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

The use and effect of Dementia Care Mapping

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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 IDcare 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 IDcare 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 personcentred 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 IDcare **(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.