b,f,g]	*N/A*	$r \geq 0.88$	$r \geq 0.75$	3.5 (1.1)	✓	1/5		✓		
UWES-9[b,h]	$\alpha \geq 0.93$	$r \geq 0.65$	$r \geq 0.46$	3.74 (1.17)	✓	9/7	✓	✓		*Subscales:* *- vitality* *- dedication* *- absorption*
Dedication	*$\alpha \geq 0.92$*	*$r \geq 0.65$*	*$r \geq 0.69$*	*3.91 (1.31)*	✓	*5/7*				
Professional efficacy[b,i]	$\alpha \geq 0.83$	*$r \geq 0.90$*	*$r \geq 0.86$*	4.87 (1.61)	✓	6/7		✓	✓	Professional efficacy
Work Perception[b,j]	$\alpha \geq 0.77$	*N/A*	r ≥ 0.52	3.65 (1.04)	✓	3/5		✓		Work perception
VIPS[b,k]	*N/A*	*N/A*	*N/A*	*N/A*		20/5	✓	✓		*Used subscales (partly):* *- quality assurance* *- communication* *- empathy and acceptable risk* *- challenging behaviour as communication* *- recognising and responding to change* *- inclusion* *- validation* *- warmth*

[a] Primary outcome; [b] Secondary outcome; [c] Landeweerd, et al., 1996; Rövekamp, et al., 2009 [d] Edvardsson et al, 2010, [e] Schepers et al., 2012 [f] Robins et al., 2001 [g] Internal consistency cannot be computed for a single-item scale. [h] Schaufeli & Bakker, 2004a; Schaufeli & Bakker, 2004b, [i] Subscale of UBOS/Maslach Burnout Scale: Schaufeli & Van Dierendonck, 2000; Schaufeli, et al., 2001; Schutte, et al, 2000, [j] De Jonge, 1995; De Jonge et al., 1995, [k] Brooker, 2011Derived from: care fit for vips assessment tool: https://www.carefitforvips.co.uk

Sample size

We determined sample size based on the MWSS-HC as primary outcome. To measure an effect size of 0.5 (i.e., a 0.2 point increase in the MWSS-HC),[37,64] given a mean of 3.50 and a Standard Deviation (SD) of 0.40, at alpha = 0.05 (two-sided) and power = 80%,[65] we needed twelve staff in each group (intervention group and control group). With adjustment for an estimated `loss to follow-up' of 25%, we needed to include 2 x 16 staff in the study.

Data analysis and reporting

First, we described the flow of participants. Second, we assessed the baseline characteristics of the staff in each research group. The differences between the two groups were tested using Pearson Chi-square tests for categorical variables and one-way analysis of variance (ANOVA) for continuous variables. Third, we compared the differences in change in time between the DCM and the CAU groups. We assessed the effects of DCM using intention to treat (ITT) analyses after the first DCM-cycle (T0 to T1) and after the second DCM-cycle (T0 to T2); all staff were analysed regardless of whether or not they had completed the intervention and any post-intervention questionnaire. For analysis we used multilevel mixed-effect model techniques in which the time points were the first level (L1), the care staff the second (L2), and the group homes wherein care staff are nested, the third (L3). We performed analyses using the unconditional means model.[66] For each outcome we calculated effect sizes for the differences in change between both groups.

We repeated these analyses with adjustment for covariates seen to have a significant influence on the intercept in the conditional means model, to examine whether this led to a major change in the outcomes. These covariates regarded age, gender, whether staff had been trained in person-centred care, and the number of years of experience in the current group home We further adjusted for the percentages at group-home level of people with profound and severe ID, and for the percentage of people with a diagnosis of dementia.

Finally, we performed a complete case analysis for the T1-T0 and T2-T0 comparisons. As an additional analysis we repeated these analyses, excluding subscales that DCM not could influence. These were three subscales of MWSS-HC: "being satisfied with the manager", "the possibilities to gain promotion", and "growth in the organisation". This also applies to one subscale of P-CAT, "environmental accessibility".

Analyses were performed using IBM SPSS Statistics version 25.0, and MLWin version 2.35. Our report followed the CONSORT-checklist.[67]

Ethical permission

The Medical Ethical Committee of the University Medical Center Groningen considered approval unnecessary (decision M13.146536), because DCM is an intervention aimed at staff. Written informed consent was obtained from representatives of the people with ID involved in the study. The trial has been registered in the Dutch Trial Register, number NTR2630.

Results

Participant flow

Figure 2 shows the flow of staff through the study. We collected data from all staff involved in each group home. In total, 221 filled in the baseline measurement, 127 in the intervention group and 94 in the control group. Overall, 136 staff in the intervention group and 106 staff in the control group completed a questionnaire on at least one time point (Figure 1). For complete case analysis we included 92 staff in the intervention group and 62 in the control group.

Background characteristics

Staff in the intervention and control groups did not differ regarding any background characteristics (Table 2). At group-home level the percentage of clients diagnosed with dementia in the DCM group was significantly higher than in the CAU group (Table 2).

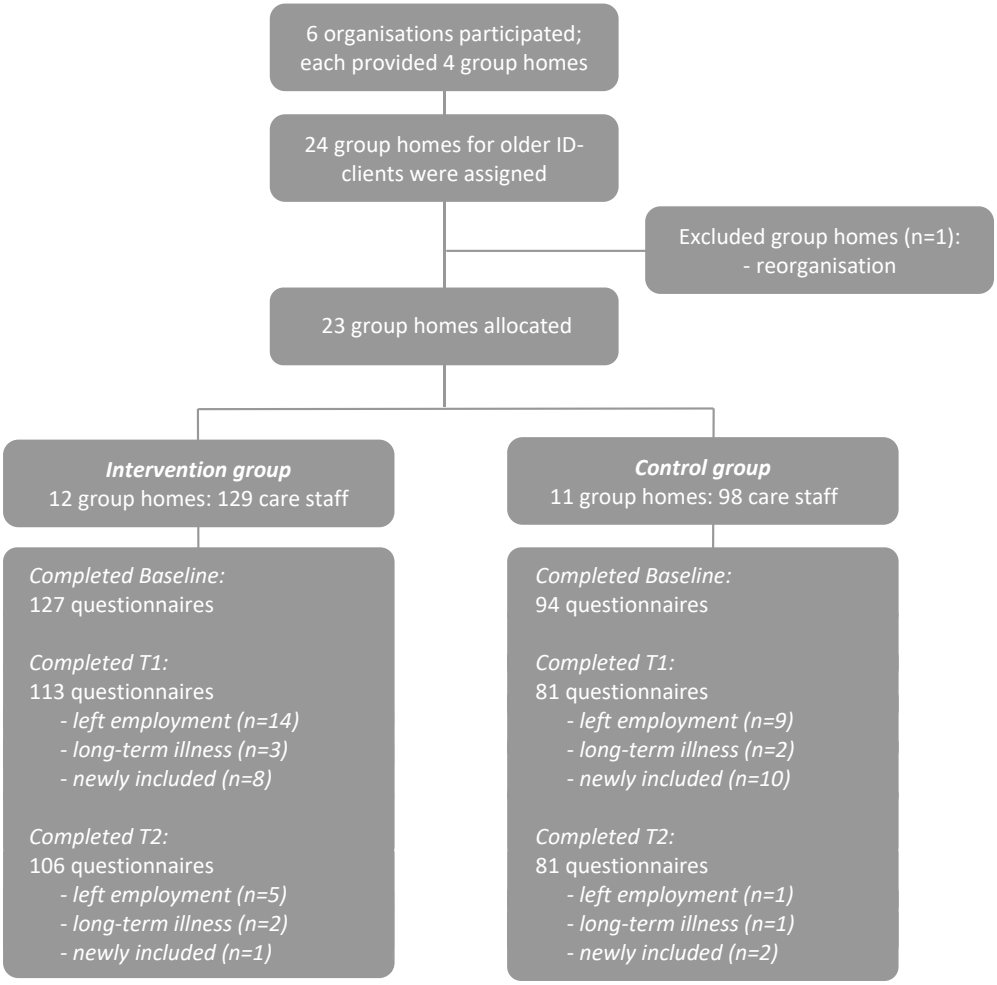

Figure 1. Flowchart detailing numbers of group homes and staff members by condition.

Table 2. Background characteristics staff and group homes

Staff	DCM	CAU	*p-value*
N	127	94	
Mean age in years (SD)	45 (12.4)	44 (12.1)	*0.68*
Female (%)	90	90	*0.50*
Education			
Elementary/secondary education (%)	9	9	*0.74*
Secondary vocational education (%)	80	77	
Higher professional education (%)	11	13	
Position			
Daily care professional (%)	63	69	*0.36*
Senior-/coordinating care professional/personal coach (%)	32	30	
Permanent employment (%)	90	93	*0.81*
Hours/week (mean)	23	24	*0.84*
Experience			
>11 years in ID-care (%)	69	61	*0.29*
>11 years in current group home (%)	32	24	*0.59*
Experienced with person-centred care (%)	84	79	*0,70*
Education of older ID-clients (%)	76	69	*0.23*
Psychosocial approach/method in group home (%)	71	71	*0.92*
Group homes	**DCM**	**CAU**	***p-value***
N	113	111	
Mean age in years (SD)	67 *(11.3)*	65 *(12.4)*	*0.38*
Female (%)	43	56	*0.05*
Mean years in current organisation (*SD)*	31 *(15.6)*	27 *(13.8)*	*0.05*
Mean years in current location (SD)	8 *(5.9)*	10 *(8.2)*	*0.033*
Clients with degree of disability			
Mild (%)	21	31	*0.004*
Moderate (%)	49	56	
Severe/Profound (%)	31	13	
Clients with dementia			
Diagnosed (%)	35	17	*0.003*
Suspicion/Signs of (%)	29	29	

Effects on primary and secondary outcomes

Table 3 presents the effects of DCM compared to CAU. Between groups we found no differences in change regarding any of the primary outcomes (MWSS-HC, P-CAT and SCIDS), between T0 and T1, and between T0 and T2. Effect sizes varied from -0.18 to -0.47 for T0-T1, and from -0.30 to -0.66 for T0 to T2. Regarding the secondary outcomes we also found no differences between T0 and T1 and T0 and T2. Effect sizes varied from 0.08 to -0.29 for T0-T1, and from -0.03 to -0.17 for T0 to T2.

Table 3. Raw means at T0, T1 and T2, based on intention to treat analyses with mixed multilevel models (n=227)

Outcome	Group	T0 (Baseline)		T1 (Three months after 1st DCM cycle		Difference in improvement T0 to T1 between DCM and CAU			T2 (Three months after 2nd DCM-Cycle		Difference in improvement T0 to T2 between DCM and CAU		
		Mean[a]	SD	Mean[a]	SD	Dif[b]	*p-value*	Effect size	Mean[a]	SD	Dif[b]	*p-value*	Effect size
MWSS-HC	DCM	3.88	0.40	3.86	0.35	-0.07	*0.67*	-0.18	3.80	0.37	-0.11	*0.52*	-0.30
	CAU	3.87	0.37	3.91	0.33				3.90	0.38			
P-CAT	DCM	3.85	0.46	3.69	0.42	-0.21	*0.48*	-0.47	3.66	0.35	-0.29	*0.42*	-0.66
	CAU	3.77	0.48	3.83	0.45				3.88	0.44			
SCIDS	DCM	52.53	8.35	53.89	7.36	1.87	*0.55*	0.24	53.41	7.75	-0.23	*0.10*	-0.03
	CAU	53.68	7.55	53.17	7.38				54.79	6.74			
SISE	DCM	4.16	0.67	4.15	0.60	-0.19	*0.12*	-0.29	4.18	0.66	-0.06	*0.33*	-0.10
	CAU	4.00	0.69	4.19	0.71				4.09	0.60			
UBES9	DCM	5.72	0.90	5.68	0.85	0.16	*0.21*	0.18	5.65	0.84	0.11	*0.12*	0.13
	CAU	5.70	0.87	5.49	0.87				5.52	0.84			
Professional Efficacy[e]	DCM	5.70	0.84	5.82	0.79	0.23	*0.89*	0.28	5.75	0.76	0.13	*0.31*	0.16
	CAU	5.79	0.78	5.68	0.83				5.71	0.74			
Work Perception[e.f]	DCM	0.00	0.94	-0.03	0.88	-0.09	*0.67*	-0.10	-0.06	0.93	-0.15	*0.98*	-0.17
	CAU	-0.02	0.76	0.04	0.86				0.07	0.82			
VIPS[e]	DCM	0.00	0.59	0.02	0.53	0.05	*0.84*	0.08	-0.01	0.62	-0.02	*0.63*	-0.04
	CAU	0,00	0,58	-0,03	0,60				0,01	0,60			

[a] Raw mean scores on the different outcome measurements; [b] based on mixed model techniques, expressing differences in change between DCM and CAU in outcomes; [c]: effect size (Cohen's d); [d] primary outcome; [e] secondary outcome. [f] Based on Z-scores; DCM: intervention group; CAU: control group – care as usual.

Adjustment for covariates did not notably affect findings; effect sizes on the primary outcomes with adjustment for covariates varied from -0.16 to -0.30 for T0 to T1, and from -0.05 to -0.52 for T0 to T2, and for the secondary from 0.07 to -0.30 for T0 to T1, and from -0.04 to -0.16 for T0 to T2. The complete case analysis yielded similar findings. Additional analyses with exclusion of less relevant subscales of MWSS-HC and P-Cat also did not affect findings.

Discussion

The lack of effect of DCM on job satisfaction and working skills seems to contradict promising findings in earlier studies on DCM in ID-care.[41,42,44,45] This contrast between our study and previous ones may be explained in several ways. First, staff scored high at baseline in all outcomes, except for competence in dementia, leading to a ceiling effect in measuring effects. Regarding job satisfaction (MWSS-HC), the participants scored one standard deviation higher than the norm population.[64] Also regarding person-centred working skills (P-Cat) and the secondary measures self-esteem, professional efficacy, and commitment to work, the participants scored high at baseline compared to the norms.[49,53,58-61,68] This may be because secondary vocational trained professionals are less accustomed to reflect on their own job performance and may base their answers on a (high) self-imposed standard.[69,70] Moreover, our finding of high engagement, involvement and dedication on the part of ID-care staff aligns with findings of previous studies among care professionals who have built long-term caring relationships with their clients. This largely differs from many other (dementia) care settings.[13,71-73] Such high self-esteem, and commitment to work may cause overestimation of their performance possibilities, reflected in taking on overly demanding responsibilities and refusing to admit mistakes in their jobs.[74-78] Moreover, an increased level of confidence is not necessarily consistent with an increased level of knowledge.[79,80]

Second, in our study DCM was carried out by ID-care professionals newly trained in the intervention, which may have weakened the intervention. Previous research has stressed the importance of strict adherence to the DCM-implementation protocol.[81-83] However, the strict monitoring of intervention fidelity in this study makes this explanation less likely.[41]

Moreover, the two previous studies to assess the effect of DCM on dementia care staff both made use of experienced mappers, but offering either one or two DCM-cycles with newly trained mappers.[37,39] None of them found significant effects on job satisfaction and care skills, but they found improvement of negative work experiences.[37,39,40]

Third, DCM may simply not lead to better job satisfaction. As in previous studies, we have connected our outcome measures to the claim that DCM increases job satisfaction. Studies on DCM that aimed at dementia care staff found improved caring skills, leading to increased job satisfaction, which included a tendency of reduced stress, burnout, and emotional exhaustion as well as less negative and more positive reactions to clients, although this was not significant.[40] DCM may thus indirectly improve some negative work experiences but its effects may be too weak to improve job satisfaction. This applies even more to the paradigm-shift towards person-centred care in the entire organisational culture.

Strengths and limitations

Our study had a number of strengths. First, we used a version of DCM already adapted to ID-care.[45] Next, our study had a large sample size, participants from a wide range of organisations, an independent data collection, ample strategies to avoid contamination and bias, a comparable control group, and a long follow-up of one year with two follow-up measurements. Furthermore, our study had low loss to follow-up.

Nevertheless, we must also note limitations. First, by using self-report questionnaires we relied fully on self-report by staff; this may have led to information bias and a less accurate measurement of change. In our study, self-reported scores at baseline were rather high and may have caused a ceiling effect, even though the outcome measures were valid and sensitive for this group. This ceiling effect may have limited the potential to measure the effects of DCM. Second, the intervention and control groups differed regarding some background characteristics. These regarded a greater severity of the disability and a higher prevalence of dementia diagnoses in the DCM-group. However, adjustment for these differences did not affect the findings. Third, the new ID-mappers were trained using a not yet fully adapted version of ID-care, although in a pilot this version had been shown to be adequate.[45] Furthermore, we have accomplished integrity checks of the products of the observation, i.e. the reports and action plans, but not of the observation process itself. We

thus cannot be fully sure of correct implementation of DCM, but the products at least had reached an adequate level. Moreover, a process analysis of the implementation of DCM in the group homes showed that this was in accordance with the DCM-in-ID protocol, and the fidelity to this protocol was strictly monitored and supported by DCM-trainers.[41]

Implications

In this first implementation of DCM in ID-care, we found no evidence that DCM increases job satisfaction, (dementia/person-centred) working skills and knowledge of ID-care staff, making it questionable whether DCM should be implemented to improve these issues. Yet prior and qualitative studies provided strong indications that person-centred care, with methods such as DCM, does improve care by enhancing the knowledge and skills of ID-care staff.[33,45,84,85] Further research is needed to elucidate this discrepancy, e.g. by in-depth interviews with participating ID-staff or direct observation, and by including more stressed staff to e.g. a lower staff/resident ratio. The effects of DCM on outcomes of older people with ID, such as quality of life, should also be examined as this may provide more proximal measures. Moreover, different outcome measures that are more closely related to the intervention such as quality of care and quality of staff-client interactions should be included. Finally, a longer follow-up period may be useful, as a transition to more person-centred care may require more time than provided by the follow-up of our study. The promising option of DCM in ID-care thus deserves further study.

Conclusion

Contrary to previous studies that reported that DCM and person-centred care provide (ID-) staff greater knowledge and skills in providing dementia care, we found no evidence that DCM increases their job satisfaction and dementia- and person-centred working skills. This discrepancy requires further study.

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Effects of Dementia Care Mapping on wellbeing and quality of life of older people with intellectual disability: a quasi-experimental study

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CHAPTER 4

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Abstract

Background The ageing of people with intellectual disability (ID), accompanied with consequences like dementia, challenges ID-care staff and creates a need for supporting methods, with Dementia Care Mapping (DCM) as a promising possibility. This study examined the effect of DCM on the quality of life of older people with ID.

Methods We performed a quasi-experimental study in 23 group homes for older people with ID in the Netherlands, comparing DCM (n=113) with care-as-usual (CAU; n=111). Using three measures, we assessed the staff-reported quality of life of older people with ID.

Results DCM achieved no significantly better or worse quality of life than CAU. Effect sizes varied from 0.01 to -0.22. Adjustments for co-variates and restriction of analyses to people with dementia yielded similar results.

Conclusion The finding that DCM does not increase quality of life of older people with ID contradicts previous findings and deserves further study.

