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

Feija D. Schaap, Geke J. Dijkstra, Evelyn J. Finnema & Sijmen A. Reijneveld


To link to this article: https://doi.org/10.1080/13607863.2017.1401582
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

Feija D. Schaap, Geke J. Dijkstra, Evelyn J. Finnema and Sijmen A. Reijneveld

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 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 12 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.

Conclusion: 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.
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 12 group homes. The data were analysed according to the principals of thematic analysis (Braun & Clarke, 2006; Guest, MacQueen, & Namey, 2011), and structured and reported using the RE-AIM framework (Glasgow, 1999).

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 4–12) 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 12 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 12 group homes for older people with ID (see Box 1 and Figure 1). 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 (Bradford Dementia Group, 2014). 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 12 homes a staff member, to become a certified, advanced, dementia care mapper. The 12 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 [FS, GD or EF] accompanied by an observer, and an interviewer [FS, AF], respectively. The discussions were structured using the empathy map, derived from the design thinking-theory (Curedale, 2013). 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 (Braun & Clarke, 2006). The five themes of this framework (Reach, Effectiveness, Adoption, Implementation, Maintenance) (Glasgow, 1999) provide a basis for evaluating the implementation of social and health interventions (Gaglio, Shoup, & Glasgow, 2013), and indicate key aspects in the implementation of psychosocial interventions (Boersma, Van Weert, Lakerveld, & Droës, 2015). 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.
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 (Brooker & Surr, 2005). It is based on Kitwood’s social-psychological theory of personhood in dementia (Kitwood, 1992). DCM was designed as observational tool to develop person-centred care of people with dementia in nursing homes (Van de Ven et al., 2013). Person-centred dementia care can be specified as: valuing people with dementia; using an individual approach that recognizes the uniqueness of the person; making an effort to understand the world from the perspective of the person; and providing a supportive social environment (Brooker, Woolley, & Lee, 2007). DCM has three main components (see also Figure 1):

A: Mappers’ training in DCM
A staff member receives a training to become a certified DCM mapper. A basic DCM mappers’ course includes four days of basic concepts and skills. To participate in research, a mapper has to achieve the level of advanced mapper. For this, a three-day course focused on the background and theory of DCM and person-centred care is needed. 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 (Van de Ven et al., 2013).

B: Organisational introductory briefing
Before the mapping (systematic observation of the actual care) takes place, the staff of a group home will receive a short introduction (two hours). This introduction provides basic understanding of the principles of DCM and person-centred care, to ensure endorsement and appropriate implementation (Van de Ven et al., 2013).

C: DCM cycle: observations-feedback-action plan
The introductory DCM organisational briefing day is followed by a DCM cycle. One cycle consists of:

1. **Observation, analysis and report.** A mapper observes four to six residents for 4 to 6 consecutive hours in communal areas. Each 5 minute time frame a code is noted to record what happened to each resident and the associated behaviour of the staff. The DCM coding protocol contains 23 behavioural category codes (BCCs), Well/ill-being (WIB) values, personal detractors (PDs), and personal enhancers (PEs) (Brooker & Surr, 2005).

2. **Feedback.** The results of the mapping are communicated to the staff. The purpose of the feedback is to observe residents’ behaviour in the context of their lives and of the care (Brooker & Surr, 2005). Feedback is presented in a non-threatening way and is intended to raise awareness of the staff of their own and residents’ behaviour, thereby motivating them to improve their competences and performance (Van de Ven et al., 2013).

3. **Action plans.** Based on the feedback, the staff draws up action plans to improve care at individual and group levels. Action plans are tools to implement in daily practice the principles of person-centred care.
We followed a stepwise procedure to analyse the data following the principles of thematic content analysis (Braun & Clarke, 2006; Guest et al., 2011). 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 [FS] read and re-read all transcriptions and set up a concept code book with initial codes, and then discussed it with the second author [GD]. Third, both authors [FS, GD] 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 (Tong, Sainsbury, & Craig, 2007).
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 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 fulfill all required preconditions for optimal implementation of DCM (Bradford Dementia Group, 2014), 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 counseling 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, 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 Uurlsings (Uurlsings, 2014)), 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 work load, 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 (Cleary & Doody, 2016; Fumiss, Lovernseed, Lippold, & Dodd, 2012; Iacono et al., 2014; Janicki & Keller, 2012; McCarron, McCollion, Fahey-McCarthy, Connaire, & Dunn-Lane, 2010; Perera & Standen, 2014; Watchman, 2014; Wilkinson, Kerr, & Cunningham, 2005). 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 (Doody, 2016; Ratti et al., 2016). 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 DCM for people with dementia (without ID) (Quasdorf et al., 2017; Van de Ven, 2014). We found the DCM-in-ID implementation protocol helpful for implementing DCM in the 12 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 (Brownie & Nancarrow, 2013; Chenoweth et al., 2015; Dichter, 2015; Jaycock et al., 2006; Leen et al., 2012; Quasdorf et al., 2017; Rokstad, Vatne, Engedal, & Selbaek, 2015). 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 (Hulscher, Laurant, & Grob, 2005; Moniz-Cook et al., 2008).

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 (Boots, de Vugt, Wijtsen, Kempen, & Verhey, 2016; Waugh et al., 2013), as long the adaptations are made based on substantial evidence and do not compromise the core elements of the intervention (Tabak, Khoong, Chambers, & Brownson, 2012). 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 (Wenger, 1998).

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 12 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 fulfills 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) (Visser, Dijkstra, Post, & Haakma, 2012). 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.

Acknowledgments

The funding institute had no role in the design, collection, analysis, and interpretation of data, nor in the writing of the manuscript or the decision to submit the manuscript for publication.

Disclosure statement

The authors have no conflict of interest to declare.

Funding

This research project was funded by the Dutch Taskforce for Applied Research [grant number RAAK PRO-4-05].

ORCID

Feija D. Schaap http://orcid.org/0000-0001-6719-6982
Sijmen A. Reijneveld http://orcid.org/0000-0002-1206-7523

References


