Older Adult Caregiving in an Amish Community

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ABSTRACT
Amish older adults represent a growing and understudied population whose current health practices, interactions with health care systems outside of their community, and care needs are unknown. Limited research exists on why, when, and how Amish older adults and their caregivers experience health care services outside of their family and community. The purpose of the current study was to describe and explore the perspectives of Amish caregivers caring for older adults and their experiences with health care services outside of their community. A qualitative phenomenological research design was used in combination with a community-based participatory framework with caregivers in a small, rural Amish settlement. Amish caregiving of older adults is a complex phenomenon that is influenced by cultural characteristics. Caregivers place significant cultural value on home caregiving, emphasize the experience as a blessing, and relate misunderstandings between themselves and outside health care providers as significant concerns.

BACKGROUND

Two thirds of American older adults have multiple chronic conditions, and treatment for this population accounts for 66% of the country’s health budget (Centers for Disease Control and Prevention [CDC], 2013). Approximately 21% of older adults live in a rural area with decreased access to health care services (West, Cole, Goodkind, & He, 2014). The exact numbers of Amish older adults and chronic disease prevalence is unknown, but most Amish individuals live in rural areas and are thought to have a similar health profile to their rural counterparts. Evidence exists that Amish individuals are increasingly seeking health care outside of their community, especially for care of individuals with illness (Farrar, 2014; Kueny, 2011).

Amish individuals place significant value on serving as a caregiver for an older adult and they are deeply involved in maintaining the care recipient’s health (Hostetler, 1993). Reverence of older adults is a consistent cultural value across the Anabaptist (i.e., groups who believe in adult baptism) cultural group spectrum. Preserving the function of older adults in the day-to-day activities of Amish community life is emphasized (Andreoli & Miller, 1998; Tripp-Reimer, Sorofman, Lauer, Martin, & Afifi, 1988). For this reason, the perspective of caregivers offers unique insight into understanding the experience of aging in the Amish community.

Remaining independent in the home environment of their choice is valued by older adults; however, the burden of disease often results in the need for various levels of caregiving support. In the United States, an estimated 60 million informal caregivers have an estimated economic value of unpaid contributions exceeding $450 billion (Feinberg, Reinhard, Houser, & Choula, 2011). Several health care trends have increased the need for and complexity of home caregiving. The current trend toward a community-based health care system increases the demand for home services and reliance on caregivers to provide greater complexity of care in the community. Americans are living longer with multiple chronic conditions and greater rates of disability, further increasing the complexity of responsibility to informal caregivers whose family structure has shifted toward smaller families and delayed marriage and child-birth, meaning fewer individuals are able to provide care with multiple competing responsibilities (Feinberg et al., 2011).

Caregivers often report meaning and satisfaction in this role despite evidence that they experience poorer health outcomes and significant emotional and financial strain (Nolan, Grant, & Keady, 1996). There is a large body of caregiving research that identifies the experience as difficult, burdensome, and having a negative impact on caregiver health (Schulz & Beach, 1999). Caregiving experiences and outcomes vary among ethnic groups (Pinquart & Sorensen, 2005), but in comparison, ethnic minority caregivers report less burden and emphasize filial responsibility and rewards of caregiving (Calderón & Tennstedt, 1998). Caregiving research is trending toward greater awareness of the variation of the caregiving experience across different ethnic groups and generations to understand how filial obligation impacts long-term caregiving success (Giger et al., 2007). For caregivers in the current study, the lived experience of caregiving for an older adult included viewing the role as a privilege requiring personal perseverance, role acknowledgement, and sharing the caring with siblings, spouses, and community members. These findings indicate that Amish caregivers of older adults may view the caregiving role differently than their non-Hispanic, White counterparts.

Most gerontological texts (Meiner, 2010; Miller, 2011) indicate that cultural competency skills are essential to the reduction of health disparity in unique ethnocultural groups. Large gaps exist in the knowledge of the Amish as a unique ethnocultural group. Specifically, little current information exists about communication methods or approaches that are culturally competent (Mentes, Salem, & Phillips, 2017). The current article describes the results of a qualitative phenomenological study of the lived experience of caregivers of Amish older adults and their interactions with health care providers outside of their community.