Background

In the past few decades the lifespan of people with intellectual disability (ID) has greatly increased. In this population age-related conditions like dementia are experienced earlier and are more prevalent than in the general population.[1,2] Moreover, pre-existing deficits and different presentation in adults with intellectual disability makes diagnosis of dementia complex. Among people with ID its prevalence is estimated to be 18% at the age of 65.[3] This prevalence is even higher among people with Down's syndrome, 68-80% of whom have developed dementia by the age of 65.[4] In fact, in this group the average age of onset of dementia is in the early 50s, much sooner than in the general population.[5,6]

Also in people with ID dementia leads to a wide range of changes in memory, functional capacity, communication, neurology, personality, and behaviour.[7] These changes can result in behaviour like agitation, resistance, depression and apathy; responses which present a challenge to care staff.[8-11] Hence ageing, and especially dementia, strongly impacts the lives of people with ID, as well as their housemates and care staff.[12-14]

Although care staff are a key source of support for older people with ID,[15,16] they often feel they lack skills to deal with the increasing complexity of care for their clients.[17-21] Knowledge and skills from regular geriatric- and dementia-care could be useful in care for older people with ID in general, and even more in cases of dementia.[17,22-25] Traditionally, care for people with ID has focused on promoting their wellbeing, learning and development of skills.[26-28] The ageing of the people with ID (and dementia) has led to a need for more care and for a more integrated and person-centred approach, which can be derived partly from standard geriatric and dementia care.[22-24]

Tom Kitwood introduced the philosophy of personhood in dementia-care to change its focus to a person-centred approach.[29,30] Evidence suggests that person-centred methods increase the quality of ID-care and are associated with psychosocial benefits and greater wellbeing among older people with ID.[7,27,31-34] One such person-centred method is Dementia Care Mapping (DCM). DCM was designed to support dementia-care staff working in psychogeriatric nursing homes to improve the quality and effectiveness of care from a person-centred approach, and thereby improving the wellbeing and quality of life of clients with dementia (see Box 1; p. 20).[35] Studies on DCM applied in nursing home settings found less affective behaviour, and physical and verbal agitation in people with dementia.[36,37] The

method was shown to be applicable, as well as a useful and valuable support to staff caring for people with ID, whether or not they had dementia.[38-40]. Schaap et al. (2018) concluded that for older people with ID, both with and without dementia, DCM was feasible when tailored to daily ID-care practices regarding the case histories and examples.[41]

Nevertheless, although DCM is feasible and is perceived as valuable in ID-care, evidence on its effectiveness is still lacking.[41,42] The aim of this study was therefore to examine the effect of DCM, compared to care-as-usual, on the wellbeing and quality of life of older clients with ID.

Methods

Study design

To assess wellbeing and quality of life in older people with ID we performed a quasi-experimental study from November 2014 to April 2016, comparing DCM with care as usual, using a baseline measurement and follow-up measurements after 7 and 14 months.

Study setting and participants

We performed a two-stage sampling, first sampling ID-care organisations, and then assigning homes per organisation to either the DCM or the control condition. First we approached all six major ID-care organisations which had at least four group homes for older clients in the north of the Netherlands; all were willing to participate (100%). Second, each organisation provided four group homes for the study. A group home houses a small number (range 4 to 12) of older people with ID in need of care, support, and supervision by care staff are living together. All participants were clients living in such group homes. The possibilities for using DCM determined our inclusion criteria for the group homes; we needed the possibility to observe four people simultaneously in a shared area (e.g. a living room) for at least two consecutive hours, the presence of at least three older people with (a strong suspicion of) dementia, and a stable team not anticipating reorganisation.

To reach a balance between groups regarding organisational culture we allocated two of the four homes per organisation to the intervention group and two to the control group. Allocation of group homes to the intervention or control groups depended on the distance

between the mapper and the group home, and on sufficient geographic distance between control and intervention homes to prevent contamination.

Intervention

The intervention consisted of two applications of a full DCM-cycle per group home, with an interval of six months. We used the DCM-in-ID–version, which was found to be feasible in ID-care for older people with ID, both with and without dementia. In this version, the core DCM principles and DCM codes were maintained but the description of the codes was adapted to ID care practice.[41,42] First, the managers of each of the twelve participating group homes selected a staff member with the required competencies to become a "DCM-mapper", i.e. a trained observer. The twelve selected staff members had the required competencies, including at least 10 years work experience with older people with ID, at least 5 years work experience in working with people with dementia, at least a bachelor's degree, and basic knowledge of person-centred care. DCM Netherlands trained these staff members to an advanced DCM-level, enabling them to carry out DCM: to observe (map), report, and provide feedback, and to instruct and support in drawing up action plans (Box 1; p. 20).[43] Second, a DCM-trainer and a mapper jointly provided all staff per group home with the DCM introductory organisational briefing. Third, the mappers carried out two full DCM cycles, consisting of 6 hours structured observation, feedback and action planning (for further explanation see Box 1; p. 20). The mappers observed four clients for 4 to 6 consecutive hours in communal areas of a group home. They reported the results of the observation to the staff in a feedback session, in order to help them understand clients' behaviour in the context of their lives and of the care.[44] Based on these reports, the staff made action plans to improve care at individual and group levels. They sent these action plans to DCM Netherlands within two months. To guarantee accurate implementation, the application of DCM (including the feedback and the action plans) occurred in close cooperation with the DCM-trainers. Further, to maintain independence and to avoid interpretation bias due to familiarity with habits, clients and colleagues of the mappers carried out DCM in each other's organisations.

To guarantee intervention adherence the DCM trainers strictly monitored the intervention and supported the newly trained mappers in following the DCM-in-ID implementation protocol.[45] This protocol includes a description of all DCM-preconditions and

of every step needed to implement DCM in ID-care.[45] This protocol ensured that DCM was implemented and applied similarly in each group home, in spite of differences in (staff-team) size, number of residents, culture and approach.

Control condition

The control group received care-as-usual (CAU; continuous care with use of regular services); support in all aspects of day-to-day life, including activities of daily living (ADL) and day-care activities) but no DCM. The control group homes were offered a DCM-training day after the study period.

Procedure

We collected data on all clients living in the group homes, with or without dementia, at three time points: at baseline, and after 7 and 14 months (i.e. three months after each application of DCM in the intervention group). For each client in the group home, two staff members familiar with the client independently filled in a questionnaire at each time point. The inter-observer agreement for each client at each time point was high (mean Kappa 0.81). In addition, for each client we asked one relative to fill in the questionnaire. Staff and relatives could choose to fill in the questionnaire on paper or web-based.

Outcome measures

The primary outcome measure regarded the quality of life (QoL) of the client as reported by staff and a close relative, measured by the Mood, Interest, and Pleasure Questionnaire (MIPQ).[46,47] This validated questionnaire was chosen because it relates best to the core elements of DCM. The MIPQ measures emotional QoL of people with severe and profound intellectual and multiple disabilities, by using proxies. It is a 23-item questionnaire using a five-point Likert scale response format. All items regard informants' observations of people over the preceding two-week period. They are divided into three subscales: the 'positive mood' subscale (9 items), the 'negative mood' subscale (7 items), and the 'interest & pleasure' subscale (7 items). Lower scores denote lower mood levels and lower levels of interest and pleasure. By summing the item-scores, the maximum possible scores for the positive mood

subscale, negative mood subscale, interest & pleasure subscale, and total scale are 36, 28, 28, and 92, respectively. See Table 1 for further details of this questionnaire.

The secondary outcome regarded adapted parts of the Quality of Living- Questionnaire for people with Profound Intellectual and Multiple Disabilities (PIMD) at the Dutch Centre for Consultation and Expertise (CCE). This questionnaire was developed to gain insight into the care for people with Profound Intellectual and Multiple Disabilities (PIMD).[48] We used only those subscales of the Quality of Living- Questionnaire that matched DCM's aims: the clients' behaviour (10 items), self-management (4 items), knowledge of staff about the individual client (15 items), and adaptations of staff and environment to respond to clients' needs (8 items). All subscales used a four-point Likert-scale from 'never' to 'always' per item. The score on each subscale is the mean of the scores on all items, where higher scores denote better quality of living.

Background characteristics

Data on background characteristics of clients included: age, sex, level of disability, dementia stages, having a syndrome, other (physical and mental) diseases, and health status as measured by the EuroQol-5D-5L, including EQ-5D-VAS (Visual Analogue Scale) for proxies.[49] Furthermore, we registered the number of years that the clients were living in homes of the organisation and in the group home concerned, whether the clients had day-care activities in- or outside the group home, and whether the clients had contact with a relative.

In addition, we examined the background characteristics of the proxies (staff). These characteristics included age, gender, education, employment, job position, experience, and training in person-centred psychosocial approaches: Method Urlings, Validation, Reminiscence therapy, Emotion-oriented care, and Gentle Care.[50-56]

Table 1. Properties of used outcome measures

Name	Internal consistency	Inter-rater reliability	Test–retest reliability	Mean (Standard Deviation)	Validated in Dutch	Nr questions/ answers (Likert)	Proxy version	Developed for	Separate use of subscales	Responsive to change	Previous use in DCM	Domains
Mood, Interest & Pleasure Questionnaire (MIPQ)[a]	$\alpha \geq 0.94$	$r \geq 0.74$	$r \geq 0.90$	62.03 (15.45)	✓	23/5	✓	People with severe/ profound ID	✓	✓		Emotional quality of life with subscales: - *Mood (positive/negative)* - *Interest & pleasure*
Positive mood subscale	*$\alpha \geq 0.93$*	*$r \geq 0.76$*	*$r \geq 0.89$*	*23.09 (7.29)*		*9/5*						
Negative mood subscale	*$\alpha \geq 0.84$*	*$r \geq 0.69$*	*$r \geq 0.86$*	*21.91 (4.64)*		*7/5*						
Interest & pleasure subscale	*$\alpha \geq 0.89$*	*$r \geq 0.69$*	*$r \geq 0.90$*	*17.03 (6.14)*		*7/5*						
Questionnaire Quality of Living (VKvB)[c,d]	N/A	N/A	N/A	N/A		37/4	✓	People with PIMD[h]	✓	✓		Used questions regarding: - *Behaviour of clients* - *Self-management of clients* - *Knowledge of staff to individual clients* - *Adaptations to care and/or environment*
EuroQol 5 Dimensions (EQ5D)[e,f,g]	$\alpha \geq 0.64$	*N/A*	$r \geq 0.72$	0.11 (0.39)	✓	5/5	✓	General population (validated for cognitive impairment)	✓	✓	✓	General health status
EuroQol Visual Analogue Scale (EQ-VAS)[e,f,g]	N/A	N/A	N/A	51.54 (21.47)	✓	1/100	✓	General population (validated for cognitive impairment)		✓	✓	Health status (0-100)

[a] Primary outcome; [b] Petry et al. (2010); [c] Secondary outcome; [d] Retrieved from http://vkvb.cce.nl/vkvb/inschrijving; [e] Background characteristic; [f] Validated for cognitive impairment; [g] Wolfs et al. (2007), Diaz-Redondo (2014); [h] PIMD: Profound Intellectual and Multiple Disabilities

Sample size

Because DCM is an intervention aimed at staff, the sample size for including group homes depended on the number of care staff required. We therefore conducted a post-hoc power analysis for clients, using as outcome the Mood, Interest and Pleasure Questionnaire (MIPQ).[46,47] A post-hoc power analysis involves a power calculation based on the collected data to show specifically how much power the study has. This analysis of the difference in effects revealed low power (< 0.8), particularly due to the small effect sizes found, which required large samples to detect. The post-hoc power estimates were 0.11 and 0.07 for interaction term interventions by T1 and by T2, respectively. We performed power analysis using a Monte Carlo simulation of the MPlus package version 8.

Data analysis and reporting

First, we described the flow of clients. Second, we described the baseline characteristics of the clients in the two groups. We tested the differences between the two groups using Pearson Chi-square tests for categorical variables and one-way analysis of variance (ANOVA) for continuous variables. Third, we compared the differences over time of the primary and secondary outcomes in the DCM and CAU groups. Because of the high inter-observer agreement we performed all analyses without further adjustments for informants. We assessed the effects of DCM using intention-to-treat (ITT) analyses after the first DCM-cycle (T0 to T1) and after the second DCM-cycle (T0 to T2). We did so using multilevel mixed-effect model techniques in which measurement moments (level 3) were nested under clients (level 2), and the clients were nested under organisations (level 1). We performed the first analysis using the unconditional means model.[57] For each outcome we calculated effect sizes (ES) for the differences in change between both groups. In this analysis the time points were the first level, the clients the second, and the group homes the third.

We repeated these analyses in three additional procedures. First we included covariates found to have a significant influence on the intercept in the conditional means model, to examine whether this had a major influence on the outcomes. Covariates included age and sex, as well as prevalence of dementia, autism, and/or of severe behavioural problems. Second, we performed complete case analyses only on those clients regarding whom we received questionnaires at all three time points. Third, we restricted the analyses to people

with ID and a diagnosis of dementia. Finally, we examined whether the results differed depending on whether or not proxy-informants had experience with a person-centred approach.

We performed all analyses using IBM SPSS Statistics version 25.0; we used SAS software for data management. We carried out the design, analysis and reporting according to the CONSORT-checklist.[58]

Ethical permission

The Medical Ethical Committee of the University Medical Center Groningen did not consider approval to be required (decision M13.146536) because DCM is an intervention aimed at staff. We performed the trial in accordance with the Helsinki Declaration and obtained written informed consent from the legal representatives (i.e. a relative or an administrative person) of the people with ID participating in the study. The trial is registered in the Dutch Trial Register, number NTR2630.

Results

Participant flow

Figure 1 shows the flow of clients through the study. In total, at least one baseline questionnaire was filled in for each of 224 clients, 113 in the intervention group and 111 in the control group. For each client two staff members had filled in a questionnaire, but most relatives reported being unable to fill in the questionnaire because they did not see their relative on a daily basis. We therefore omitted the questionnaires of relatives from the analysis. After checking the inter-observer agreement of staff for each client we used all raw data for analysis. Inter-observer agreement varied from 0.60 to 0.95, with a mean of 0.81; 0.41/0.60 indicates moderate agreement, 0.61/0.80 substantial agreement, and 0.81/1.00 excellent, almost perfect agreement.[59]

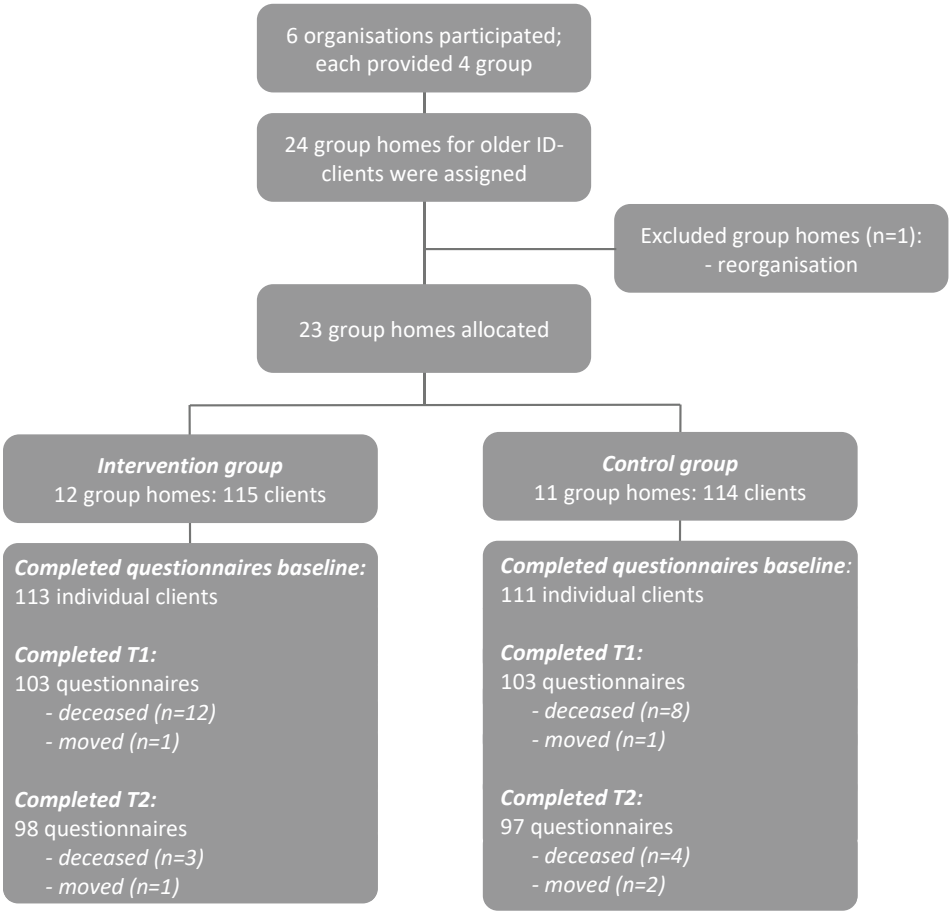

Figure 1. Flowchart detailing numbers of group homes and clients by condition.

Background characteristics

Clients in the intervention and control groups did not differ in background characteristics regarding age, gender, mean years in current location and having day-care activities, but clients in the intervention group turned out to have more severe handicaps, more behavioural problems, more dementia and a lower health- and physical status (Table 2). Between the intervention and CAU groups the background characteristics of the staff did not differ.

Table 2. Background characteristics of clients and of staff who reported on clients for the intervention ('DCM') and care-as-usual (CAU) group

Clients	DCM	CAU	*p-value*
N	113	111	
Mean age in years (SD)	67 *(11.3)*	65 *(12.4)*	*0.38*
Female (%)	43	56	*0.05*
Mean years in current organisation (*SD)*	31 *(15.6)*	27 *(13.8)*	*0.05*
Mean years in current location (SD)	8 *(5.9)*	10 *(8.2)*	*0.033*
Degree of disability (%)			
Mild	*21*	*31*	*0.004**
Moderate	*49*	*56*	
Severe/Profound	*31*	*13*	
Dementia (%)			*0.004**
Diagnosed	*35*	*17*	
Suspicion	*11*	*7*	
Signs of	*18*	*22*	
Autism	28	29	*0.85*
Psychiatric disease	22	17	*0.40*
Challenging behaviour (%)	31	29	*0.69*
Severe behavioural problems (%)	5	13	*0.034**
Mobility/motor problems (%)	53	41	*0.07*
Communication problems (incl. sight and hearing) (%)	66	45	*0.002**
Health problems (incl diabetes) (%)	58	44	*0.037**
Mean EQ5D – total (SD)	2.68 (0.78)	2.34 (0.70)	*0.001**
Mean EQ5D VAS (SD)	66.6 (10.8)	66.4 (13.0)	*0.31*
Daycare activities (%)	95	95	*0.93*
Unknown life-history (%)	19	14	*0.30*
Need for knowledge about client (%)	47	38	*0.17*
Staff	**DCM**	**CAU**	***p-value***
N	85	75	
Mean age in years (SD)	48 (11.7)	47 (11.9)	*0.78*
Female (%)	90	90	*0.50*
Education			
Only elementary and secondary education (%)	9	9	*0.75*
Secondary vocational education (%)	80	77	
Higher professional education (%)	11	13	
Position			
Daily care professional (%)	71	75	*0.40*
Senior-/coordinating care professional/personal coach (%)	24	23	
Permanent employment (%)	90	93	*0.82*
Hours/week (mean)	23	24	*0.86*
Experience			
>11 years in ID-care (%)	71	69	*0.63*
>11 years in current group home (%)	35	31	
Education of older ID-clients (%)	76	69	*0.29*
Training in person centred psychosocial approach/method[a] (%)	35	35	*0.92*

[a] These regarded: Method Urlings,[50] Validation,[51] Reminiscence therapy,[52,53] Emotion-oriented care,[54,55] and Gentle Care.[56]

* significant difference (P=<0.05)

Effects on primary and secondary outcomes

Table 3 presents the effects of DCM compared to CAU. We found no differences in change for of the primary outcome (MIPQ) between T0 and T1, and between T0 and T2. Effect sizes varied from 0.01 to 0.05 for T0 to T1, and from 0.01 to -0.15 for T0 to T2. Regarding secondary outcomes we also found no differences between T0 and T1 and T0 and T2. Effect sizes varied from 0.01 to 0.10 for T0 to T1, and from -0.09 to -0.22 for T0 to T2.

