

“A Tapestry of Voices”: Using Elder Focus Groups to Guide Applied Research Practice

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ABSTRACT. One of the more subtle consequences of ageism is the exclusion of older adults from participating in the production of knowledge about issues that concern them. This qualitative study used 15 focus groups as a forum to elicit data about *what elders themselves* see as relevant and important areas for applied research. In addition to significant data that will be used to guide research initiatives at the Sheridan Elder Research Centre, the value that emerged in the *process* proved to be the validation of self-determination by elders, a principle fundamental to the Social Work Code of Ethics. This study demonstrates that, if given the opportunity to participate in decision-making about the scope and nature of applied research, older adults will contribute a wealth of rich data. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2003 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. Elder, focus group, quality of life, applied research, qualitative, ageism, research, elder self-determination

INTRODUCTION

In Ontario, it is projected that by the year 2021, the province will be home to close to three million seniors (Statistics Canada, 1998). With these statistics,

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Journal of Gerontological Social Work, Vol. 42(1) 2003
<http://www.haworthpress.com/web/JGSW>

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Digital Object Identifier: 10.1300/J083v42n01_06

there is a critical need for research into the strategies, approaches and resources needed to serve this imminent boom. As David Foot (1998) notes in his analysis of the demographic shift in the new millennium, *Boom, Bust and Echo*, "If we prepare for the grey interlude to come, we can both enjoy the benefits and manage the inevitable challenges."

One concern is that much of our current research in gerontology is based on models of medical intervention, which are primarily problem-oriented. Statistics Canada (1998), however, reports that about seventy-five percent of people aged 65-74, and sixty-six percent of those aged 75 and older, report their health as being "good, very good or excellent." Further, one-half of elders report they are physically active and independent. Therefore, the evidence clearly appears to point towards the need for a different kind of research in gerontology; one that builds on the strengths of the aging population rather than their deficits, and stresses potential, rather than impediment. The *Sheridan Elder Research Centre* (due to open in 2003) seeks to establish a unique environment for the conduct of applied research into areas of practical concern and immediate relevance to older Canadians and those who care for, and about, them. Its director, Pat Spadafora, states,

In collaboration with consumers, industry and educational partners as well as community stakeholders, SERC will provide a platform for addressing the challenges and opportunities presented by the unprecedented growth in the number of older adults in Canada. Our Centre will become a destination for students, educators and researchers wishing to study the specific needs and wants of our elders.¹

Too often, researchers decide upon their projected areas of focus without an attempt to gain the input of those who are the target of their research. Elders represent a cohort that Kirby and McKenna (1989) describe as "being on the margins," the context of those who suffer from injustice, inequality and exploitation. They are often excluded from participating in the production of knowledge about issues that have a direct impact on them. This knowledge is organized in a way that maintains oppressive relations with elders, fuelled further by the practice of ageism in our society.

The purpose of the study, then, was to elicit data about what elders want and need to enhance the quality of their lives, in order to inform research at SERC. A second purpose was to assess the value and efficacy of using qualitative methods in elder participant research. Focus groups of elders, representing a rural/urban perspective, ethnic/racial diversity and a well-/frail-elderly continuum were thought to be the best forum through which to gain the perspective of the stakeholders, the elders themselves.

LITERATURE REVIEW

A comprehensive literature search encompassed the fields of social work, gerontology, and sociology. Several studies surfaced that were conducted with elders about what *theoretically* constitutes quality of life for them. These include: elders' perceptions of their use of computer technology (Harold, 1992; Johnson, 1995); their views on quality of life in institutions (Depaola & Ebersole, 1995); their ideas about lifelong learning (Hamil-Luker, & Uhlenberg, 2001); end of life issues (Csikai, 1999); their valuing of friendships (Greenberg, Motenko, & Embleton, 1999) and factors they see as leading to depression (Rogers, 1999). Brennan, Moore, and Smyth (1995) discuss the effects of a special computer network in increasing quality of life for caregivers of persons with Alzheimer's disease. A British study (Sobczak, 1997) explores, with residents of a care facility, the link between exercise and quality of life. In each study the topics were predetermined by the researchers.

There are some ethno-specific studies, such as Miah and Kahler's (1997) work with Asian-American elders, but again, these reveal no attempts to define quality of life *from the perspectives of the target population*. One study was found (Bach & McDaniel, 1993) that attempted focus group research with younger quadriplegic adults to identify what they saw as constituting quality of life. However, there are few studies that attempt to elicit the opinions and ideas of *elders* about what they see as important indicators of quality of life. George (1998) reviewed the "empirical research" about quality of life for older adults and concluded that the definition is "complex, with objective and subjective components." Dignity, she summarizes, is "an intangible characteristic of the social environment."