THE AMISH

The Amish, as a distinct group, began during the Protestant Reformation in Europe in the early 1500s, but like other minority groups seeking religious freedom, migrated to North America in the 1800s. A demographic study indicates the Amish population doubles approximately every 18 to 20 years and has expanded 20% from 2008-2013 (Young Center for Anabaptist and Pietist Studies, 2016). Cultural values include adult baptism, avoidance of modern technology, sequestration from mainstream society, and maintenance of a lifestyle that emphasizes religion, family, and agricultural occupations, which are similar across homogenous Amish communities (Kraybill, Weiner, & Nolt, 2013). There is ongoing debate about whether the Amish represent a religious or cultural minority group, as they share features of both. In the cur-
rent article, they are considered a unique ethnocultural group whose cultural practices and minority population status put them in a vulnerable position. Although there is a friendly relationship between the Amish and the outside community for exchange of services and help in times of crisis, they maintain a considerable distance from society (Hurst & McConnell, 2010; Kraybill et al., 2013). Despite this separation, Amish individuals have achieved a high level of adaptability and prosperity, and have a history of becoming involved in scientific research in other areas of the country (Hostetler, 1993; Kraybill & Olshan, 1994).

Amish Caregivers of Older Adults

Caring for parents and older adults is an essential part of being Amish, according to several historically situated research studies and dissertations (Andreoli & Miller, 1998; Tripp-Reimer et al., 1988; Wenger & Wenger, 1988). Amish informal and family caregivers provide the most care for aging members of the Amish community and are integral to understanding the phenomenon of Amish older adult care experiences (Palmer, 1992; Tripp-Reimer et al., 1988), but more information is needed about this process.

METHOD

Ethical Approval

The study received approval from the Institutional Review Board of the University of Oklahoma, Health Sciences Center, inclusive of the preliminary pilot work and dissertation study.

Terms

For the purposes of the current study, Amish family caregiver is broadly defined as any relative, partner, friend, or neighbor older than 17 and who has a significant personal relationship with and provides a broad range of assistance for an older adult with a chronic or disabling condition. These individuals could have been primary or secondary caregivers and live with or separately from the care recipient (Family Caregiver Alliance, 2006). Care recipient refers to an Amish older adult with a chronic illness or disabling condition, or an Amish older adult who needs ongoing assistance with everyday tasks to function on a daily basis. These tasks may include managing medications, transportation, bathing, dressing, and using the toilet (Family Caregiver Alliance, 2006).

Research Design

Qualitative Phenomenological and Community-Based Participatory (CBPR) Approach. A qualitative phenomenological design is appropriate to achieve a rich description of the lived experience of caring for an Amish older adult. This design was combined with a CBPR approach to gain detailed descriptions (Denzin & Lincoln, 2011) of the influence of cultural factors on older adult caregiving, health care use outside the Amish community, and caregiver experiences with those services—all of which are missing in the literature. The study was ethnographically informed, but not an ethnography because it focused on one cultural group in one geographic location and describes shared values, behaviors, beliefs, and language, but did not immerse researchers in the day-to-day lives of the sample (Ember & Ember, 1998; van Manen, 1990). The researcher (H.M.F.) did not live in the community or participate in caregiving activities, but a significant amount of time was spent with Amish community members at different events to develop trust, engage them in the research process, and learn about the community culture.

Using phenomenology as a research method enabled rich descriptions of the Amish caregiving experience (van Manen, 1990). A crucial step in using phenomenology is recognizing that there is an assumption that the lived experience of individuals is a conscious one representable via thematic analysis of textual descriptions (Creswell & Poth, 2017). In the current study, understanding of participant experiences developed and changed through repeated interactions with the same and new participants, which reflects the emergent quality of qualitative phenomenological research and maintained focus on describing the essence of the experience. An important aspect of a phenomenological approach is researchers’ obligation to stay within the research question framed to explore the lived experience of participants while being mindful of one’s own preconceptions through the application of reflexive practice (van Manen, 1990). Reflexive practice included awareness of the influence of stereotypes and assumptions about the Amish culture (Denzin & Lincoln, 2011). These impressions were included in field notes and considered during data analysis. Consultations with national experts who conduct research with Anabaptist groups prevented these considerations from unduly influencing study conclusions.

