

## Designer's Corner

# Gerontological Nursing Research: A Challenging But Rewarding Field

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We are continually faced with a series of great opportunities brilliantly disguised as insoluble problems.

—John W. Gardner (1912-)

"Good luck — you'll need it," a colleague once told me as I was embarking on one of my first research studies in a long-term-care setting. "You'll go *crazy* with all the problems of doing research in nursing homes," she added, obviously trying to discourage me from considering such research.

Well, I didn't go crazy, and that nursing-home study — one of many that would follow — was a great success. However, over the years I *have* come to appreciate some of the unique challenges of conducting gerontological nursing research, particularly with persons who are frail or in long-term care. While some of these challenges can be disheartening and even overwhelming, seeing the research through to the end is one of the many rewards that make research with older persons so satisfying. The purpose of this short article is to highlight some of the positive and negative issues confronting gerontological nurse researchers. These issues fall into three categories: ethical, recruitment and sampling, and measurement.

### Ethical Issues

While research with healthy, independent older adults generally does not present unique challenges, the growing number of elderly persons with dementias such as Alzheimer disease does raise ethical concerns due to their impaired ability to provide informed consent to participate in studies (Agarwal, Ferran, Ost, & Wilson, 1996; Maas, Kelley, Park, & Specht, 2002; Moore & Hollettt, 2003; Sachs, Rhymes, & Cassel, 1993; Sachs, Stocking, Stern, Cox, Hougham, & Sachs, 1994). These ethical concerns revolve around three issues: (1) the variability in a demented

person's ability to meet the normal requirements of "informed consent"; (2) the willingness, ability, and desirability of a relative or friend to give "proxy consent" for the demented person to participate; and (3) the ethical issues raised when a demented person is excluded from research due to the problems of informed consent and proxy consent.

Regarding the first issue, researchers and research ethics boards (REBs) are faced with the thorny problem of what action to take when a person with dementia can "almost" give full and informed consent to participate in a research project (Moore & Hollett, 2003). This is a complex issue without clear guidelines. According to the Tri-Council Policy Statement, for example, "many individuals who are not fully competent are still able to express their wishes in a *meaningful* way, even though such expression may fall short of meeting the requirements for informed choice" (Tri-Council Working Group, 2000, Requirement for free and informed consent, Competence section, Article 2.7; emphasis added). The Tri-Council appears to be advising researchers and REBs that persons with dementia should have a say in whether or not they participate in research, but it offers no clear guidelines on how "meaningful" their wishes have to be to influence decisions about participation or to supersede the need for full and informed consent. Indeed, the overall issue of research consent and "competence" regarding persons with dementia remains ambiguous (Marson, Schmitt, Ingram, & Harrell, 1994), as reflected in the Tri-Council guidelines:

Competence to participate in research, then, is not an all-or-nothing condition. It does not require prospective subjects to have the capacity to make every kind of decision. It requires that they be competent to make an informed decision about participation in particular research. Competence is neither a global condition nor a static one; it may be temporary or permanent. (Competence section, paragraph 1)

To resolve the ethical quandary over informed consent for persons with dementia, many researchers and REBs have suggested the use of proxy consent, whereby a surrogate decision-maker, usually a family member, makes a decision for the person with dementia with regard to participation in a research project. However, the use of proxy consent presents both pragmatic and legal difficulties. Pragmatically speaking, proxies can be very conservative or protective in their decision-making (Bowsher, Bramlett, Burnside, & Gueldner, 1993; Sachs et al., 1994; Warren et al., 1986), and securing their consent can be a challenging and time-consuming process. In addition, proxy consent entails important legal considerations. The laws on both competence and proxy consent vary from province to province and are often in a state of flux. Furthermore, researchers may be able to find a family member who is

willing to provide consent on behalf of the person with dementia, only to discover that he or she does not have the legal right to make such a decision.

Due to some or all of these ethical difficulties, many promising research projects involving older persons with dementia simply never get off the ground. As Maas et al. (2002) state, "many older persons who are mentally infirm or institutionalized are isolated from the potential benefits of research by current ethical concerns and policies for the protection of human research participants" (p. 375). This, in turn, ironically creates another ethical concern: *the exclusion of persons with dementia from the benefits of research*, simply because REBs or nursing-home administrators may be *too* concerned about ethical matters. The Tri-Council guidelines acknowledge this issue:

Although ethical duties to vulnerable populations preclude the exploitation of those who are incompetent to consent for themselves for research purposes, there is nonetheless an obligation to conduct research involving such people because it is unjust to exclude them from the benefits that can be expected from research. (Tri-Council Working Group, 2000, Section C: "Research Involving Those Who Are Incompetent to Consent for Themselves," paragraph 1)

Unfortunately, the Tri-Council offers no specific guidelines on how best to strike this fine balance. This remains the task of researchers, policy-makers, and REBs.

