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Supporting older adults' engagement in health-care programs and policies: Findings from a rural cognitive health study

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ABSTRACT

Although rural seniors are important users of health-care services, their perspectives and input remain largely absent from health programs and policies. This article explores rural seniors' perspectives to support their engagement in patient-oriented research. Guided by lay theory and cultural schema theory, participant observation, concept maps, and semi-structured interviews were conducted with 42 rural seniors in Saskatchewan, Canada. Three themes were identified: community outreach through trust and partnership-building; using flexible data collection methods such as moving to open-ended interviews rather than closed-ended surveys; and developing community-relevant dissemination strategies such as local newspaper articles, posters, and community workshops. In moving forward, collaborative research with seniors is essential to improving health programs and policies for older adults in rural communities and beyond.

KEYWORDS

Rural aging; health care services; health policy; patient-oriented research; lay theory; cultural schema theory

Introduction

As the world's population ages, the demand for health-care services for older adults is expected to increase. Recently there has been a growing interest in patient-oriented research where patients are engaged as partners in research to share their unique perspectives and lived experiences to improve health-care quality and accountability (Canadian Institutes of Health Research, 2016). The term “patient” generally refers to an individual with personal experience of a health issue as well as informal caregivers. In Canada, older adults are major users of home care, physician services, hospitals, continuing care, as well as prescription drugs (Canadian Medical Association, 2016).

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However, not all older adults have the same relationship with the health-care system such as rural and urban seniors. In particular, older adults living in rural areas have different needs than their urban counterparts and the system itself is organized and delivers care differently in rural settings. When these rural differences are taken into account, patient-oriented research can offer new insights, identify health-care barriers and supports, and improve health services for older adults living in rural communities.

Although seniors are important users of health-care services, their voices and input are primarily absent from health policy and research (Holroyd-Leduc et al., 2016). Guidance on effective strategies for conducting research with older adults is limited, especially with older adults living in rural communities (Dibartolo & McCrone, 2003). As a unique group with specific challenges, rural seniors often experience critical health inequities related to geographic isolation, limited transportation, financial challenges, and inadequate access to health and support services (Bacsu et al., 2014a). Existing studies emphasize recommendations and lessons learned from the perspective of health practitioners and policy-makers, while input from rural older adults is largely nonexistent (Dibartolo & McCrone, 2003).

In a literature review of older adults' involvement in health research over 10 years, Fudge, Wolfe, and McKevitt (2007) found that of the 2,492 citations identified only 35 articles reported involving older adults at any stage of the research process, from determining the research topics to knowledge translation. Walker (2007) asserts that older adults' under-involvement in research creates challenges for gerontologists as there is a paucity research and models to draw upon to facilitate their engagement.

Drawing on an ethnographic, community-based study focused on rural seniors' perceptions of cognitive health, this article explores key themes and strategies for supporting patient-oriented research with rural older adults. Following an overview of the study's theory, methods, and analysis, three theme areas are discussed with the objective to support research involvement of rural older adults. By focusing on ways to improve rural seniors' involvement in health research and policy, this paper provides an important contribution to geriatric health literature and the growing field of patient-oriented research.

Study background

This research was part of a larger study on rural seniors' cognitive health. This study focused on examining three objectives: 1) rural seniors' perceptions of cognitive health; 2) interventions to support and maintain their cognitive health; and 3) key strategies for supporting research involvement of rural older adults. The data collection and analysis were the same for the entire study, with the interview questions focused on this research being part

of the larger, overall study. This paper focuses on the findings related to supporting rural seniors' involvement in health research and policy; information related to rural seniors' cognitive health perceptions and interventions are published elsewhere (Bacsu et al., 2017).

Theory

This study's methodology was informed by lay theory (Furnham, 1988) and cultural schema theory (Quinn, 2005). These theories recognize the importance of lived-experiences, personal perspectives, and unique contextual (e.g., rural and urban) understandings of health issues which are important elements of patient-oriented research (Canadian Institutes of Health Research, 2016). Lay theory is generally described as the informal descriptions that people use to explain phenomena (Furnham, 1988), while cultural schema theory sheds light on the in-depth, unspoken, cultural meanings of collective knowledge and behaviors (Strauss, 2005). Lay theory is informed by one's culture in terms of illness labeling, susceptibility explanations, and treatment options (Furnham, 1988). Subsequently, when combined these theories provide an invaluable foundation for understanding rural older adults' lived experiences, unique challenges, and health perspectives within a rural context.