In addition to facilitating a participant-driven research question, principles of a CBPR approach enabled ongoing collaboration between the researcher (H.M.F.) and Amish community during all phases of the research process, and provided additional protection to Amish participants, as a potentially vulnerable population (Israel, Eng, Shulz, & Parker, 2005; Viswanathan et al., 2004). The researcher
built a partnership with an Amish elder as a gatekeeper to community access, which respected the Amish cultural value of isolation from the outside world. This elder and his wife participated in development of the research question, sampling, recruitment, data collection, interpretation of findings, and dissemination of findings to community members. This collaboration aligned with principles of a CBPR approach, in which co-learning and mutual goals are established (Kleinman, 1980; Minkler & Wallerstein, 2008). The elder initially recommended that the researcher approach dyads (husband and wife pairs) because they shared the caregiving role in the community. However, during an initial interview with a dyad, a recommendation was made to interview a widow who had experience in older adult caregiving. The elder approved the interview and encouraged the researcher to continue to use this form of recruitment. However, the researcher was not permitted to use a tape recorder; handwritten notes for interviews were used as the data collection method to be consistent with Amish traditions (Kraybill et al., 2013).

Scientific Rigor
Seeking participants’ perspectives, having community members checking transcripts, reviewing themes with participants, and continuous reflexive journaling of assumptions and stereotypes to question interpretations (Denzin & Lincoln, 2011; Sandelowski, 1986) enhanced establishing the results as credible.

Sampling
The sampling method was purposeful to recruit participants with the specific experience of caring for an Amish older adult (Marshall, 1996). Participants identified that this was the first time they had been involved in a research study and were unaware of other Amish individuals participating in similar research (Farrar & Wilson, 2013). Snowball sampling recruited additional participants with the Amish elder’s approval (Creswell & Poth, 2017; Sandelowski, 1995). Data saturation was achieved with a total sample size of 15 participants and further considered adequate, as the target population is homogenous (Sandelowski, 1995) and recurrence of initial themes was identified during preliminary work.

Data Collection
Data sources included handwritten transcriptions of interview data, field notes, and Amish-specific literature about older adult caregiving. Semi-structured interviews began with the central question, “What is your experience of caring for an older adult?”, in addition to sub-questions about experiences with non-Amish health care providers, and perspectives of health and illness (Table A, available in the online version of this article). The primary researcher (H.M.F.) transcribed handwritten notes during the interview. Some statements were not included because transcriptions are dependent on the speed of the researcher to write participants’ responses. In addition, speech tones, pauses, and variations in speech were unavailable for analysis. However, other qualitative research among similar Anabaptist Amish populations also avoided use of a tape recorder (Clausen, 2012; Hall & Kulig, 2004; Wenger, 1995).

Collaboration with the Amish elder facilitated the development of the interview guide based on Leininger and McFarlan’s (2006) Culture Care Diversity and Universality Theory and Kleinman’s (1980) interview guide for working with cultural groups. Consistent with the nature of an emergent qualitative design, the interview guide was adapted and refined during each subsequent interview, beginning with the initial interview guide developed during preliminary work (Denzin & Lincoln, 2011). Omissions of non-relevant questions occurred where participants did not have the relevant lived experience (e.g., if participants did not use hospice services, questions about those services were omitted). During development and use of the interview guide, the researcher paid attention to differences in language and body language, as well as participants’ areas of interest. This practice reflects a primary principle of CBPR approaches, in which the researcher is continuously attending to the shared experience of the research process (e.g., asking participants for clarification of an unclear word or phrase) (Israel et al., 2005).

At the conclusion of each interview or at an additional meeting with each participant, interview transcripts were reviewed with participants to promote accuracy of data and allow them to clarify meaning and change or edit responses after they had time to reflect on their answers (McConnell-Henry, Chapman, & Francis, 2011; Strebbert Speziale & Rinaldi Carpenter, 2010). During these exchanges, the researcher was aware that participants had no research involvement experience, may not speak English as a primary language, or feel comfortable during initial interactions.

A total of 15 Amish caregivers were recruited over 2 years. All participants completed informed consent prior to interviews in their homes, with interview length ranging from 1 to 3 hours. Depending on whether the participant wanted to review the transcript immediately after the
interview or later with a printed transcript, the researcher made one to two visits to each participant. Findings from the first six interviews identified that the level and type of interaction with health care systems outside of their community was a dominant feature of their lived experience of caring for older adults (Farrar & Wilson, 2013). For this reason, questions were added about interactions with providers and systems outside of their community in the revised interview guide used in subsequent interviews.