What is noticeable in the above studies that do involve elder participation is that the issues researched were chosen first by the researchers. Research from stakeholders themselves that is used to shape other research initiatives was glaringly absent. In addition, there was little evidence in this current review to suggest that elders have been consulted on matters (resulting in policy-making) that affect them directly. This research project addresses the meanings of quality of life from a context-sensitive and oppression-sensitive perspective.

METHODOLOGY

Research Question

"What kinds of things should be researched that would result in making your life better?" emerged as the primary research question. Variations such as

“In a typical day, what could be improved to make life easier?” and *“What needs to be improved for you to be able to enjoy your world more?”* were formulated to better identify issues of quality of life.

Research Design

This study was qualitative in nature and studied the phenomena that contribute to elders' quality of life, as defined by elders themselves. The experience of aging is uniquely individual, carrying with it a kaleidoscope of meanings. Effective social work interventions include helping elders to discover and establish meaning in later life, and cope with the changes that accompany the aging process. Our knowledge of “quality of life” is to be found within the meanings that people make of it: “knowledge is gained through people talking about their meanings” (Cresswell, 1998). Stewart and Shamdasani (1990) suggest that one of the more common uses of focus groups is “*generating research hypotheses that can be submitted to further research,*” thus confirming the relevance of this approach.

Focus groups have been cited in the literature to be extremely useful tools for non-profit organizations wishing to connect with the communities they serve (Edmunds, 1999; McNamara, 1999). They can be particularly useful during the development of strategic plans, in order to collect opinions and beliefs of interest to the organization (Sharken & Simon, 2000). They are inexpensive and easy (though time-intensive) to conduct.

Respondent Sampling

A total of fifteen focus groups participated in the study: this in-depth exposure to the field was designed to increase credibility. In order to capture as much depth and richness of data as possible, it was crucial to select diverse contexts within which elders' lives are lived. Halton and Peel regions are vast and diverse; as “satellite” communities of Greater Toronto, they are also characterized by large numbers of older immigrants from a variety of other countries, particularly Southeast Asia, Europe and Caribbean areas. There are indeed quite a number of specialized ethno-cultural services for elders. These present ideal avenues for New Canadian elders to participate in research, primarily because interpreters are readily available to address language barriers. Perhaps the biggest challenge of all, in terms of maximizing the potential for all voices to be heard, is the question of how to represent what might be the most marginalized of all elders who have cognitive impairments. In an attempt to be inclusive of this group, the thoughts and opinions of their caregivers, themselves often elderly, were sought as to represent their needs.

DATA ANALYSIS

The groups were conducted over a four-month period during the Fall of 2001 and the Winter of 2002. Data was collected via tape recordings. A researcher's journal was also kept to record learnings about the process.

The data tabulation and analysis in this study, as in all qualitative research, was filtered to a large extent through the lens of the researcher's subjective interpretation. Several concerns surfaced. First was the potential for reactivity: as already outlined, the presence of a younger and thus societally more "powerful" researcher might be thought to inhibit the free flow of thoughts. Second, the potential for respondent bias was evident: respondents may have been keen to volunteer only information that protected their already marginalized privacy. Finally, the possibility of ageist, stereotypical attitudes and myths on the part of the researcher, not yet surfaced and identified, threatened to affect the results.

For the purpose of increasing confidence in the study's results, certain measures were employed in order to generate credibility and authenticity:

- *Methodological Triangulation*: A quantitative evaluation form was designed to elicit data about response to the group process, which was then used as an integral part of the analysis.
- *Observer Triangulation* was provided through the presence of a social service-gerontology student when possible, to act as an observer, or, on one occasion, as a language interpreter.

Member Checking:

- i. A mailed transcription of taped data, with conclusions, was mailed to the respondents and
- ii. The final "Photograph Essay," consisting of photos and selected quotes from the session was taken back into the field, in the form of a presentation to groups which desired this.

Two parallel sets of data needed to be analyzed: the first process involved tabulating and interpreting concrete data about direct responses to the research question (this data was derived directly from the taped transcripts); the second process concerned the experience of conducting this research with this particular cohort, and insights learned in the process (data was extrapolated from the taped material, the researcher's concurrent journal notes describing learnings and reflections, and the participants' evaluation forms).

Tape recordings were transcribed, including both interviewer and respondent quotes, in a non-identifying manner into text format. Data transcription was done concurrently with ongoing focus groups: Lincoln and Guba (1994) claim that data gathering and analyzing should be an integrated process, so that each informs the other, in a fluid process where the analyzing of former interviews provides new questions and foci for those that follow. Data were then summarized and coded; journal notes were similarly treated. A manual process of data analysis included identifying themes and generating categories (Marshall & Rossman, 1999).

