Dementia Care Mapping: An innovative tool to Measure Person-Centered Care

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The important concept of quality of life has been largely ignored in relation to people with dementia. A major effort is now underway aimed at understanding the personal perspectives of people with dementia and improving their quality of life through the application of person-centered care. An innovative tool known as Dementia Care Mapping has been developed to measure the quality of person-centered care in congregate care settings such as adult day care centers and residential facilities. This article examines the person-centered philosophy as well as the components, implementation, strengths, and limitations of Dementia Care Mapping.

Key words: dementia care mapping, measurement, person-centered, quality of life

What are the elements of a good quality of life for someone with dementia? Can the quality of one's own life be accurately assessed by someone with dementia in light of profound difficulties with memory, language, and judgment? Can others serve as reliable proxies to assess well-being or ill-being on behalf of people with dementia? What is the relationship, if any, between quality of life and quality of care? Such questions address the value of interactions and interventions intended to benefit people with dementia by considering their objective and subjective experience. Until recently, there has been little attention paid to how people with dementia perceive their quality of life or the effectiveness of interventions from their viewpoint. A major effort is now underway aimed at understanding the personal perspectives of people with dementia and improving their quality of life through the application of person-centered care. An innovative tool known as Dementia Care Mapping has been developed to measure the quality of person-centered care. This article first examines the background and philosophy of person-centered care and then describes the components, implementation, strengths, and limitations of Dementia Care Mapping.

Quality of life has been defined in a variety of ways. An individual's personal sense of satisfaction with areas of life such as physical comfort, emotional well-being, and interpersonal connections are common elements in most definitions. The important concept of quality of life has largely been ignored in relation to people with dementia, mainly because of the belief that their cognitive impairments preclude accurate self-reporting. Clinical trials of antidementia drugs, for example, have seldom considered the effects of pharmacologic treatment on quality of life for people with dementia. Recent studies of dementia special care units in American nursing homes funded

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by the National Institute on Aging did not examine the issue of quality of life. In the absence of any medical treatments to stop or reverse Alzheimer's disease and related dementias, maximizing quality of life must be the guiding principle of the care of people with these conditions. Whitehouse and Rabins argue that quality of life in relation to dementia is "not an isolated concept to be included as one of many measurements of the benefits of our care, but rather... it is the central goal of our professional activity, driving the organization of both our clinical and our research efforts."[16]

Reports by caregivers have typically served as proxy measures for assessing quality of life in relation to people with dementia. However, two recent studies by Losgdon and colleagues[17] and another study by Brod and colleagues[18] concerning the ability of persons with mild to moderate dementia to self-report quality of life provide evidence that they may be more capable of providing subjective self-assessments than has been previously recognized. Among persons with advanced dementia, behavioral observations have recently been used in an attempt to assess quality of life.[19,20] A study by Albert and colleagues[21] indicated that family and institutional caregivers of nursing homes residents with dementia show good agreement on ratings of the resident's quality of life, but this study did not include resident ratings of their own quality of life. Lawton and colleagues[22,23] assessed quality of life in nursing homes by examining positive and negative affect. They used a self-report version for individuals who are able to report their own feeling states and an observational version that provides objective criteria for directly assessing residents who had lost the ability to verbally communicate their feelings. Kitwood and Bredin[24] were among the first to employ an observational method among people with dementia in congregate care settings such as adult day centers, assisted living facilities, and nursing homes through a process known as Dementia Care Mapping (DCM).

BACKGROUND AND PHILOSOPHY

DCM is more than an auditing tool to assess quality of life for people with dementia in care settings. It is an attempt to create a common language for staff to identify and meet their needs. DCM also presents many challenges to care organizations with regard to how they operate and how care is delivered to people with dementia. Its originators were not only concerned about relationships between people with dementia and staff but they were also concerned about an organization's commitment to staff. Thus, DCM is not just a means of assessing quality of life among people with dementia. It is also a means of reforming the attitudes and behavior of staff and the care organization. To understand the ambitious aims of DCM, it is helpful to first examine its philosophical basis.

DCM was initially developed in the early 1990s under the leadership of Tom Kitwood, a social psychologist and the head of the Bradford Dementia Group at the University of Bradford in England. DCM stems from Kitwood's philosophy of person-centered care as described in his many journal articles and books including The New Culture of Dementia Care and Dementia Reconsidered. Although Kitwood died suddenly in late 1998, his pioneering work continues under the auspices of the Bradford Dementia Group and a relatively small but growing number of DCM advocates in the United States.