Adjustment for the covariates did not lead to notable changes in the results, nor did complete case analysis. Repeating the analysis including only people with a diagnosis of dementia led to slightly lower means on all outcomes for each time point (decrease varying from 2.87 to 5.72 on the total score of MIPQ and 0.06 to 0.26 on the secondary measures), but did not significantly affect differences in outcomes. Findings did not differ between staff experienced with person-centred care and staff without this experience.

Discussion

This study examined the effectiveness of the intervention Dementia Care Mapping (DCM) on quality of life and wellbeing of older people with ID. We found no significant differences in effects between DCM and CAU on the outcomes; effect sizes were small.[60]

In this well-designed quasi-experimental study we found a lack of effect of DCM on quality of life, a result which contrasts with promising findings in earlier qualitative studies on DCM and person-centred ID-care.[38,40-42] This may be explained in several ways. First, we found rather high scores on most outcome measures at baseline, which may have caused a ceiling effect in measuring effects. E.g. on the primary outcome MIPQ clients scored more than one standard deviation higher than the norm population;[46] the same held to a slightly lesser degree for clients with a diagnosis of dementia. Staff members, the informants regarding client outcomes, may in general have been too positive.

Second, DCM requires a strong existing embedding of person-centred care. Because this emphasis has evolved only recently in the field of ID-care,[7,34,61] a comprehensive shared knowledge base among staff about person-centred care and dementia is lacking. This indicates room for improvement by full implementation of person-centred care in ID care for clients at different levels, as well in staff-training (staff level), culture and organisation of care (group

Table 3. Outcomes for DCM and CAU at T0, T1 and T2: means and differences in improvement, based on intention-to-treat analyses with mixed multilevel models (n=224)

Outcome	Group	T0 (Baseline)		T1 (Three months after 1st DCM cycle		Difference in improvement T0 to T1 between DCM and CAU			T2 (Three months after 2nd DCM-Cycle		Difference in improvement T0 to T2 between DCM and CAU		
		Mean	(SD)	Mean	(SD)	Dif[d]	*p-value*	ES[e]	Mean	(SD)	Dif[d]	*p-value*	ES[e]
MIPQ[a,b]	*DCM*	*83.77*	*17.66*	*83.11*	*17.09*	*0.57*	*0.69*	*0.03*	*82.77*	*16.79*	*0.15*	*0.91*	*0.01*
	CAU	85.08	17.50	83.85	17.06				83.93	16.65			
Positive Mood	DCM	30.92	8.32	30.73	8.08	0.37	*0.61*	0.05	30.46	7.86	-0.26	*0.72*	-0.03
	CAU	31.06	8.24	30.50	8.05				30.86	7.78			
Negative Mood	DCM	23.90	7.44	23.42	7.19	0.08	*0.88*	0.01	23.92	6.90	0.95	*0.11*	0.13
	CAU	24.82	7.42	24.26	7.22				23.89	6.89			
Interest/Pleasure	DCM	28.94	3.78	28.96	3.72	0.11	*0.80*	0.03	28.41	3.57	-0.55	*0.23*	-0.15
	CAU	29.19	3.72	29.10	3.67				29.21	3.50			
Behaviour of client[c]	DCM	3.19	0.51	3.14	0.50	-0.03	*0.40*	-0.07	3.12	0.46	-0.09	*0.07*	-0.19
	CAU	3.13	0.51	3.11	0.50				3.15	0.46			
Client's self-management[c]	DCM	2.92	0.79	2.93	0.76	-0.04	*0.62*	-0.05	2.92	0.71	-0.07	*0.38*	-0.09
	CAU	3.04	0.79	3.09	0.77				3.11	0.72			
Knowledge about client[c]	DCM	3.08	0.82	3.14	0.79	0.08	*0.20*	0.10	3.08	0.73	-0.11	*0.09*	-0.14
	CAU	3.14	0.83	3.13	0.81				3.26	0.75			
Adaptations to the client[c]	DCM	3.11	0.69	3.09	0.66	0.01	*0.91*	0.01	3.00	0.60	-0.14	*0.06*	-0.22
	CAU	3.17	0.70	3.14	0.68				3.21	0.61			

[a] Primary outcome; [b] Mood, Interest and Pleasure Questionnaire[46,47]; [c] Secondary outcome. [d] Based on mixed models techniques, expressing differences in change between DCM and CAU in outcomes; [e] Effect size (Cohen's d)

home level) and the organisations' underlying visions (management and organisational level).[27,62].

Third, DCM may simply not lead to a better quality of life. As in previous studies on DCM in ID-care,[36,37,43,63,64] we have based our choice of outcome measures on DCM's claim that it increases the quality of life of clients as a result of improved quality of care. However, DCM may be a too light and too indirect intervention to directly affect quality of life, even if improving quality of care. In previous studies staff claimed that they benefitted from DCM in daily care, although compliance to the action plans could be improved, as well as the provision of time and resources by management to staff.[41,42] This discrepancy deserves further study: what effect does DCM have on quality of care, and what effect does this then have for staff and clients in daily care? In addition, quality of life is a broader concept than might be influenced by DCM (pain, decline through ageing). Given the strength of our study, the lack of effects on staff-reported quality of life of clients definitely requires further attention.

Strengths and limitations

Our study has a number of strengths. First, we carefully assessed the feasibility of DCM for ID-care prior to this study with a positive result, and used this adapted DCM-in-ID version.[41] Next, our study had a large sample size, a control group receiving CAU, participants from a wide range of organisations, sufficient strategies to avoid contamination and bias, and a long follow-up of one year with two follow-up measurements. Furthermore, our study had a low loss to follow up. Finally, the inter-observer agreement between the proxies (two staff members) for the individual clients was high, and perceived as good to excellent.[59,65]

Limitations should, however, also be noted. First, we fully relied on reports of the staff, using proxy-questionnaires; this may have led to information bias and a less accurate measurement of change. Moreover, relatives generally reported being unable to assess clients' outcomes because they had no contact on a daily basis. Furthermore, due to chance we had some imbalances between the intervention and control groups, with relatively more severe disabilities and more dementia in the intervention group. However, given the pre-post design that we used, this is unlikely to have affected our findings.

Implications

We found no evidence that DCM improves the quality of life of older people with ID. As previous qualitative studies are definitely positive regarding DCM,[41,42] further research is needed to elucidate this discrepancy, e.g. by means of in-depth interviews with participating ID-staff or direct observation. Furthermore, it is uncertain whether DCM affects quality of life directly, despite its own claim. Future research should investigate the effects of DCM in daily care and its direct effects on ID-care staff and their clients. Moreover, the challenges of developing person-centred care in ID-care, including in the integration of health and social care, require better understanding.[27] The promising option of DCM in ID-care thus deserves further study.

Conclusion

Despite previous studies that reported that DCM and person-centred care increases wellbeing of older people with ID, with or without dementia, we have found no evidence that this is the case regarding quality of life. This discrepancy deserves further study.

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The first use of Dementia Care Mapping in the care for older people with intellectual disability: a process analysis according to the RE-AIM framework

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CHAPTER 5

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Abstract

Background The aging of the population with intellectual disability (ID), with associated consequences as dementia, creates a need for evidence-based methods to support staff. Dementia Care Mapping (DCM) is perceived to be valuable in dementia care and promising in ID-care. The aim of this study was to evaluate the process of the first use of DCM in ID-care.

Methods DCM was used among older people with ID and care staff in twelve group homes of six organisations. We obtained data on the first use of DCM in ID-care via focus group discussions and face-to-face interviews with: care staff (N=24), managers (N=10) behavioural specialists (N=7), DCM-ID mappers (N=12), and DCM-trainers (N=2). We used the RE-AIM framework for a thematic process-analysis.

Results All available staff (94%) participated in DCM (*reach*). Regarding its *efficacy***,** staff considered DCM valuable; it provided them new knowledge and skills. Participants intended to *adopt* DCM, by continuing and expanding its use in their organisations. DCM was *implemented* as intended, and strictly monitored and supported by DCM-trainers. As for *maintenance*, DCM was further tailored to ID-care and a version for individual ID-care settings was developed, both as standards for international use. To sustain the use of DCM in ID-care, a multidisciplinary, interorganisational learning network was established.

Conclusions DCM tailored to ID-care proved to be an appropriate and valuable method to support staff in their work with aging clients, and it allows for further implementation. This is a first step to obtain an evidence-based method in ID-care for older clients.

Introduction

The aging of the population with intellectual disability (ID), with associated consequences such as dementia, causes a need for evidence-based methods to support ID-care staff (from here: staff) in their work.[1,2] Dementia has a large impact on the lives of people with ID, as well as of their relatives and housemates, and of the staff that provides long term and intensive support and care.[3] Dementia is a relatively new phenomenon in ID-care, and staff often lacks knowledge and skills to address the behavioural changes and changing needs of their clients due to aging and/or dementia.[4-7] Evidence-based methods to support staff are therefore needed but not yet available.

Dementia Care Mapping (DCM) is used internationally and is perceived as valuable in supporting staff in psychogeriatric nursing homes.[8-13] Evidence on its effectiveness is mixed however. [9,12-15] DCM has been shown to be feasible and promising in supporting ID-care staff in the United Kingdom and the Netherlands.[16-19] DCM has been designed to improve the quality and effectiveness of care from the perspective of people with dementia.[20,21] It is a person-centred, multi-component intervention, consisting of: (1) systematic observation, analysis and report, (2) feedback to the staff, and (3) action plans created by staff after reflection on their work, based on the observed needs of clients. DCM aims at improving care at different levels: individual (clients and care givers), group (care giving teams), multidisciplinary teams and management.[14,22] Details are provided in Box 1 (p. 20). As a result of a previous pilot study we conducted on the feasibility of DCM in ID-care, DCM was tailored to ID-care in case histories and examples, without altering the core DCM-principles and DCM-codes.[16]

The aim of this study was to evaluate the process of use of DCM to ID-care practice. We gathered qualitative data from involved professional users of twelve group homes in the Netherlands. We used the RE-AIM framework to evaluate the first use of DCM in ID-care.[23] This framework has been shown to be a usable tool for evaluating the implementation of interventions. The results of this study can be used for developing an evidence-based method in ID-care for older clients.

Methods

Design

We set up a qualitative evaluation to gain insight into the first use of DCM in ID-care. We obtained detailed in-depth data from all professional users during focus group discussions, and during face-to-face interviews after the intervention, which consisted of two applications of the DCM cycle in twelve group homes. The data were analysed according to the principals of thematic analysis,[24,25] and structured and reported using the RE-AIM framework.[23]

Sample

We collected data from all professional users of DCM in ID-care practice. We provided DCM for vocational trained ID-care professionals who support people with ID living in group homes in all aspects of day-to-day life, including activities of daily living (ADL) and day care activities. In group homes, a small number (range 4 to 12) of people with ID in need of care, support, or supervision are living together. These group homes are part of larger organisations for people with ID of all ages and with various disabilities.

From each of the twelve participating group homes we included two staff members (N=24), all managers (N=10), behavioural specialists (N=7), DCM-ID mappers (N=12) and DCM-trainers (N=2). The participants attended focus group discussions or were interviewed face-to-face (Table 2). We conducted eight focus group discussions in total; four after the first cycle of DCM and four after the second. The participants in the focus group discussions were split by function category; staff from different group homes formed two groups, the managers and the behavioural scientists formed a group, and the mappers jointly formed a group. Participants who could not attend a focus group were interviewed face-to-face; these were four after the first cycle and two after the second cycle. The response rate to focus group discussions and interviews was 100%.

Ethical assessment

As DCM is an intervention aimed at staff, the Medical Ethical Committee of the University Medical Center Groningen considered that their approval was not required (decision M13.146536). All participants in this study gave their informed consent.

Intervention

The intervention consisted of two applications of a full cycle of DCM in twelve group homes for older people with ID (see Box 1; p. 20). The DCM-in-ID implementation protocol included a description of all preconditions before implementing DCM, and a description of every step for implementing DCM in ID-care.[26] In this protocol the preconditions and implementation steps on the level of mappers, the level of staff, and the level management are described. The protocol ascertained that DCM was implemented and applied similarly in each group home. It enabled a comparison of the group homes, even though these differed in (team) size, number of residents, culture and approach.

First, we trained from each of the twelve homes a staff member, to become a certified, advanced, dementia care mapper. The twelve selected staff members had the required competencies, such as experience with older people with ID, at least a bachelor's degree, and basic knowledge of person-centred care. Next, each mapper carried out DCM twice in the same group home, with an interval of seven months. Each mapper mapped a group home that was no part of the organisation to which he or she was affiliated, to avoid conflicts of interest. In each group home, four older clients were mapped simultaneously. After the mapping, the mapper presented the results in a report and in a feedback session to all available staff and the manager of mapping session the group home, whereupon staff wrote up action plans for better support of their clients. The action plans drawn up in the first DCM-cycle, were part of the second cycle, and were explicitly mentioned by the mapper in the feedback session. This provided staff the opportunity to reflect on their planned action in routine, daily care.

Procedure and measures

After each application of DCM, we obtained qualitative data on the first use of DCM in ID-care by professional users. We used focus group discussions, which is a specific method for gaining in-depth knowledge, on the experiences of staff, managers and behavioural specialists, ID-DCM mappers, and DCM-trainers were discussed. Those who could not participate in a focus group discussion were interviewed face-to-face; see Table 2.

The focus group discussions and interviews were semi-structured, led by a discussion leader [FDS, GJD or EJF] accompanied by an observer, and an interviewer [FDS, ASF], respectively. The discussions were structured using the empathy map, derived from the design

thinking-theory.[27] The empathy map facilitated tracing of the 'pains and gains' of the participants, allowing them to discuss what they 'think and feel', 'say and do', 'hear' and 'see' about the first use of DCM in ID-care. This provided in-depth information of the participants' opinions and experiences on the use of DCM in ID-care.

Data analysis and reporting

The aim of this study was to evaluate the process of the first use of DCM to ID-care practice. We used the RE-AIM framework for a thematic analysis of the data on the implementation process.[25] The five themes of this framework (Reach, Effectiveness, Adoption, Implementation, Maintenance).[23] provide a basis for evaluating the implementation of social and health interventions,[28] and indicate key aspects in the implementation of psychosocial interventions.[29] We used the original definitions and underlying key questions of the RE-AIM model to measure its five key themes. We measured Reach as the proportion of staff that participated in all DCM activities during the study, i.e. involved in the introductory meeting, the feedback sessions and the action plan writing. Efficacy was measured as the perceived impact of DCM in daily care. We measured Adoption as the number of organizations willing to adopt DCM, and the intention of staff and managers to continue and extend the use of DCM in ID-care. With regard to Implementation, we measured fidelity to the DCM-in-ID protocol, including preconditions and consistency of the implementation. We measured Maintenance as the extent to, and how DCM was suitable in the long-term for ID-care. Table 1 shows the original definitions of the RE-AIM framework, as well as the operationalisations that we used in this study.

Table 1. Description of the definitions of the RE-AIM framework, way of measurement in this study and identified related (sub-)themes

Original definition	Definition of DCM in ID-study	Related (sub-)themes in DCM in ID-study
Reach The absolute number, proportion and representativeness of individuals who are willing to participate in a given intervention or program	**Reach** The proportion (%) of staff that participated in all DCM-activities (meetings and action plans) during the study.	No related themes, reach is measured as number
Efficacy The impact of an intervention on outcomes, including potential negative effects, quality of life and economic outcomes	**Efficacy** The perceived impact of DCM in the care for older people with ID.	Perceived use in practice Perceived impact (comparison to) Other methods
Adoption The absolute number, proportion, and representativeness of settings and the individuals within those settings who deliver the program and who are willing to initiate a program. Use of qualitative data to understand setting level adoption and staff participation	**Adoption** The number of organizations willing to adopt DCM. The intention of staff and managers to continue and extend the use of DCM in ID-care.	Demand for tools Expectations Ensuring implementation Support and commitment of staff and management Conditions for continuation
Implementation The fidelity to the program protocol and adaptations made to the intervention during the study. Costs of intervention in time and money. Consistency of the implementation across staff, time, setting and subgroups -focus is on process	**Implementation** The fidelity to the DCM-*in-ID* protocol, including preconditions. Consistency of implementation with focus on process.	Mappers' competences Basic and advanced training Support DCM in implementation Commitment of management Fulfilment of preconditions Re-organisations Experience of staff in person-centred care
Maintenance The extent to which a program becomes institutionalised or part of the routine of organisational practices and policies. If and how the program was adapted long-term	**Maintenance** The extent to, if and how DCM is adapted long-term to ID-care.	Continuation and further implementation Learning network Tailoring of DCM to ID-care Expansion to other target groups Individual mappings

We followed a stepwise procedure to analyse the date following the principles of thematic content analysis.[24,25] First, we transcribed verbatim the contents of the focus group discussions and interviews. We used Atlas.ti computer software (version 7.5) for the analysis (Atlas.ti Scientific Software Development GmbH, Germany). Second, the first author [FDS] read and re-read all transcriptions and set up a concept code book with initial codes, and then discussed it with the second author [GJD]. Third, both authors [FDS, GJD] coded and compared transcripts. Based on this comparison we refined, relabelled and regrouped the codes until reaching consensus. Finally, after coding all transcripts, we divided the codes into definitions of the RE-AIM framework as shown in Table 1, and reported the results according to these themes.

The reports consisted of two parts. First, we described the characteristics of the sample. Next, we reported on the first use of DCM in ID-care using the definitions of the RE-AIM framework. The design, analysis and reporting of the focus group discussions and interviews were performed according to the COREQ-checklist: Consolidated Criteria for Reporting Qualitative Research.[30]

Results

Characteristics of sample

In total, 57 professional users of DCM in ID-care participated in either a focus group discussion or a personal interview (Table 2). Of these, in both cycles 22 attended a focus group discussion or an interview, 18 in the first cycle and 17 in the second.

Table 2. Participants of the focus group discussions and interviews

	1st cycle		2nd cycle	
	FGD	**IV**	**FGD**	**IV**
Nr. of FDG/IV	**4**	**4**	**4**	**3**
Nr. of participants				
Mappers	*12*		*9*	*3*
Staff	*14*	*2*	*13*	*3*
Managers	*5*	*5*	*7*	
Behavioural specialists	*2*		*5*	
*DCM-trainers**	*2*	*2*		

FGD: focus group discussions, IV: interview

** Both DCM-trainers participated each in a focus group discussion with mappers and with managers*

First use

In analysing the process of the first use of DCM in ID-care, the RE-AIM framework was used, and described where relevant. An overview of the (sub-)themes related to the five definitions of the RE-AIM framework is given in Table 1.