Data Analysis

Consistent with a qualitative approach, data analysis occurred concurrently with data collection. After each interview, transcript and field notes were processed and verified through member checking. Interview data were then inductively explored line-by-line to identify initial codes that reflected the main idea of each passage of text statements organized by research questions (Miles, Huberman, & Saldana, 2014). These codes were one- to two-word titles of the main idea of the group of responses to a particular set of questions. These codes reflected a pattern of responses across multiple participants, which evolved into key themes that were longer titles describing the essence of the narrative sections similar in idea. Throughout data transcription and coding, focused attention to participants’ statements and their reality rather than the researcher or outside data maintained neutrality (van Manen, 1990). After interview transcription, the original codes were reviewed to identify if they still fit the data and themes representing the collection of transcripts as a whole, as recommended by Saldana (2013).

Participants often described their experiences as direct answers to a specific question or impressions of the experience. These descriptions were rarely sequential in nature and often combined events from multiple interactions or caregiving experiences in one story. Word-for-word representations of participant statements are limited, as these interviews were not audiorecorded.

RESULTS

Lived Experience Caring for Amish Older Adults

Six major themes emerged from participants’ lived experiences of caring for Amish older adults. The community elder and participants are partners in the research findings and, to respect the collaboration, the themes are preceded by a key phrase from a participant. The semi-structured interview guide used collected demographic information about the caregivers and care recipients, care recipient disease diagnoses, and descriptions of the caregiving environ-
for more knowledge, and perceptions of health care outside of their community. Descriptions of their caregiving experiences provide insight into how a generic approach to caregiving support from non-Amish providers is insufficient to meet the unique cultural needs of this population of caregivers.

"Schuldigekeit"/Meaning of Caregiving. When asked to describe why caregiving is important to them, all participants described the role of caregiver from a responsibility perspective and as a manifestation of their cultural values. Schuldigekeit is a German word meaning duty or to do one's duty (Kueny, 2011), and participants typically paired one-word statements such as “privilege” and “gift” with a definition of what Schuldigekeit means to the Amish (e.g., “responsibility, when we were young they took care of us and now that they are older...we should take care of them”). Throughout the interviews, there was a clear declaration that participants “want to take care of our old people, not put them in a home” and “if at all possible, you want to keep at home.” Although participants seemed to recognize the term “caregiver,” there was no distinction made between types of caregivers or caregiving as an official role. The act of caring was described as a shared responsibility (e.g., participants simultaneously described the use of schedules and how other community or family members helped so they could continue to work, meet other family obligations, or attend church services).

"It's the One Thing I Can Still Do for Her, that I Can"/Rewards of Caregiving. When asked about rewards or positive aspects of being a caregiver, descriptions often emphasized how meeting the individual care recipient’s needs provided a sense of satisfaction, as one caregiver explained: “When we can both feel at the end of the day we

