

Discourse

Realizing the Imperative of Clinical Nursing Research: The Experiences of a Collaborative Research Program in Long-Term Care

Pamela Dawson

The demographics of Canadian society are creating at least two imperatives for nurses and all health-care providers. The first is to create services sufficient to meet the health needs of the expanding aging population. The second is to undertake relevant research sufficient to ensure that the services created are as effective as possible. Health services for the aging population are frequently interrelated with the living environments of this population — a small but significant proportion of older people require a congregate environment where health care and supportive services are provided on a 24-hour basis, while other older people depend on home-care services in order to remain in their own homes.

When older people live in long-term-care environments, the assistance they receive is frequently delivered by nonprofessional workers. In order for nursing research to meet the test of relevance, it must take into account this mix of nursing personnel, in the questions that are asked, the subjects who are recruited, and the interpretations that are drawn from the results.

This is the background that influenced the creation, 4 years ago in Toronto, of the Collaborative Research Program—Long Term Care (CRP-LTC). Three long-term-care facilities, Baycrest Centre for Geriatric Care, Queen Elizabeth Hospital (now Rehabilitation Institute of Toronto), and Sunnybrook Health Science Centre, were teaching hospi-

Pamela Dawson, R.N., M.S.N., is Director, Collaborative Research Program – Long Term Care, and Assistant Professor, Faculty of Nursing, University of Toronto, Ontario.

tals for the University of Toronto, and the Faculty of Nursing of the U of T was deeply involved with all three facilities. Each of the three organizations had research resources and conducted some clinical research, but it became clear that if we pooled our resources each organization would benefit (and we were arrogant enough to believe that nursing research would benefit as well). Since that time, Providence Centre has joined CRP-LTC as an affiliate and is participating in the research programs.

Each partner makes an annual contribution to a central fund that allows the CRP-LTC to employ a full-time director and part-time research assistants. The nurse executives from each organization agreed to second me from Sunnybrook, where I had worked as a clinical nurse specialist in long-term care for many years and had conducted a number of research studies. The advantage to this approach was that I knew the Toronto environment and had a track record of externally funded research conducted in service settings; thus the program could start immediately, which would not have been the case if we had to undertake an external search. I am supported by a management committee consisting of the nurse executives and a research planning committee on which sit researchers from each organization.

The mission of the CRP-LTC is:

to develop nursing-specific and multidisciplinary programs of research in order to learn about the experiences of residents living in long-term care and to develop innovations in care which enhance their quality of life.

The mission is informed by the reality of the collaborating partners and the values and beliefs they share. Three of the partners provide residential care, in settings ranging from assisted-living apartments to chronic-care hospitals. Consequently, understanding how residents experience their environments, and their lives in these environments, is critical to improving the environments. Furthermore, the partners share the belief that nursing is primarily responsible for creating and maintaining environments that contribute to residents' improved quality of life, and that all innovations derived from research should have as their objective improved quality of life as perceived by the residents.

Because of the program's commitment to relevant research, considerable effort went into defining the research programs. This was a critically important undertaking: it was essential for us to identify themes and commit ourselves to conducting studies that build on each other, lest we end up undertaking a number of unrelated studies that individually might be justified but collectively would not move the science

of nursing ahead in any substantial way. Among the strategies we used in making these decisions were interviews with nurses at all levels in the participating organizations, a review of the mission statements of the organizations, and identification of the research interests of the individual researchers who would be contributing their time. Finally, a 1-day retreat was held for all participating researchers, to review the input that had been received and to come to final decisions. Four programs of research were selected, each comprising specific themes.

Quality of Life

The first program, *Quality of Life*, has three themes: quality of life of persons with Alzheimer's disease, the meaning of dignity and feeling respected, and the meaning of feeling understood and listened to. It might be argued that sufficient research has already been conducted on quality of life and that the limited resources of the CRP-LTC should be directed to other, less studied areas. There is no question that quality-of-life research has become a growth industry with particular concentration on measurement (Gill & Feinstein, 1994). However, the long-term-care sector has not been the focus of the majority of this work, and the cognitively impaired have received even less attention. There are some excellent papers on individual concepts of what constitutes quality of life — for example, Schwartz's (1975) observations on self-esteem as the essence of quality of life for the aged — but there is little research that confirms or extends these individual conceptions.

Dr. Gail Mitchell, Chief of Nursing at Sunnybrook, heads the team working on quality-of-life themes. This program is central to the overall initiative, and it builds directly on work that Mitchell and colleagues had previously undertaken at Queen Elizabeth Hospital (Mitchell & Jonas-Simpson, 1995). In the earlier work, residents had identified the contributions of nurses as central to their quality of life but indicated, unfortunately, that many of these contributions led to a diminution rather than an increase in quality. A theme that emerged in this earlier work was waiting for assistance and care. Because there is very little understanding of what waiting means, Mitchell, Kolodny, et al. (1998) undertook to "explore the lived experience of waiting," using a phenomenologic approach in interviewing 45 residents of the three collaborating institutions.

