The potential of Dementia Care Mapping as a practice development tool for occupational therapists in South Africa

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ABSTRACT

The quality of care for persons living with dementia in institutional care settings is of global concern. The provision of person-centred care (PCC) for people with dementia is internationally recognised as best practice, which promotes possibilities for people with dementia to experience well-being. However, there remains a lack of evidence of approaches that can help to support delivery of PCC for older people with dementia in long-term care, in South Africa. Dementia Care Mapping (DCM) is a successful practice development tool, originating in the UK, used for supporting the implementation of PCC. However, to date it has not been considered for use by South African occupational therapists working in residential care facilities. This article defines the components of the DCM tool, its process of use and potential outcomes for care practice. In an attempt to scrutinise the value of findings from an occupational therapy perspective, the Kawa Model is drawn upon to explain how the data from DCM can be interpreted. The Kawa Model provides a strong focus on how a sense of being is promoted by a person’s context, and is an established vehicle to aid understanding of the potential for application of PCC in South African care facilities.

Key words: Dementia, person-centred care, occupational therapy practice development

Introduction

The quality of care for persons living with dementia in institutional or formal care settings, is of global concern to professionals working in this field. The provision of person-centred care for people with dementia is becoming internationally recognised as representing an approach that supports best practice. This is reflected in a range of international policy and strategy documents that highlight the importance of a person-centred approach to support the delivery of PCC. As occupational therapists working in a client-centred way, we are encouraged to value “respect, partnership and enablement” when we endeavour to address the needs of the persons with dementia. In the dementia care field, client-centred practice can be interchangeably used with the term person-centred care. Therefore, in this article we will use the term person-centred care (PCC) to reflect this client or person-centred approach.

Person centred care has been defined as a value base which recognises the inherent value of all humans; the taking of an individualised approach to care that recognises the need to take into account individual choices, preferences and needs; an approach to care where the perspective of the person with dementia lies at the heart of care provided; the provision of a supportive social psychology or environment which recognises the needs of people with dementia. Whilst PCC is considered best practice, a predominant concern is that formal caregivers are not equipped with adequate knowledge or skills of this approach to enable them to address the complex needs of this very vulnerable population. People living with dementia are reliant on formal caregivers to support them to live a life where well-being is possible. Poor quality care is associated with poor well-being and quality of life for people with dementia, linked to an increase in the presence of behaviours that staff find challenging in the way of distress reactions, such as aggression, agitation, restlessness, hallucinations and apathy. Internationally, the behaviours that staff find challenging have also been linked to significant associated healthcare costs including increased risk of hospitalisation, use of emergency rooms and production of excess disability in the person. Excess disability is a decline in the functional abilities of people, which occur more rapidly than would otherwise be expected. This is clearly of concern to occupational therapists whose role is to support maintenance of independence and maximum abilities.

However, these distressed reactions are not an inevitable consequence of dementia. They are often caused by the care practices and the environment that surrounds the person with dementia and by poorly managed physical health and pain. They are also an expression of unmet needs by a person with dementia in response to poor quality care often caused by lack of stimulation and engagement. Therefore, the presence of low well-being and high levels of distressed reactions in individuals with dementia in formal care settings are associated with organisational aspects of care and the care culture. (The care culture refers to care practice allowed, accepted and/or promoted by supervisors and/or organisational guidelines unique to a facility.) This should be addressed through the use of psychosocial interventions that focus on the quality of care practice and which increase opportunities for engagement and occupation.

In his seminal work on PCC, Kitwood outlined the five key psychological needs of people with dementia that lie at the heart of providing PCC, and which should be met through supportive care practices. They are: identity, attachment, comfort, occupation and inclusion. In PCC these psychological needs are met. Where care quality is poor they are not met or are undermined by care practices. At the centre of these five psychological needs is love, demonstrating the recognition of relationship and interdependence between the person with dementia and their caregivers. Clearly as abilities decline, people with dementia become increasingly dependent on formal caregivers for their psychological needs to be met. Often, however, the social environment or social psychology of a formal or institutional care setting does not serve to support psychological needs, resulting in distress and reduced well-being for the person with dementia.