Methods

Community-based research

Guided by a community-based research (CBR) approach (Wallerstein & Duran, 2010) and an ethnographic methodology (Quinn, 2005), participant observation and semi-structured interviews were conducted with 42 rural older adults. Community-based research (CBR) has been defined as a collaborative approach to research that recognizes each partner's strengths and aims to combine knowledge to improve health outcomes and disparities at the population level (Wallerstein & Duran, 2010). In this study, CBR was fostered by having a community advisory committee and the older adult participants engaged in all aspects of the research processes, from identifying the research questions to developing the knowledge translation strategies.

This study received ethical approval from the Behavioral Ethics Board at the University of Saskatchewan (Beh14-19). Informed written consent was obtained from the participants prior to any form of data collection (e.g., interviews and participant observation). No participants received any form of payment or compensation in this study.

Community advisory committee

A community advisory committee was assembled to provide critical input and local expertise throughout the study. The committee was comprised of three older adults who were local leaders within the communities such as a former mayor. Meetings were held with the community partners to identify and discuss cognitive health concerns in the rural communities. Since many rural older adults had lost loved ones and friends to dementia there was widespread support and a shared interest in pursuing the study. Over time, the distinction between the community advisory committee and the older adult participants became blended as they provided guidance, time, and insight throughout the study.

Data collection

Recruitment method

Community partners from the advisory committee helped to recruit potential participants while paying close attention to ensure representation of key variables, such as age and gender. Many of the rural older adults who were recruited in this study also participated in a previous longitudinal study with the researcher (Bacsu et al., 2014a, 2014b). This immersion with many of the participants over time helped to foster trust and build strong relationships within the community. Potential participants were recruited by word-of-mouth with the help of the community advisory committee members. A recruitment script was used by the community partners to provide an overview of the study. With the seniors' consent, their contact information was provided to the researcher. The researcher then followed-up with the seniors to provide additional study information, answer any questions, and to schedule an interview time.

Study participants & research location

The participants in this study included 42 rural seniors (e.g., 14 men and 28 women), ages 60 to 87 years. Five seniors were unable to continue throughout the study due to illness and travel. The seniors lived in the rural communities of Young and Watrous which are located in the agriculturally based province of Saskatchewan, Canada. Saskatchewan is a sparsely populated province with approximately 1,147,733 people; 389, 676 people live in towns, villages and rural municipalities of which 95,607 are older adults aged 60 years and older (Saskatchewan Ministry of Health, 2014). Saskatchewan's towns, villages and rural municipalities are aging, with approximately 25% of the population consisting of older adults aged 60 years and older.

Semi-structured interviews and concept maps

Two waves of semi-structured, face-to-face interviews were completed with the same group of independent, community-dwelling, adults aged 60 years and older. Conducting two waves of interviews with transcription and coding occurring between the interviews, enabled more in-depth examination and a form of member checking where the second wave of interviews built on the initial study findings. The interview guides for the two waves consisted of different questions. The full-length interview guides have been previously published for each of the interviews (Bacsu et al., 2017). Each interview lasted approximately 1 hour in length and was conducted in the seniors' homes.

The first wave of interviews was conducted from February to May 2014, with 42 seniors (e.g., 14 men and 28 women). The second wave of interviews was completed in July to September 2014, with 37 seniors (e.g., 12 men and 25 women). During the second wave of interviews, the participants were given a concept map (Figure 1) which summarized the first wave of interview findings into a visually accessible framework (Trochim, 1989; Wheeldon & Mason, 2009). The concept map was instrumental in supporting more in-depth and comprehensive discussion in the second wave of interviews. Rural older adults appreciated that they were able to pose questions, provide feedback, and share reflections. The concept maps promoted seniors' engagement in the research as it enabled them to identify relationships, pose questions, and share direct insights by drawing on the map. Appendix A provides a visual representation of two concept maps with participants' feedback (see Figure 1).