Person-centered care is based on the humanistic position that the "personhood" of individuals with dementia should be preserved through positive interactions. This philosophy stems from Kitwood's theory about dementia being more than a neurologic phenomenon resulting in cognitive impairments that can also lead to social and psychologic disintegration. He argued that disintegration occurs mainly as a result of the destructive social environment in which people with dementia find themselves. He cited examples of people with dementia being stigmatized or dehumanized by others. Although Kitwood allowed that disintegration may be alleviated or hastened by one's personality or coping style, in his opinion, individual attributes play a minor role in one's overall quality of life. He attributed great importance to the social environment—it can lead to a disintegration of self and personal worth but also holds potential for enhancing the individual and halting or slowing disintegration. In this context, good care by others enables the person with dementia to feel supported, valued, and socially confident, regardless of cognitive impairments. In other words, quality of life is intimately connected to the quality of care.

After many years of observing people with dementia in congregate care settings, Kitwood believed that their well-being and ill-being could be measured. He and Kathleen Bredin first devised a list of "indicators of relative well-being" that could be identified among people with dementia that takes into account basic psychologic and social needs. These indicators include a dozen different abilities:

1. Retains the assertion of desire or will
2. Able to express a range of emotions
3. Able to initiate social contact
4. Displays affectional warmth
5. Displays social sensitivity
6. Has self-respect
7. Shows acceptance of others with dementia
8. Uses humor
9. Uses creativity and self-expression
10. Shows evident pleasure
11. Shows helpfulness
12. Able to relax

According to Kitwood, these indicators of well-being could be seen in positive interactions occurring among those with dementia in care settings or between persons with dementia and staff. However, indicators of ill-being (including signs of unattended sadness or grief, sustained anger, anxiety, boredom, apathy, withdrawal, despair, or physical discomfort) could be also seen in negative interactions or when meaningful activity was lacking in care settings. Kitwood criticized prevailing social norms that marginalized people with dementia and contributed to their loss of self-esteem and alienation from other people. Moreover, such depersonalizing attitudes were often reflected in care settings in which the humanity of people with dementia was undermined by a "malignant social psychology."^{26(p136)}

To delineate attitudes that were generally supportive from those that diminished the well-being of people with dementia, Kitwood^{14} compared elements of what he termed "the two cultures of care."^{(p136)} The "old culture" pathologizes people with dementia, sees dementia as a hopeless medical condition, and defines care as a set of basic physical tasks. In the "new culture," the individuality of each person with dementia is respected, dementia is seen primarily in psychologic and social terms instead of in terms of neurologic deficits, and care is defined as a highly skilled and compassionate endeavor. Kitwood's views on the two cultures of care are summarized in Table 1.

The contrasting old and new cultures of care illustrate Kitwood's dissatisfaction with traditional views toward dementia and dementia care. However, he also expressed hope that the tendency to dehumanize people with dementia could be replaced by more respectful attitudes and behaviors. His sense of optimism for creating supportive and caring environments is at the core of person-centered care. At the same time, Kitwood emphasized that for staff to provide person-centered care, they too must feel supported in their own personhood by the organization that employs them. Therefore, person-centered care encompasses the humanity of the people with dementia and their direct care providers.

The first step in learning the person-centered philosophy is to recognize prevailing stereotypes about dementia, people with dementia, and approaches to care and then be challenged to envision a better quality of life for those with dementia. Embracing the person-centered philosophy essentially entails a process of changing personal and organizational attitudes and behaviors by looking at how to best meet the needs of people with dementia. As part of this process, the DCM tool can be used to measure how the person-centered philosophy is being applied and how the application of this philosophy contributes to the change of culture in the care setting. The DCM tool is basically a means to measure the level of well-being or ill-being of persons with dementia. Through feedback and in-service training, staff members are motivated to generate practical ideas for improving quality of life.