<table>
<thead>
<tr>
<th>Participant Demographics</th>
<th>Location of Care Recipient</th>
<th>Caregiver Age/Gender</th>
<th>Care Recipient Age/Gender</th>
<th>Disease</th>
<th>Sibling Involvement</th>
<th>Equipment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Same residence</td>
<td>62/F</td>
<td>92/F</td>
<td>Hip injury, type 2 diabetes mellitus</td>
<td>Yes + community network</td>
<td>Hospital bed, oxygen, and catheter</td>
</tr>
<tr>
<td></td>
<td>Same residence</td>
<td>78/F</td>
<td>94M</td>
<td>CVA</td>
<td>No + community network</td>
<td>Hospital bed and wheelchair</td>
</tr>
<tr>
<td></td>
<td>Same residence</td>
<td>60/F</td>
<td>92/F</td>
<td>Hip injury, type 2 diabetes mellitus</td>
<td>No + community network</td>
<td>Hospital bed, oxygen, and catheter</td>
</tr>
<tr>
<td></td>
<td>Same residence</td>
<td>63/F</td>
<td>94M</td>
<td>CVA</td>
<td>No + community network</td>
<td>Hospital bed, wheelchair, and gait belt</td>
</tr>
<tr>
<td></td>
<td>Different residence, same property</td>
<td>52/M</td>
<td>94M</td>
<td>Hip injury, type 2 diabetes mellitus</td>
<td>No + community network</td>
<td>Two-retired primary care physicians, home health</td>
</tr>
<tr>
<td></td>
<td>Different residence, same property</td>
<td>53/F</td>
<td>94M</td>
<td>CVA</td>
<td>No + community network</td>
<td>Primary care physician, hospice</td>
</tr>
<tr>
<td></td>
<td>Different residence, same property</td>
<td>85/F</td>
<td>90/F</td>
<td>CVA</td>
<td>Yes + community network</td>
<td>Hospital bed, air conditioner, and bedside commode</td>
</tr>
<tr>
<td></td>
<td>Different residence</td>
<td>63/F</td>
<td>90s/M</td>
<td>Alzheimer’s disease, hip injury, lower extremity amputation</td>
<td>Yes + community network</td>
<td>Hospital bed and lift</td>
</tr>
<tr>
<td></td>
<td>Different residence</td>
<td>63/F</td>
<td>90s/F</td>
<td>Cancer</td>
<td>Yes + community network</td>
<td>Hospital bed, air conditioner, and bedside commode</td>
</tr>
</tbody>
</table>
Caregiving in an Amish Community

did our best...no matter if there are ups and downs.” Participants often related caregiving anecdotes that expressed gratefulness and overcoming difficult care recipient behaviors. For example, one participant described a good day as one that followed a night during which everyone was able to rest (normally the care recipient was awake throughout the night, repeatedly trying to get up to wander or go to the bathroom).

“When You Just Couldn’t Do Nothing Right”/Difficulties in Caregiving. Difficult caregiving experiences often included problem-solving situations in which the caregiver felt inadequate about knowing how to respond in the caregiving role. No participants used the word “burden” to describe caregiving experiences; however, during interviews, there were nonverbal expressions of sadness such as looking down, tearful expressions, and repeated pauses in speech that indicate other emotions that could be explored in future studies. Most participants discussed how a lack of older adult caregiving experience was associated with a lack of confidence in their decisions. Often, retrospective statements about their feelings coincided with expressions of inadequacy (e.g., “If she was in a lot of pain and we didn’t know what you could do to ease it...that was difficult” and “when you just couldn’t do nothing right”).

“Ther Was Not Understanding”/Interactions With Health Care Providers Outside of Their Community. Many participants indirectly referred to their interactions with health care providers and systems outside of their community. The interviewer asked direct questions about the type of care received outside of their community and caregiver impressions of their interactions with providers. These stories usually included confusion about home medication regimens, concern about paying for services, access of services, and mixed opinions about services.

Three of 15 participants expressed confusion with home medication regimens, and others explained that discharge

<table>
<thead>
<tr>
<th>Caregiver Age/Gender</th>
<th>Location of Care Recipient</th>
<th>Care Recipient Age/Gender</th>
<th>Location of Care Recipient</th>
<th>Equipment</th>
</tr>
</thead>
<tbody>
<tr>
<td>30s/F</td>
<td>Different residence</td>
<td>90s/F Cancer</td>
<td>Different residence</td>
<td>Hospital bed, air conditioner, and bedside commode</td>
</tr>
<tr>
<td>60s/M</td>
<td>Different residence</td>
<td>80s/F CHF</td>
<td>Different residence</td>
<td>Hospital bed, wheelchair, and bedside commode</td>
</tr>
<tr>
<td>60s/F</td>
<td>Different residence</td>
<td>80s/F Dementia</td>
<td>Same residence</td>
<td>Hospital bed, wheelchair, cane, walker, and bedside commode</td>
</tr>
<tr>
<td>60s/F</td>
<td>Same residence</td>
<td>90s/F Debilitation, CVA</td>
<td>Same residence</td>
<td>Hospital bed, wheelchair, and catheter</td>
</tr>
<tr>
<td>60s/M</td>
<td>Different residence</td>
<td>60s/F Debilitation, CVA</td>
<td>Different residence, same property</td>
<td>Hospital bed, wheelchair, and catheter</td>
</tr>
<tr>
<td>60s/M</td>
<td>Different residence</td>
<td>90s/F Debilitation, CVA</td>
<td>Different residence, same property</td>
<td>Hospital bed, wheelchair, and catheter</td>
</tr>
</tbody>
</table>