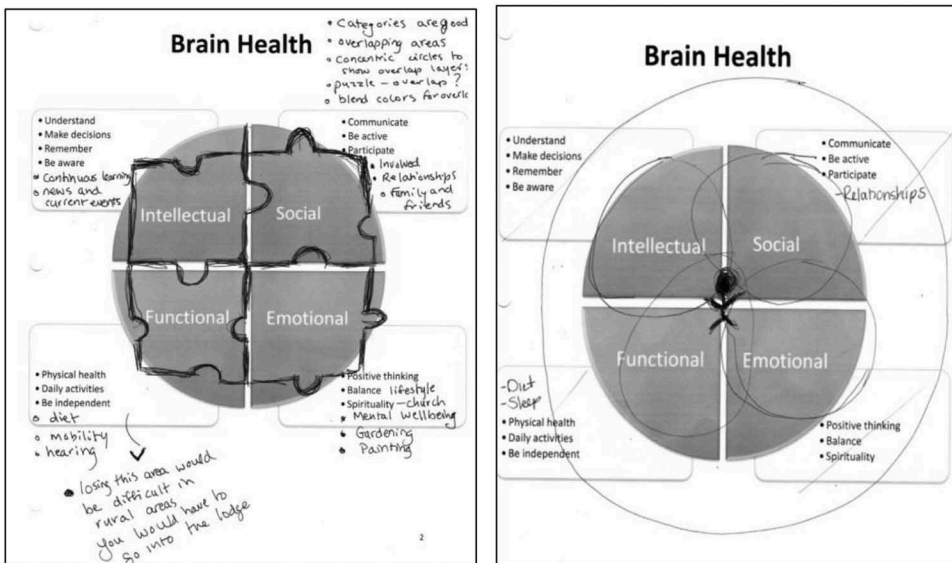


Figure 1. Concept maps.

In both waves of the interviews, each of the participants were continually asked for feedback and to share their views on the research topic, questions, question-wording, engagement, research methods, and knowledge translation strategies. For example, the interview guides both included questions where the rural seniors were asked to evaluate the study by addressing different questions (see [Appendix B](#)). In addition, participants were asked about their satisfaction with the research processes used in the study. This was a crucial element of the study as it helped to ensure that participants remained engaged with the research by reflecting their interests and concerns that motivated their participation in the first instance (Wallerstein & Duran, 2010).

Participant observation

Participant observation was conducted by spending time and visiting over 7 months with five rural seniors to observe day-to-day routines, activities, facial expressions, and body language. Participant observations were also made by attending local events and during the two waves of interviews. A comprehensive description of the study's participant observation methods, analysis, and findings has been recently published and provides in-depth information related to rural seniors' cognitive health interventions (Bacsu et al., 2017).

Data analysis

The two-waves of interviews were audio-recorded and transcribed verbatim. Participants were provided with the option to review their transcripts to confirm accuracy of the information. Guided by Braun and Clarke's (2006) six-step method of thematic analysis, the interview transcripts and field notes were analyzed for key themes and relationships within the data. The coding was completed by the lead researcher with input from the research team to discuss the code list, data interpretations, and themes. A journal was kept to provide an audit trail to document and outline how the data were coded and organized into themes. The data were coded according to the code list using the software Atlas.ti 7 (2013). To help make sure that nonverbal data from the participant observation was not lost, a code created to document nonverbal data such as facial expressions, activities, laughter, body language, and long pauses (Bacsu et al., 2017). Lay theory and cultural schema theory were used to analyze the data for cultural metaphors, idioms and any nonverbal communication that was included in the field notes and coded. Measures of rigor were incorporated throughout the research to ensure credibility and trustworthiness of the study's findings, and an in depth-discussion on the study's data analysis and measures of rigor have been previously published

(Bacsu et al., 2017). Community workshops were facilitated to share findings and to enhance the accuracy of the researcher's interpretation of the data through member checking and local input.

Results

Based on the rural cognitive health study, three key themes for supporting patient-oriented research with rural older adults were identified: 1) community outreach through trust and partnership building; 2) using flexible data collection methods; and 3) developing community relevant dissemination strategies for knowledge translation (KT).

1) Engaging in community outreach: Trust and partnership building

Throughout this study, rural seniors commented that they appreciated the researcher's time and interest spent in the community by getting to know them. A rural senior stated, "First I saw you at cards and now at bowling, and I think it is good that you actually have an interest in getting to know our interests and what we partake in." During the study, several invites were received to attend events (e.g., musical entertainment, birthdays, coffee groups, exercise groups, coffee groups, bowling, and dances), conduct participant observation, and spend time with rural older adults to see what day-to-day activities may be contributing to their cognitive health. A rural older adult stated, "We need to let people know that this research is coming from the community..To let them know that yes we have talked to you and that this information on brain health is important to us." Lay theory and cultural schema theory supported the identification of cultural metaphors and idioms used by the rural seniors in describing the importance of relationships and trust with the researcher. A participant asserted, "We don't want to air our dirty laundry, and especially to someone we have never met." This statement refers to the respondent not wanting to share private information about themselves to researchers they don't know. Another participant asserted, "When they [researchers] phone out.. I want to hang up on them."