Person centred care (PCC) in the South African context

In South Africa, ensuring the provision of quality dementia care and an appropriately skilled dementia care workforce to deliver this, is aggravated by a primary care focus within the public health care sector. Therefore, the limited resources available are not readily...
accessible to the many non-profit and/or non-government welfare organisations in charge of residential care facilities. South Africa has not identified dementia as a national health priority and, therefore, there is little concern with the quality of care being provided to this vulnerable group of people, and there is no governmental incentive for providers to address this. However, as indicated by a recent study funded by Alzheimer’s Disease International, there is a growing number of older people with dementia in the South African population. If the quality of care is not adequately addressed now, not only will vulnerable people unnecessarily suffer a poor quality of life, but formal care provision in the future may be more costly than is necessary due to increased presence of distressed reactions to low care quality.

As occupational therapists, our role is to support the occupation and well-being of the people with whom we work. This forms an important component of a person-centred approach to care and, therefore, occupational therapists have a key role to play in promoting good quality PCC for people with dementia. A major challenge for us when working in formal care settings with people with dementia is to identify practical ways in which residents’ quality of life can be addressed through varied participation in meaningful occupations. We also have a role in ensuring that formal caregivers and/or occupational therapy assistants are equipped to recognise and facilitate engagement and to understand how to identify and appropriately support distressed reactions of people with dementia. Whilst as occupational therapists we can have an impact on well-being, the key to quality of life for persons with dementia, predominantly lies in the hands of the formal caregivers, as they have the most direct contact with residents. If caregivers do not understand the importance of, and are not equipped to facilitate meaningful engagement, or to understand and derive meaning from the residents’ behaviour, there is limited scope for delivering sustained quality care. If staff do not understand that distressed reactions are a reflection of the care they deliver and not just due to the person having dementia, then residents can easily be subjected to a malignant social psychology. This includes labelling (i.e. being labelled as aggressive, playing up or attention seeking), invalidation (failing to recognise their subjective reality or experience), banishment (removal from public areas to isolation in their room) and ignoring (treating them as if they are not there). It can also lead to increased use of physical and chemical restraints.

Change is always difficult within organisational settings. Changing care practices and cultures, when routines (i.e. ways of doing and thinking) have been the status quo for many years, is challenging. Therefore, occupational therapists in South Africa would benefit from a tool that can assist with providing care home staff with evidence about whether and how PCC is provided and maintained. Without this, the staff team about DCM and its purpose, observation, analysis and feedback to the staff team about DCM and its purpose, observation, analysis and feedback to the staff team. Dementia Care Mapping (DCM) is an observational tool set within a practice development cycle that includes briefing the staff team about DCM and its purpose, observation, analysis of data and preparation of a report, feedback to the staff team and collective action planning, implementation of action plans and ongoing monitoring and re-mapping. DCM has been used for a range of purposes including individual and group care planning and staff training needs identification.

The first author has used DCM to support the reviewing of quality of services in clinical settings within the South African context.
She has also used it to provide explicit evidence of good practice and to identify areas requiring development. However, to date there are no other trained users of DCM in the country. The author sees great potential for this tool in supporting the work of occupational therapists with people with dementia in South Africa.

In this article, the potential contribution of DCM for helping occupational therapists in South Africa to promote PCC for persons with dementia living in care facilities, is explored. To do this, the Kawa Model is drawn upon, as this occupational therapy model provides a strong focus on the importance of the context surrounding a person which is also a key component of PCC. The Kawa Model is utilised to explain how DCM data could inform the occupational therapist about the many potential factors that could be enabling or disabling for the person with dementia within the residential care context in which he/she is living.

Interpreting DCM through a KAWA perspective

Lim and Iwama\(^{17}\) state that the Kawa Model provides a framework for occupational therapists to consider the unique context, including day-to-day realities and circumstances that shape the occupational world of a person. As explained above, the ability of a person with advanced dementia to ‘belong’ (be part of their social environment), as well as to ‘do’ (engaging in meaningful occupations), is already impeded but could be aggravated even more by an institutional setting.

The Kawa Model is usually applied through obtaining narratives from the individuals themselves. Clients are encouraged to tell their own stories about their occupational lives and day-to-day realities\(^{38}\), using a river metaphor. As most residents with advanced dementia find communication challenging, DCM could be used in this instance to provide the occupational therapy consultant with a means to capture, understand and explain the observed context and to identify areas requiring development. However, to date there are no other trained users of DCM in the country. The author sees great potential for this tool in supporting the work of occupational therapists with people with dementia in South African care homes. They particularly reflect a weak or poor quality river wall and bottom that is not reflective of PCC. The author’s experiences and reflections of mapping in these 10 facilities (3 in the Western Cape, 1 in the Northern Cape, 3 in the Free State, 1 in Mpumalanga and 1 in the Northwest Province) were to inform how DCM can be used effectively in an occupational therapy context (see Tables 2a, b and c).

