



GREY MATTERS

A GUIDE TO COLLABORATIVE RESEARCH WITH SENIORS

Nancy Marlett and Claudia Emes

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ISBN 978-1-55238-536-4

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Dorothy Dooley

Now that we have trained researchers, other groups want our seniors to do interviews for them, but they assume they will volunteer. We think the seniors should be paid like any other researcher once they are trained.

2

Resilience and Seniors: What We Did and What We Learned about Doing Research

This is the story of a large seniors' organization that decided it was time seniors had more say in research that could affect their lives. It is the story of 250 seniors who decided resilience was an important research topic because it spoke to their strengths, and it is about seventy seniors who took up the challenge to learn about research and conduct research about resilience. These were ordinary seniors, from 56 to 90 years old and from all walks of life, occupations, and education. They were salespeople, teachers, ranchers, politicians, managers, and homemakers. Over three years they paved the way for others to take up the challenge of using research as a tool for personal and social change.

When the Kerby Centre of Excellence was created, few understood the power waiting to be unleashed. While Kerby had

encouraged researchers from the University of Calgary to conduct research at the Kerby Centre, few if any projects were done with seniors as full partners, nor did the research come back to Kerby in ways that could be used to improve the services Kerby provided for seniors. The biggest challenge was how to have seniors recognized by researchers as researchers. This chapter is an overview of the first few years in this journey.

While telling the story of the early stages of a shift from “seniors as subjects” to “seniors as researchers,” we also introduce the rest of the manual. The process is shown in Table 1, starting with the introductory workshops that set the research agenda, through the four phases of collecting data on each of the four research methods, and finally to the evaluation and write-up phase.

Table 1. Flowchart of six steps of a research project.

| PHASE | WHAT WAS DONE | OUTCOMES |
|-------------------------------|--|---|
| Introductory workshops | Two workshops using focus group method at the Kerby Centre of Excellence Two workshops in the Town of Cochrane | Resilience agenda approved Six resilience study groups started: health, leisure, learning, rural, ethno-cultural and spirituality Pilot proposal submitted and approved by CIHR |
| Field-work training | Training and practice sessions at the Kerby Centre Study groups became research groups Recruited partner sites for each of the six research teams Observed and recorded in partner site | Senior researchers seen as researchers within partner sites Seniors skilled at observing, recording, familiar with observer bias |
| Interviews and questionnaires | Review of field observations to prepare for interviews Training at the Kerby Centre of Excellence Follow-up sessions with research teams to prepare questionnaires for partner site | Developed, tested and evaluated questionnaires Senior researchers interviewed key people in partner sites Analyzed data from questionnaires and from taped interviews |

| | | |
|---------------------------------------|--|---|
| <p>Focus groups</p> | <p>Review of interviews to prepare for focus groups</p> <p>Training at the Kerby Centre of Excellence in focus groups</p> <p>Negotiated with partner sites to develop the focus groups</p> <p>Senior researchers conducted focus groups in each of the partner sites</p> | <p>Senior researchers competent in focus group roles</p> <p>Analyzed data and wrote report for partner site</p> |
| <p>Narratives</p> | <p>Training at KCE for senior researchers alongside interviewees</p> <p>Interviews conducted same day with graduate student mentors</p> <p>Follow-up interviews and analysis</p> | <p>Seniors competent at taping interview, compiling stories from tapes, and data analysis</p> <p>Analysis of stories by PhD students and senior researchers (university course)</p> |
| <p>Evaluation, reports and manual</p> | <p>Four group evaluation sessions by total research group – senior researchers, principal researchers and Kerby staff</p> <p>Ongoing group discussions with seniors.</p> | <p>Developed evaluation methods as a group</p> <p>Final report written by principal researchers and project staff then shared with team leaders</p> <p>Manual drafted by principal researchers for future field testing</p> <p><i>Grey Matters</i> written with seniors</p> |

A. Setting the Agenda

The KCE invited seniors from the Kerby Centre membership, a group of experienced researchers from local post-secondary institutions, representatives from the City of Calgary, and representatives from the Calgary Health Region to share their experience and help create a research plan for the Centre of Excellence. After much discussion, the seniors at the table suggested resilience as an important aspect of healthy aging.