Rural seniors also described that spending time in the communities was critical to understanding their rural context A participant stated, "I find that even with people I have met, you might become good friends, but once you go and see where they are at and can visualize them in their own homes, it gives a different perspective." A senior woman stated, "Sometimes it's challenging because there are these people that think, 'Okay, you just phone out to the communities..' But it is a different experience when you are actually in our community."

2) Using flexible data collection methods

Study modifications were made based on participant feedback including moving from closed-ended surveys to open-ended interview guides, adding concept maps as an alternative form of data collection, and spending time in the communities and with the participants through participant observation. Flexible data collection methods that were adaptable to the participants' feedback, needs, and preferences were integral to the study's success. For example, one of the study's adaptations included moving to open-ended interviews rather than closed-ended survey questions. Rural older adults also described that they preferred in-person interviews rather than closed-ended surveys or telephone questionnaires. A rural senior commented, "In surveys it's more, get on, get finished.. Okay that's answered, next one, next and in face to face interviews you are more capable of bringing in something else." A rural woman noted, "I much prefer the face to face.. it's just my preference, I do quite a few telephones surveys but I do prefer face to face interviews." In discussing questionnaires, a rural senior stated, "Talking one-on-one it's easier than filling out a questionnaire." Rural older adults identified issues of question framing in questionnaires and surveys with limited response options. A rural senior stated, "I don't care for questionnaires or surveys because it's too one sided, I did a survey the other day, they structured it in a way where my answers were not there... they don't really want my views." Another senior noted, "I like the conversation style, you can pick up so much just by listening to the stories."

The participants identified the concept map as a useful tool to solicit personal insight. For example, the participants described that they liked the clarity of the concept maps and that they could provide direct feedback by drawing on the map ([Appendix A](#)). A rural older adult stated "This [concept map] makes it a lot more clear, I like that I can see this.. I remember thinking after the first interview that I should have answered some questions differently." A participant commented, "I don't think there's anything missing here at all, it looks pretty well done." Another rural senior asserted, "I think this really makes sense.. I mean the categories in this picture makes sense to me."

The rural seniors identified participant observation as a valuable method for gathering non-verbal data such as body language, personal experiences and local surroundings. For example, a rural senior stated, "When you ask me a question, I give you an answer and you can pick up whether or not I'm still mulling over something in my head and then get it out.. There's body language." Another person responded, "Because you are one-on-one, you even see the facial expressions, people feel more at ease too." Seniors also recognized the importance of participant observation for understanding unique factors related to personal experiences and the local community context (e.g., road conditions, weather, geographic distance, daily activities, and services). A participant commented,

“That’s one way of you getting to know us better is in our surroundings.. It kind of gives you an idea about our experiences.”

3) Developing community relevant dissemination and knowledge translation strategies

Participants provided input and local expertise on effective ways to share study findings with diverse audiences including older adults, community leaders, and policy-makers. For example, rural seniors described that a community workshop or a seminar would allow them to provide insight and give feedback on the study findings. A rural senior stated, “Once you’re finished with your research, it would be great to share your findings in a workshop, I think it would work if well you had a group of people together because sometimes somebody will bring up a topic and then somebody else will feed off that.” A rural senior stated, “You should come to the seniors’ centre and talk about brain health, and to all the different seniors groups in the province, you should go on tour..” Another rural older adult suggested, “Seminars would be beneficial as far as I’m concerned.” Building on the seniors’ comments, this study used community workshops to attain local insight, stimulate reflection, and discuss whether the findings accurately reflected the seniors’ perspectives.

Rural seniors identified the newspaper as a useful method to broadly share findings. For example, a rural senior man suggested, “You could put an article in the local newspaper, it doesn’t have to be all the findings, maybe just the highlights and put a website where people can get more information and print it off if they wish.” A rural senior noted, “I guess the newspaper, most of us get the newspaper and read it.”

Rural seniors also discussed targeting different audiences by putting up posters to share events and information with various members of the public. A rural older adult commented, “There’s billboards around town and then if it’s an eye-catching poster that could catch their attention but definitely the newspaper.” Subsequently, posters were used to advertise the community workshops in several locations such as the hair salons, banks, medical clinics, seniors’ centers, recreational facilities, rural municipality offices, town offices, libraries, restaurants, bakery, bulletin boards, grocery stores, and pharmacies. Additional forms of knowledge translation included usage of the local television stations, bi-annual newsletters, magnets in place of business cards, electronic billboards, towns’ events calendars, and local blogs.