Rather than discuss observations from each of the individual care facilities, the evidence from the first author’s experiences has been generalised to identify broader principles that have emerged from conducting all 10 maps. This has provided a picture of the current care provision for people with dementia in South African care homes. They particularly reflect a weak or poor quality river wall and bottom that is not reflective of PCC. Tables 2a, 2b, and 2c (see pages 35 to 37) contain extracts from the maps as an example of data generated that forms the foundation for the discussion below.

Task orientated care

DCM observations revealed many examples of personal detractions (poor quality staff interactions) and few personal enhancers (positive staff interactions). Many of the detractions related to a task orientated focus, where completing a list of daily tasks as quickly as possible, in an inflexible way, was the main priority. Personal detractions included acts of treachery (i.e. telling lies as a means of facilitating co-operation during care), objectification (i.e. treating residents as dead lumps of matter/as if they are “things” not people) and labelling (i.e. stereotyping according to behaviour). Personal detractions appeared to be the only way that many staff had of coercing or forcing residents to co-operate during care so as to complete their long list of chores as quickly as possible. Through observation it appeared that staff felt the rewards of completing care tasks quickly and efficiently by being able to withdraw from direct care and to watch television or drink tea at the nurses’ station. Clearly, constant exposure to such negative care practices that undermine psychological needs, is likely to cause confusion, distress and reduced well-being, which are likely to increase the numbers and size of rocks and driftwood in the river of an individual with dementia (Figure 3 on page 37).

Low levels of resident well-being and engagement

Data from the maps indicated that residents spend most of their time being inactive - either passively observing what is going on around them, being withdrawn or even sleeping during the day. Although these high levels of inactivity could be due to the fact that residents experienced high levels of disability, residents were often frustrated due to tray tables or sheets restraining them in their rooms. Even when residents were awake and aware of their surroundings, staff indicated that restricting residents physically, kept them from roaming which prevented falls and that this was a safety measure. On some units staff also found it easier to use incontinence wear with all residents, which impacted on both the residents’ dignity as well as the homelike atmosphere, due to the invasive odour. Therefore overall it appeared as if neither the living situation accommodated or enhanced remaining positive attributes of residents (i.e. driftwood), nor did the environment promote aspects of human dignity and personhood.

Personal reflections and discussion

The driving force behind the well-being of persons with dementia, especially those who have already become disabled to the stage at which they need continuous support and supervision, is their social

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### Extracts from Observation Notes

<table>
<thead>
<tr>
<th>Time</th>
<th>Resident 1</th>
<th>Resident 2</th>
<th>Resident 3</th>
<th>Resident 4</th>
<th>Resident 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:20</td>
<td>2 staff pulls upright &amp; to side without talking to her. Eyes opens briefly, re-adjusts herself, eyes closes.</td>
<td>Sleeping? Eyes closed, head bowed</td>
<td>Same as above.</td>
<td>Fidgets with zip of track suit top while talking &amp; laughing.</td>
<td>Scratches head. Eyes closed.</td>
</tr>
</tbody>
</table>

### Derived Behaviour Code Category and Mood and Engagement Value for each Time Frame

<table>
<thead>
<tr>
<th>Time</th>
<th>F-1 (being fed while experiencing discomfort)</th>
<th>U-3 (not responded to while being quite uncomfortable)</th>
<th>B+1 (observing, neutral mood)</th>
<th>D+1 (attempts to put mug away, neutral mood)</th>
<th>Q</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:15</td>
<td>N-1 (sleeping while experiencing discomfort)</td>
<td>N-1 (sleeping while experiencing discomfort)</td>
<td>C-1 (withdrawn and unengaged)</td>
<td>Y+3 (experiencing positive emotions while engaged with self)</td>
<td>N (sleeping)</td>
</tr>
<tr>
<td>11:20</td>
<td>P-1 (assisted to sit upright but still experiences discomfort)</td>
<td>C-1 (withdrawn and unengaged)</td>
<td>C-1 (withdrawn and unengaged)</td>
<td>T+1 (seeking tactile input, neutral mood)</td>
<td>D+1 (cares for self, neutral mood)</td>
</tr>
</tbody>
</table>