Another team (Mitchell, Jonas-Simpson, et al., 1998) has just launched a study to better understand the "lived experience of being listened to." Although being listened to is critical to quality of life and interpersonal relationships (Gerteis, Edgman-Levitan, Daley, & Del-

banco, 1993; Hanestad, 1996; Mitchell & Jonas-Simpson, 1995; Webb & Hope, 1995), research indicates that patients do not frequently experience this phenomenon (Koch, Webb, & Williams, 1995; Mitchell & Jonas-Simpson). The research team was unable to locate any studies that explicate what patients mean when they say they are or are not being listened to. In order to help nurses and other health-care providers to change their practice and listen in a way that residents find meaningful, it is necessary to understand what behaviours convey true listening.

This research program and all the studies within it are guided by Parse's theory of human becoming (Parse, 1981, 1992, 1995). Briefly, the researchers search for meanings, paradoxical patterns, and plans that are linked to universal experiences.

To date, all of the studies undertaken within this program have been funded by small seed grants awarded through CRP-LTC competitions.

Caring/Relating

The second research program, which is closely related to the first, focuses on *Caring/Relating*. Studies have shown that the most critical element in residents' quality of life is their relationships with nursing staff (Kayser-Jones, 1991). As with quality of life, there is much rhetoric about the elements of caring and relating that make a difference to patients but little in the way of research to explicate what these elements are and how they are constituted into a meaningful whole that is experienced as a fulfilling interpersonal relationship. This program has two specific themes: the participation and involvement of residents and families in the caring process, and activities and interactions that convey a spirit of caring to residents and families.

This research team is led by Dr. Diane Buchanan of the Baycrest Centre, and the studies involve both quantitative and qualitative methods. One foundational study (Dawson, Spee, et al., 1998) seeks to determine whether Resident Assessment Profiles such as the RUGS-III tool used to determine care requirements and funding levels are congruent with concerns and priorities identified by the residents and their family members. In this era of "patient-centred care," it is surprising how little research has been conducted into what residents in long-term care identify as their concerns and priorities, what they would like to participate in and have control over, and what the outcomes of this participation would be (Cahill, 1996; Davies, Laker, & Ellis, 1997; Kane

et al., 1997). This study will identify what care the residents want control over and which aspects of care they and their families wish to participate in, and it will allow both residents and providers in long-term care to challenge what funders consider important — versus what care recipients would like to see provided and paid for.

A second study in this program addresses the theme of enhancing the resident/nursing staff relationship. Kathy McGilton, a doctoral student in the Ph.D. program in nursing science at the University of Toronto, is conducting a field study based on Winnicott's (1960) theory of relationships, in which the culture and practices on a long-term-care unit will be changed to emphasize continuity of resident/health-care-aide relationships; enhanced ability of health-care aides to communicate with residents and to identify and value unique characteristics of each resident; and increased support, from registered nurses and the nurse manager, to the aides for the emotional side of their work. A particularly challenging component of this study was the measurement of the relationship, which involved translating and quantifying concepts identified in earlier qualitative work.

Freedom and Mobility

The third research program asks: What knowledge, attitudes, beliefs, and practices concerning mobility, and its relationship to quality of life, do health-care providers carry, and what interventions enhance freedom and mobility? This program is headed by Dr. Cheryl Cott, a professor in the Department of Physical Therapy. While most members of the research teams are nurses, the intention of the CRP-LTC was not to focus exclusively on nursing but to involve other health disciplines concerned with quality of life.

This program was begun with an examination of the meaning of mobility for both residents and long-term-care staff, in order to provide baseline information for future interventions. While focus groups were being held to gather the data for the first study, Dawson, Cott, et al. (1998) were aware that previous research suggested that physical exercise and walking/talking programs could enhance the overall functioning of residents in long-term-care facilities. Among the benefits are improved communication (Tappen, 1988), increased independence in ambulation, improved walking endurance (McRae et al., 1996), and decreased incontinence during the day shift (Jirovec, 1991). All of these studies had paired a staff member with one resident, and some studies did not have strong research designs; hence the work suggests rather than demonstrates. A proposal was developed, funded

require during different points in the convalescent trajectory?" "What is the role of nursing within a collaborative framework of multidisciplinary practice?" "What are the indicators that nursing has made a difference to patient and family outcomes?"