Challenges

A key challenge of the study was balancing the high expectations from the community with feasible study deliverables (e.g., this study cannot fund the

recruitment of family physicians). In order to sustain local partnerships and avoid unrealistic expectations from the older adults, it was important to be honest, open, and straightforward about the study deliverables. For example at the onset of the research, a memorandum of agreement (MOA) was collaboratively developed to outline the objectives, responsibilities, and study deliverables. Although the study's deliverables were discussed in advance and outlined by the MOA, throughout the study it was necessary to continually reiterate the study outcomes in order to balance the communities' expectations.

During the study, it became evident that highlighting study outcomes, actions, and next steps were essential to sustaining momentum, participation, and support for the research. For example, a frequent question received throughout the study was, "What have you been doing with the study findings?" Over time, several strategies were developed to proactively address this question. Successful strategies included knowledge translation (KT) activities which involved communicating regularly on study updates through multiple methods including the community workshops, local newspaper, community reports, and biannual newsletters. A lesson learned was that it was essential to keep the KT material brief, clear, and to-the-point as many of the community leaders, policymakers, and seniors were too busy to read lengthy documents.

The community advisory committee provided input on how to best reach community members and ensured that the KT material was culturally relevant. Over the course of the study, the community advisory committee became more forthcoming in identifying specific KT actions to support the study's outcomes. For example, a community partner suggested targeting policy-makers and sending personalized, hand-delivered invites to attend the community workshops with briefing notes to government leaders to facilitate provincial awareness of the study. It was necessary to continually highlight that while it was possible to inform policy-makers of the study's findings this did not ensure any form of policy change.

Discussion

Given the rural aging demographic and the increasing prevalence of chronic conditions, there is a growing need for patient-oriented research to support health care and support services for rural older adults. Approximately, 75–80% of seniors report having one or more chronic conditions in Canada (Canadian Institute for Health Information, 2011). As patients, rural seniors often experience unique challenges in accessing health and support services, such as limited home care, public transportation, family physicians, health screening, and long term-care (Bacsu et

al., 2014a). Research partnerships and engagement are vital to addressing the unique health-care challenges and needs of rural older adults.

Patient-oriented research requires innovative theories, methodological tools, and novel strategies to facilitate collaboration with rural older adults. New approaches are critical to facilitating patient involvement in research from developing trust and partnerships to supporting knowledge translation. However, in order to promote collaborative research with older adults, more studies need to document and publish effective strategies employed (Doyle & Timonen, 2010).

By drawing on the findings and processes from a rural cognitive health study, this article discussed relevant theories, methods, and strategies for supporting patient-oriented research with rural older adults. Guided by lay theory and cultural schema theory, participant observation, concept maps, and semi-structured interviews were conducted with 42 rural seniors in Saskatchewan, Canada. During this study, rural seniors offered their insight, expertise, and feedback on various aspects of the research from local research priorities to knowledge translation strategies.

Dibartolo and McCrone (2003) assert that a potential barrier to rural seniors' participation in research may include a general suspicion toward "outsiders" and research itself. Subsequently, this study found that community outreach played a vital role in supporting trust and partnership building with rural seniors. Successful strategies used to support outreach included being visible and having a presence in the community, working in close collaboration with community partners, spending time in the communities, and getting to know the rural seniors' beyond the scope of the study.

Participants in this study emphasized the need for research that was locally relevant and meaningful. Wallerstein and Duran (2010) assert that it is essential for researchers to work in collaboration with community members in order to address research priorities of local importance. Since many rural seniors had lost close family members and friends to dementia, there was a mutual interest in pursuing this research. Rural seniors did not want to be involved in research for the sake of research but wanted to ensure that there were tangible outcomes from the study's results. A memorandum of agreement was used to identify the study's outcomes and highlight study updates.

Throughout this study, rural seniors provided their insight to support effective knowledge translation strategies for sharing study findings. Subsequently, working in collaboration with rural older adults allows researchers to be sensitive to the local context, specific needs of the older adults, and tailor the dissemination approaches to the requirements of the rural communities (Dibartolo & McCrone, 2003). Rural seniors' have lived-expertise and community insight to support relevant knowledge translation strategies for moving research into policy and programs. For example, an older adult suggested hand-delivering personalized community workshop

invites with briefing notes to government leaders to facilitate provincial awareness and uptake of the study's findings.