### Observed Personal Enhancers and Personal Detractors (relates to staff behaviour)

<table>
<thead>
<tr>
<th>Time</th>
<th>PD15d Ignoring</th>
<th>PD15d Ignoring</th>
<th>PD15d Ignoring</th>
<th>PD15d Ignoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:15</td>
<td>PD15d Ignoring</td>
<td>PD15d Ignoring</td>
<td>PD15d Ignoring</td>
<td>PD15d Ignoring</td>
</tr>
<tr>
<td>11:20</td>
<td>PD13d Objectification – being treated as a dead lump of matter</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Figure 2a: Example of DCM data generated by maps on 23 October and 2 November 2009 for the period (s) 9:20-10:45; 11:15-13:25; 6:05-8:20
### Tabled Summary of Behaviour Code Categories for 6 hour map in association with a Graphic Display of the Same Information

<table>
<thead>
<tr>
<th>Participant</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>N</th>
<th>P</th>
<th>R</th>
<th>T</th>
<th>U</th>
<th>Y</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>27</td>
<td>38</td>
<td>26</td>
<td>85</td>
<td>41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>27</td>
<td></td>
<td>194</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>11</td>
<td>17</td>
<td>87</td>
<td>37</td>
<td>51</td>
<td>83</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>296</td>
</tr>
<tr>
<td>3</td>
<td>33</td>
<td>32</td>
<td>54</td>
<td>17</td>
<td>22</td>
<td>91</td>
<td>25</td>
<td>23</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td>304</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>15</td>
<td>13</td>
<td>29</td>
<td>10</td>
<td>53</td>
<td>7</td>
<td>33</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>304</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>7</td>
<td>7</td>
<td>30</td>
<td>33</td>
<td>7</td>
<td>15</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>105</td>
</tr>
<tr>
<td>Group</td>
<td>33</td>
<td>49</td>
<td>114</td>
<td>68</td>
<td>29</td>
<td>105</td>
<td>299</td>
<td>117</td>
<td>23</td>
<td>99</td>
<td>117</td>
<td>150</td>
<td>1203</td>
</tr>
</tbody>
</table>

### Tabled Summary of Total Mood and Engagement Values in association with a Graphic Display of the Same Information

<table>
<thead>
<tr>
<th>Participant</th>
<th>-5</th>
<th>-3</th>
<th>-1</th>
<th>+1</th>
<th>+3</th>
<th>+ 5</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>15</td>
<td>5</td>
<td></td>
<td></td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>2</td>
<td>45</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>56</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>24</td>
<td>25</td>
<td>1</td>
<td></td>
<td>5</td>
<td>57</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>32</td>
<td>14</td>
<td></td>
<td></td>
<td>18</td>
<td>49</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>Group Totals</td>
<td>0</td>
<td>11</td>
<td>89</td>
<td>89</td>
<td>15</td>
<td>0</td>
<td>204</td>
</tr>
</tbody>
</table>

**Figure 2b:** Example of DCM data generated by maps on 23 October and 2 November 2009 for the period(s) 9:20-10:45; 11:15-13:25; 6:05-8:20
### Tabled Summary of Personal Detractors and Personal Enhancers for complete 6 hours of observation

<table>
<thead>
<tr>
<th>Psychological need</th>
<th>Highly detracting</th>
<th>Detracting</th>
<th>Enhancing</th>
<th>Highly enhancing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort</td>
<td>7</td>
<td>9</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td></td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attachment</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>4</td>
<td>26</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Inclusion</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>13</strong></td>
<td><strong>53</strong></td>
<td><strong>9</strong></td>
<td><strong>0</strong></td>
</tr>
</tbody>
</table>

*Figure 2c: Example of DCM data generated by maps on 23 October and 2 November 2009 for the period (s) 9:20-10:45; 11:15-13:25; 6:05-8:20*

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**ROCKS**

(Problematic life circumstances. Difficult to change).

- Dementia is a disabling condition.
- Cognitive function progressively declines.
- Verbal abilities progressively decline.
- Residents’ inability to recognise people impacts negatively on their perception of a supportive environment and intensifies their experience of fear and anxiety.

**DRIFTWOOD** (Personal attributes that could have a + or – affect)

- Immaterial: e.g. friends, siblings, staff
  - Often family and/or friends stop visiting after a while and therefore the social context on units is mostly determined by staff.
  - Residents are not expected to engage in any activities besides eating and drinking. (When spontaneous reminiscence was observed, it was not initiated by staff and they disrupted the process with scornful remarks.)
  - Staff is not trained in PCC and positive person work, and a malignant social psychology was evident on wards in terms of:
    - Objectification - residents were cared for and not involved in the process. E.g. clothes protectors (bibs) were fastened and feeding took place without consent from residents.
    - Labelling - residents were not addressed by their first names, but labelled by their surnames or words associated with old age like ‘grandma’.
    - Treachery - residents were lied to, to convince them to eat. E.g. one was told his daughter was waiting for him.
    - Mockery - e.g. one was made fun of while he was reminiscing about buying ewes for his farm.
    - Withholding - both verbal and nonverbal requests for attention and support were ignored regularly by staff.