**THE TOOL**

DCM involves making a series of detailed observations over a period of 6 hours in a care setting. One or more evaluators use a specially designed tool to measure the activity or inactivity of up to five people with dementia and to assess their well-being or ill-being. DCM attempts to take into account the subjective experience of those with dementia by "mapping" their behaviors. Twenty-four possible categories of behavior are documented in successive time frames, every 5 minutes on each person. The categories represent virtually every activity that can be observed in a care setting. Much meaningful data can be gathered over the course of 1 or more days. Thus, a team of two can evaluate 10 people with dementia on any given day.

The tool quantifies the personal effect of activities and other interactions that people with dementia have with each other and staff members during this period of time. At all times, each evaluator or "mapper" is trained to consider the viewpoint of the person with dementia who is
<table>
<thead>
<tr>
<th>Issue</th>
<th>Old culture</th>
<th>New culture</th>
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<tr>
<td>Dementia</td>
<td>Dementia is an inevitable part of aging that has no treatment and results in loss of all memory and personal identity.</td>
<td>Dementia is caused by brain diseases, which can be prevented and treated. How a person is affected is vitally dependent on the quality of care.</td>
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<td>Treatment</td>
<td>Medications are aimed at alleviating behavioral symptoms and improving memory.</td>
<td>Means to prevent, delay, or slow decline through medical and psychosocial interventions must be developed.</td>
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<td>Dementia care</td>
<td>Symptoms need to be controlled. The work requires low ability, little inspiration, and few qualifications; rewards are few.</td>
<td>This is one of the richest areas of human work, requiring high levels of ability, creativity, and insight.</td>
</tr>
<tr>
<td>Experts</td>
<td>Doctors possess the most reliable and relevant knowledge.</td>
<td>Skilled and insightful practitioners possess the most reliable and relevant knowledge.</td>
</tr>
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<td>&quot;Us and them&quot;</td>
<td>Those with dementia are significantly different than the rest of humanity because of their diminished cognitive status.</td>
<td>Those with dementia are equal members of the human race. All persons are damaged in some way.</td>
</tr>
<tr>
<td>Assessment</td>
<td>It is important to have a clear and accurate understanding of a person's impairments to chart decline over time.</td>
<td>It is important to have a clear and accurate understanding of a person's background, abilities, tastes, interests, values, and spirituality.</td>
</tr>
<tr>
<td>Care priorities</td>
<td>Care is concerned with providing a safe environment, meeting basic needs, and giving physical care in a competent way.</td>
<td>Care is concerned with the maintenance and enhancement of personhood. Physical care is only part of the care of the whole person.</td>
</tr>
<tr>
<td>&quot;Problem behaviors&quot;</td>
<td>These behaviors are triggered by brain pathology and must be managed quickly and efficiently.</td>
<td>These behaviors should be viewed, primarily, as attempts at communication, related to an unmet need.</td>
</tr>
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<td>Institutional care</td>
<td>People with dementia require medical attention in psychiatric units or nursing homes patterned after hospitals.</td>
<td>Those with dementia require home-like settings, which emphasize a social model of care involving a variety of individual and group activities.</td>
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<tr>
<td>Direct care staff</td>
<td>Staff are &quot;servants of the organization,&quot; and it is not necessary to take their needs seriously.</td>
<td>Personhood of staff must be respected if they are to respect the personhood of those in their care.</td>
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<tr>
<td>Research</td>
<td>There is not much that can be done positively for a person with dementia until there are medical breakthroughs.</td>
<td>There is a great deal that we can do now through human insight and skill.</td>
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Source: This is an adaptation of the table "Two cultures of dementia care" from Dementia Reconsidered by Tom Kitwood (Open University Press, 1997) with kind permission of the publisher.

Being observed. In fact, mappers are advised to merge as much as possible into the care setting without influencing the environment. However, allowances are made for the necessity of helping persons with dementia and any significant interaction between the mapper and a person being observed is excluded from data collection.

Before the period of observation, administrative and direct care staff members in the care setting are oriented to DCM, given facts about the tool, and briefed on how data will be collected and used. Administrators and managers need to understand that direct care staff will have access to data and are integral to the process of improving care. Staff members are assured that the observations and data will not be used to assess their job performance. They are also informed that a feedback session will be held later to examine the data and to elicit their ideas on improving the well-being of residents or clients. The goal is to obtain the cooperation of staff members so that DCM is viewed as an opportunity to appreciate how staff members influence the quality of life for people under their care.

