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A Tapestry of Voices: Using Elder Focus Groups to Guide Applied Research Practice - Report Series # 1

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Report Series - # 1

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

Project Team

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About SERC (Sheridan Elder Research Centre)

Through applied research the Sheridan Elder Research Centre (SERC) will identify, develop, test and support implementation of innovative strategies that improve the quality of life for older adults and their families.

1. Wherever possible, older adults participate in the identification of research questions and contribute to the development of research projects at SERC.
2. We conduct applied research from a psychosocial perspective which builds on the strengths of older adults.
3. Our research is intended to directly benefit older adults and their families in their everyday lives. The process of knowledge translation takes our research findings from lab to life.
4. SERC affiliated researchers disseminate research findings to a range of stakeholders through the SERC Research Report Series, research forums, educational events and other means.
5. A multigenerational approach is implicit, and frequently explicit, in our research.
6. To the extent possible our research is linked to and complements academic programs at the Sheridan College Institute of Technology and Advanced Learning.

EXAMPLES OF SERC RESEARCH

The Built Environment	Information & Communication Technology (ICT)	Human Communication	Public Policy	Other research interests
- Indoor/Outdoor Design - Graphic Design	- Accessible computing - Age appropriate games	- Hearing/low vision - Vision - Language	- Elder Abuse - Ageism	- Self image/self esteem - Care-giver support

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The exclusion of older adults as active participants in the production of knowledge regarding issues that concern them is a subtle form of ageism. This qualitative study used 15 focus groups as a forum to identify the areas of applied research that elders themselves see as relevant and important. In addition to eliciting significant data to guide future research initiatives at the Sheridan Elder Research Centre (SERC), the elders validated the principle of self-determination, which is fundamental to the Social Work Code of Ethics. This 2002 study demonstrated that, if given the opportunity to participate in decision making about the scope and nature of applied research, older adults significantly contribute to the research process.

1. Purpose

The root problem concerning research in gerontology is that much of the emphasis has been on models of problem-oriented, medical intervention. This would include, for instance, research on the effects of deteriorating physical ability. Consequently, very little attention is devoted to understanding the dynamics of productive aging. Considering the fact that the majority of older adults report “good” or “excellent” health (75% of those aged 65-74; Statistics Canada), there is a need for a different kind of research in gerontology. New research needs to increase its focus on the strengths of the aging population. SERC aspires to establish a unique environment to conduct applied research, with an emphasis on areas that are of practical concern and immediate relevance to older Canadians. The full report of this study not only examined the existing body of knowledge regarding sociological literature about older adults, but also explores whether or not the qualitative method is an appropriate approach to gerontological research.

The focus in many studies reflects foci that are decided upon by the researcher, often without input from the target group themselves. Since older adults represent a cohort that often suffers from injustice, inequality, and exploitation. SERC considers this group to be fundamental to the development and direction of research. This particular study utilized several focus groups comprised of elders who represented both rural and urban perspectives, ethnic and racial diversity and older persons identified as “well or frail” along the health continuum. The purpose of this study was two-fold; to elicit data concerning what elders want and need in order to enhance their quality of life and to assess the value and efficacy of qualitative methods in elder participant research.

2. Methodology

2.1 Research Design

This study was qualitative in nature and studied the phenomena that contribute to an elder’s quality of life as defined by older persons themselves. Qualitative research has the ability to identify meaningful reality by observing its participants in a naturalistic setting where elders live and socialize. This method allows for an in-depth understanding of the subjective thoughts, values and experiences of the target sample.

In order to accurately assess elders, it is not enough to offer the researcher's definition of "quality of life" but to observe what quality of life actually means and how it is experienced by the elders themselves. The experience of aging is uniquely individual and focus groups can provide a forum for the expression of a wide range of opinions and attitudes. Further, focus groups serve to help generate future research hypotheses which are based on the opinions of the elders themselves, thus making a qualitative approach most appropriate.

2.2 Respondent Sampling

Fifteen focus groups were included in this study, with a sample consisting of both rural and urban perspectives, ethnic and racial diversity and a "well-frail" continuum. This widely diverse sample incorporated geographic, socioeconomic and cultural variations in order to understand the widely diverse context in which elders live. The main concern was to maximize the potential for all voices to be heard.

In some situations, this was difficult and required some accommodation. For cognitively impaired older adults, caregivers were included to vicariously represent the perspective of care receivers. Non-English speaking participants employed the use of interpreters to address language barriers, making it possible for their opinions to be clearly heard.

2.3 Research Question

The primary research question was focused on the elder's quality of life. Researchers posed the following question to the participants; "What kinds of things should be researched that would result in making your life better?" Sub-questions warranting more specific responses were then asked, such as; "What needs to be improved for you to be able to enjoy your world more?"

2.4 Method

A letter of intent and an introduction to the research project were mailed to individuals and agencies working with established groups of elders. If requested, a synopsis of the project, a list of research questions and a sample release form were mailed. Next, participants chose a date and time convenient for both the researcher and the elder respondents. Participants were then given a comprehensive release of information contract. This document was crafted in clear, simple and direct language. Participants were then given a list of open-ended, general research questions followed by more specific and focused questions pertaining to research initiatives already undertaken by SERC.

Older adults were then given a "script" to introduce the study, which outlined both the content and process of the focus group session. The "script" helped to develop a protocol to be used universally when approaching prospective respondents. The focus groups were held over a period of four months from the fall of 2001 to spring 2002. During this time, data was collected via tape recordings as well as through the researcher's journal.

