Opinion Piece

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

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BSTRACT

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^{1,2}. 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 approach²⁻¹⁶. 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 dementia¹⁸. 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 19. Poor quality care is associated with poor wellbeing 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 distressed reactions, such as aggression, agitation, restlessness, hallucinations and apathy 20,21 . Internationally, the behaviours that staff find challenging have also been linked to significant associated healthcare costs^{22,23} including increased risk of hospitalisation^{24,25}, use of emergency rooms²³ 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 expected²³. 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 dementia²⁶ and by poorly managed physical health and pain^{27,28}. They are also an expression of unmet needs by a person with dementia in response to poor quality care^{28,29,30} often caused by lack of stimulation and engagement³¹. 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 culture²⁸. (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^{29,32-34}.

In his seminal work on PCC, Kitwood³⁵ 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^{1,36}. 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 population¹. 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 psychology³⁵. 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)³⁷. 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 over time, and what they can do to improve this. Dementia Care Mapping (DCM) is an observational tool set within a practice development process or cycle which has been used internationally to assess and improve the quality of dementia care. A full description of the DCM tool and process is available elsewhere (e.g. Brooker and Surr³⁷), however, in brief, DCM involves a trained observer (mapper) observing 5-8 people living with dementia for a period of time. The length of time depends on the reason for observation and can range from a series of short maps (30-60 minutes) to lon-

Table 1: Summary of Behaviour Code Categories (BBC)

	, -, -,			/	
Α	Articulation	K	Kum and go	V	Vocational
В	Borderline	L	Leisure	W	Withstanding
С	Cool	N	Nod land of	х	X-cretion
D	Doing for self	0	Objects	Y	Yourself
E	Expressive	Р	Physical	Z	Zero option
F	Food	R	Religion		
G	Going back	S	Sexual expression		
ı	Intellectual	Т	Timalation		
J	Joints	U	Unresponded to		

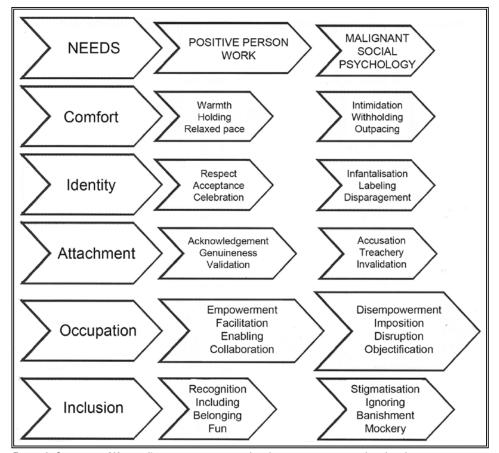


Figure 1: Summary of Kitwood's concepts associated with maintaining personhood and preventing a malignant social psychology

ger 6+ hour observations. The mapper observes the experiences of the person with dementia from his/her perspective. Every five minutes the mapper records the person's behaviour from a list of 23 behaviour category codes (BCCs) (see Table 1) and chooses an associated mood and engagement value (ME) from a six-point scale (-5, -3, -1, +1, +3, +5). In addition the quality of staff interactions is recorded as and when interactions occur. These are framed in terms of positive interactions (personal enhancers) based on Kitwood's³⁵ concept of positive person work and negative interactions (personal detractions) based on Kitwood's concept of malignant social psychology (see Figure 1). Over the observation period a detailed picture of the care experience emerges. The observation is 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 Iwama¹⁷ 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 realities³⁸, 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 for these vulnerable residents.

