

Discourse

Making Moments Matter

Dorothy Pringle

I am going to argue in this Discourse that two of the greatest challenges facing gerontological nursing research are understanding the quality of the lives lived by severely cognitively impaired people, particularly those in residential facilities, and finding effective ways of ensuring that these people have the opportunity to live as rich, interesting, and pleasurable lives as they are capable of. By asserting this agenda, I mean not to diminish other research foci in the area of aging but rather to nudge — no, that is not strong enough — to *compel* more nurse researchers to attend to these topics. I acknowledge that we still have much to learn about the prevention of disability and illness in later life, the management of disorders that are common in the senior years — incontinence, limited mobility, diminished vision, depression, and a host of others — but we are aware of the need to continue to work on these. Nurse researchers have already made important contributions to understanding them and to developing effective interventions for dealing with them.

Family caregivers, particularly of people who are cognitively impaired, have been the subject of much research attention over the last 25 years. We have learned a great deal about caregivers' lives, their personal characteristics, their health status, and their sources of stress and the interventions that reduce this stress. Faran (2001) provides a useful summary of the types of caregiver intervention studies that have been carried out since the 1980s, the research issues that have surfaced and how they have been managed, and what has been learned from these studies. She goes on to identify the kinds of studies that are still needed: those with caregivers of many different cultures, those with caregivers in different types of caregiver-care recipient relationships, and those that focus on different sets of health outcomes. Caregiving research has been on the nursing research agenda since its inception and should remain on the agenda, but, in keeping with the proposed research agenda, I would add to Faran's list the need for studies that examine how family caregivers know if the care recipient is content, happy, or experiencing pleasure at some level. What are the indicators that family caregivers use? How universal are these indicators? What do caregivers do that generates positive

responses from dependent family members, and how much of this is carried forward from their earlier life experiences? How do these sources of pleasure change over the course of the deterioration in cognitive function, and how do the caregivers adapt to and compensate for these changes? The information generated from this type of research would be invaluable to the nursing staff of long-term-care facilities in assuming their day-to-day responsibilities with persons who are cognitively impaired.

It is important to acknowledge the critical advances in the care of cognitively impaired residents in long-term care that have resulted from research in the last decade. Nursing research has made significant contributions to these advances. For example, Wells and Dawson have been developing knowledge about reducing “excess disabilities” and reinforcing “retained abilities” in cognitively impaired individuals (Wells & Dawson, 2000, 2002), gone on to develop the reliability and validity of their assessment tools (Wells, Dawson, Sidani, Craig, & Pringle, 2000), and then demonstrated the effectiveness of teaching nursing staff how to use these skills in morning care to reduce distress and disturbed behaviour (Wells et al.). The concepts of excess disability and retained ability have taken hold in long-term care; in many facilities it has become part of the philosophy and practice to support retained abilities and eliminate excess disability.

Over this same period, the management of disturbed behaviour has received much attention. The incidence and types of disturbed or disruptive behaviours, such as yelling and striking out, exhibited by some cognitively impaired people, and the triggers for these behaviours, have been described (Beck et al., 1997, 1998), and effective ways of intervening have been developed and tested (Beck et al., 2002; Forbes, 1998). Unfortunately, it seems that a reduction in disturbed behaviour has become the preferred outcome for quality of care and health services research in long-term care. Is this good enough? Is it not possible to move beyond reducing negative behaviour, to increasing positive aspects of the behaviour of cognitively impaired persons as indicators of the quality of care provided and the quality of their daily lives? I believe this is not only possible but essential if we are to create the kinds of environments these people need in order to thrive.

A recent editorial in the *British Medical Journal* states: “Only relatively recently have we understood that people with dementia need to be more than clean, warm, and comfortable. Many staff may still believe that people with dementia are unaware of the world and unable to benefit from interaction” (Marshall, 2001, p. 410). I would restate this somewhat. I think most staff — make that nursing staff — do know that those with even advanced cognitive impairment are aware of at least some elements

of their world and benefit from particular kinds of approaches and relationships. I believe what is missing is an acknowledgement that it is their responsibility to ensure that the persons for whom they are responsible have the best possible day they can have, in addition to ensuring that they are clean, warm, and comfortable. This speaks to nursing's responsibility for residents' quality of daily life.