The DCM tool consists mainly of the Behavior Category Codes and a scale of well-being and ill-being.
that assesses each behavior observed in a 5-minute time frame. The Behavior Category Codes consist of 24 domains concerning what a person with dementia is or is not doing at any particular time (see Table 2 for a selected list). For example, Category K (walking) refers to the activity of walking that may have taken place during a 5-minute time period. The categories do not correspond exactly to distinct types because walking may not have been the only activity that took place within 5 minutes. However, a specified category represents the dominant behavior exhibited during that time period. In relation to each observed behavior, the mapper also assigns a numerical rating to assess well-being (+1, +3, +5) and ill-being (−1, −3, −5). For example, if someone with dementia is enjoying a meal, then a positive score is chosen in relation to that behavior (Code F). The Behavior Category Codes, the six-item scoring scale, and their operational definitions have been refined through extensive field testing by Kitwood and colleagues over the past decade. The current tool and the accompanying training manual represent the seventh version of DCM.21

Episodes in which a person with dementia experiences a particularly beneficial interaction or else is demeaned in some way are also recorded as footnotes on the data sheets. Positive events refer to interactions with staff that significantly increase well-being for the person with dementia. For example, a woman who seems anxious and lost in her surroundings is greeted warmly by a staff member who invites her into a group activity that had a calming effect. This simple act of hospitality has an immediate positive effect, and such occurrences are signs of a supportive social environment.

Personal detractors are brief interactions between staff and residents that are presumed to lead to a decrease in a resident’s self-esteem and detract from well-being. In other words, such episodes are “put downs.” They may be overt or subtle in nature. For example, when a staff member talks so quickly to a resident with dementia to the point where comprehension is not possible, this is termed “outpacing.” Although this behavior on the part of the staff member was not intended to cause any confusion, it resulted in a negative outcome for the resident. By becoming aware of the consequence of this behavior from the vantage point of the resident, further instances of outpacing can hopefully be avoided. These negative events are also recorded as footnotes on data sheets.

**DATA ANALYSIS AND FEEDBACK**

After data are collected, analysis is carried out in a variety of ways and results are discussed with all staff members in the care setting. Detailed observations provide insight into how persons with dementia are engaged or disengaged in activities and consider the effect of such activities on their well-being or ill-being. Data are then used by staff to discuss how to best maintain good care or improve care practices for each person with dementia or the group as a whole.

Figure 1 is a sample data sheet representing 70 minutes of mapping data on three clients of The Club Adult Day Center. In the Behavior Category Code (BCC) row, a code represents the primary activity that took place for each 5-minute period. Below each box is a score for the person’s well-being or ill-being during that corresponding time frame. In the case of Joan, she took part in a word game during the first three time frames beginning at 10:30 am and thus the Behavior Category Code is designated “I” for an intellectual activity. Joan was highly involved in this activity and displayed signs of well-being and success (as shown by numerical ratings of +3 and +1). She then chatted with a neighbor (Code A), looked at pictures in a magazine (Code M), and showed them to the neighbor. She later enjoyed helping to set tables for lunch (Code L) and then had a nice lunch (Code F). Each activity and corresponding well-being score are written on the data sheet for each 5-minute period. In the second example involving Lucy, she at first participated in the word game (Code I) but then showed signs of irritation and was therefore rated as being in a state of ill-being (as shown by numerical ratings of −3 and −1). In addition, the

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<tr>
<td><strong>Selected List of Behavior Category Codes</strong></td>
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<tr>
<td><strong>Code</strong></td>
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<tr>
<td>A</td>
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WIB means the sum of the WIB values; TF means the sum of the relevant time frames.

Notes: Personal Detractor: 10:35 am Ignoring (moderate) Lucy was blatantly ignored as she tried to participate in the word game.

**Figure 1.** DCM data sheet

The first piece of analyzed data consists of a Well and Ill-Being (WIB) score for each person who is mapped. An individual's score is computed by totaling the numerical scores on the data sheet and then dividing the total by the number of time frames. In the case of Joan, her WIB score was +1.7 over the period of 70 minutes, thus displaying a fairly high level of well-being. Her numerical scores totaled 26 and this number was divided by 14 time frames comprising the 70-minute time period. In Lucy's case, she did not fare as well and her score was +0.7. In John's case, his overall WIB score was +0.8, about the same as Lucy's score, although they had much different kinds of activities. Individual scores can be illustrated on a graph to show differences among the group of persons who were mapped. These scores are to be used for discussing how to improve care, plan more suitable activities, and increase well-being. In addition to individual scores, inferences about the social environment can be drawn by calculating the well-being or ill-being scores for the entire group that is observed. This score results from all of the scores being tallied and then divided by the number of time frames. This numerical score attempts to measure the quality of life and quality of care within the broader social environment and can also be used for marking successes and areas for improvement within the care setting.