Through the Kawa Model, life in most high care units for persons with dementia could be perceived to be influenced by the following factors:

- ❖ The water represents life flow or life energy³8. The significance of water portraying the essence of life for a very vulnerable population is even more significant as it emphasises the impact (but also the responsibility) of the surroundings. The residents' well-being could therefore be noted by their 'doing', and engagement in meaningful occupations would be reflected by the DCM Behaviour Code Categories, e.g. playing table games (leisure activities), singing (expressing themselves) or chatting about a past event (reminiscence). Therefore, the more evidently pleasurable activities residents engage in would result in stronger life flow associated with more profound experience of life energy.
- The surroundings are referred to as river wall and river bottom i.e. the social and physical environmental context³⁸. The role of caregivers forms a predominant part of the social context for the residents with advanced dementia. Positive and negative interactions (identified by the DCM personal enhancers and personal detractors respectively) play a very important role in the level of comfort and belonging that a resident experiences. Besides the care setting, other noteworthy factors relating to the physical and social contexts of care units are that, often residents share bedrooms and have a lack of privacy, or that family members do not live close by and only visit occasionally.
- The <u>rocks</u> the disabling and problematic life circumstances that impede residents' flow of life³. For example, fear and confusion caused by the disabling and progressive nature of dementia could be intensified by unskilled and ill-equipped staff members.
- The <u>driftwood</u> the "personal attributes and resources" of residents "... that can positively or negatively affect the subject's circumstances and life flow"^{39:149}. For example, poor relationships with overworked staff, mundane routines on care units and other effects of institutionalisation.

As the aim of an occupational therapy service would be to ensure greater life flow for residents with dementia, this implies that the occupational therapy consultant needs to identify rocks and driftwood, as well as build a stronger river wall and river bed. In the above explanation it is evident that DCM measures both quality-of-life as well as quality-of-care¹⁸. Data generated could assist the occupational therapy consultant to identify ways to build the river bed and walls and to identify rocks and driftwood and thus enhance PCC.

Besides the above theoretical interpretation of the domains of the Kawa Model in comparison to DCM, a more practical approach is also presented for consideration. The first author completed 10 maps within the South African care industry as part of an ongoing DCM skills development programme. 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).

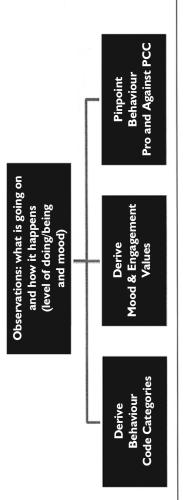
Low levels of resident well-being and engagement

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 chairs. 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





Extra	Extracts from Observation Notes				
Time	Time Resident 1	Resident 2	Resident 3	Resident 4	Resident 5
10:15	Bread dipped in tea fed from front. Fed sips	Sits lifting feet, trying to move	Open & closes eyes. Notices staff walking	Calls out, 'Sister!' Puts mug	Not in area.
_	of tea. Tries to talk, but is not acknowledged.	forward. Repeatedly moves L leg up	by.	on floor next to chair leg.	
	Fed 2 nd sandwich. Slips down – folding &	+ down.		Sits & bows head forward.	
	unfolding arms.				
11.15	Tilted to side, sleeping.	Restrained by tray table in front.	Restrained by tray table in front. Back to	Talks & laughs in Xhosa to	Sits & sleep.
		Sleeping.	resident on R. Sits with head in hand,	himself.	
			eyes open – staring.		
11.20	2 staff pulls upright & to side without talking	Sleeping?	Same as above.	Fidgets with zip of track suit	Scratches head.
	to her. Eyes opens briefly, re-adjusts herself,	Eyes closed, head bowed		top while talking & laughing.	Eyes closed.
	eyes closes.				
Deriv	Derived Behaviour Code Category and Mood and Engagement	and Engagement Value for each Time Frame	n Time Frame		
10:15	F-1 (being fed while experiencing	U-3 (not responded to while being	B+1 (observing, neutral mood)	D+1 (attempts to put mug	Q
	discomfort)	quite uncomfortable)		away, neutral mood)	
11:15	N -1 (sleeping while experiencing	N-1 (sleeping while experiencing	C-1 (withdrawn and unengaged)	Y+3 (experiencing positive	N (sleeping)
	discomfort)	discomfort)		emotions while engaged with	
				self)	
11:20	P-1 (assisted to sit upright but still	C-1(withdrawn and unengaged)	C-1 (withdrawn and unengaged)	T+1 (seeking tactile input,	D+1 (cares for self,
	experiences discomfort)			neutral mood)	neutral mood)
Obse	Observed Personal Enhancers and Personal Detractors (relates to staff behaviour)	etractors (relates to staff beha	viour)		
10:15	10:15 PD15d Ignoring	PD15d Ignoring	PD15d Ignoring	PD15d Ignoring	
11:20	PD13d Objectification – being treated as a				
	dead lump of matter				
į		3 0000			