Nurse researchers have long been interested in patients' quality of life as an outcome of treatment for specific diseases and disorders (Harrison, Juniper, & Mitchell-DiCenso, 1996), but I believe that nursing has not yet wholly embraced the notion that it is the nursing staff's responsibility to ensure that cognitively impaired older people have the best quality of daily life possible, and that includes taking care of their "being" as well as their bodies. It is nursing's responsibility because of the nature of cognitive impairment. When you cannot remember, you cannot anticipate; you do not derive pleasure from remembering what a lovely time you had at the concert, nor from looking forward to a visit with your grandchild. What matters in the moment-to-moment life in long-term-care residences is the responsibility of nursing staff. It is our domain. Others — social workers, recreational and occupational therapists — come and go, and it is their responsibility to attend to enhancing the quality of the residents' lives while they are with them. But it is nurses or their surrogates, health-care aides or personal-support workers, who stay and do. It is the nursing staff who are there when residents awake, have baths, eat meals, go for walks, have naps, get ready for bed, and enjoy pleasurable activities. The activities of daily living are the tapestry on which nurses sew the individual stitches of the day. They can be all one colour and have single strands, or they can be multicoloured and have single, double, or multiple strands. I believe it was Powell Lawton (Lawton, Van Haitsma, & Perkinson, 2000) who first spoke of the quality of *daily* life, a concept that is different from quality of life. David Streiner (personal communication, July 25, 2003) takes it one step further and suggests that, with this population of cognitively impaired people, we should be interested in "improving the quality of the moment." But what constitutes a high-quality moment, and how many high-quality moments does it take to make a high-quality day? If people who are cognitively impaired are to have good days that vastly outnumber not-so-good days, it will be because nursing staff give the creation of quality moments the priority they now give to bathing, feeding, and skin care.

What does this mean in terms of a research agenda? Clearly, we need to understand what individuals who are cognitively impaired experience, particularly what they experience as pleasurable or as distressing. The slate is not blank on this matter. Mitchell and Kolodny (1996) were among the first to interview cognitively impaired residents of an institution

about their daily lives. Perhaps their most interesting finding is that the residents' lives, as viewed by the residents themselves, were not as bleak as they looked. Investigators in Sweden (Zingmark, Norberg, & Sandman, 1993; Zingmark, Sandman, & Norberg, 2002) used a combination of participant and non-participant observation of residents and interviews with their care providers to determine what everyday life was like for severely impaired women living in a small special-care unit and how to make them feel at home in this environment. The care providers reported that play and joy were important, and this objective was achieved by including fun as part of daily activities (Zingmark et al., 2002). But there are many other questions to be answered. Is assessing affect the best way, or the only way, to determine whether a particular approach is effective? What about those individuals who no longer demonstrate affect? Can affect be "resuscitated" through the use of particular interventions? Are there some effective ways of working with this population generally, or must a quality-intervention map be developed for each person? Are some people more effective than others in creating high-quality moments — for example, are family members more effective than staff? Are staff who are consistently assigned to a person more effective than skilled staff who work with the person only periodically?

It is not possible to deal with quality-of-life topics without at least some philosophic basis, and, fortunately, we have been well served in this area by the work of Kitwood (Kitwood, 1997, 1998; Kitwood & Bredin, 1992) and Sabat (1998). Kitwood, while challenging some of the assumptions about the biological basis of Alzheimer disease, was a pioneer in trying to determine what people with dementia experience, and he used this background to assert the central role that personhood plays in quality of life. He argues passionately that an individual's personhood does not change when he or she becomes cognitively impaired. For Kitwood, personhood is "the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (1997, p. 8). Sabat supports this view, arguing that the "treatment" of those who are cognitively impaired must be based on the idea of personhood. Sabat extends this thinking and introduces the concept of selfhood, the ascribing of which does not depend on others. If "caregiving and quality of life are about preserving, conserving, sustaining, nurturing, and eliciting... personhood" (Jennings, 2000, p. 175), what does this mean for nursing staff in relation to the cognitively impaired residents in their care?