A subcommittee of seniors and researchers then applied to the Canadian Institutes of Health Research (CIHR) for funding to run a workshop on resilience to test the interest in resilience as a research topic among seniors and to further develop specific research questions and methods about resilience and aging. A group of retired professors from the University of Calgary and Kerby seniors helped design and facilitate the day. They brought a love of research and their excitement about involving others in research.

I couldn't believe how much time we spent arguing about that first workshop – the right questions, how to get everyone involved, what to do with the information and how to reach our goal. After three planning sessions, I began to realize that this was really different from the kind of research I was familiar with where researchers are in charge. I hope all the planning and technology pays off. (BM, 2004)

We began the workshop by discussing people's experience of resilience because we wanted to start afresh and not be confined by definitions created by others.

I kept wondering why they wouldn't just tell us what resilience was, it was just a little vague guessing what everyone else thought. Eventually it became clear what we were doing. It was an interesting collection of people and I'm always

pleased when people can come to their own understanding.
(NM, 2005)

We had tablet computers that allowed recorders to write notes in longhand at the tables and transmit the notes to a central computer so that we could analyze what was happening. In the morning, workshop participants worked in small groups sharing their stories of resilience and thinking about what they had learned about resilience from their stories. Ongoing summaries were projected on a very large screen so that everyone could see their ideas take form. All felt part of the process and were intrigued to see their individual and small-group ideas on the large screens. Sharing ideas through technology meant that we didn't have to listen to each group present its findings. The feedback was immediate and easily led to consensus, as can be seen by the following quotes:

The recorders were extremely unobtrusive. Everyone was encouraged to speak and they were listened to. The recorders would check with us by asking if what they read from their recorded notes was what we said. (GQ, 2005)

It was stimulating! If someone was saying things that were similar to me it confirmed my thoughts. However if it was different, that's when I learn. Sometimes you shuddered when you heard what some people had been through. (NM, 2005)

In the afternoon, the focus shifted and groups were encouraged to think about the questions that were raised in their discussions. Each group came up with three to five questions that they wanted answers to. Again, with the rapid recording through the tablet computers and the ability to analyze group data, we were able to see themes or directions emerging.

Table 2. Questions and research themes from Kerby Focus Group, 2005.

| RESEARCH THEMES | HOW DO THESE ADD TO RESILIENCE? |
|-------------------------------|--|
| Ethno-cultural uniqueness | Is resilience affected by cultural values and traditions? |
| Spirituality | How do faith and belief impact on people's sense of resilience? |
| Health of individuals | How does health influence resilience? |
| Learning | Does access to opportunities to learn and grow impact on resilience? |
| Rural living | Do people in rural areas have a different way of understanding resilience? |
| Physical activity and leisure | How does activity and leisure support resilience? |

Although it was not part of the agenda, there seemed to be a great deal of enthusiasm in the group and people asked to form groups defined by the above areas. The retired professors, along with several others from the workshop, joined the groups to help refine research questions for a future pilot project.

B. The Pilot Project Proposal

An application to the Canadian Institutes of Health Research – Institute of Aging (CIHR–IA) for the pilot project, Sites and Sources of Resilience, a study of how to engage seniors in doing research about seniors, came from the above groups (Appendix 3). We were also able

to clarify the research questions in two workshops that were conducted in Calgary and Cochrane, a small community west of Calgary. It was apparent that seniors wanted to be an integral part of the research so we made a concerted effort to use Participatory Action Research (PAR) principles to ensure full participation. We also capitalized on their interest in learning and working in groups: we transformed the study groups into research teams.

The research was developmental in that we began with basic research skills and each step in the project built on the accomplishments of the last:

- The results of observation phase were used to design the interview questionnaire phase.
- The results of the interview questionnaire phase led to the focus group phase.
- The focus group phase set the stage for narrative research.

C. Organization of the Project

The project itself was complicated by the desire of the seniors to learn about research and to learn by doing research in the area that interested them. Each research group had a partner site related to their question. These sites worked with the seniors researchers in learning how to conduct research. This added a layer to the organization.

Figure 3 shows the research organization.