The profession that has knowledge of patients' and families' needs will not only find itself in a strong position to meet the many challenges of the new health care system but will also be in a unique position to influence its direction. The right type of knowledge is dependent on asking the right set of questions. We believe that nursing has been asking the right questions. Now what we need to do is to find the answers.

cognitive impairment and dementia (Wells, Ens, Cowan, Irvine, & Rogers, 1997).

This has been a brief tour of the programs and some of the research undertaken by the CRP-LTC in its short existence. It is meant to illustrate the advantages, for the development of nursing research — in this case research focused on institutionalized older people — of collaboration across a number of organizations. While we have not accomplished all that we had hoped to do by this date, we do believe we would have accomplished less had we not been working together. The responsibility of not letting colleagues down has served as a great incentive for getting work accomplished. There is also consensus that the research we are undertaking is clinically relevant. We have the advantage of being a group of nurses who straddle the research/practice line. Our research questions are our practice questions. We experience the same frustrations as staff nurses in having to wait for research to produce the answers, but the frustration is tempered by the fact that we are aware of how all the studies are proceeding and are informed by all the literature reviews. This is a very different experience from working alone or with a sole group within one's own institution.

The collaboration is not without its challenges. It is obvious from the research programs, themes, and individual projects that there is considerable overlap across the programs. A good example of this is the study on walking/talking, which is categorized under the *Freedom and Mobility* program but could just as easily be listed under *Living with Cognitive Impairment*. Does this matter? It may be that we have too many programs and that as the whole initiative evolves the programs will be reconceptualized and reduced in number so that the entire program of research becomes more focused. A side effect of developing a collaborative arrangement such as ours is that participating individuals come with a wide range of interests and areas of special knowledge. These drive what they want to study, because they know where the gaps in research are. This is very different from building a program around a central theme and recruiting and paying researchers to focus on that theme. Rarely in nursing are we in a position to do the latter, so we must respect the interests of our colleagues who are invited to work together. Experience in working together builds common interests and facilitates agreement on what the research priorities should be. The more focused the research program, the greater the likelihood that a substantial contribution to knowledge will be made; thus the overlaps in our four programs will likely serve us well in the future.

Our team of researchers is composed of individuals with very different research training and research traditions. We do not always agree, and some of the disagreements are based on profoundly different research values. We have been able to work together, however, because we have profoundly similar values about what is important for older people, and this helps us respect each other's work in building the knowledge that will serve older people.

The CRP-LTC is an experiment, but it is also an adventure for all of us who are involved. We think we are creating a model of collaboration that can serve other groups of nurses dispersed across a number of organizations but with similar research interests. A critical and probably essential element of our collaboration is the role I play as full-time director. Knowing something of the financial circumstances of our collaborative partners, I think it is unlikely that any one of them would have the resources to fund my position and provide me with research assistants and seed money to stimulate the development of studies that are important to the success of the program. Sharing these expenses has made the collaborative program possible. Thus collaboration among the executive heads of the organizations has been and continues to be crucial.

We gave ourselves 5 years to create a program of research. We are just beginning our fourth year and have much to show for our first 3 years of collaboration. We have developed momentum in writing grant applications and abstracts for presentations and, now, articles reporting on our completed studies. These are very important indicators of success, but the most important will be change in nursing practice informed by our work.

References

- Aronson, M.K., Post, D.C., & Guastadisegni, P. (1993). Dementia, agitation and care in the nursing home. *Journal of the American Geriatrics Society*, 41, 507-512.
- Burgener, S.C., Jirovec, M., Murrell, L., & Barton, D. (1992). Caregiver and environmental variables related to difficult behaviours in institutionalized, demented elderly persons. *Journal of Gerontology (Psychological Sciences)*, 47, 242-249.
- Cahill, J. (1996). Patient participation: A concept analysis. *Journal of Advanced Nursing*, 24, 561-571.
- Cohen-Mansfield, J., Marx, M., & Rosenthal, A. (1990). Dementia and agitation in nursing home residents: How are they related? *Psychology and Aging*, 5, 3-8.