Data analysis also consists of a Behavior Category Grid that summarizes the frequency of the 24 Behavior Category Codes. This grid illustrates the types and diversity of activities that occurred during a mapping period. It is preferable to have a range of activities that keep people with dementia engaged and in a state of well-being. Such data give insight as to the effectiveness of scheduled and unscheduled activities. For example, if a grid shows that the majority of persons being mapped spent their day sleeping, it is clear that the available activities are not suited to their needs and alternatives should be considered.

After the data have been collected and analyzed, the mappers meet with staff to give feedback about the care setting. Individual WIB scores, a group WIB score, and the Behavior Category Grid are used to discuss ways of improving care at the individual and group levels. Data regarding personal detractors and positive events are also discussed. The feedback or debriefing session is intended to support and reward staff as well as to suggest areas for improvement. Ideas for improvement are supposed to be elicited by staff instead of the mappers offering a list of recommendations. Feedback is an interactive and developmental process in which staff members share their suggestions about improving care.

A fundamental tenet of the person-centered philosophy is that well-being grows out of the relationship between
the caregiver and the person with dementia. Data clearly show if a person with dementia is in a state of well-being or ill-being. The DCM process also empowers caregiving staff to take responsibility for improving the care setting. If programmatic changes are mandated by administration, the changes may not be embraced or implemented. DCM is a tool for caregivers to evaluate the outcomes of their care practice and to plan for improvement.

**Strengths of DCM as an evaluative tool**

When used as an evaluative tool within a care organization, the DCM process presents its own set of strengths and limitations. Clearly, the most important strength lies in the fact that the application of DCM achieves the goal of increasing the well-being of persons with dementia. This outcome occurs when the method is applied in its classic form, including in-service training of staff members about the method, the mapping itself, and interactive feedback sessions. Thus far, only three studies have been published on the effectiveness of DCM in improving quality of care. All of these studies were carried out in England over the past decade and demonstrated good results. Wilkinson described the use of DCM in six settings including adult day care and nursing homes. He concluded that it has value in promoting quality assurance and staff training. Barnett described the immediate positive effect of DCM in improving the well-being of residents in one nursing home. Brooker and others completed a large study of DCM in nine care settings over a period of 3 years as part of a quality assurance initiative by the British National Health Service. They demonstrated positive improvements in the quality of care and concluded that DCM is an efficacious audit tool in formal care settings. Currently, a 4-year study exploring the quality of life of people with dementia living in residential settings provided by the Methodist Home in England is underway. Another study is being completed in nursing homes and adult day care centers in Wales. DCM is designed to improve care and the quality of life for persons with dementia, and there is strong evidence that these goals are achievable.

When staff members understand the method, its implications for the well- and ill-being of persons in their care, and the potential to change care practices, they are quick to think of means to implement better care practices. They can take action to hone their interpersonal skills and take pride in their ingenuity and empathy. The common language of the person-centered care philosophy, as supported by the data gathered in the DCM practice, is key to empowering staff, increasing job satisfaction, and building teamwork. Thus, there are clear benefits for staff too. For example, major benefits have already been documented on the Dementia Special Care Unit of Heather Hill Hospital Health and Care Center in Chardon, Ohio, where DCM has been used since March 1998. The staff turnover rate among nursing assistants on this unit was 18.2% in 1997, quite low compared with the national rate of 97% reported by the American Health Care Association. However, with the introduction of DCM at Heather Hill over the next 2 years, the turnover rate decreased to 12.9% in 1998 and 8.7% in 1999. It should be noted that a reduction in staff turnover was not evident among other units at Heather Hill where DCM was not implemented.

