THE CHALLENGES OF DATA COLLECTION IN RURAL DWELLING SAMPLES

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ABSTRACT

Data collection in rural areas presents unique problems that impact the research process and thus the outcomes of the research. Some of the issues that must be accounted for include utilization of appropriate tools when studying rural dwelling persons, location of appropriate participants, rural health issues, environmental barriers, and ethical considerations. Researchers must be aware of these unique problems and issues and consider the impact of these issues on the integrity of the data.

INTRODUCTION

It has been recognized that research in rural areas presents unique and varied challenges for the researcher (Shreffler, 1999; Wilkes, 1999). These challenges are further confounded by variances in cultures across the wide spectrum of rural settings. This discussion will relate some of the issues that challenged the rural research process, including utility of tools developed with urban and suburban persons in rural areas, location of appropriate participants, rural health issues, environmental barriers, and ethical considerations related conducting research with a rural dwelling sample.

To gain insight into the experience of heart failure of older rural women, the authors conducted research with a convenience sample of 45 older women in rural upstate New York. The research question focused on health promotion behaviors and involved older rural women with heart failure who were referred by primary care physicians or nurse practitioners. Data was collected during visits of one of the authors to the women's homes. The women were not reimbursed for participation. This article discusses the experiences of the authors during this data collection process. Findings of this research process indicated that more research with rural residents is necessary if we are to understand the unique differences seen in rural populations while accounting for the unique issues inherent in data collection in rural areas.

APPROPRIATE RESEARCH TOOLS FOR RURAL POPULATIONS

One goal of research into rural nursing issues is to confirm that nursing interventions have similar usefulness in rural populations that is found with urban and suburban counterparts (Turner & Gunn, 1991). Because the majority of research in health care issues has been performed with urban or suburban populations, some of the basic premises of data collection and data analysis may not be reliable when transferred

without adaptation to research with persons living in rural settings (Turner & Gunn, 1991). Similarly, most data collection instruments and procedures have been developed with urban or suburban populations, and thus may have questionable reliability and validity when used in vastly differing rural geographic regions. An enormous challenge remains for nursing researchers to create new methods to uncover issues that must to be brought to light to improve rural health care.

ENVIRONMENTAL BARRIERS

This study was based in the Finger Lake region in upstate New York. While good roadways crisscross the area, the homes of the women in the study tended to be 25 to 50 miles from major roads, in small villages or farming communities. A few of the women lived on roads maintained as seasonal use only roads. When data collectors made arrangements to meet with women in their homes, travel to meet with the subjects often involved driving distances of 60 miles or further with the major portion of the distance occurring in remote areas. In spite of the best efforts of the data collectors to obtain clear and accurate directions to the homes, frequently it was found that the directions received were sketchy and difficult to follow. Several of the women appeared unable to give accurate directions, and some gave the authors grossly incorrect estimates of mileage. This problem may be related to the infrequent travel of many of the women for any distance away from their homes, or that they may have been inexperienced with giving directions because they did not drive themselves. Less than 50% of the women drove themselves to their local doctor's offices, and less than 20% drove themselves further away from their homes than to the office of their cardiologist. Several times the women asked family members to assist in giving directions. On more than one occasion we were given instructions that were impossible to follow, such as directions including where people "used to live", or landmarks that turned out to be missing. The authors learned to allow plenty of extra time to obtain directions locally, and to ask for extra information such as the color of buildings or special landmarks, or unique topography. We found cellular telephones and detailed local maps to be invaluable resources. We also learned to locate stores and gas stations along the way where we might be able to return for directions. The fact that rural residents tend to know most people in the area was useful in finding our participants.

The homes we visited mirrored the socioeconomic circumstances of the rural upstate New York area. The majority of the women stated that they were living on Social Security benefits only. Single-family homes were the most common living arrangement, as were family farmsteads where multigenerational families lived together. Only a few of the women lived in apartments or trailers. About half of the women lived alone, with most of the remainder living with only one other person. The mean length of residence of this sample was 26 years. These findings mirrored Lee's (1993) description of rural residences with most persons living in single-family homes and residing in same community for the majority of their lives.

LOCATING APPROPRIATE PARTICIPANTS

The design of this study called for accessing rural women who were presently being treated for heart failure through local health care providers, who were asked to recommend women who might be willing to discuss their experience of heart failure with the authors. In every instance the providers stated that they knew their clients well and had treated most of them for many years. The providers related that they liked having this type of relationship with their clients. Interestingly, this phenomenon compliments research findings that have shown that rural residents prefer to know their health care providers (Pierce, 2001; Casarett 1991) found that rural health care workers were friends and neighbors with their clients, and that rural clients found it important to have "neighborly" relationships with their health care provider (p. 252).

Most of the approximately twenty rural providers we contacted were very willing to cooperate and were pleased to be able to be involved in some way with research. Several of them spoke of the dearth of research opportunities in their rural practices and were supportive of any research endeavors with their clients. Most of the physicians and nurse practitioners felt that research of this nature that focused on the experience of living with heart failure was critically important to improving rural health care.

Because the rural health care providers tended to know their clients well, they appeared to make judgments about who would and would not participate in this research. These judgments possibly were their methods of protecting their clients as well as an attempt not to waste the time of the researchers. The providers could easily list the patients they cared for with heart failure and seemed to know a great deal about the living situations of each person. Of course, the possible impact of this culling process on the reliability and validity of sample cannot be overlooked.

Some of the providers stated that they were aware that the treatment regimes they were prescribing for their clients with heart failure differed from those currently espoused in the heart failure literature. They related the fact that knowing their clients included insight into what medications these clients would be willing to take. One physician said that she ordered the old standard medications that her clients had been taking for many years rather than to attempt to switch them to newer, more expensive drugs that she felt quite sure they could not afford to take.