D. Naming the Participants

We had some trouble deciding on the titles for the partners and finding a balance between everyday language and academic language to depict the various roles in Figure 3. Although we spent a great deal

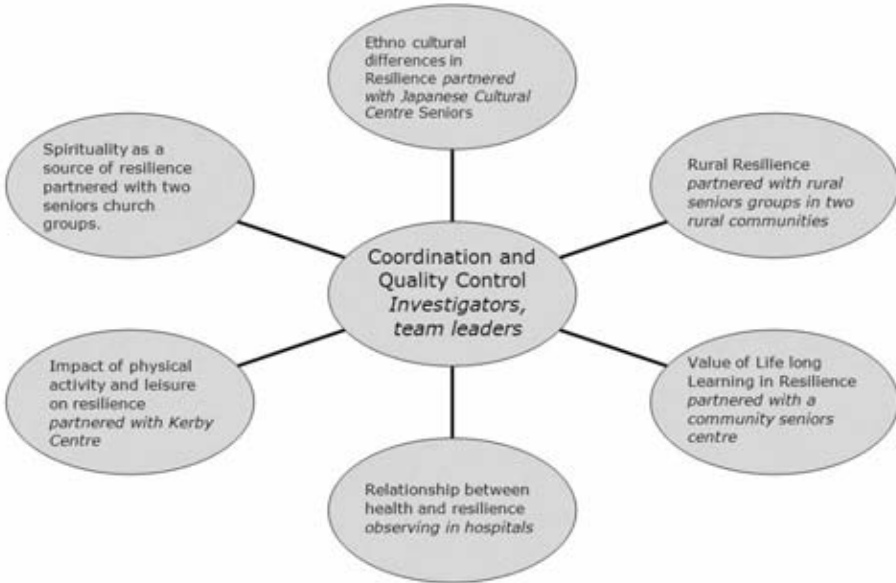


Figure 3: Organizational chart for pilot project.

of time debating terms before submitting the grant, the debates continued. The following titles were finally negotiated to describe those who were involved:

Senior researchers. These are the aging adults who participated in the research project. Senior researchers had three linked roles: to learn about research, to be studied as they conducted research, and to conduct research. There was confusion about these roles, especially since most had signed up following the introductory workshops on resilience to study the topic they had chosen.

Group leaders. Retired professors from the university, community researchers, or elected seniors. Each leader acted as a mentor, providing instruction, guidance, and supervision as needed to a group of three to seven senior researchers.

Research group. The three to seven senior researchers worked relatively independently, with the guidance of their group leader. Some groups met regularly outside of the required sessions and each developed its own style and roles. Most groups nominated a coordinator who worked with the project staff person to collect data and evaluations, organize notices, and schedule meetings with the partner sites.

Partner sites. These were the agencies, programs, or groups of seniors who were recruited as a research site for each group/topic. For example, seniors' programs in churches acted as research sites for the spirituality research group. The Japanese Cultural Centre was the primary research site for the ethno-cultural research group. The Seniors Centre in Okotoks was a site of the rural research group.

Investigators. University researchers named in the grant proposal worked closely with the director of the KCE and the project staff. Investigators handled the grant requirements as well as liaison with the university and the Kerby Centre. Along with the project staff and group leaders they oversaw both the planning and evaluation of the project.

Advisory committee. This consisted of representatives from the City of Calgary, the Calgary Health Region, post-secondary institutions, the Kerby Centre Board and the team leaders. They were responsible for keeping their constituents informed, advising on direction and results and arranging small funds when necessary.

Total team. Senior researchers, group leaders, principal investigators, and sponsors were involved in all policy changes, training events and evaluation sessions.

The following four sections tell the story of each of the research methods studied: field-work, interviews, four groups, and narratives.

E. Field-work Observations and PAR

Always having been an inquisitive sort, I found the observation process interesting. I was struck by the seriousness of people and how briskly they moved around. (RM, 2005)

We chose field-work as the first research approach because we wanted to introduce research as part of everyday life. Here the “field” was a partner research site that represented the topic area. We adopted participant observation as the method because it provided a natural and practical introduction to research roles. In this method, seniors joined in with the activities of the site they had chosen.