Another area of positive effect on staff lies in the arena of staff in-service training and education. Feedback given after a mapping session provides direction for care planning by the care team. The care planning process itself becomes a rich, comprehensive, and concise team experience. Goals are then described in measurable terms. For example, staff members might suggest how a resident's well-being score could be raised or that certain behavior categories that are absent from the person's daily routine could be added to promote socialization. At times, personal detractions might be discussed and ways of decreasing or eliminating them considered. Regularly repeating the DCM process after the staff has set and applied strategies can clarify whether their interventions were successful.

**Limitations of DCM**

Just as a high degree of organizational quality is achieved when DCM is used in a care setting, so too a high degree of organizational commitment is needed to implement this process. This commitment is twofold: to the matter of education of staff to the person-centered philosophy and to the mapping process itself. In each of these com-
ponents, this commitment involves an investment of time and money.

The matter of staff education should be addressed first. Persons who wish to be mappers must take the DCM Basic User Course that involves successful completion of a 3-day course. It is preferred that more than one person from a care setting attend the course so that there can be internal monitoring of mapping practice. This requirement means that administration must release staff to attend the workshop as well as pay the course tuition. Advanced training requires successful completion of another 3-day course. Moreover, if one wants to achieve the status of Evaluator or Trainer, a more comprehensive course of studies must be completed.

If a care organization chooses to implement DCM, it is crucial to understand that it is a highly labor intensive process and one that, if used developmentally, must be applied with consistency. Approximately 8 hours are needed to complete the mapping process, including staff preparation, mapping, and data processing. After data are processed, a feedback session takes place with staff that requires additional time and energy. Mapping and feedback sessions on an ongoing basis are the next steps in implementing the process. With each mapping session, the same commitment of time and staff involvement must be considered. Thus, limited funding and staff shortages can present barriers to the use of DCM in a care setting unless there is a strong organizational commitment.

The few published studies about the efficacy of DCM and the lack of rigorous study on the reliability and validity of the tool also present some limitations. Although face validity is strong because DCM attempts to determine what is going on in a care setting by observation, no formal studies or comparisons with other measures of quality have been conducted thus far. As use of the method becomes more prevalent and as further research examines the method, these limitations will be addressed.

FUTURE DIRECTIONS

Although DCM has been widely used in care settings through the United Kingdom, it is just beginning to be used in the United States. Just prior to his death in late 1998, Kitwood visited the United States and taught the Basic DCM Course at Heather Hill Hospital Health and Care Center. Since then, staff members of Heather Hill, the only recognized American trainers of the DCM method associated with the Bradford Dementia Group, have trained more than 200 persons at the Basic User Level. It is expected that DCM training will take place at numerous sites throughout the United States in the coming years and that it will be used in a growing number of care settings. Plans are being outlined to establish clinical centers of excellence where DCM is routinely practiced in a developmental fashion and to establish training centers where DCM is taught and researched. These centers will provide opportunities to refine the tool, make it culturally sensitive to North American care organizations, develop software to streamline the mapping process, and formulate training protocols.

In summary, DCM appears to be a practical tool for evaluating the quality of dementia care and an innovative means of gaining insight into the subjective experience of those with dementia. It is also an important means for safeguarding the personhood of people with dementia and takes into account the well-being of their caregivers. However, DCM is also time consuming and costly and requires a high degree of staff and administrative commitment. Therefore, implementing DCM in care settings may seem prohibitive at first glance. As the tool is refined and its current limitations are addressed, it hopefully will become more attractive for use in North American care settings.

CONCLUSION

In an article entitled, "Can we risk person-centered communication?" Faith Gibson argued that "The costs of perpetuating the old culture of dementia are too great to countenance and too unethical to contemplate." Although implementing a program like DCM is indeed costly, so too is maintaining the old culture of dementia care. When a solid investment in is not made in people—be they staff or residents or clients—the locus of concern is the organization's welfare. Both the people who are cared for and those who provide care are affected in a variety of negative ways if they are not the primary locus of concern. Little or no investment in human resources too often results in poor care practices that ultimately affect the organization's welfare. When staff members are not empowered to open themselves to persons with dementia and to each other as members of a care team, outcomes such as staff conflict, turnover, and job dissatisfaction seem inevitable.

Owners, board members, and administrative teams of care organizations have the power to enrich the lives of people in their care and their direct care staff by embracing a person-centered philosophy. In light of the hazards of continuing the old culture of dementia care, it is a change worthy of consideration. DCM points the way to the new culture of care.
REFERENCES