It is important to note that local collaboration and input have substantial implications around participant expectations for patient-oriented research, especially in terms of program and policy deliverables. For example, it is necessary to consider policy and program implications and whether policy decisions will be influenced by the study's findings. Subsequently, it is vital to be honest, open, and realistic, and to develop a memorandum of agreement to collaboratively outline the study's deliverables at the onset of the research.

Gerontology literature is beginning to recognize the practical and ethical imperatives for conducting research with older adults (Doyle & Timonen, 2010; Giunta & Thomas, 2015). Minkler (2004) suggests that the core issue is democratization of knowledge and power, such that "the experiential knowledge of community members is valued and knowledge that previously was the purview of scholars is accessible physically and intellectually to community participants" (Minkler, 2004, p. 686). As the rural demographic ages, there is a growing need for patient-oriented research to improve health and support services for rural older adults. In moving forward, collaborative research with seniors is essential to developing new insights, identifying health supports and barriers, and improving health policies and programs for older adults in rural communities and beyond.

Conclusion

As the population ages, the health-care system is going to have to adapt in a variety of ways from the development of new policy initiatives to meet the needs of a diverse aging population to the reallocation of resources from areas of service where there are now fewer needs to those where needs are increasing. Patient-oriented research that strives to value the lived experiences and insight of older adults is a vital component in developing appropriate policy. Recent literature recognizes the need for more studies to identify key strategies to support older adults' involvement in research (Giunta & Thomas, 2015). In order to support healthy aging in rural communities, it is imperative to engage in flexible methodological approaches that facilitate local knowledge and input in meaningful ways.

Drawing on an ethnographic, community-based rural cognitive health study, this article discussed key themes for supporting patient-oriented research with rural older adults. By discussing relevant theories, methods, and strategies for supporting patient-oriented research with rural older adults, this paper provides a unique contribution to geriatric health literature. In moving forward, collaborative research with seniors is vital to improving

health policies and programs for older adults in rural communities and beyond.

Disclosure statement

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Appendix A. Concept Maps

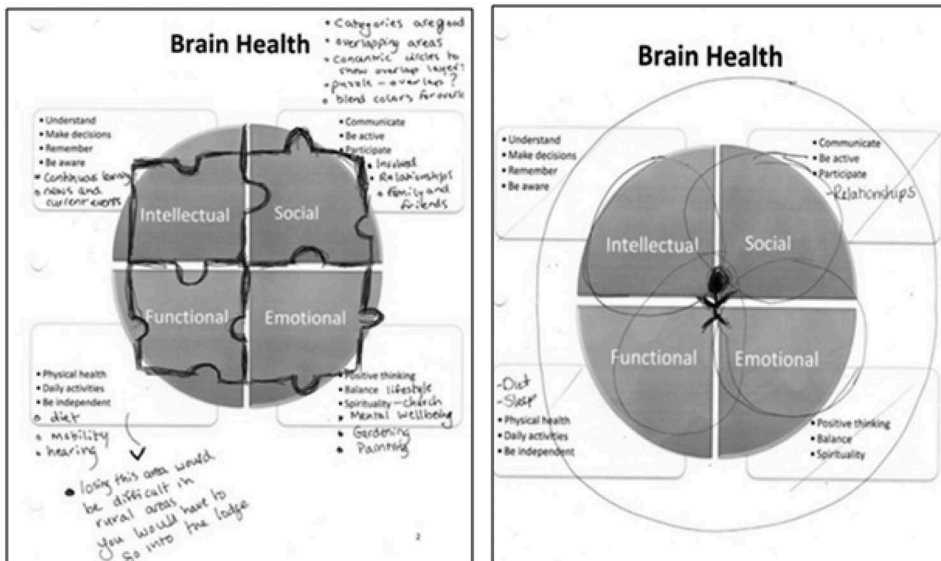


Figure 1.

Appendix B. Study Evaluation Question Examples

**Part of the larger cognitive health study interview guides.*

- (1) Do you have any ideas on ways to strengthen this project?
- (2) Are there any other questions that should be asked?
- (3) Did you experience any challenges or barriers to participating in the study?
- (4) What do you think is the best way to share health information with older adults in your rural community?
- (5) Do you have any questions about cognitive health that you would like to learn more about?