As a researcher I was keen to observe everything about people’s behaviour, the way they talk, laugh, walk and listen. I respect myself and have the self-confidence to do the observation, especially observing the body language. (AR, 2006)

The goals of the field-work/participant observer sessions were:

- Visit and learn about the chosen partner site.
- Explain and practice a research role.
- Learn observer roles while participating fully, partially or observing passively.
- Record observations of behaviour noting time, space, people present, activities and conversations.
- Compare recordings with other senior researchers and discuss sources of differences in their observations.
- Discuss how to minimize bias in recording.
- Evaluate the field-work as a research method to be used by seniors.

The field-work workshop was conducted by Joan Ryan, a retired professor and anthropologist, who had trained communities in northern Canada to use research as a tool for social change and self-determination. She told stories about what communities were able to achieve. She taught that the foundation of good research is observation and recording. We were also visited by two disabled Aboriginal researchers who shared their research within their communities. They spoke about being marginalized within their communities and how this changed as they learned how to conduct research.

The research groups practised observing activities within the Kerby Centre. They then shared their findings and discussed how each person saw and recorded from his or her own perspective. They discussed how these perspectives were influenced by their values and experience. They also discussed how to hold their opinions in check while observing and recording.

The senior researchers decided that they needed an observation booklet and one was prepared after the session for the researchers to use in the field. This is included in Appendix 4. The following quote is from the summary of an observation of three hours:

As an observer, I just got a general feeling of comfort, people smiled at each other, they stopped to chat when they were getting materials, there didn't seem to be anyone who was more important than anyone else. There was one woman however who talked a lot and said a lot of negative things. (SR, 2006)

The senior researchers were now ready to observe at the partner sites. The process of obtaining agreements with partner sites reaffirmed how difficult it is to conduct partnership research in community settings. The opportunity to be involved in research, even when presented by seniors, was met with caution and concern about the agenda, how the information was going to be used, confidentiality, and the partner site's responsibility in the project. Once all of the negotiations and

release forms were signed, the seniors spent two to five hours “in the field,” observing and participating at their partner site.

As first-time researchers, they were tentative and nervous. They felt they didn’t have clear enough roles, and they felt awkward watching people or talking with people, but this changed for most observers.

I wasn’t sure precisely what I was doing and what I should be looking for but I was surprised that I didn’t find watching people or taking notes any way embarrassing. (RM, 2006)

The observation booklets worked well and the group leaders generally commented on the accuracy and thoroughness of the observations. Senior researchers recorded activities, interactions, hierarchies within the groups, and their perception of the mood of the group.

In Chapter 3, field-work methods are expanded to include oral histories and collections.

F. Surveys and Questionnaires

Personally, I would have liked to have prepared questions and was a little concerned about where the open approach might lead us. I ended up being happy with the simple guide we had prepared of a few questions that I could refer to. I was able to feel that we were getting the info we wanted with our planned strategy. I felt good learning how to be a researcher using a method that was new to me. (SR, 2006)

At this stage the senior researchers used the information from their first visit to design a set of questions for the coordinator or president of the partner site and any others who were interested in being interviewed. The principles and goals of this session were to:

- Learn more about their partner site;
- Establish a working relationship with the leader of the program at the sites;
- Introduce the senior researchers to more structured research;
- Develop a questionnaire based on the observations of the group to gain information about the history and functioning of the partner sites;
- Interview and record answers to questions;
- Analyze the data gathered from the questionnaire; and
- Report back to partner site and research team.

Some of the groups developed open-ended questionnaires that ended up as conversations, whereas others developed very structured questions with prepared options for answers. We learned a lot about the advantages and disadvantages of the different strategies in the discussions that followed. The open-ended questions were easy to administer and difficult to analyze, whereas the closed questions produced somewhat boring and expected answers but were easy to analyze.

The session was conducted by Dr. Bob Stebbins, one of the research group leaders and a retired professor from the University of Calgary. He was able to provide an overview of more formal research expectations and focused on how to design questionnaires that would answer the questions people had. Chapter 4 looks at interviews and questionnaires in detail. It took relatively little time to teach the skills and the end results were easily analyzed in preparation for the next large step forward.

