

DEMENTIA CARE MAPPING – Evidence Review

Additions/edits by Adelina, 9th September

Dementia Care Mapping (DCM) is one way of implementing person-centred care. It involves continuously observing the behaviour of people with dementia and the care they receive. Dementia Care Mappers record their observations to improve the way people are supported in formal care settings, such as care homes and hospitals. It aims to capture small things which lead to happiness or distress and use this information to enhance people's care plans, and improve the environment of care homes and other care settings.

There is a training manual and formal DCM training programmes are run by the School of Dementia Studies, University of Bradford.

Key points:

- DCM aims to recognise that every person with dementia has a unique and individual identity, and encourages staff to see things from their perspective
- Some studies have shown DCM to have a positive effect on agitation, falls and depressive symptoms. Results from other papers have been less conclusive
- Some studies have found DCM have a detrimental effect on the quality of life of people with dementia, but researchers suggest this may be due to variations in the way it was implemented
- The findings on the cost-effectiveness of DCM are mixed: one study found in Australia it was not cost-effective, while another study in the Netherlands found it was cost-neutral

DCM involves the recording of specific types of behaviour according to different codes and categories, and is normally carried out over multiple sessions lasting several hours each.

DCM helps to capture the processes and outcomes of care, particularly in formal settings such as nursing homes. The feedback from mapping sessions is used by care professionals to develop action plans and improve the quality of care in the future.

It is also used by researchers as a tool for measuring outcomes in audits and evaluations as the results of a mapping session include well-being scores for individual people.

The methodology was developed by the Dementia Research Group at the University of Bradford following detailed observations of people with dementia in a variety of settings.

Typically, a DCM observer will undergo an accredited training programme lasting between two and four days.

The DCM manual (Bradford Dementia Group 2005) sets out guidelines on how to conduct DCM observations, which include observing up to five people with dementia over a representative time period. The observers record the person's behaviour, emotional state and interactions with staff at five minute intervals.

The method of observation and recording is based on 24 categories of behaviour, known as behavioural category codes (BCCs). They include categories such as 'articulation' (interacting with other people), 'coming and going' (autonomously walking, standing or moving), 'nodding' (sleeping, dozing or nodding off) and 'intellectual activity'.

The behaviour and interactions are also categorised as ‘personal detractors’ and ‘personal enhancers’, which can have negative and positive effects on a person’s well-being respectively.

Why is DCM important?

DCM is closely related to the objectives and philosophy of person-centred care. For people with dementia, person-centred care has four key features, which are all adopted in the DCM approach:

- (a) valuing people with dementia and those who care for them, (b) treating people as individuals, (c) viewing the world from the perspective of the person with dementia, and (d) providing a positive social environment for the person with dementia to better experience well-being (Brooker, 2004).

It is based on the psychological theory of ‘personhood’, as articulated by Kitwood and Bredin (1992), which aims to recognise that people with dementia can still reach a level of well-being despite deterioration in their cognitive functioning.

Used effectively DCM can help care providers to recognise people’s individual identities and improve their well-being.

DCM is mentioned in the National Institute for Health and Care Excellence (NICE) and Social Care Institute for Excellence (SCIE) Guideline on supporting people with dementia and their carers in health and social care (2006) as an area in which further systematic research is required.

Does Dementia Care Mapping work?

A large-scale investigation identified a positive effect on agitation among people with dementia in a randomised controlled trial (RCT), in which participants were randomly divided into three groups. In the first group, researchers delivered dementia care mapping to care home residents, who also received usual care; in the second, participants received another type of person-centred care; in the third, people only received usual care (Chenoweth et al 2009). The agitation levels in the DCM and person-centred care groups were significantly lower than the control group. There were also fewer falls in the DCM group, but no significant effects on symptoms of depression or anxiety.

Another randomised controlled trial (Rokstad et al 2013) tested the effect of the intervention on levels of agitation on a group of 446 participants, using two different measures for this outcome. It found no significant effect for the first measure (BARS), but a positive effect for the second (NPI agitation). It also found a positive effect on symptoms of psychosis in people with dementia.

This pattern of varied results continued in another RCT (Van de Ven et al 2013) testing dementia care mapping, involving 265 people with dementia. It found no significant effect on agitation among the participants; in addition, people who received DCM were observed to have more symptoms of mental illness compared to the control group.

The results from research regarding the quality of life of people receiving DCM were inconclusive. Two studies found no significant effects on people with dementia and their quality of life (Chenoweth et al 2009; Dichter et al 2015) while another (Van de Ven et al 2013) even showed reductions in the quality of life of participants. However, the authors of one of those studies, conducted in Germany (Dichter et al 2015), suggested that variations in the way the DCM intervention was delivered may have affected the results. In this case,

the programme was delivered by care professionals with experience of dementia care mapping. However, the authors said the results may have been different had the research team provided greater support in the DCM programme's delivery.

Other evaluations DCM found positive effects on people's well-being (Yasuda et al 2016; Brooker et al 1998), although in these studies there were no control groups to provide a comparison.

Is DCM cost-effective?