Reach

Almost all available staff (94%) participated in all DCM-activities (see Box 1; p. 20); those not participating were absent due to work shift or sickness. Facilitating to the reach was the content of the DCM-meetings. Staff, especially in group homes with few team meetings, appreciated the opportunity to share their knowledge and approaches. They reported that the DCM-meetings enabled them to discuss their individual clients, even as the group of clients, and the whys and wherefores of their daily practices.

Efficacy

Staff, behavioural scientists and managers all valued DCM highly in the care for older ID-clients. They found that it provided insights into how clients perceived care, and gave them concrete cues for providing tailored and more person-centred care. They valued the mappings and feedback by an independent mapper and found it to be insightful, the feedback made them aware of their own actions and their own behaviour to their clients. Evaluating care from the perspective of the client was new to them and improved their understanding of clients. For example: they understood better what could cause challenging behaviour in clients (with or without dementia), gained insight into the potential of easy-going clients whom they had underrated, and discovered in some clients irritations of which they had not been not aware. However, some staff members criticised that mappers did not provide concrete plans for individual clients; for they had expected more instant and ready-made solutions, although an inherent part of DCM is creating concrete plans by staff members themselves. A second criticism was that some mappers did not have in-depth knowledge of dementia, and could not add much knowledge for teams that had received previous training about older clients with ID and dementia.

Mappers, staff, behavioural scientists and managers mentioned the added value of DCM as a generic approach, whether or not for clients with dementia and/or behavioural problems.

They appreciated the cyclic and methodical character of DCM. They further mentioned that DCM helped them to apply the theoretical knowledge and other (person-centred) methods in which they previously had been trained; DCM gave this (theoretical) knowledge a practical dimension by means of concrete action plans. Finally, they expressed a demand for a complementary version of DCM with individual observations in private areas (such as the clients' own apartment) or during activities of daily living (ADL), because most challenges for staff to provide good care occur during ADL, for example while dressing the client.

Adoption

All participants intended to adopt and expand the use of DCM in their organisations. However, the ways they intended to adopt DCM differed. Options included were: once each half year for all clients, or upon request in case of behavioural problems, or for new clients in group homes. However, the integration of the ideas of DCM and person-centred care differed in the group homes. Although most participants reported being enthusiastic about DCM and mentioned that it met a need, actual compliance depended on the commitment of staff and managers, and on strong support and coordination by the manager, or a staff member with a leading role, in coordinating DCM. Because DCM was applied by means of this study, the compliance to the procedures and plans were not yet fully integrated into regular care routines in each group home. Some managers, mappers and DCM-trainers mentioned that full integration of the routines and ideas of DCM and person-centred care takes more time and experience. In addition, adoption of DCM in the participating group homes, as the managers mentioned, depends on the financial resources of the organisations and thus on decisions by the management board.

Implementation

The implementation of DCM in the group homes was in accordance with the DCM-in-ID protocol, and the fidelity to the protocol was strictly monitored and supported by DCM-trainers. This step-by-step protocol was followed, but despite it turned out that the group homes could not fulfil all required preconditions for optimal implementation of DCM,[26] such as mappers' skills, safe and stable teams, and provision of enough time and resources.

Regarding performance quality, i.e. the mappers' skills, after finishing the basic and advanced mappers training, the newly trained mappers felt they were not fully capable of

carrying out DCM on their own. Therefore, strong support was needed for implementation; DCM mappers needed counselling and close cooperation with the DCM-trainers. The mappers reported various reasons for needing such support: first, all mappers found the training informative, but due to wide variation in their educational levels, the training did not fit all mappers. Second, mappers and trainers expressed that advanced training followed basic training too quickly (within four months), without allowing enough time for practical experience in between. Third, not all mappers had the required competences, such as planning, drawing up reports, providing feedback, and implementation skills. Fourth, in practice the mappers found the training and implementation of DCM more time-consuming than they had expected. Carrying out DCM: being present during the introductory meeting, observing (mapping), drawing up a report, and providing feedback, took more time than calculated. Finally, the mappers reported that carrying out DCM was not possible within their regular jobs; moreover, not all mappers were partially exempt from their daily jobs while applying DCM.

As for the staff and managers, the success of DCM was dependent on their commitment, their organisation of care, and their underlying visions. First mentioned was the openness and commitment of the teams to DCM, such as willingness to reflect on their own actions and work. For example, the instability and insecurity of some teams, due to reorganisations in management and savings in budget, resulted in less openness to the feedback of DCM and less commitment on the part of staff and managers. Second, the amount of experience of applying person-centred care was mentioned as an important factor. Some teams were already trained in the use of a person-centred approach (i.e. method Urlings[31]), and reported that DCM helped them to understand and apply this approach in practice. Third, staff mentioned that the action plans were concrete and were discussed very often during work time, especially in work meetings, although managers sometimes had to pay extra attention to them. Nevertheless, some staff reported that their own action plans were not always put into practice due to a high workload, as well as to difficulties in translating and fitting their actions and reports into the registration systems. However, in two group homes with a registration system focused on goal attainment, the actions carried over into practice, both with the individual clients as with the client group altogether. Lastly, managers of some group homes perceived the implementation protocol of DCM as too hierarchical. They found it unnecessary to focus mainly on management, with meetings organised only for managers and

emphasis on their allotted coordinating role. They suggested a more bottom-up approach, including staff in the implementation and coordinating process, and thereby gaining more commitment by the teams.

Maintenance

All participating organisations expressed the wish to continue the use of DCM, although the steps differ per organisation. One organisation (a) will implement DCM in a new centre of knowledge for older people with ID. Another organisation (b) will train staff and behavioural scientists to become advanced DCM-ID mappers in their organisations. Three organisations (c,d,e) drew up an implementation plan. In another organisation (f), two advanced mappers applied the training for DCM in individual ID-care settings and used both versions (i.e. the 'regular' and the individual version) complementary to each other through their organisation, for people with or without dementia.

Although maintenance of the intervention was not yet guaranteed in the participating organisations, respondents gave a number of suggestions for further and optimal use of DCM-in-ID. These were for example: more attention for dementia and person-centred care in the mappers' training, tailoring the case histories in the DCM-in-ID manual and mappers' training to ID-care, and using DCM in individual situations in private areas and during ADL in ID-care.

To support a sustainable application of DCM in ID-care, a multidisciplinary, inter-organisational learning network was established to support and empower DCM-ID mappers in the use and implementation of DCM in their organisations. This learning network had two main purposes: first, increasing the mappers' skills by face-to-face exchange of their mutual knowledge, and second, empowering the mappers to stimulate implementation by using a bottom-up approach in their organisations. This learning network consists of a bi-monthly meeting, wherein the participants introduce their own issues. The meetings and their contents are prepared by the participants, supported by two teachers.

Discussion

With this qualitative study we have described the first use of DCM in ID-care. Regarding the use of DCM in ID-care practice, the professional users rated DCM positively regarding its reach, efficacy, adoption, implementation, and maintenance. All participants agreed that DCM as

supplementary method added to the psychosocial approaches that they currently used in daily practice. First, DCM provided them new skills and knowledge in caring for older people with ID and dementia, and made them respond better to the needs of their clients. In our study this was reflected in the high reach (94%), the high perceived efficacy, and the high willingness to adopt DCM in routine care practice. The need for a method is widely reported in studies of staff working with older people with ID*;* the increasing age and accompanying implications (like dementia) of clients requires a method to support staff in their work.[1,5,16,32-36] That DCM meets this need is reflected in our study in the considered efficacy and the willingness to adopt DCM in regular practice.

Furthermore, we found that participants were positive about the insights that DCM gave as to how clients, whether or not with dementia, perceived care, and about the concrete cues for providing tailored and more person-centred care. The principles of person-centred care are new, yet increasingly used in ID-care.[37,38] Our study showed that even though staff are often trained in (person-centred) methods or visions, the application of this in practice remains difficult. DCM with its cyclic, methodical character, turned out to be helpful in understanding, translating and applying the principles of these methods and visions. Moreover, we found that in group homes with staff experienced in person-centred care, DCM was more successful.

The reported challenges concerned the implementation of DCM in practice and its further implementation through the organisations. This confirms findings of Van de Ven (2014) and Quasdorf et al. (2017) in their studies on the implementation of DCM for people with dementia (without ID).[39,40] We found the DCM-in-ID implementation protocol helpful for implementing DCM in the twelve group homes with varying cultures, team characteristics, and habits in care, even though the protocol needs some further tailoring to ID-care. Moreover, our study showed, that fulfilling all preconditions in practice is difficult and is dependent indeed on the culture, team characteristics, and care habits of each group home. The success of implementation was dependent on the commitment of staff and managers and the presence of a staff member or manager with a leading role. Previous research of DCM concluded that to reach optimal results, the implementation and fulfilling of preconditions (such as commitment and a person-centred care compliant vision) require strong and accurate attention.[10,15-17,40-43] Adequate realisation of the preconditions should be considered before

implementing DCM, to avoid the Type III error for undermining the credibility of an intervention by a poor delivery.[44-46]

The tailoring of DCM to ID-care was an iterative process. We assessed in this study a version of DCM that had been tailored to ID-care, based on the results of a piloting of DCM we conducted previously to examine the feasibility of DCM in ID-care. This previous tailoring of DCM to ID-care concerned purely case histories and examples, without changing the original principals and codes of DCM. The results of this RE-AIM based assessment will be used for a further similar tailoring of DCM to ID-care. The discussion and refining after each use is a proven method for attuning interventions to the target group,[47,48] as long the adaptations are made based on substantial evidence and do not compromise the core elements of the intervention.[49] The tailoring of the mappers' training, such as more attention to knowledge of dementia and person-centred care, strengthened the core elements of DCM for ID-care. The tailoring of the manual, codes, and case histories have been justified by the daily practices of ID-care.

Furthermore, to establish a multidisciplinary, interorganisational learning network to support and empower DCM-ID mappers in the use and sustainable implementation of DCM in their organisations a more bottom-up approach was added.[50]

Strengths and limitations

A key strength of this study was our use of a multi-informant design to examine the first use of DCM in ID-care settings. The results from the different perspectives of all participating group homes turned out to be complementary and did not conflict. Moreover, we examined the first use of DCM in practice in twelve different group homes of six different organisations for people with ID, each with its own vision, culture, team characteristics, and habits in care; this enhances the validity of our results for routine ID-care practice. Our findings are thus likely to represent a wide range of ID-care.

A limitation of this study is that we fully rely on qualitative reports. These may be biased due to, for instance, the additional attention to professionals as part of the study, and do not yield a full quantification of the implementation process. This evidently deserves further study.

Implications

This study showed that, due to a lack of evidence-based methods in ID-care and the strong demand for cues for putting theoretical knowledge into practice, DCM fulfils a strong demand and is perceived to be valuable and usable in the care of older people with ID. Therefore, the tailored version of DCM for ID-care, allows for wider implementation in the care for these older people.

The implementation of DCM in ID-care required strong attention. We recommend the use of a further tailored DCM-in-ID protocol as it seem to allow flexibility to fit in various situations. Further, we recommend considering to split the implementation of DCM into two parts: a part aimed at (higher) management and a part aimed at practice. Next, the required DCM preconditions for successful implementation in ID-care should be reconsidered. For example: for optimal compliance to the mappings and the feedback in ID-care, DCM should be carried out by an ID-care behavioural specialist. Next, further tailoring of the mappers training to ID-care, such as paying more attention to knowledge on dementia, will strengthen the core elements of DCM. Furthermore, as the combination of DCM with person-centred care appeared to be successful, a broader (theoretical) knowledge on the part of staff in person-centred care should be considered.

The outcomes of this RE-AIM based assessment of the implementation led to a further tailoring in the DCM-manual, implementation protocol and mappers training for DCM-in-ID. For example, more attention on dementia was provided in the training for DCM-in-ID mappers, to increase their knowledge of dementia. Second, to increase the knowledge and competence of mappers and staff in providing person-centred care in ID-settings, an e-learning module of person-centred care was added to the basic mappers' training and made optionally available to staff. *Next,* the design of the advanced DCM-training was changed; the content of the training was divided into modules, allowing mappers to choose which skills they needed to improve in order to become independent DCM-mappers in ID-care. Moreover, based on the experiences in this study, a training in DCM in individual ID-care settings was developed, based on the DCM version for individual settings used in Dutch home-care situations for people with dementia (DCM-OT).[51] Finally, one DCM-ID mapper was being educated to be deployed as a DCM-ID trainer, and will in turn be able to train new staff to become (advanced) mappers.

Finally, the effects and further use of the fully tailored version of DCM to ID-care should be evaluated, also with quantitative measures. This could include a cost-analysis and the evaluation of the adapted version for individual observations in private areas. Such further assessment may help to come to an evidence-based method for older people with ID.

Conclusion

With this qualitative study we have described the process of the first use of DCM in ID-care for older people. All professional users rated the use of DCM-in-ID positively regarding its reach, efficacy, adoption, implementation, and maintenance. DCM-in-ID meets a need for a supplementary method regarding aging ID-clients, and adds to the currently used psychosocial approaches in daily practice, and thus allows for further development and wider implementation in ID-care. The DCM-implementation protocol provided sufficient guidance to avoid implementation errors, but the protocol should be further tailored to ID-care and should be adhered to more closely, especially regarding meeting the required preconditions.This study is a first step to obtain an evidence-based method of ID-care for older clients, whether or not with dementia, and allows further research to assess the effectiveness.

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Use of Dementia Care Mapping in the care for older people with intellectual disabilities: a mixed method study

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CHAPTER 6

Submitted

Abstract

Background The ageing of people with intellectual disabilities (ID), with associated with diseases like dementia, calls for new types of care. Person-centred methods may support care-staff in this, an example being Dementia Care Mapping (DCM). DCM has been shown to be feasible in ID-care. We examined the experiences of ID-professionals regarding DCM.

Methods We set up a mixed-method study, using quantitative data from care-staff (n=136) and qualitative data (focus groups, individual interviews) from care-staff, group home managers and DCM-in-ID mappers (N=53).

Results DCM provided new knowledge regarding dementia and person-centred care as well as insights into the causes of clients' behaviours, and it enabled professional reflection. However, although DCM offered an applicable theory and coordination of daily care, its implementation required further attention.

Conclusion DCM is perceived as a valuable method in ID-care. However, its effectiveness in ID-care with respect to quality of care, staff-client interactions, and job-performance requires careful assessment.

Introduction

The increasing number of older people with ID and associated diseases such as dementia calls for new types of care.[1-4] Several studies have outlined the difficulties encountered by ID-care staff in dealing with psychosocial age-related issues of their clients, such as dementia.[5,6] Although staff have a strong commitment to help residents to remain in their own homes, they often lack knowledge and skills regarding older people with ID, in particular those with dementia. This lack impedes adequate care.[7-11] Therefore, ID-care staff have expressed a need for methods, knowledge and skills to support their older clients.[6,9,12-14] Such guidance can be found within person-centred methods, derived from regular dementia care.[11,15-17]

In caring for older people with ID, person-centred methods may contribute to the shift from task-focused to more supportive care.[18,19,20,21] Person-centred care, as understood from Kitwood's philosophy of personhood, has four major elements, summarized in Brooker's VIPS-framework: (1) an assertion of the absolute value of all human lives, regardless of age or cognitive ability; (2) an individualised approach, recognizing uniqueness of the person; (3) an understanding of the world from the perspective of the person; (4) a positive social psychology, enabling the person to experience relative well-being.[22-24] Person-centred care can yield more effective interactions between clients and care professionals.[19,25,26] and better collaboration of staff in coordination of care.[27,28] In ID-care, however, person-centred methods, usually derived directly from regular dementia care, are often used in an unsystematic way,[29,30] even though previous research has strongly indicated that they should be customised to be successful.[31,32]

One such person-centred method, Dementia Care Mapping (DCM), designed to support staff in their daily care for people with dementia, has also been adapted to ID-care.[14,33] DCM has characteristics that enhance innovation in ID-care; it is a structured psychosocial method, based on the principles of person-centred care, aimed at increasing the quality of care.[34-37] DCM is a cyclic method, consisting of a structured observation of six hours, followed by feedback on this observation to the whole care-team, and action planning (see Box 1; p. 20). This helps staff to reflect on their own routine behaviour and interactions in daily care, thereby improving care from a client-centred perspective.[24,38] DCM has been shown to be feasible and promising in supporting staff in caring for older people with ID (whether or not with dementia) in both the United Kingdom and the Netherlands.[14,33-36]

Findings on the effects of DCM in ID-care are, however, conflicting. On the one hand, research did not show DCM to have positive effects either on the quality of life of older people with ID,[29] or on the job satisfaction of ID-care staff.[39] On the other hand, staff reported that DCM provided adequate psychosocial methods and approaches to care for older people with ID.[14,33] Further assessment of the reasons underlying these experiences of staff may contribute to a better understanding of DCM in ID-care. The aim of this study is therefore to examine the experiences and opinions of staff and group home managers in the use of DCM in ID-care, and the factors underlying their evaluation of this method.

Methods

Study Design

To obtain information from ID-care professionals on their experiences in using DCM-in-ID we used quantitative and qualitative methods after each of two DCM-cycles. The quantitative method involved collecting data on the opinions of staff members after each application of DCM, via questions in a follow-up questionnaire for a quasi-experimental study on DCM. The qualitative method involved collecting in-depth data from all ID-care staff after each DCM-cycle, using focus group discussions and face-to-face interviews. We performed the design, analysis and reporting according to the COREQ-checklist.[40]

The study was performed in accordance with the Helsinki declaration and informed consent was obtained from all participants.[41] The Medical Ethical Committee of the University Medical Center Groningen considered their approval not to be required, as DCM is an intervention aimed at staff level (decision M13.146536).

Dementia Care Mapping in ID-care

DCM-in-ID consists of a structured observation of six hours, followed by feedback of this observation to the whole care-team, and then action planning (see Box 1; p. 20). First, in each group home four older clients were mapped simultaneously in two or three moments, by a mapper not affiliated with the group home. Second, the mapper presented the results to all available staff and the manager of the group home in a report and in a feedback session focused on dementia and person-centred care. Third, as part of the feedback, staff wrote up

an action plan to improve support of their clients in daily practice. The action plans were sent to DCM Netherlands and were explicitly discussed by the mapper in the feedback session after the next cycle. This provided opportunity for staff to reflect on their planned action in routine daily care (see Box 1 and Figure 1, p. 20).

Procedure and sample

We collected both quantitative and qualitative data among ID-care staff from twelve group homes for older people with ID from six organisations in the north of the Netherlands. In each group home live a small number (range 6 to 12) of people with ID in need of care and support. The care and support deal with all aspects of everyday life, including activities of daily living (ADL) and day care activities. DCM-in-ID was carried out twice, with an interval of seven months, along with a quasi-experimental study. We collected both qualitative and quantitative data at two time points three months after application of each DCM cycle.

The quantitative data regarded responses to questionnaires by care-staff in each of the twelve group homes (N=136). From each group home we included all staff with regular employment, and excluded students doing an internship. Staff could fill in the questionnaire either on-line or on paper. Data were anonymised by giving each staff member an identification number.