G. Focus Groups

It is critical for the researcher to remain focused on the topic of the research. I had to learn to avoid injecting personal opinions or stories about resilience. Be ready to ask related questions if the participant's input lacks detail. Be alert to discomfort on the part of participants. Be a good listener. Be friendly but neutral during the break. Socializing, while important, should be done after the session is ended. I need more experience researching to be able to really do this well. (AH, 2006)

By this stage the senior researchers were anxious to move into researching the topic of resilience and move beyond getting to know their partner sites. The groups had become much more cohesive and wanted to work as a team. For the first time they were able to choose specific research roles as part of their teams. The focus group research had the following goals:

- Introduce the topic of resilience in the partner sites.
- Recruit focus group participants.
- Learn how to negotiate research agendas with the partner site participants.
- Take on specific roles within the overall research strategy.
- Practice and support each other in conducting the focus group.
- Design an evaluation and administer it.
- Analyze data from focus group research.
- Prepare reports for the partner site.

The introductory session on focus groups was conducted by one of the principal investigators, Nancy Marlett, who combined the lessons that had been learned to this point in the study. These lessons were: provide structure, use storytelling, build on group strengths, and enable groups to adapt methods to suit the needs of their topic and their partner site. The training workbook is included in Appendix 5.

During the training session, each group was encouraged to work through a structured workbook making suggestions to customize a research protocol that they could then take to the partner sites to negotiate and run their focus group. The following is a reaction to the experience:

As all participants had been mailed an invitation in advance outlining the purpose of the focus group, the topic of the day and the questions we would be exploring together, everyone felt comfortable and at ease in the setting. They expected to have their responses recorded and seemed unconcerned. As a result my recording felt comfortable, it was done as unobtrusively as possible. (AH, 2006)

Roles were well-defined, for example, who would make the room arrangements, who would greet the participants, who would do the recruiting, who would operate the flip chart, and who would provide comic relief. The details are included in Chapter 5: Focus groups and the workbooks and examples of reports are included in Appendices 7 and 8.

At this stage, the work of the senior researchers expanded as they took on more administrative duties. They recruited participants, negotiated the agenda, set up the focus groups, lead the group discussion, and recorded and analyzed the data. They also prepared reports to give to the participants. Each group worked in different ways, depending upon the team leader, the strengths within the group, and the nature of the focus group partners.

Without exception, this experience was the highlight of the research for the seniors. They felt that they had taken control of the research process, that they had learned a great deal about conducting research and that they were stronger not only as researchers but as people. As the groups met to analyze their data and write their reports, they began to understand the important contributions that they could make as researchers.

By this time, senior researchers and partner sites were familiar with each other; they had a base of trust that made recruiting participants relatively easy. The researchers felt competent and empowered and this made the seniors in the focus groups feel secure and open.

Everyone commented on the professional skill level of the senior researchers, their ability to structure and pace the day, their ability to engage participants, to honour the differences in the group, and to provide feedback about the direction of the research. The researchers themselves noted their surprise at how effective they were and how their earlier training was beginning to pay off. Most of all they enjoyed working with other seniors and conducting research.

H. Narrative Research

The process of taping the interview gave me a “hands free” conversation. I tried my best to only listen, but found myself wanting to get in there with my own opinions. It was good not to have to take notes as well as interview. I would have missed a lot of the detail which was so interesting to hear, and later to analyze. (MW, 2006)

Buoyed by their success in the focus groups, the senior researchers looked forward to the challenge of conducting follow-up interviews with their chosen participants from the focus groups. Nancy Marlett, who had worked with many other marginalized groups

using narrative methods, relished the challenge of building on what had been effective in the focus group to develop a peer-based narrative interview process. Because the seniors were familiar with storytelling approaches, the senior researchers were able to move beyond basic narrative methods to create an in-depth interview process that introduced several new aspects to the research experience:

- Recruit a partner and prepare them for the interview experience;
- Interview using a peer-to-peer approach following a research script;
- Deepen their understanding of resilience with a knowledgeable participant;
- Learn specific skills related to in-depth interviewing, such as pacing, probing, synthesizing, and motivating;
- Manage tape recording and transcribing; and
- Analyze taped data and compile stories of resilience.