Tapes and journals were transcribed within two weeks of conducting, and each listened to at least twice more to capture depth and nuances. The material was painstakingly combed through for emerging dominant themes.

RESULTS

Process

Knowledge of group work theory and practice enabled the social work researcher to bring greater depth to the data gathered, as well as increase sensitivity to participants' stories and needs. Feedback via anonymous evaluation forms included: "She handled the group well, including as many as wanted to participate"; "The leader suggested different aspects to consider"; and "If we strayed from the topic, she steered us back."

As Barrett and Kirk (2000) forewarned, there proved to be specific challenges to working with diverse groups of older respondents. Generally, the prevalence of sensory deficits is greater in this population (Edmunds, 1999). Hearing and sight impediments necessitated the employment of particular group leadership skills, in order to ensure maximum participation of all voices. Often, the respondents were not used to meeting in a discussion group: this resulted in some behaviours (monopolization, frequent interruptions, etc.) that can potentially disrupt group process. Frequent repetition and refocusing was required in order to ensure that all group members remain involved and heard. Many elders enjoy being part of a group, capitalizing on the opportunity for socialization. One respondent claimed, "We need more opportunities to talk like this!"

Seidman (1991) suggests that interviewing participants who are much younger or much older "takes a special type of sensitivity on the part of the interviewer, who must know how to connect to (children) or seniors without patronizing them." The interviewing skills of encouraging, clarifying and summarizing are primary in working with an older clientele. Although many

respondents indicated afterwards that the experience had been a very validating one for them, they also stated that this was an unusual event, in that they were not often asked for their opinions. Frequent encouragement to repeat and/or expand on their comments was needed. However, this had to be balanced with the need, at times, for silence: a normal dynamic of aging is the brain's need for more time to process information. One man appealed, "We need more time to process things!"

Several issues arose around the use of technology. While no one appeared to be nervous or objected to the use of a tape recorder, its value was limited as a technological tool. In a group larger than four or five, frail elderly voices could not be heard clearly on the tape. The practice of frequently repeating and summarizing comments helped to capture details on the tape. A secondary gain to this practice was to encourage and increase participation from those who had not clearly heard or fully understood the initial comment.

The presence of a second researcher, a social service-gerontology student, proved to be very valuable, and helped to increase both clarity of data retrieval and group cohesion, as well as providing for observer triangulation.

Finally, the ethical issue of power inequity arose, as it should in all research with elders. There is an inevitable power discrepancy, Kimmel (1988) claims, when "subjects" for social research are drawn from disadvantaged and relatively powerless segments of society. Elders are, by virtue of their age, accorded lower status in North American society, and thus are in a position of relative powerlessness. Much encouragement and recognition were needed to validate the contributions of participants: universally, the groups responded slowly to encouragement, and warmly to verbal validation. In summary, the focus group discussion was very valuable in offering participants an opportunity to increase self-worth through self-determination.

Content

Naturally, the issues that respondents identified differed according to the context in which they live out their lives. For example, respondents who live in institutions were primarily interested in improving the attitudes and behaviours of the professionals who were their caregivers, and increasing opportunities for social interaction. Caregivers of cognitively impaired elders were interested in researching ways to gain some respite, as well as increasing environmental safety and public understanding and tolerance of dementing diseases. Elders who had emigrated from another country focussed on ways to increase independence and decrease social isolation, while remaining with family. Independent, higher-functioning elders were concerned about technology, communication and access to social events.

However, there were some universal concerns expressed by all participants, which relate generally to the problems experienced simply through becoming older. These included: physical/ bodily changes, sensory disabilities and deficits in environmental design, ageist attitudes, transportation and the issue of advancing technology.

The biological, senescent processes experienced in "normal" aging were frequently identified as robbing older adults of their ability to effectively manage their environment. In fact, one of the strongest themes to emerge was the cry for changes in environmental design, in order to increase elders' control and sense of personal empowerment. Comments about environmental issues included, "Doors are too heavy . . . and elevators need to be more useable, with bigger buttons . . . we need more public seats and benches to rest . . . and higher public toilet seats and grab bars . . . we can't work bathroom faucets with arthritic hands, and can't open those silly little jams and milks in restaurants . . . and better lighting in public places!" Often comments were made about the use of colour: "I can't see dark print on dark paper . . . and carpeted steps that are the same colour as the level ground."

Housing alternatives was another general area identified for research initiatives. Several respondents clamoured for "more affordable services so I can stay in my own home. . . ." However, comments about housing options were very individual. Some claim they "want to live in a community with mixed ages . . . but not in the 'boonies!'" while others asserted, "I want to live with others my age. I don't want kids running around. But not in high-rise buildings." One respondent firmly stated, "Don't put me with old people. They're dying all the time!" An almost universal factor (except for the example of negative case analysis where some ethnic elders chose to live with adult children) was "I NEVER want to live with my kids!"