Qualitative data were obtained from two staff members per care facility (N=24), as well as a manager (N=10), a behavioural specialist (N=7), and a DCM-ID mapper (N=12) from each group home. We conducted a total of eight focus group discussions, four after the first application of DCM and four after the second (Table 1). The discussions were categorised according to staff function: two regarded staff members from various group homes, one regarded managers and behavioural specialists, and one regarded all DCM-mappers. The focus group discussions and individual interviews were semi-structured, led by a discussion leader [FDS, GJD or EJF] accompanied by an observer [FDS, GJD, ASF], and by an interviewer [FDS], respectively. Individual interviews were held with participants who could not attend a focus group, four after the first cycle and two after the second cycle. The interviews and focus groups lasted approximately 1.5 hours, and were audio recorded and then transcribed in full.

Topics and measures

The quantitative data were derived from self-developed open and closed questions for evaluating the use of DCM in daily ID-care. We asked whether and to what extent DCM was a usable and practical addition to care. These questions were incorporated in follow-up questionnaires in a quasi-experimental trial. The qualitative data were gathered using the empathy map, derived from the methodology of the design-thinking theory.[42] This method was developed to provide in-depth information regarding opinions and experiences of participants.

Data analysis and reporting

We analysed and reported the data in three steps. We first described the background of the sample. We then reported on experiences and opinions of staff regarding the use of DCM in ID-care after each DCM-cycle. We finally reported on which factors influenced the evaluation of this method by staff, group home managers and DCM-in-ID mappers. We performed separate analyses for quantitative and qualitative data.

We analysed the questionnaire data on experiences and opinions of staff in response to the closed questions using descriptive statistics, with IBM SPSS statistics (version 25). We tested the differences between both measurements using Pearson Chi-square tests. We analysed the qualitative data and open questions following the principles of conventional content analysis,[43] and thematical analysis,[44,45] respectively, both with use of Atlas.ti computer software (version 7.5) (Atlas.ti Scientific Software Development GmbH, Germany). After verbatim transcription of the contents of the focus group discussions and interviews, the first author [FDS] read and re-read all transcriptions, set up a concept code book with initial codes, and then discussed it with the second author [GJD]. Next, both authors [FDS, GJD] coded and compared transcripts. Based on this comparison we refined, relabelled and regrouped the codes until reaching consensus. We reported these results according to the themes derived from the data: understanding of the clients, professional reflection, knowledge and skills, organisation of care, and use in daily care. These themes provided the

basis for analysing the open questions in the questionnaire. After coding all open responses we divided the codes into the four themes, according to which we then reported the results.

Results

Background characteristics

Table 1 provides information on the background characteristics of the participating staff and on the group homes involved in the study. The participants were mostly (senior) daily care professionals (95%) with secondary vocational training (80%). All were relatively experienced staff (69% had over 11 years of experience) and most had received training in person-centred care and in caring for older people with ID, respectively 84% and 76%.

Table 1. Background characteristics of the work setting

Staff	
N	136
Mean age in years (SD; range)	45 (12.4; 20-65)
Female (%)	90
Position	
Daily care professional (%)	*63*
Senior-/coordinating care professional/personal coach (%)	*32*
Permanent employment (%)	90
Working hours/week (mean)	23
Education	
Elementary/secondary education (%)	*9*
Secondary vocational education (%)	*80*
Higher professional education (%)	*11*
Experience	
>11 years in ID-care (%)	*69*
>11 years in current group home (%)	*32*
Training in person-centred method(s) (%)[a]	84
Education in care for older people with ID (%)[b]	76
Work setting of staff in group homes	
Average number clients per group home (range)	9 (6-12)
Mean age of clients in years (SD; range)	67 (11.3; 34-92)
Clients with disability, by degree	
Mild (%)	*21*
Moderate (%)	*49*
Severe/Profound (%)	*31*
Clients with dementia	
Diagnosed (%)	*35*
Suspicion/Signs of (%)	*29*

[a] Method Urlings [46], Validation [47], Reminiscence therapy [48,49], Emotion-oriented care [50,51], and/or Gentle Care [52].
[b] Training in methods named above or a self-developed training by the organisation.

Table 2. Opinions and experiences regarding DCM in ID-care, in % (N=136)[1]

	Measurement	(totally) agree (%)	Neutral (%)	(totally) disagree (%)
Information about clients				
DCM is a good approach to map general behaviour of clients	1	81	19	1
	2	84	12	4
DCM is a good approach to map challenging behaviour of clients	1	72	25	4
	2	79	19	2
DCM is a good approach to map our way of providing care	1	68	29	3
	2	61	35	4
DCM provided me new insight in working with older people with ID	1	40	52	8
	2	51	35	14
Because of DCM I can better interpret residents' behaviour	1	43	46	12
	2	47	41	12
Professional reflection				
Looking at care from the clients' perspective was eye-opening for me	1	39	33	28
	2	41	42	18
DCM made me more conscious of my interactions with the residents	1	56	34	11
	2	58	33	9
DCM helped me provide better care to the residents	1	45	47	8
	2	47	41	12
DCM made me feel more confident in providing care to my clients*	1	16	65	20
	2	31	52	17
DCM gave me more job satisfaction	1	8	66	27
	2	10	66	24
Knowledge and skills				
DCM made me work in a more person-centred way	1	35	50	14
	2	43	43	14
DCM gave me more knowledge of dementia	1	36	42	22
	2	45	39	16
DCM provided tools for providing 'good care'	1	54	40	6
	2	64	29	7
Organisation of daily care				
DCM is a valuable addition to the methods we are currently using	1	62	30	8
	2	65	29	6
Discussing clients with the whole team had added value for me	1	80	20	-
	2	78	20	2
Discussion with the whole team provided new insights	1	71	27	3
	2	76	19	6
I find DCM-action plans supportive in daily care	1	68	27	4
	2	72	26	3
Use in daily care				
I find DCM useable in daily care	1	65	33	3
	2	70	26	4
DCM is also useable in care for residents without dementia	1	75	25	-
	2	79	19	2
The DCM report has little added value for me	1	10	39	51
	2	11	43	45
Maintaining the action plans was not practicable	1	21	58	21
	2	21	48	31

[1] Due to rounding the results could add up from 99 to 101

* Significant difference between measurements 1 and 2 (P=<0.05)

Opinions and experiences regarding DCM in ID-care

The quantitative data indicated that the majority of all participants in the group homes (61% to 84%) agreed in both measurements with the statement that DCM is a good way to map clients' behaviour, and provides new cues and insights for giving support to their clients (Table 2). About half of the participants (40% to 51%) agreed with the statements that DCM provided new insights into their work, that it helped to understand clients' behaviour, and that taking the perspective of the client was eye-opening. This made them more conscious of their own behaviour towards their clients, and helped them to provide better care. Furthermore, whereas after the first cycle of DCM 16% of the staff reported that DCM gave them more confidence in providing care for their clients, after the second cycle this was 31%, a significant increase. Moreover, after the second cycle of DCM the staff were even more positive about the benefits of DCM. However, staff stated that DCM did not influence their job satisfaction. Of the staff 35% to 64% agreed with the statements that they worked in a more person-centred way after DCM, and had gained more knowledge of dementia as well as more knowledge and skills for providing 'good care'. Overall, at both time points 62% to 80% of all staff in the group homes found DCM a very usable and valuable addition in daily care. However, although the action plans were perceived as useful (68% to 76%), to maintain them in daily practice turned out to be difficult. Between 75% and 79% found DCM useable also in care for older residents without dementia.

Underlying factors

The factors underlying staff experiences and opinions were derived from the qualitative data and the open questions in the questionnaire. Table 3 describes participants in the focus group discussions and personal interviews. The results of staff experiences in the use of DCM in ID-care from a professional perspective were reported per theme as derived from the qualitative data: information about clients, professional reflection, knowledge and skills, organisation of care, and use in daily care. The following paragraph will elaborate on these topics.

Table 3. Participants in focus group discussions (FGD) and individual interviews (IV)

	First measurement		Second measurement	
	FGD	**IV**	**FGD**	**IV**
Nr. of FGD/IV	**4**	**4**	**4**	**3**
Nr. of participants				
*Mappers**	*12*		*9*	*3*
Staff	*14*	*2*	*13*	*3*
*Group home managers**	*5*	*5*	*7*	
*Behavioural specialists**	*2*		*5*	

** Participants took part in both measurements, whether in a focus group discussion of an interview*

Information about clients

We found the most dominant underlying factor for the experiences with and opinions on DCM to be the degree of insight which DCM provided regarding the causes of specific client behaviours. Examples were behaviour caused by over- or under-responsiveness, physical discomfort (cold, inappropriate furniture and aids), and (behavioural) consequences of dementia. Staff highly appreciated DCM's accurate and detailed mapping of the behaviour, which gave them confidence in the method. Staff reported that the feedback of the mapping made them more alert to clients' behaviour and needs. Furthermore, the mapping and feedback helped staff to connect current challenging, behaviour to clients' histories. Staff also gained insight into the influences of external and environmental factors on the behaviour of clients (opening and closing doors, client sitting alone, client getting no attention, many staff going back and forth), and on interaction with other clients. Moreover, staff reported that DCM changed their perspective on optimal care and led to a different way of working, which in turn affected the behaviour of the clients. They mentioned that clients were more at ease and that the groups had a calmer pace during the day. Nevertheless, staff and managers mentioned that two cycles of DCM were too short to confirm a decisive difference in behaviour of clients. They did, however, expect to see an effect after a longer, more routine application of DCM.

> *"I thought, through my experience and all other courses, that it was important to divide my time and attention over everyone, and not just to the demanding residents or residents with challenging behaviour. After being*

observed with DCM I have noticed that I do not do that right. Whereas I thought I was doing it very consciously." (Staff 6.2)
"You look at it very differently. You are more critical. When I look at client J., I often let him colour. I thought he liked it, but DCM showed that J. likes colouring at first, and then he just goes on because he has a pencil, but he does not like it anymore. DCM provides a lot of awareness, so that you also offer something different. You change activities, think about it consciously." (Staff 1.2)

*"I noticed that we talk a lot in the team meetings about the residents with problems. Through DCM we noticed that by observing those without problems also a lot of profit is to be gained. Someone just sits in the room and does nothing. We became aware of this through DCM. We can then offer something. And indeed, when you offer something, you also have to enable the person to stop again, because we forgot that. (...). There is more to do than focus on those who cause problems." (*Staff 3.5)

"The biggest thing we noticed is the great influence of staff on the mood of the clients. From our observation it became very clear that when staff leave the group the dynamics change completely. And you notice the frustrations of employees who say: if we could only be more present, then that client would be more at ease. Would have fewer negative interactions with his neighbour client. We knew that, but it was confirmed again." (Manager 5.1)

Professional reflection

Staff, managers and mappers reported that DCM improved their professional reflection, thereby providing a basis for a different care approach. The mapping and feedback sessions made them increasingly aware of their own professional behaviour and the effect of their interactions with clients. The open questions and the qualitative data indicated agreement among staff that DCM creates awareness by mirroring their professional behaviour, thereby providing a base for change in their behaviour. It made them aware of their own blind spots in their care and interactions, and in dealing with the behaviour of their clients. This led to more consciousness and alertness. Furthermore, they became more aware of the conscious and unconscious influence of staff members on both clients and group processes, and the resulting staff-client behaviour and interactions.

"Yes, more consciously. That you focus on one client and take the time for it. Do not fly past, things like that ... just walk, don't fly by, but adjust your pace." (Staff 3.2)

"What they told me in the team was that it was so helpful that an external person came to observe, who could also comment on the blind spots of staff. This became very clear in the feedback. Observation is, in my opinion, one of the most powerful things we have. Just watch: what is happening to him? And then get out of your ordinary habits. Because the employees are all doers. And they are all used to certain behaviour of their client, but they do not know what is behind it. I liked it so much: one of our clients was always fiddling with her hands. Employees know that this is happening, but not under what circumstances and why so often and how it affects the client, and why she does it. That emerged because of DCM, and we had a discussion about it, and then we could do something with it." (Manager 3.1)

"A number of outcomes from the observations were very practical, things like: 'client cannot reach the floor with her feet', for example. There is a lot of waffling after that observation, like: 'What is wise? Should we do something or not do something? Why is that client sitting there? And if she has an adjusted chair there, then...' So it caused a lot of discussion in the good sense of the word. And not everything can be solved right away, but at least the consciousness of 'gee, we didn't even notice that she cannot reach the floor with her feet'. Just as you said, that fiddling." (Manager 5.2)

Knowledge and skills

In general, DCM provided more knowledge and skills on ageing and dementia, and on person-centred care. Staff indicated that they knew better what they were doing in their work, and why. According to staff, managers and mappers this resulted in more person-centred, deliberate and in-depth care, which was highly appreciated. DCM gave them more ground in providing care; they were able to relate care to the needs of the client, based on the theory of person-centred care, as well as to the consequences of ageing and dementia. Staff reported that by making the needs of the clients visible using Kitwood's five dimensions of personhood[53] improved the interpretation and explanation of clients' behaviour. This was reflected in the action plans; the proposed actions had a theoretical basis in person-centred care and knowledge of dementia.

Staff who indicated not having gained more knowledge of dementia did confirm that DCM helped them to put into practice the knowledge they had gathered from prior courses. Staff and managers stated that where (person-centred/dementia care) knowledge was often latently present, DCM provided the tools to put this knowledge into practice.

"DCM makes you think about: what are you doing, why do you do this and what needs of the client does this meet?" (Staff 6.8)

"DCM provides a practical dimension [to prior knowledge - FDS] (...). Employees said: 'yes, we work in a person-centred way', but what does that mean in daily practice? They might do it in their heads, I guess. And I also know that staff are convinced that they do it. But DCM shows how it is on all levels of care, and whether it is true. (...) But it also helps in discussing how we are working together. But then, it does not last. And staff say: 'but we had a course'. Then I think: 'What of it has remained in practice after a year?' DCM helps to put it into practice so that it lasts." (Manager 1.1)

"I think a nice thing about this method is that you really start at baseline. You identify certain things, and then you can work on expertise. We are used to throwing in a method or a training, and then getting started. And now [with DCM - FDS] you start with: how do we do things? And because of actively involving staff, a solid ground is created to continue working with existing methods. That all still needs to be done, but I think this a very good start." (Manager 5.1)

Organisation of daily care

According to most staff and managers, DCM helped to improve the organisation of daily care. In the qualitative data and open questions of the questionnaire they reported that the method created more mutual exchange within the teams, more coordination and conformity of care, and a greater feeling of being a team. Staff were not aware that they used different approaches which may have caused confusion in clients. The exchange within the teams stimulated staff to come up with a mutual action plan for both individual clients and the group, in consultation with the behavioural scientist and the manager but not being guided only by the ideas of the behavioural scientists. Staff and managers reported that this brought more responsibility, greater depth, and more deliberate actions of staff into daily care. This was appreciated by most staff, although some found it difficult to deal with the responsibility as well as the reflection on their own actions in daily care. Most greatly appreciated was the systematic, methodical and repetitive cycle of DCM, because this had been insufficiently present in routine daily care.

"The actions are very practical, because you learn to take the perspective of the client. What that person needs. That is what we discuss, and then we try to do the same." (Staff 2.3)

"*She [the mapper – FDS] really knew how to get the conversation going, to ask critical questions. That was a major profit for the team, to get in touch with each*

other in that way. And they feel a need to continue together like that. That could indicate how the team normally works, but yes, this certainly added something for them. What they also found out within the team is that they now do the morning rituals very differently, they coordinate a lot more. Like: 'Gosh, how do you do that in the morning with that client? How do you get him out of bed?' That is now being discussed much more clearly. And also adapted to each other, and agreed that we are going to do it like that now." (Manager 2.1)

"DCM is a lot more methodical, with clear methodical steps. Other courses and approaches don't have that; these are often more general visions. This is not contradictory; DCM maps what a situation looks like and goes into 'what to do then'? And then you go into what you don't know, which is more diagnostic." (Manager. 3.2)

"I found it [DCM - FDS] very different from what we normally did automatically, yes, certainly complementary. What we normally did when we saw challenging behaviour was: look at the methods, at vision or at courses or training, and then we would look at what we do in practice. With DCM we start with what happens in daily practice, and then apply what we have learned. It is just very practical. (...) For the team it was really a very pleasant way of working. Talking in a very different way. (...) It immediately gave direction and clear advice. That was really nice." (Manager 3.1)

Use of DCM in daily care

Staff, managers and mappers reported that they found DCM very practical and applicable. In the qualitative data and open questions they almost unanimously agreed that they would like to continue DCM in daily care and recommend it to other, comparable, organisations. However, for maintenance and implementation participants suggested some improvements. First, the action plans should be incorporated in the personal plans of the clients and in the registration systems. Second, the action plans should become a standard part of the team meetings. Third, the managers and the behavioural specialists should provide support in setting up attainable action plans, because some staff found it difficult to set up such plans themselves. Finally, staff wanted to use DCM more periodically, e.g. each half year and in cases of new clients in the group home, and if possible, also for individual observations, so as to focus more on problems in private areas, like assisting individual residents in activities of daily life (ADL).

*"The conversation becomes easier. Especially in case of difficult decisions or differing opinions. With DCM the focus is no longer on the diverse opinions and perspectives of everyone around the client, but the needs of the person in question are the starting point." (*DCM-in-ID-mapper 4.1)

"For us it works well: the staff member reports the things indicated by DCM. That may be that someone is always very lonely, or someone who seems very easy gets a bit neglected. A goal-oriented report was made by the personal coach; at least three times a day an attention moment was given, besides the regular care moments. And then you could score whether you had done that ... If you see that your colleague has done a certain thing, then you think 'Oh, that is actually very nice', but you also notice yourself thinking, 'I also can't say I did nothing'. It encourages you to do something yourself." (staff 4.2).

"Yes, we have something to do with that. You have to keep it alive, at least I do. It is a method that is being used, certain things have pointed out and have to be implemented in practice. Staff have to get used to that. It is not all clear and easy and ready to be immediately put into practice, it does not work like that. It's a translation, of course. It is an attempt. (…) But the question is how to keep that alive? The action is clear and must be translated into practice." (manager 2.2)

"It strikes me that at our location, DCM really has been an eye-opener; we have to do much more with policies regarding care for older people; it has to be much more structured in the organisation. And many more DCM-mappings, many more things need to be developed in terms of the policy to provide good care for older people. DCM is a great part of that; that you can see." (Manager, 5.1)

Comparison of results of both measurements

Comparison of the data from both measurements showed that after the second cycle of DCM staff were even more positive about the benefits of DCM (Table 2). We found both in the quantitative and qualitative data that the answers of staff given after the first cycle were aimed mostly at the clients and their behaviour. After the second DCM-cycle staff spoke more about their own professional reflection. This was also the case regarding the provision of person-centred care. After the first cycle, staff were quite convinced that they worked in a person-centred way. After the second cycle, staff agreed more strongly that this could be improved. They reported having become more aware that DCM is not an instant solution, but that they had to contribute themselves. They remarked that provision of care became more in line with the wellbeing and needs of the clients, rather than task-driven or habitual. Moreover, in the multi-organisational focus groups we observed that care staff found it

inspiring and helpful to hear about and learn from each other's experiences. Furthermore, we found that in group homes with staff experienced in person-centred care (f.i. using method Urlings), DCM was more successful. Finally, we found that staff belonging to one group home did not find DCM to have added value next to existing methods because of the mapper's way of providing feedback.