The senior researchers and the people they were interviewing were trained together to reinforce equality in peer-to-peer research. All participants were given manuals to work with during the training day. Once the protocol was explained, the peer pairs, along with a graduate student or other resource person, conducted the interviews.

The experiences of the narrative interview were not as positive as the focus group, partly because it was rushed and despite our attempts to provide materials beforehand, some participants did not get the materials in enough time to prepare. This emphasized the need for preparation beforehand.

This was an advanced research technique and was unfamiliar to most. Many of the seniors felt unprepared to conduct these powerful interviews. Some felt nervous or frustrated with the equipment, others wanted more privacy in the interview process, and others found it difficult to engage seniors on a one-to-one basis. Nevertheless, the interviews produced very telling and provocative stories, which led to interesting information about resilience that would not have been achieved in any other way. Most senior researchers were quite amazed by their ability to extract stories and data from the interviews and the tapes.

I have enjoyed this experience but have a lot to learn about “picking up” on important points in the interview and getting the interviewee to elaborate. Also, I am not very good at expressing myself in writing, about putting down what I had experienced with the interviewee. (MW, 2006)

While some were shy about compiling stories and relied on other team members to assist in preparing their analysis, the stories were of very high quality. The method used was felt to hold promise within a larger research project where more time and support would be available. One senior researcher reported being a little tentative at first as this is a topic that asks people to dig into past experiences and often their innermost feelings, but said later:

Even though we hardly knew each other, we discovered we had experienced similar things in our lives. In other words there was already a kinship. Questions were handled easily and any problems were easy to clarify. (RM, 2006)

The research protocol has the potential of being adapted to research that requires in-depth narrative interviews about complex topics. In a follow-up session with seniors who wanted to learn more about

narrative interviewing, it was clear that seniors were able to conduct interviews using the forms at an advanced level. Narrative interviews were then analyzed as part of a seminar course with seniors and PhD students on the topic of Resilience and Aging. The results are included in Chapter 6. The narrative interview guide and training material is included in Appendix 9.

I. Evaluation and Follow-Up

The project itself was only a year long but the evaluation and follow-up discussions were still active two years later. The standardized evaluations designed as part of the project to assess the methods and the senior researchers' reactions to the methods did not begin to tap the profound changes that had occurred. There were a number of all-day sessions where we reflected on what we had done and how to move ahead. The goals of the evaluation were:

- Identify challenges to teaching research with seniors;
- Adapt existing research methods;
- Identify which methods seniors like to use and which methods they excel at;
- Collect evaluations of the process by partner sites;
- Identify changes in seniors self-concept as a result of the training; and
- Decide on directions for future research.

These sessions led to a number of presentations and articles about the findings. Most who heard about the project were surprised – surprised that seniors were interested in research, that we had taught

formal research methods and that a different view of resilience was emerging. The following are some suggestions about evaluation in this type of research:

Don't wait to evaluate. We had evaluation forms for senior researchers to fill out at the end of each method. These were not very effective because they seemed to be extraneous and not connected to the actual project. Very early in the process, we began to see the advantage of informal discussions about challenges and opportunities. Full team meetings that planned the next step were much more effective in evaluating the process. In these discussions, seniors had immediate feedback and saw their suggestions implemented.

Have some distance in evaluation. To save funds, the investigators and staff conducted the evaluation but it became apparent that, while the evaluator needed to be part of the project, he or she needed to focus on the evaluation, to record what was happening and to tailor the evaluation to the needs of the project. A participant observer/evaluator would be more effective, especially if that person was a senior.

Separate sharing from evaluation. Research involving seniors needs to provide time to share ideas and feelings. When sharing and evaluation are combined, there was a tendency to see things as black and white. After the project was over and the formal evaluations were complete, we were able to achieve a much deeper understanding of the process because our discussions were not about good and bad, they were about changes in knowledge and self-concept.

This chapter has provided a general overview of the CIHR research that investigated the potential for seniors to be involved in research. Much of the manual has evolved as we applied what we learned to other projects. We recognize that without this opportunity to experiment, the dream of seniors-led research would still be at the concept stage.



Penny Jennett

What fascinated me was the whole idea of seniors researching seniors, and being part of a project that provided seniors with some tools to provide input into how their stories are told.