One final ethical consideration in gerontological research — regardless of whether the participants suffer from dementia — is the impact of the research team's departure once the study is completed, particularly if it is conducted in a long-term-care centre. For elderly long-term-care residents, who may be experiencing monotony and loneliness, participation in a research project can be a vital source of social contact and stimulation. When the research team leaves at the end of a project, such participants can be left with feelings of loss, particularly social loss. In a recent study, Hagen, Armstrong-Esther, and Sandilands (2003) found that the withdrawal of a beneficial and enjoyable activity in nursing homes — in this case an exercise program for the institutionalized elderly — appeared to actually make people worse off than if they had never been offered the activity. While life-satisfaction scores increased as persons participated in the exercise program, after the program was stopped (because the research funding had come to an end) life-satisfaction scores fell to levels lower than those for persons who had never participated in such a program. Similarly, Higgins (1998) found that when her qualitative research study with elderly long-term-care residents ended, many residents seemed to grieve the loss of the conversation and intimacy

associated with participation in the project. Clearly, researchers need to anticipate and plan for effects (and their ethical implications) associated with the termination of research projects involving the elderly.

### **Recruitment and Sampling Issues**

Gerontological nursing research presents some challenging issues involving under- or over-representation of population subgroups. Women, certain cultural groups (e.g., Aboriginal persons), persons with dementia, and persons in rural areas are often under-represented in gerontological research samples (Bowsher et al., 1993). In addition, while large numbers of frail elderly persons live at home — many more than live in institutions — recruiting from this largely invisible population is notoriously difficult, as these people may have little contact with the formal health-care system and typically do not respond to such recruitment strategies as newspaper advertising (Hawranik & Pangman, 2002; Phillips, 1992). Thus, traditional samples for gerontological nursing research tend to be over-represented with either the well elderly living in the community or older persons without cognitive impairment living in long-term-care institutions.

Residents of long-term-care facilities also present unique recruitment challenges. The administrators of these institutions, fearful of or uncertain about the ethical and legal issues surrounding competence and informed consent, may deny access to residents and/or records even before the residents are given a say in whether they will participate (Bowsher et al., 1993; Maas et al., 2002). Further, even if administrative support for the research is forthcoming, staff members, often coping with sub-minimal staffing conditions, may find it difficult to attend to routine care needs, let alone additional research demands. Thus, the research team may not be able to count on staff for assistance with any part of the research — including recruitment of residents — and may have to adapt their research activities to the realities of staff workloads and routines.

In addition, recruitment of a sample of long-term-care residents can be challenging due to the comparatively small size of long-term-care facilities, which average approximately one hundred residents. This restriction is compounded by the fact that many residents, because of cognitive impairment or general frailty, may find the data-collection methods (e.g., interviews) too demanding, be unable to provide informed consent, or fail to meet inclusion criteria (Bowsher et al., 1993; Hawranik & Pangman, 2002). In order to obtain a sufficiently large sample, a researcher may have to consider a multi-site study, which can be complex, logistically difficult, and costly. The use of numerous long-term-care facilities to obtain an adequate sample also threatens the homogene-

ity of the sample, since facilities vary in terms of the kind of resident they specialize in (Bowsher et al., 1993). Finally, when recruiting samples, researchers must take into account the attrition rates for elderly research participants, which are higher than those for younger participants and can reach upwards of 25% for nursing-home samples (Bowsher et al.).

### **Measurement Issues**

The reliability and validity of various measures used to collect data from older persons, especially the frail elderly, can be a substantial problem, particularly when the measures have been developed with younger populations (Bowsher et al., 1993; Burnside, Preski, & Hertz, 1998; Phillips, 1992). Among the frail elderly, low energy, fatigue, cognitive impairment, illiteracy, sensory deficits, and even test anxiety can all affect the reliability of a research measure. Measurement validity can be threatened as well. For example, while the commonly used mini-mental status examination may give us valuable information about certain aspects of mental status, it does not necessarily tell us how a frail older person will perform in the context of their own home — such as whether they will remember to turn off the stove (Phillips, 1992). Likewise, many outcome measures in gerontological research are based on gross screening tools that may lack the sensitivity necessary to pick up the small, subtle changes that can result from many nursing interventions with older adults. Finally, as Phillips (1992) points out, many commonly used outcome measures may in fact be inappropriate for elderly persons. As an example, a decrease in depression scores is often seen as a desirable outcome, yet for many older adults depression may actually be an effective coping strategy (Phillips, 1992).

### **Conclusion**

This short article is intended merely to raise awareness about the various issues and challenges confronting gerontological nurse researchers. For more information, the reader is encouraged to consult some of the excellent references listed below. Despite the many challenges, particularly those of an ethical nature, gerontological nursing research is a richly rewarding and exciting field of study. Join just one of the many research teams comprising wonderful individuals who are passionate about the elderly, or attend just one meeting at which the results of your research are implemented to improve the nursing care of older persons, and you will be hooked. So give gerontological nursing research a try. And don't worry — you won't go crazy; in fact, you'd be crazy not to give it a try!

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