2.5 Data Collection Measures

Several measures were employed in order to generate credibility and authenticity. Methodological triangulation was provided through a post hoc evaluation form designed to elicit data about responses to the focus group process. This information was an integral part of the analysis. A second measure of observer triangulation was provided through the presence of a social service worker-gerontology student as an observer. Finally, a third measure was employed for authenticity.

Member checking was used whereby participants were mailed a transcription of the tapes along with conclusions. A “photograph essay” consisting of photos and selected quotes from the session was presented to various groups in the field. Feedback from both the mailed transcripts and the presentation of the photograph essay was incorporated into the results.

2.6 Data Analysis Process

Data based on direct responses to the research questions (derived directly from the taped transcripts) was tabulated and interpreted. Data was extrapolated from the transcripts, the researcher’s journal, and participant evaluations. It was then summarized and coded by organizing the information into templates with open coding used to identify themes. Finally, the researcher looked for any patterns or connections between these categories that presented a recognizable theme.

3. Results

3.1 Data Analysis Findings

The issues that respondents identified differed according to the context in which they live their lives. Respondents who live in institutions were primarily interested in improving the attitudes and behaviors of their professional caregivers and increasing opportunities for social interaction. Caregivers of cognitively impaired elders were interested in increasing environmental safety as well as public understanding and tolerance of elders with diseases such as dementia.

Elders who emigrated from other countries focused on ways to increase independence and decrease social isolation. Other elders were concerned with technology, communication and access to social events.

Universal concerns related to adapting to the aging process included physical changes, sensory disabilities, ageist attitudes, transportation and the issue of advancing technology. Many elders considered the “normal” biological aging process to be detrimental to their ability to effectively manage their environments.

One of the strongest themes to emerge was the need for changes in environmental design in order to increase the elder’s sense of control and personal empowerment. In the future, public buildings are going to require considerable physical adaptations in order to be accessible to elders. This includes a shift away from the use of subdued

lighting in foyers and elevators that can be a safety hazard for seniors. Many complained of vision difficulties that make street signs, labels on products and printed material close to impossible to read.

Another theme became apparent as many seniors requested more affordable services in order to be able to remain in their own homes. Unfortunately, support services required to stay at home are increasingly expensive. Another recurring theme was the desire to reduce barriers between generations. Most elders wished to foster understanding, acceptance and tolerance in an intra-familial context as well as within broader society.

Among those elders who have immigrated to Canada, there was a general theme of perceived lack of respect. They expressed concerns about being marginalized as well as being isolated in their own homes. Isolation and loneliness appeared to be the primary concerns of elders who lived on their own. Social isolation was often cited as a deterrent to quality of life.

New learning also became a prominent topic with some older adults who perceived a loss of personal contact with the advancing use of technology. However, more affluent seniors were ready to accept technology with the most important factor being availability of instruction necessary to attempt new learning. Finally, a positive approach and a sense of humor seemed to be the most valued commodities to cope with the effects of aging.

3.2 Limitations

Data tabulation and analysis in any qualitative study is filtered to an extent by the researcher's subjective interpretation. Primarily, there is potential for reactivity given the presence of a younger (and thus more societally powerful) researcher who could possibly inhibit the flow of free thoughts. Also, a dominant or opinionated member of a focus group could have biased responses.

Given that the focus group sessions were held in institutional settings, elders may be even further disempowered because of their dependency on staff. An issue of social desirability was also present as it became evident that participants were eager to please the researcher, which may have skewed their responses. Next, there was potential for respondent bias as participants volunteered only the information that protected their privacy or ensured harmonious relationships with the agencies on which they were dependent. Also, confidentiality and anonymity were compromised when a staff member would unexpectedly enter the room.

Furthermore, the audiotapes of the focus group sessions were available to all participants in that group as well as the representative agency, which may have had an effect on the elder's responses. Finally, there is the possibility of unconscious ageist, stereotypical attitudes or myths on the part of the researcher, which again could compromise results. When attempting to build interpretive categories, the researcher

might force excerpts into categories or themes that he/she has in mind, rather than allowing the themes to develop naturally based on participant experience.

4. Implications for Research and Policy

- It is, in fact, possible and important to include the voices of persons with cognitive impairments in qualitative research.
- A qualitative design enables older persons themselves to determine what areas of research are to be examined, therefore making the research relevant and appropriate.
- There is an ever present and growing need for changes to environmental design to assist elders with physical challenges. Some suggestions include:
 - Brighter lighting in elevators and foyers;
 - Larger buttons in elevators, larger print and bold font for labels and signs.
- The most frequently cited deterrent to quality of life for elders is social isolation. Future research should focus on different ways to engage older adults in various activities.
- Affordable resources and community programs are in high demand and require greater funding in order to increase quality of life for the vast number of seniors in Canada.
- There is a need for greater access to instruction to assist older adults with new learning (such as instruction about how to use the Internet and other advanced technology).

5. Conclusions

Previous gerontological research has often prohibited elders from being involved in the production of knowledge. This study hypothesized not only that elders have valuable insights into improving their own quality of life, but that focus groups provide elders with a forum to exercise self-determination (a fundamental value of social work practice).

The qualitative research method employed in this study yielded ample thematic issues from the elders themselves. The results outlined suggest that it is not only the concrete data that is of value, but that the process of involving older persons empowers them and validates their self worth. While this study advances gerontological research, it is necessary for similar qualitative research to be conducted. The experience of aging must be heard and honored with thoughtful exploration by facilitating open discussion between social workers and elders. This study will offer new conceptual and practice perspectives for the field of gerontology and associated practice.

A full report on this research study can be found in the *Journal of Gerontological Social Work*, Volume 42, Number 1, 2003. ISSN: 0163-4372