Discussion

With this mixed-method study we examined the experiences and opinions of staff and group home managers on the use of DCM in ID-care. In general, we found that professionals valued DCM positively in the care for older people with ID, with or without dementia. The method provided insights into the behaviour of clients, enabled professional reflection, provided new knowledge and skills regarding dementia end person-centred care, and helped to apply this theoretical knowledge in practice. However, we found that not all group homes completely fulfilled the DCM-preconditions which had previously been found to be successful.[33] Finally, we found that staff appreciated DCM even more after the second cycle than after the first.

The quantitative data indicated that the majority of participants found DCM a very usable and valuable addition to daily care. It provided new insights into clients' behaviour and into their own professional behaviour, and gave new cues for organisation of care. Furthermore, most of the staff reported having gained more knowledge and skills for dementia- and person-centred care. However, staff stated that DCM did not influence their job satisfaction, a result also found in previous research: feedback as provided showed DCM to be helpful and possibly leading to enhanced job-performance,[54] but showed job performance hardly to have affected job satisfaction.[55,56]

We found, first of all, that the dominant underlying factors for positive experiences with DCM in ID-care were that DCM increased insights both into the behaviour of both clients and professionals. The insight into clients, related to new knowledge regarding dementia and person-centred care, led to more understanding of the causes of their behaviour and ideas for more tailored care. Furthermore, DCM improved professional behaviour; the method enabled professional reflection and provided guidance in ID-care, which we found had been uncommon for daily ID-care staff. These factors may contribute to coping with challenges in

long-term care. Our study and previous ones indicated that long-term care relationships are important for understanding the behaviour of clients, but can also cause blind spots and impede a critical look at one's own professional behaviour.[9,57-61] Previous research showed that strong bonds with clients and high engagement with work may lead to ID-care staff taking on overly demanding responsibilities and refusing to admit mistakes in daily work.[57-59] Moreover, previous studies found that professional reflection and understanding are important to overcome this habitual professional behaviour and these blind spots; such reflection could lead to improved job-performance.[54,62-64] We found that DCM helped to achieve this because it provides recurring feedback and reflection on job-performance, in combination with greater knowledge regarding dementia and person-centred care: factors not yet common in ID-care.[30]

A second value of DCM seems to be its provision of new knowledge and skills regarding dementia like person-centred care, cues to coordinate care, and a methodical tool to apply knowledge in practice; these have not been reported for any other method in ID-care. This report by professionals contradicts the large number of existing approaches for providing care and support to people with ID,[65,66] which often lack either a theoretical, scientific or methodical base.[30,67] We found that DCM provided an underlying theory for staff in daily care provision by relating the needs of clients to Kitwood's five dimensions of personhood. This led to more deliberation of individual staff in daily care, which are factors associated with improved job performance.[56,68,69] Staff reported that the methodical cycle helped them to sustain the application of theoretical knowledge in practice, and to bridge the gap between knowing and doing, as also shown in previous research.[70,71] Furthermore, the improved coordination and conformity of care provided by DCM created in staff a feeling of being a team, which previous research has also shown to be an enabling factor for providing good care.[72,73] DCM thus provides an applicable theory for the provision of daily care.

Third, staff reported that DCM also helped to apply a more person-centred approach, which was perceived as helpful to fulfil the individual clients' needs. However, staff experienced a conflict between person-centred working and the task-oriented organisation of care and registration systems. This conflict was also noted in previous studies on applying person-centred care; even though staff are highly motivated and convinced that they should deliver person-centred care to their clients, if the organisation of care remains task-oriented, staff are forced to continue working in a task-oriented way.[74,75]

To be successful DCM requires fulfilment of preconditions, which we found were not always present, such as a strong base of person-centred care throughout the organisation. Previous research on DCM indicated that to reach optimal results the fulfilling of these preconditions is of major importance.[14,33,75,76] For future implementation of DCM, adequate compliance to the preconditions should be maximised.

Finally, we found that staff were more positive about DCM after the second cycle. This has also been shown in previous research regarding its use in dementia care.[75,77] This could be for several reasons: first, the DCM-in-ID mappers had become more experienced in carrying out DCM and were therefore able to provide better feedback. Second, staff had become more aware of what DCM entails: not instant solutions, but reflection on professional behaviour and finding solutions themselves. Previous research showed that this mechanism is common after implementing a new intervention; participants have to become used to working with it.[70,72,78,79] Related to this is that the answers of staff after the first DCM-cycle were aimed mostly at (the behaviour of) clients, but after the second cycle they were aimed at reflection on their own professional behaviour. Previous research showed that when not in control, staff are inclined to attribute problems in daily care to the clients' behaviour.[56,80] This suggests that after the second DCM-cycle, staff are used to doing more professional reflection and are more in control of their daily work, which may lead to improved job-performance.

Strengths and limitations

A key strength of this study was our use of a multi-informant and multi/mixed-method design to examine the opinions of care staff and managers on DCM in ID-care settings. Moreover, we examined the use of DCM in practice in 12 group homes from six organisations for people with ID, each home having its own vision, culture, team characteristics, and habits in care; this enhances the validity of our results for routine ID-care practice.

A limitation of this study is that we rely fully on reports by professionals. These reports may be biased due to social desirability and a Hawthorne effect, related to the additional attention to professionals as part of the study. However, this is not very likely because the methods used in de interviews and focus groups enabled staff to perform critical reflection and take part in in-depth discussion. This makes a Hawthorne effect not very plausible, although it cannot be ruled out.

Implications

Our finding that DCM provides new knowledge and skills for staff caring for older people with ID could bridge the gap in the changing approach to care for this group.[81] The method was perceived as useful for applying theoretical knowledge in practice, also knowledge gained from previous training and courses. However, for a routine application of DCM a broader (theoretical) knowledge on the part of staff in person-centred care should be considered. Moreover, to enable staff to provide more person-centred care, a shift would be advisable towards person-centred care throughout the whole organisation, a shift from registration systems to a person-centred compliant vision.

Although we found that staff valued DCM in daily care practices, and indications that DCM might improve job-performance and quality of (person-centred) care for older people with ID, previous research has found no evidence on the quality of life of people with ID nor on job-satisfaction of care staff.[29,39] The effectiveness of DCM should thus be assessed in a study aimed at outcomes in the direct care process, such as job-performance, quality of (person-centred) care and quality of staff-client interactions.

Conclusion

Staff considered the use of DCM in ID-care to be a valuable additional method to support them in their work with ageing clients. We found that DCM gave insights and consciousness, new knowledge and skills, a (person-centred) theoretical base, and a methodical cycle to sustain knowledge in practice. This indicated that DCM could improve the quality of care and job performance of staff. However, the implementation and maintenance of DCM need further attention, as does compliance to the action plans. Future research should follow up on the effects of DCM in ID-care on quality of care, quality of staff-client interactions, and job performance.

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General discussion

CHAPTER 7

The greatly increased life-expectancy of people with intellectual disabilities (ID), with increasing rates of dementia and related behavioural changes, is creating new care challenges. This calls for adaptations in the provision of care by professional care staff and creates a need for new knowledge and skills. While many studies have reported on ageing and related conditions like dementia and the related need for psychosocial methods,[1-4] few specific interventions exist to address the needs of older people with ID, and evidence of their effectiveness is scarce.[5] DCM, a person-centred method derived from regular dementia care, could also be supportive for ID-care staff in their daily work with ageing clients with dementia. The main objective of this thesis was to examine the use and effect of Dementia Care Mapping (DCM) in care for older people with intellectual disabilities and dementia.

In this chapter we will first summarise the main findings in relation to each research question. Next, we will discuss these findings in their broader theoretical and practical context. After that we will address methodological considerations regarding this study. Finally, we will reflect on the implications of our findings for practice and suggestions for future research, and present our general conclusion.

Main findings

Research question 1 (Chapter 2): *Is DCM feasible in care for older people with ID and dementia?*

We found DCM to be feasible in care for older people with ID and dementia. No major adaptations are needed to tailor DCM to ID-care settings. However, small modifications in DCM-codes, tailoring the examples to ID-care, and shorter observation periods are required, due to the different nature of care in ID-settings. Regarding observation periods, two or three time frames, each with a minimum of two hours, could better replace the original six hours of consecutive observation. When tailored in this way to intellectual disability care, DCM is a useful support to ID-care staff, and its effectiveness can readily be assessed.

Research question 2 (Chapter 3): *What is the effect of DCM on job satisfaction and caring skills of ID-care staff?*

We found that DCM had no effects on our primary outcomes, job satisfaction and caring skills of ID-care staff. Effect sizes between the intervention- and control groups varied from -0.18 to -0.66, none of them being statistically significant. On all outcome measures we found high scores of ID-care staff at baseline, including the secondary outcomes: engagement, self-esteem, involvement and dedication.

Research question 3 (Chapter 4): *What is the effect of DCM on the quality of life and wellbeing of older people with ID?*

We found that DCM had no effects on the quality of life and wellbeing of older people with ID, whether or not they had dementia. Effect sizes between the intervention and control groups regarding the primary outcomes were small, varying from 0.01 to -0.22, none being statistically significant. On all outcome measures we found high scores of older people with ID at baseline.

Research question 4 (Chapter 5): *What are the reach, efficacy, adoption, implementation, and maintenance of the first use of DCM in care for older people with ID?*

Among ID care staff we found a high perceived efficacy, and a high willingness to adopt DCM in routine care practice; this was reflected in the high reach, i.e. 94%, of the staff participating. Regarding efficacy**,** staff considered DCM valuable; it provided them with new knowledge and dementia- and person-centred caring skills. Managers intended to adopt DCM in daily care. Furthermore, the intervention was implemented as intended. As for maintenance, DCM was further enriched in casuistry with ID-care examples, and a version of DCM was developed for individual ID-care settings.

Research question 5 (Chapter 6): *What are the experiences regarding the use of DCM in ID-care from a professional perspective?*

Care staff reported that DCM provided them with new knowledge and skills: new insights into clients and the causes of their behaviour, and greater awareness of their own behaviour.

Moreover, we found that DCM provided valuable cues to coordinate care by providing a theoretical base in daily care. However, to be successful DCM requires fulfilment of preconditions, one being a strong person-centred base for care in the entire organisation, a base which was not present in every participating group home.

Reflection on main findings

Three main themes emerge from the findings of our thesis. These themes address the value of DCM for professional care staff, the value of DCM for older people with ID, both with and without dementia, and the integration of DCM in daily ID-care practice.

The value of DCM for care staff

We found that staff considered DCM to be helpful in the care and support of older people with ID (Chapters 2, 5 and 6). However, our quantitative study indicated that DCM had no effects on job satisfaction and caring skills of care staff (Chapter 3). We will here discuss these contradictory results.

First of all, this thesis showed that DCM meets the needs of ID-care staff regarding skills and knowledge required to provide dementia and person-centred care, and of the changing nature and intensity of providing care (Chapters 2, 5 and 6). We also found that the methodical cycle of DCM helped to operationalise person-centred care and to put new knowledge and skills into practice. These results are in line with previous research showing that ID-care staff lack knowledge regarding the trajectory of ageing, as well as the boundaries between age-related memory decline, cognitive impairment and dementia, and they require greater knowledge and skills to cope with the changing psychosocial age-related conditions of their clients.[4-7] ID-care staff had generally attained their knowledge of ageing from experiences during their work, and not from their initial social or pedagogic education.[6,8,9] The application of new knowledge and skills depends on the capacity of ID-care staff to learn and fulfil new roles and skills;[10,11] feedback such as that provided in DCM proved helpful and potentially beneficial for job performance.[12] Furthermore, we found that the opportunity which DCM provided for staff to reflect on their own job performance, as well as to actively participate in planning the care practices of direct care staff, was highly appreciated (Chapters 3 and 6).

Although it was new for them, and sometimes perceived as difficult, staff appreciated being able to reflect on their performance and to have their knowledge taken seriously in the application of care. These findings attest to the potential value of DCM as a method to improve care for older people with ID.

However, in a quasi-experimental study we found DCM in ID-care to have no effects on the job satisfaction and caring skills of staff (Chapter 3). As in previous studies of others on DCM in dementia care, we have based our outcome measures on the assumption that improving quality of care increases job satisfaction.[13-16] These previous studies indicated that DCM improved caring skills; findings, albeit not-significant, indicated that staff experienced reduced stress and emotional exhaustion, as well as more positive reactions to clients.[15] Our current study suggests, however, that DCM does not have the assumed 'two-stage' effect of DCM on job satisfaction. This has been confirmed by other research indicating that specialised training and increased job performance are not important factors influencing job satisfaction.[17,18] Using job satisfaction as a primary outcome measure, as we did in this study, might be too far away from the outcomes actually realised by DCM. More proximal outcome measures, such as quality of care and quality of staff-client interactions, might provide more sensitive measures of DCM's effects.

Furthermore, we found the professional engagement, involvement and dedication of care staff to be very high; this may have influenced measuring effects of DCM, leading to a ceiling effect (Chapters 3, 4 and 6). High job satisfaction has previously been found to be common among staff who have long-term caring relationships with their clients,[2,19-21] as well as among ID-care staff in the Netherlands, who, compared to their international colleagues, have higher levels of job satisfaction and greater involvement in their work.[22,23] However, this high engagement and involvement on the part of care staff has been shown to result in taking on overly demanding responsibilities and refusing to admit mistakes in daily work,[24-28] which may have resulted in information bias regarding job satisfaction. For more precise measurement of effects we therefore recommend using methods other than self-reports.

The value of DCM for older people with ID

Regarding the value of DCM for older people with ID, our quantitative study using appropriate and validated questionnaires indicated no effects on clients' quality of life (Chapter 4). As in

previous studies on DCM in dementia care,[13,15,16,29,30] we have again based our choice of outcome measures assuming that the quality of life of clients would increase as a result of improved quality of care. As many studies have outlined, social interaction and provision of care and support by care staff can increase the quality of life of people with dementia.[31-35] Some studies regarding DCM in nursing homes reported heterogeneous results, including some positive results related to agitation, falls and neuropsychiatric symptoms.[13,15,29,36] These previous studies and our current one do not, however, confirm the assumption that DCM affects quality of life. As in the case of job satisfaction, the assumption that DCM directly affects quality of life is not supported by evidence.

We found that professionals considered DCM valuable for addressing psychosocial needs and for tailoring care to individual clients (Chapters 2, 5 and 6). Previous research showed that person-centred care was likely to lead to psychosocial benefits for individual clients with ID, as well as for the whole group.[5,6,33,37-39] Within the theory of person-centred care, staff found Kitwood's five dimensions of personhood ('Kitwoods Flower') to be useful in fulfilling individual clients' needs (Chapter 6). Although the long-term care relationships and strong bonds generally shared by people with ID and care staff[5,40-42] have been shown to be important for understanding (the behaviour of) clients, they can cause blind spots in the perception of professionals and impede a critical look at the provision of care.[2,19,25,43] Staff reported that DCM helped to address this issue by evaluating care objectively, making care staff more aware of the problems and increasing their knowledge of dementia, thereby helping them to provide more tailored care (Chapters 2, 5 and 6). Our study thus showed that, despite its apparent lack of effect on the quality of life of clients, DCM was perceived as helpful in providing daily care for older people with ID.

Integration and added value of DCM in daily care

This thesis confirms the feasibility of DCM to support the provision of daily care for older people with ID, with and without dementia (Chapter 2), and gives a ground for further implementation of DCM in ID-care. However, we found that proper implementation of DCM requires fulfilment of specific DCM preconditions. This has been confirmed by previous research: successful integration of interventions like DCM in daily care practice depends on factors related to the characteristics of the intervention, the context within the organisation,

the individuals involved, and the way the implementation process is organised and performed.[44-46] Factors related to the organisational context (e.g. care culture and organisation of care) are considered particularly important for integration of interventions in daily care.[44,47,48] Studies on DCM in nursing homes reported obstacles similar to those we encountered, and were related to how the organisational context affected the fulfilling of DCM-preconditions.[14,30,49-54] Assuring the realisation of preconditions is likely to improve implementation.[16,49,52] However, as DCM is a multi-component method to be applied in practice, realising all preconditions can be problematic.

We have found that for integration of DCM in daily care practice, it is crucial to have a person-centred approach throughout the entire organisation, with staff skilled and experienced in applying person-centred care and assisted by a person-based support system. This confirms findings in other studies on routine dementia care in nursing homes.[16,36,53] We found that this person-centred base is not yet present in ID-care, although several studies indicated that a person-centred point of view should be the guiding principle in providing quality of care for older people with ID, and would correspond well with existing ID-care practices and culture of care.[5,6,33,37,55,56] Other research has shown that full implementation of a person-centred approach in ID-care is slow because of barriers in the philosophy and culture of care, influenced by lack of experience on the part of staff and managers, staff workload, and a task-oriented organisation of care.[43,57-60] Thus, for a proper application of DCM, organisations need to choose for person-centred care, not only in vision, but also in practice throughout the organisation (e.g. in registration systems).

We found that DCM has the characteristics to be a successful intervention in ID-care: it enables professional reflection and guidance by providing a theoretical base for daily practice, as well as utilisation of the new theoretical knowledge within a methodical cycle and coordination of care (Chapter 6). We found that such an approach was not yet very common among ID-care staff.[61,62] Although care staff and managers greatly influence the quality of the care provided and are essential for the integration of interventions,[6,63,64] previous research has indicated that ID-care organisations often fail to put the staff's capacities to use.[65] ID-care staff have often expressed feeling powerless in their roles, and excluded from organisational dialogue.[64-66] DCM, to the contrary, involves staff in the direct care process, gives professionals responsibility for their behaviour, and puts their knowledge to use in direct care (Chapter 6). This is in line with research findings regarding practice leadership and

empowerment of daily care staff, which are positively related to their practice and job performance.[65,67] Our results thus showed that the integration of DCM in daily care practice can be improved by involving and empowering staff in the organisation of care.

Methodological considerations

We used both qualitative and quantitative research methods to examine the use and effects of DCM in care for older people with ID. Below, we will discuss the advantages of this mixed methods approach, and subsequently discuss the strengths and limitations of both methods regarding the quality of the samples, the quality of the information obtained, and the causal inferences that can be made.

Combining quantitative and qualitative methods

An important strength of this thesis was its mixed methods approach. Combining qualitative and quantitative methods can be highly valuable in the evaluation of (psychosocial) care interventions,[68-70] each method complementing and enhancing the other.[70-73] We used the qualitative approach of conducting focus group discussions and interviews with participants, who were participating in a quasi-experimental quantitative study. A strength of this mixed methods approach was that it improved our understanding of processes of the intervention, thereby revealing potential explanations for lack of effects in the quantitative study.[68,70] The qualitative study nuanced the outcomes and explained their underlying mechanisms, thereby providing the insight necessary to tailor the intervention even more to ID-care.[68,74] Moreover, in the different methods we found conflicting opinions on the same topics, which broadened our understanding of the problems involved.