Indeed, a recurring theme was the need to research ways to reduce the barriers between generations, and to foster understanding, tolerance and acceptance on all sides: this need was identified in both intra-familial and wider social contexts. This theme of lack of respect was especially evident with older people who have come from a different culture. They lament, "We feel dishonoured by the young ones. They do not understand us . . . we deserve respect." They frequently expressed feeling marginalized; "We are not of value here . . . we have not the sense of community we left back home." They are isolated in their homes, as their family are all out during the day. The issue of transportation emerged as a critical one, especially for rural elders, who represent the 24.2% of the elderly population of Canada living in rural settings (Statistics Canada 1999).

Several participants lamented the lack of time to devote to life quality, and the whirl of "busyness" that predominates in contemporary society. Little time

is left for reflection about the larger, existential issues of life. A general aging theme was “We can’t move as fast when we’re older . . . slow everything down!” “Life is going very rapidly and I don’t feel I’m capable of keeping up with it, because everything inside is slowing down. Also, there’s a change going on inside you; you’re weighing your life, and what you’ve done.”

The topic of new learning, especially around technology, was a popular theme, though comments were very varied. One exclaimed, “I’m the regular computer queen! My grandchildren e-mail me all the time.” Others claim, “I think the increase in use of computers is a nuisance. It trivializes our lives, and it’s not good for our social lives . . . it depersonalizes.” Universally, however, respondents claimed that the most important factor was the availability of instruction; furthermore, the teacher must “take things VERY slowly and be prepared to come back several days in a row.” The factor of *time* in learning new things was a repeated refrain.

For caregivers of cognitively impaired elders, the use of a computer for information and communication purposes was often highly valued. “It’s the only thing that seems to keep my husband calm . . . I can spend hours on the computer with him just watching,” said one caregiver. Another claimed the “chat groups” enabled her to meet other caregivers online, thus reducing her sense of isolation.

The prevalence of ageism, and respondents’ reactions to it, was a topic of universal interest. Some stated they respond with humour as a coping strategy. Others are more direct, however, claiming that they would not tolerate ageist attitudes from anyone: “I tell people who treat me like a child to bugger off!” And, “They’re not going to push me around, as long as I have a brain in my head!” Some are downright angry: “You can have ten university degrees, but when you get old, you’re treated like a dummy.” In all groups, respondents were generally open about fully sharing themselves in real and genuine ways.

LIMITATIONS

There are disadvantages to conducting focus group research: because participants’ responses are not independent of one another, the generalizability of results is restricted. Furthermore, by its nature, focus group research is not fully confidential or anonymous, because information is shared among others in the group. For some elders, whose privacy has already been compromised by living in a group setting, loss of dignity and respect may result. This cohort has particular needs, simply by being older. Edmunds suggests that elders are perhaps more skeptical about participating in focus groups as they are often targeted in fraudulent schemes. She also cites poor sight and hearing as potential deterrents.

CONCLUSION AND IMPLICATIONS

The hypothesis of this current research project was that elders have valuable insights and opinions about a range of indicators of quality of life that might be further researched by the Sheridan Elder Research Centre. In addition, it was hypothesized that focus groups might provide a forum for elders to exercise self-determination, a fundamental value of social work practice. This study's results reveal that, indeed, elders' participation in decision-making about research activities is valuable, if challenging to elicit. To date, researchers have perhaps not extended sufficient opportunities to them for their voices to be heard by those who have power to create changes for them. From a social work vantage point, which has as one of its basic tenets the principle of "beginning where the client is at," the lack of available research is unfortunate.

The context in which elders live their lives is a marginalized one, due to the de-valuation of older people in North American society. The challenges involved in conducting qualitative research using focus groups with elders, with the goal of increasing their right to self-determination, have already been described in this paper. This research study has yielded valuable insights into focus group methodology. The results suggest that not only is the concrete data itself valuable, but the process of involving elders is a successful strategy in empowerment. The experience of aging must be heard and honoured with thoughtful exploration. Shifting demographics give rise to new challenges and calls for addressing issues pertinent to a new wave of assertive, self-determined elders. In turn, the opportunities for evolving roles to be filled by health and human services professionals working with active older adults will undoubtedly emerge. This study, along with further research, will offer new conceptual and practice perspectives for the field.

NOTE

1. Spadafora, P. Sheridan Elder Research Centre brochure, 1999, p. 2

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DATE MANUSCRIPT RECEIVED: 10/18/02
DATE MANUSCRIPT SENT FOR BLIND REVIEW: 11/08/02
DATE MANUSCRIPT RE-RECEIVED
IN ACCEPTABLE FORM: 05/12/03