Other researchers have used quantitative methods to assess a cognitively impaired individual's quality of life. Lawton and his colleagues (Lawton, Van Haitsma, & Klapper, 1996; Lawton, Van Haitsma, Perkinson, & Ruckdeschel, 1999) developed an observational scale (Apparent Affect Rating Scale, AARS) that allows for the quantification of five affective

states (pleasure, anxiety/fear, anger, sadness, interest) in those with advanced impairment, which, they argue, provides some evidence on quality of life. They also advocate for assessment using a set of objective indicators, including a home-like environment and reasonable staff-patient ratios, to complement the observed indicators. Brod and his colleagues (Brod, Stewart, & Sands, 2000), building on Lawton's work, developed the Dementia Specific Quality of Life Model, or D-QoL (Brod, Stewart, Sands, & Walton, 1999), an assessment tool for use with those who are still capable of participating in an interview. The scale operationalizes their view that quality of life in this population includes both positive and negative affect, feelings of self-esteem and belonging, and the ability to appreciate the beauty in nature and in one's surroundings. Perhaps some of these attributes could be assessed through observation as well. Another useful assessment approach that can be applied at individual and group levels is Dementia Care Mapping, based on Kitwood and Bredin's (1994) work. Trained staff observe, on a predetermined schedule, the indicators of personhood — for example, interacting with others, being socially engaged, or doing work or pseudo work — which are then converted to a quantitative score that indicates whether care is satisfactory or needs improvement. These tools are relatively new and need much more use before it can be determined whether they are sufficient to assess the effectiveness of interventions to improve quality of daily life, including the moments that matter, if additional tools and methods are required. Despite these and other initiatives, this area is still in an early phase of development. Much more attention needs to be focused on conceptualizing the quality of daily life and quality of the moment in the cognitively impaired elderly population. The range of qualitative and quantitative methods that have so far been used to study various issues illuminates the need for creative research strategies to investigate this population when interviewing has limited potential.

This research agenda involves two particular issues: moving the agenda forward, and getting nursing staff to assume primary responsibility for ensuring that people who are cognitively impaired have the best possible quality of daily life. Several factors may serve to propel this research forward. Because of the aging of our population and the resulting increase in the number of people who are cognitively impaired, more people will have parents and grandparents with cognitive impairments and will insist that their lives be lived as fully as possible. Even without this reality, however, I think the opportunity to be creative and to bring innovative approaches to understanding behaviour and to testing different ways of being with and engaging these people will become irresistible to some of our best researchers. Perhaps a competition funded by the

CIHR Institute of Aging for research on ways of contributing to the quality of daily life of those with advanced impairment would be an appropriate incentive. But how do we get nurses to agree that we must incorporate making moments matter into our daily work with these people? To use an earlier analogy, how do we get them to sew the tapestry using multiple colours and strands? First we have to learn how to sew, and that is what research will bring us. Then we have to teach students and nursing staff how to sew, and that will require more research. Only then will we be in a position to hope that the rewards of bringing highly textured, interesting, and enjoyable days to the hundreds of thousands of cognitively impaired older people living out their days in long-term-care facilities will be so compelling and so reinforcing that nurses would not think of caring for them in any other way.