A limitation of the mixed methods approach is that it requires more effort and expertise than the use of only one method.[71,75,76] Furthermore, during the study we did not fully integrate, relate or combine the quantitative and qualitative data in an iterative process, for example by using the outcomes of the first qualitative data analysis for further data collection decisions. However, in this Discussion section we have combined the findings of the studies, integrating the data in order to gain a more complete picture, seen from various perspectives.[68,77] In the following paragraphs we will reflect separately on the quality of the

samples, the quality of the information obtained, and the inferences as to the causality of both qualitative and quantitative studies.

Quality of the sample

Our design involved a diverse study sample of participants from two group homes from two different organisations in the feasibility study, and in 24 group homes from 6 organisations in the subsequent effect studies and (process) evaluations. The group homes were representative of ID-care for older people in the Netherlands; we included nearly all existing group homes for this group in the north of the Netherlands. This provided a representative sample, making our findings potentially generalisable for ID-care in the Netherlands.

Regarding the **qualitative samples**, a key strength was the use of multiple types of informants with different backgrounds: ID-care staff, group home managers, DCM-in-ID mappers, and DCM trainers. We thus obtained information regarding the use of DCM in ID-care from different perspectives: from both users (care staff and managers), and providers (DCM-in-ID mappers, and DCM trainers). Previous studies focused mainly on the perspective of providers. However, as in most qualitative research, generalisation of this sample may be tentative. Nevertheless, the main goal of this qualitative research was not generalisation, but rather the obtaining of in-depth information on a broad range of experiences and opinions, by using a representative sample.[78]

Regarding the **quantitative sample**, a strength was the inclusion of twelve group homes belonging to six different care-organisations for people with ID in the north of the Netherlands. From these group homes we included a complete sample of ID-care staff and older clients with ID (Chapters 3 and 4). This resulted in a large sample size for studies regarding the effects of an intervention in ID-care (staff: N=221, clients: N=224), and prevented selection bias. To balance the representation of organisations in the control and intervention groups, of the four group homes per organisation we allocated two homes to the intervention group and two to the control group. Allocation of a group home to the intervention or control group depended on the geographical distance between the mapper and the home, as well as on sufficient geographic distance between control and intervention homes to prevent contamination. Next, the very high response rates limited the likelihood

of selection bias: almost all staff and clients participated: response rates were respectively 85% and 87%. Furthermore, we had a low loss to follow-up (16%).

A limitation of our **quantitative sample** is that we were unable to collect data from the older people with ID themselves, nor from their relatives, to assess quality of life. Although relatives were included in the study, most of them reported being unable to assess clients' outcomes because they had no contact on a daily basis. Second, due to chance, regarding background characteristics we had some imbalances between the intervention and control groups in the quasi-experimental studies, finding relatively more severe disabilities and more dementia in the intervention group. However, adjustment for these differences did not affect the findings.

Quality of information obtained

Regarding the quality of the obtained **qualitative data**, by performing focus group discussions and interviews we were able to study in-depth the experiences of care-staff, managers, DCM-in-ID mappers and DCM-trainers. To assess the quality of these qualitative data, we used the concept of 'trustworthiness' as an equivalent to the quantitative concepts of 'validity' and 'reliability'.[79,80] The trustworthiness of qualitative studies includes the following criteria: credibility, dependability, confirmability and transferability.[79-82] These criteria correspond respectively to the quantitative criteria: internal validity, reliability, objectivity and generalisability.[79-82]

A first strength regarding the *credibility* (the 'truth') of the findings was our use of a multi-informant design to examine the application of DCM in ID-care settings.[83] Informants consisted of the receivers (staff and managers) and providers (DCM-in-ID mappers and DCM-trainers) of DCM. A second strength was the use of methods that facilitated critical reflection on DCM. In the feasibility study (Chapter 2) we used a thoroughly developed topic guide for a semi-structured approach; we structured the process-evaluation (Chapter 5) and experiences and opinions of staff (Chapter 6) using the empathy map derived from the design thinking-theory.[84] A third strength was that we conducted several interviews (N=7) and focus group discussions (N=8) with groups split into categories by function: two groups for staff from different group homes, one group for managers and behavioural scientists, and one group for mappers. This facilitated a safe environment for critical reflection.

A strength regarding *dependability* (findings that are consistent and can be repeated) was our thorough description of the extensive data collection and analysis procedures, including checking the transcripts for completeness and accuracy, multiple coding, deduction of themes by experienced qualitative researchers, and discussion of results with the research team as well as experts in dementia- and ID-research. These procedures also strengthened the *confirmability* of our research (findings based on experiences and ideas of respondents rather than researcher bias, motivation or interest).[79-82] Furthermore, to strengthen *confirmability* we used comprehensive frameworks for both the feasibility study and the process analysis, which allowed us to examine both as broadly as possible. The inclusion of twelve group homes from six main organisations, each with its own vision, culture, team characteristics, and habits in care, enhanced the '*transferability*' (generalisability) of the results to other ID-care organisations in the Netherlands.[79-82] Finally, the results from the different perspectives of all participants from different group homes turned out to be complementary rather than contradictory, which also strengthened the *transferability*.

A limitation of the qualitative data is that we relied entirely on professional reports. These may have been biased due to social desirability and a Hawthorne effect, related to the extent of attention to professionals as part of the study. However, this is unlikely because the methods used in the interviews and focus groups discussions enabled staff to perform critical reflection, making social desirability less probable.

Regarding the quality of the **quantitative data**, a first strength is that we used two informants, i.e. two staff members, to assess independently each client's quality of life. Inter-observer agreement between the proxies for the individual clients was high, and perceived as good to excellent. A second strength was that to measure both job-satisfaction and caring skills of staff we used validated and sensitive questionnaires which has also been used in prior research regarding DCM. To assess clients' quality of life we used proxy-questionnaires best related to the aims of DCM.

Our quantitative studies also had one major limitation: the use of self- and proxy-report questionnaires in our quasi-experimental study. We fully relied on these self- and proxy reports by staff, which may have led to information bias and a less accurate measurement of change.[85,86] Furthermore, we found high values on most outcomes, both at baseline and follow-up, causing a ceiling effect. This may have been caused by involving professionals with

a secondary vocational training, who might be less accustomed to reflect on their own job performance and may base their answers on a (high) self-imposed standard[87,88] and thus be too positive. Furthermore, as discussed in the 'Reflection on main findings', the high engagement, involvement and dedication to work on the part of ID-care staff may have led to information bias regarding job satisfaction.[24-28] This raises the question of whether self- and proxy reports are the best sources to assess effectiveness of interventions among ID-care staff or whether we could better use observations.

Inferences on causality

Our study has several strengths with regard to causality. The first strength is its well-designed quasi-experimental study with large sample sizes, participants from a wide range of organisations, independent data collection, ample strategies to avoid contamination and bias, a comparable control group, and a follow-up of one year with two follow-up measurements. We performed multilevel analyses in order to take into account both each group home and either its staff or clients (Chapters 3 and 4). Moreover, we carefully assessed the feasibility of DCM for ID-care, with a positive result, prior to further assessment by means of quasi-experimental studies (Chapter 2). A second strength has to do with the qualitative studies. Our use of appropriate methods for data collection among multi-informants, and our extensive, in-depth data collection and analysis increased our insights into the factors underlying effective use of DCM in practice (Chapters 2, 5 and 6). Finally, the complete study occurred in the context of routine ID-care, thereby enhancing the generalisability of our results.

In spite of our relatively strong quantitative research design we did not find effects regarding job satisfaction of staff and quality of life of clients (Chapters 3 and 4). This can be explained in several ways. First, as indicated above, a ceiling effect may have occurred in the questionnaires of staff and of clients in the quasi-experimental studies, possible because of secondary vocational trained professionals being less accustomed to reflect on their own job performance and basing their answers on a (high) self-imposed standard. Also the high engagement, involvement and dedication to work of ID-care staff may have contributed to this bias. This ceiling effect has limited the potential to measure the effects of DCM. A second explanation for not findings effects of DCM is related to the implementation and application

of DCM in ID-care. In line with previous research we have stressed the importance of strict adherence to DCM-implementation protocol (Chapters 3, 5 and 6).[49,52,89] Previous research has reported that DCM was effective in highly controlled conditions in an experimental trial and that better fidelity to the implementation protocol could improve its effectiveness.[89,90] Although we have placed great emphasis on adherence to the protocol, and taken care to have fidelity to the protocol strictly monitored and supported by DCM-trainers, the quality of adherence could at some points be improved (chapter 5). This applies in particular to the performance quality of the mappers, as well as the support by managers in providing sufficient time and resources.

Regarding performance quality, i.e. the mappers' skills: despite finishing basic and advanced mappers' training, the newly trained mappers were not always fully capable of carrying out DCM on their own, and needed counselling and close cooperation with the DCM-trainers. As for support by managers, the success of DCM was dependent on their commitment to the intervention and their willingness to enable both mappers and care staff team to carry out DCM properly; this involved providing time and resources and supporting the application of DCM in practice (Chapter 3). Other studies also showed that group home managers played a major role in motivating staff to use interventions consistently, including providing time and resources to do this properly.[34,91,92] However, in our study some managers perceived the implementation protocol of DCM as too hierarchical because it starts with higher management; they suggested using a more bottom-up approach, including staff in the implementation and coordinating process, and thereby gaining more commitment on the part of staff.

A third explanation is that DCM may simply not lead to better job satisfaction and increased quality of life of clients. As in previous studies on DCM in ID-care, we have based our choice of outcome measures on DCM's claim that it increases job satisfaction and quality of life as a result of improved quality of care. Previous studies on DCM aimed at dementia care staff found that improved caring skills led to increased job satisfaction, including a tendency toward reduced stress, burnout, and emotional exhaustion as well as fewer negative and more positive reactions to clients; however, these findings were not significant.[15] DCM may thus indirectly improve some negative work experiences but its effects may be too slight and too indirect to lead to better job satisfaction and quality of life.

Different outcome measures related to quality of care might be more accurate for assessing this aspect of DCM.

Implications for practice

This thesis showed that DCM has no effects on job satisfaction of care staff and quality of life of clients, but does have the necessary characteristics to make it a successful intervention to improve the quality of care for older people with ID. It can help to bridge the gap between apparently separated principles of care and wellbeing, who seem to converge in people with ID as they age. These are promising results for daily care practices. This reported awareness-raising impact suggests that DCM can make a difference in quality of care and job performance of staff, thereby providing benefits for older people with ID, whether or not with dementia.

Our results also showed that the integration of DCM into daily care practice can be improved. This pertained most importantly to the choice of organisations for person-centred care, and a person-centred base of knowledge on the part of care of staff. For example, staff knowledge of person-centred care can be improved by adding an e-learning module on person-centred care aimed at care-staff. Furthermore, we suggest training solely behavioural specialists as mappers; they have broad knowledge of several syndromes, their observations can easily be integrated within their daily work, and they often have required competencies such as planning, drawing up reports, and providing feedback. This thesis also demonstrated that to increase the quality performance of DCM in ID-care the training of mappers should include more knowledge regarding dementia and person-centred care in ID-care. Moreover, adaptations are needed to tailor DCM to ID-care settings in care examples and casuistry. Finally, we detected a need to expand the method for mapping in private areas, i.e. in the clients' own rooms; such a method is currently being developed.

We further found that staff perceived DCM to be helpful in that it increased the involvement of daily care staff in setting up care plans and activities for their clients. To improve the psychosocial quality of life of people with ID, effective staff practices are crucial to help introduce changes into care and the care culture. Such involvement of daily care staff in ID-care plans and activities is not yet common. This argues for more leadership by daily care staff, to which DCM could contribute.

Furthermore, to increase the quality of care for this specific group of older people with ID, new combinations of professional backgrounds within the care teams should be considered. The current group of vocational trained staff with social or pedagogic education should be complemented with staff with a nursing background, whose initial education has given them more knowledge regarding dementia care. This might lead to a more inter-professional care approach, tailored to the changing needs of the ageing clients. Also, to enhance reflection on the possibilities of leadership for staff, in combination with an increased awareness of the complexity of care for older clients with ID and dementia, the inclusion of more staff with bachelor training (social, educational and nursing) should be considered. This could contribute to more person-centred and integrated care for older people with ID, in which the principles of DCM might be helpful.

Implications for future research

Our study does not provide evidence that DCM improves job-satisfaction of care staff and quality of life of clients, possibly because of the use of outcome measures not related closely enough to the intervention. Future research should focus on outcome measures regarding quality of care, quality of staff-client interactions, and job performance as more proximal measures for the effects of DCM.

Furthermore, we found that self- and proxy reports by ID-care staff are not the most suitable for measuring effect, because these staff are not very accustomed to reflect on their own work. Future research should apply different methods, including direct observation.

Evidence regarding caring approaches for older people with ID remains scarce. This study is an attempt to improve care for this group; future research should expand this, focusing on improving the quality of care, also by emphasising person-centred and integrated care. Furthermore, until now most research on ID-care regarding older people and person-centred care is aimed at client-outcomes. Because change in daily care starts with changing the work approach of care staff, future research should focus on the function of care-staff, both team-based and individual.

Conclusion

We found DCM to be a feasible intervention in the care of older people with ID. Its theoretical and methodical basis makes it applicable in daily ID-care, along with other existing methods. Although we have not found any evidence that it affects the job satisfaction of care staff or the quality of life of clients, our study indicates that DCM raises the awareness of ID-care staff regarding the psychosocial wellbeing of their ageing clients in daily care. DCM can make a difference to the job performance of staff and the quality of care, and holds benefits for older people with ID, whether or not with dementia. Future research should examine the effect of DCM on job performance of care-staff and quality of care, and the resulting effect on older people with ID.

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SUMMARY

In the past few decades, the lifespan of people with intellectual disabilities (ID) has greatly increased. This increasing number of older people with ID and associated diseases, such as dementia, calls for new types of care and support. Several studies have outlined that ID-care staff encounter difficulties in dealing with the psychosocial age-related issues of their clients, in particular with dementia. Therefore, ID-care staff express a need for methods, knowledge and skills to support their older clients.

Person-centred methods may provide such support in caring for older people with ID, and may promote the shift from task-focused to more integrated, person-centred care. However, in ID-care, person-centred methods are often directly derived from regular dementia care, and mostly applied inconsistently, although previous research has strongly indicated that methods should be customised to ID-care to be successful. A person-centred method not yet used in ID-care is Dementia Care Mapping (DCM), which has been designed to support staff in their daily care for people with dementia. It is a structured, cyclic, observation method, based on the principles of person-centred care. DCM is designed to support care staff and aims at improving the quality of care and, in turn, the job satisfaction of care staff and the quality of life of clients. DCM might be a promising method to support ID-care staff in their daily work with ageing clients with dementia.

The main objective of this thesis was to examine the use and effects of DCM in care for older people with ID and dementia. This has been translated into the following research questions:

1. Is Dementia Care Mapping feasible in care for older people with intellectual disabilities and dementia?
2. What is the effect of Dementia Care Mapping on job satisfaction and caring skills of ID-care staff?
3. What is the effect of Dementia Care Mapping on the quality of life and wellbeing of older people with intellectual disabilities?
4. What are the reach, efficacy, adoption, implementation, and maintenance of the first use of Dementia Care Mapping in care for older people with intellectual disabilities?
5. What are the experiences regarding the use of Dementia Care Mapping in ID-care from a professional perspective?

To answer whether DCM is feasible to support ID-care staff in their daily work with older people with ID and dementia, we set up a qualitative study, using the framework for feasibility studies of Bowen et.al (2009) (**Chapter 2)**. After application of DCM in two group homes for older people with ID, each in three daily situations, we assessed the feasibility of DCM from different perspectives: staff (N=24), managers (N=2), DCM-mappers (N=2) and DCM-trainers (N=2). We consulted scientific experts in dementia and ID-research regarding the design and the results. We found DCM to be feasible with minor adjustments in intellectual disability care for older people, whether they had dementia or not. DCM met a strong demand for a method to support staff in caring for older people with ID, and was found to be implementable, acceptable, practical and adaptable. Minor adaptations were needed to tailor DCM to ID-care settings; only small modifications in DCM-codes and examples and smaller observation periods would be necessary, because of the different character of care in ID-settings compared to psychogeriatric dementia care in nursing homes. We concluded that when fully tailored to ID-care, DCM is feasible and useful for practice in providing person-centred care and support for older people with ID.

To examine the effect of DCM on the job satisfaction and caring skills of ID-care staff, we conducted a quasi-experimental trial in 23 locations of six care organisations in the north of the Netherlands **(Chapter 3)**. We used self-assessed staff outcomes: the Maastricht Work Satisfaction Scale in Health Care (MWSS-HC) for the primary outcome regarding job satisfaction, the Person-Centred Care Assessment Tool (P-CAT) for measuring person-centred care, and the Sense of Competence in Dementia Care Staff Scale (SCIDS) to measure the sense of competence of staff in dementia care (N=227). We found that DCM had no effects on these outcomes; effect sizes varied from -0.18 to -0.66. We suggested several possible explanations for this lack of effects. First, the high scores on baseline in all outcomes might have caused a ceiling effect. Second, the high scores on the secondary outcomes could indicate that staff overestimated their own performance. Third, DCM may have been a too indirect intervention to affect job satisfaction directly. For future research, an alternative approach to measure the effects of DCM could be to choose outcome measures more closely related to the intervention, such as quality of care and quality of staff-client interactions.

In our quasi-experimental trial focusing on older clients (N=224) with and without dementia, we also examined the quality of life and well-being of older people with ID **(Chapter 4)**. We used the Mood, Interest and Pleasure Questionnaire (MIPQ) as primary

outcome, complemented with questions from the Dutch Centre for Consultation and Expertise for assessing staff-reported quality of life and wellbeing of older people with ID. We found no significant differences in effects on the outcome measures; effect sizes were small, varying from 0.01 to -0.22. This lack of effect can be explained in several ways. First, the high scores on the outcome measures at baseline may have caused a ceiling effect. Second, DCM may not lead to a better quality of life, because DCM may be too light and too indirect an intervention to directly affect quality of life.

To assess the implementation of DCM, we conducted a qualitative study using focus group discussions and in-depth interviews with daily care staff (N=24), managers (N=10) behavioural specialists (N=7), DCM-ID mappers (N=12), and DCM-trainers (N=2) **(Chapter 5)**. For the analyses, we used the RE-AIM framework. In this study, we found a high perceived efficacy, as well as a high willingness to adopt DCM in routine care practice, as reflected in the high participation *reach* (94%). Regarding *efficacy,* staff considered DCM valuable; it provided them with new knowledge and skills for the provision of daily care. Participants intended to *adopt* DCM, continuing and expanding its use in their organisations. We found that DCM was *implemented* as intended, and strictly monitored by the DCM-trainers. However, the mappers did not yet feel fully capable of carrying out DCM on their own, and needed support from the DCM-trainers. Furthermore, as the combination of DCM with person-centred care appeared to be successful, a broader (theoretical) knowledge on the part of staff in person-centred care would be necessary. As for *maintenance*, DCM was enriched to ID-care in casuistry, and a version for individual ID-care settings was developed, both as standards for international use. We found that DCM tailored to ID-care proved to be an appropriate and valuable method to support staff in their work with aging clients, which allows for further implementation.