- Material: e.g. wealth, special equipment
  - Poverty – as many residents only receive a state pension, funds for individual specialised equipment that could enhance independence is not available.
  - Limited government support to care facilities results in a low ratio of staff to residents and this diminishes the opportunity for embracing PCC as staff often is overwhelmed by demands.

**RIVER WALL AND FLOOR**

(The client’s environment)

- Some units had pets, e.g. chickens, cats and/or fish tanks, which added to a homely-like atmosphere. Upkeep and hygiene were a priority in these situations and staff sometimes saw this as an added burden.
- Secure units provided safety, but often had an institutional feel in terms of furniture used, communal ablutions available and shared bedrooms.
- On some units staff found it easier to use incontinence wear with all residents which impacted on both the residents’ dignity as well as the homely-like atmosphere due to the invasive odour.

*Figure 3: Dementia Care Mapping interpreted through the context of the Kawa Model*
context. This social context (as the river wall and river bottom) is mostly provided by staff on care wards and in care homes, and is the most significant aspect that impacts on residents’ flow of life and life energy. When the social context does not contribute to supporting the psychological needs of a person with dementia, their inner world will not remain intact, nor will they be able to engage with the world around them\textsuperscript{40}.

The multi-dimensional dynamics at play for persons with dementia who are in care, involve not only the specific needs of the individual, but also factors relating to the institution, community and the specific micro-society on the ward. Ill-being, as was observed during the maps, is unintentionally fostered when “inadequate care” is “delivered in a culture where physical tasks are valued but relationships between the person and their carer(s) are not” \textsuperscript{40,16}.

The Kawa Model\textsuperscript{39} reminds us that for elderly persons with dementia in institutional care, the focus of the river is on that period just before it reaches the ocean – the most precious part before the end of life. In addition to so much of the river’s course over time being available to staff for gaining an understanding of the residents (for example, by utilising life story work in care planning), fostering a culture for true living in the moment would promote life energy and flow in the care facility for residents and staff alike. DCM data can offer occupational therapists important information about the river that we may be unable to gain from speaking with people with more advanced dementia whose communication is significantly impaired.

Therefore, the challenge for quality care in South Africa is not the need for financial expenditure for upgrading physical resources, but rather ensuring that members of staff acknowledge their role in providing a social context for residents with dementia. It takes no more time to speak to a person before moving them in a wheelchair, or while supporting them to eat a meal and it can often take less time to perform care tasks if they are completed with respect, care and consideration and do not therefore produce distressed reactions, but rather ensuring that members of staff acknowledge their role in the need for financial expenditure for upgrading physical resources, as staff members working in institutionalised care are not equipped to engage in positive person work. Ignorance is the main disabling factor preventing the institutionalised environment from fostering belonging and interdependence between staff and residents. Staff members do not know how to embrace the fact that residents on wards are dependent on them for maintaining their personhood (as much as for their physical care), and that they as staff can shape these persons’ wellbeing. Perhaps if a person-centred approach could be initiated with staff that would allow caregivers to experience interdependence with management the foundations for changing the care culture in organisations would be laid. DCM can be used as a way of raising awareness and knowledge and to actively involve and empower staff in changing care practices through its inclusive feedback and action planning cycle.

The first author’s exposure and use of DCM as both a tool and process for developing PCC in institutional settings in South Africa was a very positive experience. As an occupational therapist, finding the evidence of specific engagement or lack of engagements in activities (e.g. active and passive leisure, reminiscence, or work-like activities) was very useful for considering how to develop residents’ occupational engagement. The first author personally experienced Brooker’s sentiment that DCM could provide ‘a shared … focus across professional disciplines, care staff and management teams’ for an overall addressing quality-of-care\textsuperscript{10}. DCM could therefore provide support for care facilities in South Africa to heed Prince et al.\textsuperscript{ts} recommendations in establishing national policies, programmes and legislation, as well as the development of human resources (especially through training) that would promote PCC and directly address the well-being of all residents in institutional care.

References:


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