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





× Behaviour Categories Tabled Summary of Behaviour Code Categories for 6 hour map in association with a Graphic Display of the Same Information Group Behaviour Profile ¥ O O 9miT lo % Total Z В **Participant** Group

Group WIB Profile % of Time Total 56 57

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

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Participant

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Group Totals

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

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te 6 hours of observa	Highly enhancing						-
cers for comple	Enhancing	3			2	1	o
ersonal Enhan	Detracting	6	13	1	26	4	53
nal Detractors and F	Highly detracting			1	4	1	13
Tabled Summary of Personal Detractors and Personal Enhancers for complete 6 hours of observation	Psychological need	Comfort	Identity	Attachment	Occupation	Inclusion	TOTALS
Tal							

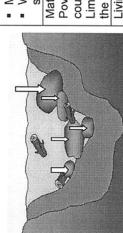
Figure 2c: Example of DCM data generated by maps on 23 October and 2 November 2009 for the period (s) 9:20-10:45; 11:15-13:25; 6:05-8:20

DRIFTWOOD (Personal attributes that could have a + or – affect)	umstances.	
ROCKS	(Problematic life circu	Difficult to change).

Dementia is a disabling condition.

Cognitive function progressively declines. Verbal abilities progressively decline.

Residents' inability to recognise people intensifies their experience of fear and impacts negatively on their perception of a supportive environment and



mmaterial: 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 scomful 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
 - Withholding both verbal and nonverbal requests for attention and support were ignored regularly by Mockery – e.g. one was made fun of while he was reminiscing about buying ewes for his farm.

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

Living situation

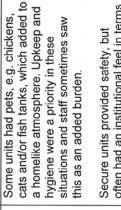
Residents were supervised and not isolated in care facilities.

Residents were often frustrated due to tray tables or sheets tying them to their chairs. Staff felt that There was little privacy and residents could feel embarrassed during self-care routines. restricting residents physically kept them from roaming and prevented falls.

Figure 3: Dementia Care Mapping interpreted through the context of the Kawa Model



(The client's environment)



of furniture used, communal ablutions often had an institutional feel in terms available and shared bedrooms.

residents which impacted on both the On some units staff found it easier to homelike atmosphere due to the residents' dignity as well as the use incontinence wear with all invasive odour.



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 them⁴⁰.

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" 40:16.

The Kawa Model³⁹ 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 from the person with dementia. Likewise supporting people to maintain abilities around daily living activities such as eating and drinking independently can mean that mealtimes require less staff resources than if every resident requires full staff support to eat and drink. Therefore, care home staff should know how to view the person with dementia as someone who is still living – and thus should be empowered to acknowledge each resident for who he or she is as a person and to provide independence supporting, PCC accordingly⁴⁰. Only when staff members are made aware of exactly in what way they are having a positive or negative impact on residents' lives, can they take ownership thereof. Involvement in an on-going DCM process, when results are fed back to the staff team within the Kawa Model context, could ensure that caregivers feel part of the process and take ownership for their role in promoting the water flow towards the ocean for each resident.

Conclusion

The Kawa Model underpinned by interdependent views of occupation, is clearly aligned with the underpinning philosophy of the PCC approach, particularly in the meeting of psychological needs through relationships with others. Therefore, the environment and living situation in care units are the key to PCC and should be supportive and comforting. The focus of staff observed during the maps was on the *human body* and not on *human beings*, therefore a PCC approach would assist to restore and improve the flow of the water in each resident's life

Unfortunately PCC will remain elusive in South Africa as long 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 care 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-care¹⁸. DCM could therefore provide support for care facilities in South Africa to heed Prince et al.'s³⁶ 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.

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