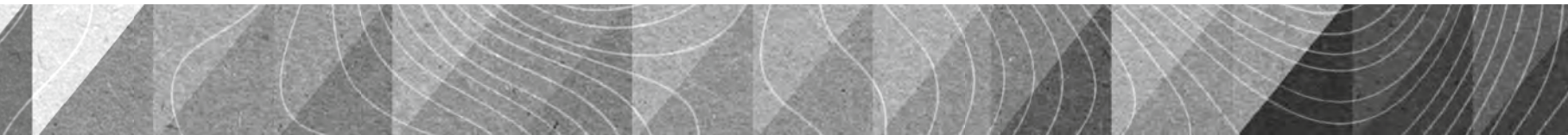
Furthermore, we examined the experiences of professional users regarding DCM in ID-care **(Chapter 6)**. We set up a mixed-method study with quantitative data (questionnaires) from care-staff (N=136) and qualitative data (focus group discussions, individual interviews) from care-staff, group home managers and DCM-in-ID mappers (N=53). All participants considered the use of DCM in ID-care to be a valuable additional method to support them in their work with ageing clients, with and without dementia. Professionals reported that DCM gave insights and awareness in their work. Furthermore, DCM provided them new knowledge and skills, a (person-centred) theoretical base, and a methodical cycle to sustain

knowledge in practice. This might bridge the gap in the changing needs of their ageing clients. However, the implementation and maintenance of DCM need attention, as does the practical compliance to the action plans. Furthermore, to be successful, DCM requires fulfilment of preconditions, a major one being a strong person-centred base throughout the organisation.

Chapter 7 provided an overview of the main findings and a discussion of the results, addressing methodological considerations and a reflection on the implications of our findings for practice and future research. We discussed results related to three core themes: the value of DCM for care staff, the value of DCM for clients, and the integration and added value of DCM in daily care. A central issue in the discussion is the discrepancy between the lack of effects regarding job satisfaction for care staff and quality of life of clients and the positive opinions of the participants.

The mixed-methods approach, using both quantitative and qualitative methods, enhanced our understanding of processes of the intervention. Using a relatively strong quantitative research design, we found no effects regarding job satisfaction of staff and quality of life of clients. An explanation may be that the high engagement, involvement and dedication of care staff may have led to overestimation of their own skills, and in turn also to a ceiling effect in the measuring of effects. Furthermore, DCM may simply not lead to better job satisfaction and increased quality of life, because these outcome measures are too far away from the objectives of the intervention. However, staff perceived DCM as a useful method for improvement of care for older people with ID, with and without dementia. The perceived impact on awareness of staff regarding the psychosocial wellbeing of their ageing clients could contribute to greater use of person-centred care, if DCM is adequately implemented and embedded in daily care practice. Future research should examine the effects of DCM on job performance of care-staff, quality of care, and quality of staff-client interactions, and how these improvements at the professional level affect the wellbeing and quality of life of older people with ID.

SAMENVATTING



Mensen met een verstandelijke beperking leven steeds langer. Deze vergrijzing en hieraan gerelateerde aandoeningen als dementie stellen nieuwe eisen aan de zorg en ondersteuning. Uit verschillende onderzoeken komt naar voren dat professionals in de zorg voor mensen met een verstandelijke beperking het lastig vinden om te gaan met de veranderingen die bij cliënten kunnen optreden als zij ouder worden. Dit geldt met name wanneer cliënten dementie krijgen. Medewerkers geven aan dat zij behoefte hebben aan methodieken, kennis en vaardigheden waarmee zij hun oudere cliënten beter kunnen ondersteunen.

Persoonsgerichte zorgmethodieken kunnen mogelijk voorzien in deze ondersteuningsbehoefte en helpen bij de omslag van taakgerichte naar meer integrale, persoonsgerichte zorg. In de zorg voor mensen met een verstandelijke beperking worden persoonsgerichte methodieken echter vaak zonder aanpassingen aan de doelgroep overgenomen uit de psychogeriatrische ouderenzorg en bovendien niet consequent toegepast. Onderzoek heeft laten zien dat deze methodieken pas succes kunnen hebben in de zorg voor mensen met een verstandelijk beperking als zij aan deze doelgroep zijn aangepast. Een persoonsgerichte methodiek afkomstig uit de psychogeriatrische ouderenzorg die nog niet in de zorg voor mensen met een verstandelijke beperking wordt toegepast, is Dementia Care Mapping (DCM). DCM is ontwikkeld om medewerkers te ondersteunen in de dagelijkse zorg voor mensen met dementie. Deze gestructureerde, cyclische, observatiemethode gaat uit van de principes van persoonsgerichte zorg. Het doel is het verbeteren van de zorgkwaliteit en daarmee ook van de arbeidstevredenheid van medewerkers en van de kwaliteit van leven van cliënten. Dit maakt dat DCM een veelbelovende methode is om medewerkers in de gehandicaptenzorg te ondersteunen in hun dagelijkse werk met oudere cliënten met dementie.

In dit proefschrift is onderzocht hoe DCM gebruikt kan worden in de zorg voor oudere mensen met een verstandelijke beperking en wat dit oplevert. Hiervoor zijn de volgende onderzoeksvragen geformuleerd:

1. Is DCM toepasbaar in de zorg voor oudere mensen met een verstandelijke beperking en dementie?
2. Wat is het effect van DCM op de arbeidstevredenheid en zorgvaardigheden van professionals die zorg verlenen aan mensen met een verstandelijke beperking?
3. Wat is het effect van DCM op de kwaliteit van leven en het welzijn van oudere mensen met een verstandelijke beperking?

4. Wat is het bereik en de doelmatigheid van DCM en in welke mate wordt het gebruik van DCM geaccepteerd, geïmplementeerd en gecontinueerd in de zorg voor oudere mensen met een verstandelijke beperking?
5. Wat zijn de ervaringen van zorgprofessionals in het gebruik van DCM?

Om te onderzoeken of DCM toepasbaar is in de zorg voor oudere mensen met een verstandelijke beperking en dementie, hebben we een kwalitatieve studie opgezet. Hiervoor hebben we gebruik gemaakt van het model voor haalbaarheidsstudies van Bowen e.a. (2009) **(Hoofdstuk 2)**. We hebben de toepasbaarheid van DCM onderzocht bij twee woonlocaties voor oudere mensen met een verstandelijke beperking. DCM werd in beide locaties uitgevoerd in drie verschillende dagelijkse situaties. De toepasbaarheid werd onderzocht vanuit verschillende gezichtspunten: vanuit medewerkers (N=24), leidinggevenden (N=2), DCM-observatoren ('mappers') (N=2) en DCM-trainers (N=2). We hebben de opzet en resultaten daarnaast voorgelegd aan een groep wetenschappelijke experts op het terrein van de zorg voor mensen met dementie of de zorg voor mensen met een verstandelijke beperking. DCM bleek met kleine aanpassingen toepasbaar te zijn in de zorg en ondersteuning voor oudere mensen met een verstandelijke beperking, zowel met als zonder dementie. DCM was daarmee een oplossing voor de vraag naar een methode die medewerkers ondersteunt in hun dagelijkse werk. De methode bleek bovendien uitvoerbaar, passend, en haalbaar. De aanpassingen waren klein en betroffen alleen aanpassingen in DCM-codes en casuïstiek. Daarnaast waren er kortere observatieperioden nodig doordat de zorgsetting voor oudere mensen met een verstandelijke beperking verschilt met psychogeriatrische verpleeghuizen. We concludeerden dat DCM toepasbaar en bruikbaar is bij het bieden van persoonsgerichte zorg en ondersteuning, mits de methodiek volledig is afgestemd op de zorg voor oudere mensen met een verstandelijke beperking.

Vervolgens hebben we een quasi-experimenteel onderzoek uitgevoerd op 23 woonlocaties van zes zorgorganisaties in Noord-Nederland om het effect van DCM op de arbeidstevredenheid en zorgvaardigheden van professionals in de zorg voor mensen met een verstandelijke beperking te onderzoeken **(hoofdstuk 3).** We gebruikten zelfbeoordelings-vragenlijsten voor medewerkers: de Maastrichtse Arbeidssatisfactieschaal in de Gezondheidszorg (MAS-GZ) voor arbeidstevredenheid, het Beoordelingsinstrument voor Persoonsgerichte Zorg (P-CAT) voor het meten van persoonsgerichte zorg, en de Schaal voor

Competentiegevoel voor Medewerkers in de Dementiezorg (SCIDS) om de zelf ervaren competentie van medewerkers in dementiezorg te meten (N=227). We vonden dat DCM niet leidde tot een significante verbetering op deze primaire uitkomstmaten ten opzichte van gebruikelijke zorg; de effectgroottes waren niet significant en varieerden van -0,18 tot -0,66. Voor het uitblijven van effect zijn verschillende verklaringen mogelijk. Ten eerste hebben de hoge scores op de nulmeting van alle uitkomstmaten mogelijk tot een plafondeffect geleid. Ten tweede kunnen de hoge scores op de secundaire uitkomstmaten erop wijzen dat de medewerkers hun eigen prestaties hebben overschat. Ten derde is DCM mogelijk te weinig gericht op arbeidstevredenheid om daar een meetbaar effect op te hebben. In toekomstig onderzoek naar de effecten van DCM wordt geadviseerd te kiezen voor uitkomstmaten die dichter bij de interventie liggen, zoals bijvoorbeeld kwaliteit van zorg en kwaliteit van de interacties tussen medewerkers en cliënten.

In een quasi-experimentele studie onder oudere cliënten met een verstandelijke beperking (N=224) met en zonder dementie hebben we de kwaliteit van leven en welzijn onderzocht **(hoofdstuk 4)**. We hebben de Gemoedstoestand, Betrokkenheid en Plezier-vragenlijst (MIPQ) als primaire uitkomstmaat gebruikt, aangevuld met vragen van het Nederlands Centrum voor Consultatie en Expertise, om de kwaliteit van leven en welzijn van ouderen met een verstandelijke beperking te boordelen, zoals gerapporteerd door medewerkers. We vonden dat DCM niet leidde tot een significante verbetering op deze uitkomstmaten ten opzichte van gebruikelijke zorg; de effectgroottes waren klein en niet significant, variërend van 0,01 tot -0,22. Dit gebrek aan effect kan op verschillende manieren worden verklaard. Ten eerste hebben de hoge scores op de uitkomstmaten bij aanvang mogelijk een plafondeffect veroorzaakt. Ten tweede leidt DCM mogelijk niet tot een betere kwaliteit van leven omdat DCM een te lichte en te indirecte interventie is om de kwaliteit van leven te beïnvloeden.

Om de implementatie van DCM in de zorg voor mensen met een verstandelijke beperking te beoordelen, hebben we een kwalitatief onderzoek uitgevoerd met behulp van focusgroepen en diepte-interviews met medewerkers (N=24), managers (N=10) orthopedagogen (N=7), DCM-mappers (N=12) en DCM-trainers (N=2) **(hoofdstuk 5)**. Voor de analyses hebben we het RE-AIM-model van Glasgow e.a. (1999) gebruikt. In deze studie vonden we een hoge waargenomen werkzaamheid, evenals een grote bereidheid om DCM in de dagelijkse zorg en ondersteuning te gebruiken, tot uiting komend in een hoge participatie

(94%). Medewerkers vonden DCM waardevol: het leverde hen nieuwe kennis en vaardigheden op voor de dagelijkse zorg en ondersteuning. De deelnemers waren voornemens DCM te blijven gebruiken en vaker in hun organisaties toe te passen. We hebben vastgesteld dat DCM werd geïmplementeerd zoals bedoeld en strikt werd gecontroleerd door de DCM-trainers. De DCM-mappers voelden zich echter nog niet volledig in staat om DCM zelfstandig uit te voeren en hadden ondersteuning van de DCM-trainers nodig. De persoonsgerichte benadering van DCM bleek van meerwaarde te zijn, maar een bredere (theoretische) kennis van medewerkers in persoonsgerichte zorg was nodig voor een structurele inbedding in de dagelijkse praktijk. Om DCM verder als standaard te gebruiken werd de methodiek verrijkt met casuïstiek en voorbeelden uit de zorg voor mensen met een verstandelijke beperking en werd tevens een versie voor individuele observatie ontwikkeld. De resultaten hiervan bieden een standaard voor nationaal en internationaal gebruik. We concludeerden dat DCM, aangepast aan de zorg voor mensen met een verstandelijke beperking, een geschikte en waardevolle methode is om medewerkers te ondersteunen in hun werk met oudere cliënten en daarmee mogelijkheden biedt voor verdere toepassing.

Hiernaast hebben we de ervaringen van professionele gebruikers met DCM in de zorg voor mensen met een verstandelijke beperking onderzocht **(hoofdstuk 6)**. We hebben een *mixed methods*-studie opgezet met kwantitatieve gegevens (vragenlijsten) van zorgmedewerkers (N=136) en kwalitatieve gegevens (focusgroepen, individuele interviews) van medewerkers, locatiemanagers en DCM-mappers (N=53). Alle deelnemers beschouwden DCM in de zorg voor mensen met een verstandelijke beperking als een waardevolle aanvullende methode om hen te ondersteunen in hun werk met oudere cliënten, met en zonder dementie. Professionals rapporteerden dat DCM hen inzichten en bewustwording in hun werk gaf. Bovendien bood DCM hen nieuwe kennis en vaardigheden, een (persoonsgerichte) theoretische basis en een methodische cyclus om kennis in de praktijk te brengen en te borgen. Zij waren van mening dat zij hiermee beter konden voorzien in de veranderende behoeften van hun oudere cliënten. De implementatie en voortzetting van DCM hebben echter aandacht nodig, evenals de praktische naleving van de actieplannen. Een succesvolle implementatie van DCM vereist bovendien dat aan een aantal voorwaarden wordt voldaan. Een essentiële voorwaarde bleek dat de hele organisatie een sterke basis heeft wat betreft de principes van persoonsgerichte zorg.

Hoofdstuk 7 geeft een overzicht van de belangrijkste bevindingen en een bespreking daarvan, met aandacht voor de methodologische aspecten en een reflectie op de implicaties van onze bevindingen voor praktijk en onderzoek. De bespreking van de bevindingen betrof drie kernthema's: de waarde van DCM voor zorgmedewerkers, de waarde van DCM voor oudere mensen met een verstandelijke beperking en de integratie en toegevoegde waarde van DCM in de dagelijkse zorg voor ouderen met een verstandelijke beperking. Een belangrijk punt in deze bespreking is de discrepantie tussen het gebrek aan effecten op de arbeidstevredenheid van zorgmedewerkers en de kwaliteit van leven van cliënten, en de positieve meningen over DCM van de deelnemers.

De *mixed methods*-benadering, met zowel kwantitatieve als kwalitatieve methoden, heeft het inzicht in de toepasbaarheid en effecten van DCM vergroot. Met onze kwantitatieve onderzoeksopzet vonden we geen effecten wat betreft de arbeidstevredenheid van professionals en de kwaliteit van leven van cliënten. Een verklaring hiervoor kan zijn dat de sterke betrokkenheid van zorgmedewerkers geleid heeft tot een overschatting van hun eigen vaardigheden, en dat dit vervolgens een plafondeffect heeft veroorzaakt bij de effectmetingen. Een andere mogelijkheid is dat DCM niet tot een hogere arbeidstevredenheid en een verhoogde kwaliteit van leven kan leiden, omdat deze uitkomstmaten te ver af staan van de inhoud van de interventie. Uit de kwalitatieve studies bleek dat medewerkers DCM echter als een nuttige methode beschouwden voor het verbeteren van de zorg voor ouderen met een verstandelijke beperking, zowel met als zonder dementie. De door DCM toegenomen bewustwording van medewerkers van de behoeften en welzijn van hun ouder wordende cliënten kan bijdragen aan meer persoonsgerichte zorg, mits DCM adequaat geïmplementeerd en ingebed wordt in de dagelijkse zorgpraktijk. Toekomstig onderzoek moet gericht worden op de effecten van DCM, op de prestaties van zorgmedewerkers, de kwaliteit van zorg, de kwaliteit van medewerker-cliënt-interacties, en op hoe deze verbeteringen het welzijn en kwaliteit van leven van ouderen met een verstandelijke beperking beïnvloeden.

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About the author

Feija Schaap was born on September 18th 1981 in Sint Nicolaasga, the Netherlands. After graduating from the RSG Magister Alvinus (HAVO) in Sneek (1999) she studied social work at the NHL University of Applied Sciences in Leeuwarden. After the propaedeutic year she moved to Groningen to study educational sciences at the University of Groningen. After first studying special needs, education and youth care (orthopedagogiek), she obtained her Master of Science degree in 2005 in social educational theory (andragogiek). Next she sequentially was social worker in homeless care, social scientific researcher, project leader in patient participation and quality of care, and researcher at the research group Living, Wellbeing and Care at the NHL Stenden University of Applied Sciences.

From 2013 to 2019, Feija worked as a PhD student at the Department of Public Health of the University Medical Center Groningen and at the NHL Stenden University of Applied Sciences. She studied the use and effect of Dementia Care Mapping in the care for older people with intellectual disabilities. The project was financed by SIA-RAAK and in 2017 nominated for the RAAK-award for being the most innovative applied research. Throughout her academic training she followed several courses and supervised students at the Bachelor and Master level. She also coordinated the Research Pub at the Department of Health Sciences, Community and Occupational Medicine of the UMCG and the PhD network of the NHL Stenden University of Applied Sciences.

Feija continues her work at the research group Care and Wellbeing at the NHL Stenden University of Applied Sciences as researcher and project leader in establishing a Master's degree within the academies of social work and health care.

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Towards a person-centred approach for older people with intellectual disabilities

The use and effect of Dementia Care Mapping

1. Door systematische observatie en feedback creëert Dementia Care Mapping bewustwording bij medewerkers over hun handelen – *dit proefschrift*
2. Het cyclische karakter van Dementia Care Mapping biedt meerwaarde in de zorg voor mensen met een verstandelijke beperking – *dit proefschrift*
3. Dementia Care Mapping helpt medewerkers hun theoretische kennis toe te passen in de praktijk – *dit proefschrift*
4. Grote betrokkenheid van medewerkers bij hun cliënten is zowel een voorwaarde als een valkuil voor het verlenen van goede zorg – *dit proefschrift*
5. Een voorwaarde voor het daadwerkelijk verlenen van persoonsgerichte zorg is dat de gehele organisatie sterk persoonsgericht georiënteerd is – *dit proefschrift*
6. Voor het verklaren van kwantitatieve resultaten is zorgvuldige analyse van kwalitatieve uitkomsten essentieel – *dit proefschrift*
7. Ervaringen in dit onderzoek wijzen eens te meer uit dat bewustwording de eerste stap naar verandering is
8. Zorg en welzijn zijn georganiseerd als afzonderlijke domeinen, maar zijn in mensen niet te scheiden. Dit proefschrift is een pleidooi voor een meer integrale benadering.
9. Not everything that can be counted counts, and not everything that counts can be counted – *William Bruce Cameron*
10. Look for the bare necessities – *Baloo*
11. Life is not like water. Things in life don't necessarily flow over the shortest possible route – *Haruki Murakami*
12. De omgeving van de mens is de medemens – *Jules Deelder*
13. Once you do something, you never forget. Even if you can't remember – *Zeniba*
14. Andere ogen zorgen er niet voor dat je als die ogen gaat kijken, maar dat je zelf 'als nieuw' gaat zien – *Hadewijch*