Two studies considered the costs of the DCM intervention against the outcomes for people with dementia. A study in Australia found the use of DCM was not cost-effective, as the other person-centred care intervention to which DCM was compared obtained slightly better outcomes (in this case reduction in agitation) at lesser cost (Chenoweth et al 2009). However, that study included only the costs of the intervention and, while those who received DCM reported lower falls, the lack of data on other health care costs (for example hospitalisation) means that any reduction in use of health care services from the reduction in falls will not have been taken into consideration.

Another study in the Netherlands (van de Ven et al 2014) found that, although DCM did not result in improvements in the primary outcomes, it was cost neutral, as it effectively reduced the costs of outpatient hospital appointments, compared with usual care. The authors found that the costs of implementation of the intervention were almost negligible (\$0.63 per resident per day).

Ongoing research

A randomised controlled trial in multiple sites across England is under way, in which dementia care mapping is being tested in care homes in West Yorkshire, Oxfordshire, and London. It will explore the effectiveness of the intervention in terms of costs and outcomes for people with dementia, focusing on the levels of agitation (Surr et al 2016), across a sample of 50 care homes, involving 750 residents.

The NICE/SCIE guideline on supporting people with dementia and their carers in health and social care is being updated, with a revised version due to be published in 2018. It is expected that DCM will be discussed in this guidance in the context of the latest research.

Further information

The School of Dementia Studies at the University of Bradford has a range of online resources related to DCM: <http://www.brad.ac.uk/health/dementia/dementia-care-mapping/>

This includes a short introductory document to DCM: <http://www.brad.ac.uk/health/dementia/dementia-care-mapping/file-downloads/Introduction-to-Dementia-Care-Mapping.pdf>

It also organises regular training courses on DCM in various locations in the UK: <http://www.brad.ac.uk/health/dementia/training/training-courses/dementia-care-mapping-for-realising-person-centred-care/>

OVERALL FINDINGS FOR DCM

	Effectiveness for person with dementia	Family carers	Professional care workers	Cost-effectiveness	Strength of evidence	Whether already implemented in the UK
Agitation	✓=				✓✓✓	✓
Symptoms of depression and anxiety	✓=				✓✓	
Quality of life	✓=X				✓✓	
				=X healthcare consumption, number of falls, and psychotropic drug use = Effect on challenging behaviour and associated costs of increased agitation (staff time, potential for falls, use of restraints) X	✓✓	

EVIDENCE TABLE KEY

Does it work?

✓ Worked well

✓= Worked well in some studies and made no difference in others

✓=X Mixed results; worked well in some studies, made no difference in others and some found negative impacts

= Made no difference

=X Made no difference in some studies and others found negative impacts

X Negative impact

Is it cost effective?

✓ It was cost effective

✓= It was found to be cost effective in some studies and cost neutral in others

=X It was found to be cost neutral in some studies and not cost effective in others

X It was not cost effective

What is the strength of evidence?

This rating will depend on a range of factors such as the type of research for example if it was a Randomised Controlled Trial (RCT) and the number of people who participated in the study.

✓✓✓ High Quality

✓✓ Moderate quality

✓ Low quality

Individual studies

Study	Does it work for person with dementia?	Does it work for family carers?	Is it cost effective?	Strength of evidence
1. Chenoweth et al 2009 RCT, 289 participants, Australia	Agitation ✓ Symptoms of anxiety, depression and other psychiatric disorders =		Effect on challenging behaviour and associated costs of increased agitation (staff time, potential for falls, use of restraints) X	✓✓✓

	Quality of life =			
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Study	Does it work for person with dementia?	Does it have an effect on staff?	Is it cost effective?	Strength of evidence
2. Van de Ven et al 2013, RCT, 265 participants, Netherlands	Agitation = Quality of life X Symptoms of anxiety, depression and other psychiatric disorders X	Job-related stress ✓ Job satisfaction =		✓✓✓

Study	Does it work for person with dementia?	Does it work for family carers?	Is it cost effective?	Strength of evidence
3. Yasuda et al 2016, 40 participants, before-and-after study, Japan	Well-being ✓			✓

Study	Does it work for person with dementia?	Does it have an effect on staff?	Is it cost effective?	Strength of evidence
4. Brooker et al 1998, 3-year evaluation, 324 participants, UK	Well-being = Dependency = Challenging behaviour ✓			✓✓

Study	Does it work for person with dementia?	Does it work for family carers?	Is it cost effective?	Strength of evidence
5. Van de Ven et al 2014, Economic evaluation, 265 participants, Netherlands			Cost-neutral (healthcare consumption, number of falls, and psychotropic drug use =)	✓✓✓

Study	Does it work for person with dementia?	Does it work for family carers?	Is it cost effective?	Strength of evidence
6. Dichter et al 2015 234 participants, RCT, Germany	Challenging behaviour = Quality of life X			✓✓✓

Study	Does it work for person with dementia?	Does it have an effect on staff?	Is it cost effective?	Strength of evidence
7. Jeon et al 2012 194 participants, RCT, Australia		Job-related stress ✓ Psychological distress ✓		✓✓✓

Study	Does it work for person with dementia?	Does it have an effect on staff?	Is it cost effective?	Strength of evidence
8. Rokstad et al 2013, 446 participants, RCT, Norway	Agitation ✓= Symptoms of depression ✓ Other symptoms of mental illness ✓ Quality of life			✓✓✓

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