References

- Beck, C., Frank, L., Chumbler, N. R., O'Sullivan, P., Vogelpohl, T. S., Rasin, J., et al. (1998). Correlates of disruptive behavior in severely cognitively impaired nursing home residents. *Gerontologist*, 38, 2, 189–198.
- Beck, C., Heithoff, K., Baldwin, B., Cuffel, B., O'Sullivan, P., Chumbler, N. R., et al. (1997). Assessing disruptive behavior in older adults: The Disruptive Behavior Scale. *Aging and Mental Health*, 1(1), 71–79.
- Beck, C. K., Vogelpohl, T. S., Rasin, J. H., Uriri, J. T., O'Sullivan, P., Walls, R., et al. (2002). Effects of behavioral interventions on disruptive behavior and affect in demented nursing home residents. *Nursing Research*, 51(4), 219–228.
- Brod, M., Stewart, A. L., & Sands, L. (2000). Conceptualization of quality of life in dementia. In S. M. Albert & R. G. Logsdon (Eds.), *Assessing quality of life in Alzheimer's disease* (pp. 3–16). New York: Springer.
- Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The Dementia Quality of Life measurement (D-QoL). *Gerontologist*, 39(1), 25–35.
- Faran, C. J. (2001). Family caregiver intervention research: Where have we been? Where are we going? *Journal of Gerontological Nursing*, 27(7), 38–45.
- Forbes, D. A. (1998). Strategies for managing behavioural symptomatology associated with dementia of the Alzheimer type: A systematic review. *Canadian Journal of Nursing Research*, 30(2), 67–86.
- Harrison, M. B., Juniper, E. F., & Mitchell-DiCenso, A. (1996). Quality of life as an outcome measure in nursing research: "May you have a long and healthy life." *Canadian Journal of Nursing Research*, 28(3), 49–68.
- Jennings, B. (2000). A life greater than the sum of its sensations: Ethics, dementia, and the quality of life. In S. M. Albert and R. G. Logsdon (Eds.), *Assessing quality of life in Alzheimer's disease* (pp. 165–178). New York: Springer.
- Kitwood, T. (1997). The experience of dementia. *Aging and Mental Health*, 1(1), 13–22.
- Kitwood, T. (1998). Toward a theory of dementia care: Ethics and interaction. *Journal of Clinical Ethics*, 9(1), 23–34.

- Kitwood T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 269–287.
- Kitwood, T., & Bredin, K. (1994). *Evaluating dementia care: The DCM method*, 6th Ed. Bradford, UK: Bradford Dementia Research Group, Bradford University.
- Lawton, M. P., Van Haitsma, K. S., & Klapper, J. A. (1996). Observed affect in nursing home residents. *Journal of Gerontology, Psychology and Social Science*, 51, 3–14.
- Lawton, M. P., Van Haitsma, K., & Perkinson, M. (2000). Emotion in people with dementia: A way of comprehending their preferences and aversions. In M. P. Lawton & R. L. Rubinstein (Eds.), *Interventions in dementia care: Toward improving quality of life* (pp. 95–119). New York: Springer.
- Lawton, M. P., Van Haitsma, K., Perkinson, M., & Ruckdeschel, K. (1999). Observed affect and quality of life in dementia: Further affirmations and problems. *Journal of Mental Health*, 5(1), 69–81.
- Marshall, M. (2001). Editorial: The challenge of looking after people with dementia. *British Medical Journal*, 323(Aug. 25), 410–411.
- Mitchell, G. J., & Kolodny, V. (1996). Quality of life: Residents of long-term care facilities speak out. *Picker Report* (Spring/Summer), 10–11.
- Sabat, S. R. (1998). Voices of Alzheimer's disease sufferers: A call for treatment based on personhood. *Journal of Clinical Ethics*, 9(1), 35–48.
- Wells, D. L., & Dawson, P. (2000). Description of retained abilities in older persons with dementia. *Research in Nursing and Health*, 23(2), 158–166.
- Wells, D. L., & Dawson, P. (2002). A framework for developing nursing knowledge about the effects of dementia on older persons' abilities. *Journal of Applied Gerontology*, 21(1), 90–102.
- Wells, D. L., Dawson, P., Sidani, S., Craig, D., & Pringle, D. (2000). Effects of an abilities-focused program of morning care on residents who have dementia and on caregivers. *Journal of the American Geriatrics Society*, 48(4), 442–449.
- Zingmark, K., Norberg, A., & Sandman, P. O. (1993). Experiences of at-homeness in patients with Alzheimer's disease. *American Journal of Alzheimer's Care and Related Disorders and Research*, 8, 10–16.
- Zingmark, K., Sandman, P. O., & Norberg, A. (2002). Promoting good life among people with Alzheimer's disease. *Journal of Advanced Nursing*, 38(1), 50–58.

Dorothy Pringle, RN, BScN, MS, PhD, is Professor of Nursing and Dean Emeritus, Faculty of Nursing, University of Toronto, and Senior Researcher, Kunin-Lunenfeld Applied Research Unit, Baycrest Centre for Geriatric Care, Toronto, Ontario, Canada.