IMPACT OF RURAL DWELLING ON HEALTH

The women that we studied were captives of the "triple jeopardy" related to living in rural areas, including advanced age, poor economic status, and relative isolation from health care services (Henderson, 1992, p.62). Many described struggling with role changes as well as decreased physical and mental capacity. In spite of these disadvantages, the women in this study for the most part rejected the sick role described by Lee (1993). As is the case with many rural persons, the women in this study talked about being able to do the routine chores around their homes, with their families, and often cited involvement in their churches and charities such as clothing and food banks. This mirrors the definition of health ascribed to rural persons by Long and Weinart (1989) as being able to work. They expected to go about their daily routines and saw illness as part of the aging process. In spite of relatively advanced New York Heart Association

classification levels indicating declining cardiac function, they tended to rate their health as good. One woman who was nearly blind, oxygen dependent, and lived alone rated her health at the highest level. The older rural women in this study indeed represented the notion of the survivor elite (McCullough, 1991), who exude a high level of hardiness and tend to evaluate health in positive ways.

While it has been commonly written that rural residents often tend to resist outsiders, the authors found the women in this study were willing to open their doors to researchers. All of the women were at home during the first visit making repeat visits unnecessary. None of the women asked for identification from the researchers but we gave them our business cards as a method of identification. While this lack of distrust may have related in part to the fact that an appointment had been set in advance, we also sensed it as an act of welcoming us, as an acquaintance of their health care provider, into their homes. We also felt that they were comfortable with nurses entering their homes, perhaps reflecting the widely held notion that nurses constitute the most trusted profession. While we were clearly “outsiders” (Long & Weinart, 1989), we were in each instance treated with respect and with a very welcoming manner.

Once we were inside the subjects’ homes, many of the women created a social atmosphere where we were treated as welcomed company. Often we were served beverages and home baked goods. In addition, we were shown antiques, quilts, handwork, pictures of family members, and other favorite memorabilia. One subject was a nurse who had trained in the early part of the century who related several stories of her nurse’s training days seventy years ago. As the study progressed, we learned to allow extra time for each visit. We planned on time to accept refreshments, as well as for the subjects to show us their favorite items and to reminisce about their life experiences (Newburn, 1991). In most cases we were invited to return for another visit or to share the results of the study. The hospitality went both ways when one author occasionally delivered fresh lake trout to one subject who spoke of missing trout since her husband had passed away.

A number of the women expressed surprise that nurses would be willing to travel so far away from the university, and they also seemed surprised to find that their experiences were important to study. Most said that they did not think they had anything important to say. However, while they stated this, most of the women were very willing to talk about their lives and were eager to be helpful to the researchers and to other persons with heart failure. It was notable that this group was willing to share information about their health experiences, but they did not ask for any advice or additional assistance from the researchers. They may have perceived the authors as researchers only, rather than as active health care providers.

ETHICAL ISSUES IN RURAL RESEARCH

Throughout the study, it was common that the women wanted to put a positive light on their health experiences. There was also a sense on the part of the authors that the subjects often seemed to want to please the researchers by choosing the ‘right’ answers, almost as if they were going to be graded. One woman was willing to refer to her tax returns, so she would be able to answer the income level question as accurately as possible. We were concerned that this need to have the right answer might be related to a concern that the authors would report findings back to their health care providers. While

we assured the women we would not share any information with their health care providers and that there were no “right” answers, it seemed clear that they remained concerned about this issue. Even though the researchers repeatedly reminded the women that the information was confidential, it is possible that the lack of anonymity (Long & Weinart, 1989) that is characteristic of rural areas may have biased their answers. Also, some were clearly using the only provider in their area, and may have been concerned about causing any problems with that relationship if they answered in a way that might displease the provider.

Similarly, we developed a concern that the women might feel obliged to participate if they were referred by a health care provider they trusted or knew very well. While we tried to be clear that they were under no obligation to participate unless they were doing so for their own reasons, the authors remained concerned that the women felt obligated to be of assistance to their health care providers and thus the researchers they were associated with. Additionally, the women seemed very trusting of the research process. We found that the women rarely read the consent form carefully, in spite of our best efforts to make sure that they were aware of the conditions of the consent they were signing. We did not access reading or comprehension levels, but this would probably add valuable insights into the research findings.

One surprising finding was that all of the women stated they took their medications as ordered, and this included those with complex medication regimes as well as those who might have had faulty reasoning and/or comprehension skills. This response pattern may have been related to not wanting to alienate providers, or to not wanting to admit if they were unsure about how to take their medications. The latter may reflect the hardiness factor as described by McCullough (1991).

The issue of a lack of anonymity was evidenced at several points in the data collection process. Because we were visiting residents in small towns where “everyone knew everyone else”, we experienced situations were subjects would say that they had heard that we visited a neighbor. We also found that the women were eager to tell us the names of other neighbors that they knew who would be willing to talk with us. We did ask those persons to participate in this study.

CONCLUSION

As we review these issues, the concern for the integrity of the research process may have unique implication in rural areas. The power of the contacts in rural areas where unique relationships exist must be carefully scrutinized to ensure that integrity of the research process is maintained. Signifiers of power of a researcher also must be carefully considered when studying vulnerable populations (Geldens, 2002). While the outsider status of a researcher can be a barrier, the use of insider connections should be used with caution. It must be a paramount responsibility of the researcher to protect the participants yet foster research outcomes that are in the best interests of all participants (Geldens, 2002). As more is learned about the intricacies of rural communication patterns, it is critical that this information be shared and used to perform credible rural research in the future.

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