A Collaborative Research Program in Long-Term Care

- Davies, S., Laker, S., & Ellis, L. (1997). Promoting autonomy and independence for older people within nursing practice: A literature review. *Journal of Advanced Nursing*, 26, 408-417.
- Dawson, P., Bruce, B., & Wells, D.L. (1994). *Evaluation of a clinical program for elderly people with cognitive impairment*. Paper presented at the 47th Annual Meeting of the Gerontological Society of America, Atlanta, GA.
- Dawson, P., Cott, C., Sidani, S., Wells, D.L., Bourret, E., Boutcher, F., Brachvogel, S., Janes, N., & Diamond, M. (1998). *The effects of a walking/talking program on communication, ambulation, urinary incontinence, and functional status in persons with dementia*. Unpublished grant application, CRP-LTC, Toronto, ON.
- Dawson, P., Spee, R., Hill, E., Kerr, M., Krock, M., Landesman, A., Nault, J., Reid, N., Robinson, K., & Rook, M. (1998). *Is the RAI compatible with resident centred care? An evaluation of the Minimum Data Set and resident assessment protocols with the residents' own concerns and priorities*. Unpublished grant application, CRP-LTC, Toronto, ON.
- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T.L. (Eds.). (1993). *Through the patient's eyes: Understanding and promoting patient-centered care*. San Francisco: Jossey-Bass.
- Gill, T.M., & Feinstein, A.R. (1994). A critical appraisal of the quality of quality-of-life measurements. *Journal of the American Medical Association*, 272(8), 619-626.
- Hanestad, B.R. (1996). Nurses' perceptions of the content, relevance and usefulness of the quality of life concept in relation to nursing practice (Abstract). *Nursing Science & Research in the Nordic Countries*, 16(1), 17-21.
- Jirovec, M.M. (1991). The impact of daily exercise on the mobility, balance and urine control of cognitively impaired nursing home residents. *International Journal of Nursing Studies*, 28(2), 145-151.
- Kane, R.A., Caplan, A.L., Urv-Wong, E., Freeman, I.C., Aroskar, M.A., & Finch, M. (1997). Everyday matters in the lives of nursing home residents: Wish for and perception of choice and control. *Journal of the American Geriatrics Society*, 45, 1086-1093.
- Kayser-Jones, J. (1991). The environment and quality of life in long term care institutions. *Nursing & Health Care*, 10(3), 125-130.
- Koch, T., Webb, C., & Williams, A.M. (1995). Listening to voices of older patients: An existential-phenomenological approach to quality assurance. *Journal of Clinical Nursing*, 4, 185-193.
- McRae, P.G., Asplund, L.A., Schnelle, J.F., Ouslander, J.G., Abrahams, A., & Morris, C. (1996). A walking program for nursing home residents: Effects on walk endurance, physical activity, mobility and quality of life. *Journal of the American Geriatrics Society*, 44, 175-180.
- Mitchell, G.J., & Jonas-Simpson, C.M. (1995). *Quality of life in chronic care: The resident's perspective*. Unpublished manuscript, Queen Elizabeth Hospital, Toronto, ON.

- Mitchell, G.J., Jonas-Simpson, C., Doyle, D., Jones, G., Fisher, A., Spee, R., & Linscott, J. (1998). *The lived experience of being listened to*. Unpublished grant application, CRP-LTC, Toronto, ON.
- Mitchell, G.J., Kolodny, V., Vander Laan, R., Lyon, P., Linscott, J., Flint, F., Pilkington, B., Wiesenthal, S., Carson, G., & Thomson, A. (1998). *Exploring the lived experience of waiting*. Unpublished grant application, CRP-LTC, Toronto, ON.
- Parse, R.R. (1981). *Man-living-health: A theory of nursing*. New York: Guilford Press.
- Parse, R.R. (1992). Human becoming: Parse's theory of nursing. *Nursing Science Quarterly*, 5, 35-42.
- Parse, R.R. (1995). *Illuminations: The human becoming theory in practice and research*. New York: National league for Nursing. (Pub. No. 5-2670.)
- Schwartz, A.N. (1975). An observation on self-esteem as the linchpin of quality of life for the aged: An essay. *Gerontologist*, 15, 470-472.
- Tappen, R.M. (1988). *Communication assessment for the cognitively impaired: Instrument*. Coral Gables, FL: University of Miami.
- Webb, C., & Hope, K. (1995). What kind of nurses do patients want? *Journal of Clinical Nursing*, 4, 101-108.
- Wells, D.L., Dawson, P., LeClerc, C., Sidani, S., Brachvogel, S., Boutcher, F., & Janes, N. (1998). *Psychometric evaluation of a feeding abilities instrument for persons with Alzheimer's Disease*. Unpublished grant application, CRP-LTC, Toronto, ON.
- Wells, D.L., Dawson, P., Sidani, S., Craig, D., & Pringle, D. (1996). *Effects of an abilities-focused program of morning care on the behaviours of residents with dementia and on caregivers' perceptions about care giving*. Unpublished grant application, CRP-LTC, Toronto, ON.
- Wells, D.L., Ens, I., Cowan, L., Irvine, D., & Rogers, N. (1997). *A critical review and synthesis of the literature on agitation related to cognitive impairment and dementia*. Unpublished grant application, CRP-LTC, Toronto, ON.
- Winnicott, D.W. (1960). The theory of the parent-infant relationship. In P. Buckley (Ed.), *Essential papers on object relations* (pp. 233-253). Washington: American Psychological Association.