Note. F = female; NP = nurse practitioner; M = male; CVA = cardiovascular accident; CHF = congestive heart failure.
Participants expressed mixed opinions about interactions with health care providers outside of their community in the home setting. Participants related a mixture of feelings, such as “wonderful” and unease (e.g., “some of them spent more time than others” and “we liked them okay except those two nurse aides who were so rough with him; he just knew they were going to roll him out of bed”). The most prominent difficult events encountered were financial, transportation, and equipment issues. Several participants discussed the difficulty arranging for home oxygen equipment that was not dependent on electricity, discharging from inpatient care without time to arrange for a driver to take them home, or confusing actions on the part of emergency medical services. These discussions highlighted an Amish pragmatic perspective on focusing on the details of a problem. For example, when explaining paramedic services, one participant remarked:

They just drove around, they didn’t know their roads…and it took over 20 minutes to get there…pathetic…then got there, they had to send him right away so they called a helicopter and took another 20 minutes to get him to town for that and they could have been halfway there if they had just gone…. It just didn’t make sense.

**DISCUSSION**

Caring for older adults is a universal human phenomenon expressed in a variety of ways according to diverse cultural and individual factors (Cromwell et al., 1996). There is an abundance of literature on caregiving burden (Tarlow et al., 2004). Similar to other ethnic minority groups (Miyawaki, 2016), participants perceived the role of caregiver as a filial responsibility and gift (Beachy, Hershberger, Davidhizar, & Giger, 1997; Wenger & Wenger, 1988). No participants viewed the experience as negative in the context of burden; when they expressed frustration or sadness, it was related to their own inadequacies or failure to meet a standard of caregiving that they or the community expected of them.

In the sixth theme, findings reflect that participant experiences varied in the type and quality of interaction with health care providers outside of their community. Participants expressed concerns regarding health care cost, access, and confusion over treatment regimens. Considering that the cost of health care is three to five times higher in individuals older than 65 (CDC, 2013), and that Amish individuals generally do not use formal insurance, there are significant financial implications for miscommunication regarding treatment costs. These experiences represent a unique Amish narrative of cultural misun-
understandings that are difficult for the Amish community to resolve with outside clinicians. A gap in understanding exists regarding how Amish individuals negotiate health care services across cultural boundaries, which include differences in language, values, and needs.

LIMITATIONS

Limitations of the current study include the small sample from only one geographic location and use of handwritten notes. An additional limitation is the difficulty in disseminating study results throughout the Amish community, who communicate with other communities primarily through in-person visits and mail. From a phenomenological perspective, this study explored caregiver experiences at a fixed point in time (van Manen, 1990), so findings may be limited to participants' perspectives at only one point in time. The Ordnung, an unwritten prescription for Amish dress, lifestyle, and interaction with the outside world, directs the Amish lifestyle and varies widely among communities, districts, states, and countries, so it is difficult to generalize traits for all Amish communities. Considering these differences among Amish communities, the conclusions made are not representative of the Amish as a whole.

IMPLICATIONS

The current study has two significant implications for health care science and research methodology. The first is greater understanding of the Amish perspective on the meaning of being a caregiver for an older adult. This understanding enhances descriptions of the experience across a continuum of care in and outside of the home. Existing literature about Amish caregiving does not emphasize the specific challenges, needs, desires, and perspectives of Amish caregivers. By using a phenomenological approach with a CBPR framework, the evidence retains cultural nuances. These nuances are essential to understanding the unique perspective of Amish caregivers of older adults who provide home care to a population at significant risk for health disparity, are uninsured, and experience significant barriers to understanding and using health care outside of their community. Evidence suggests that Amish individuals are increasingly accessing health care outside of their community and quality descriptions of their unique needs are essential to the provision of quality, culturally competent care.

A second implication is the application of a research approach with a religious minority group that specifically addresses the inherent power differential of the research process. Use of a qualitative approach in combination with principles of a CBPR approach reveals new information about participant experiences caring for Amish older adults and interactions with health care services outside of their community, and may inform strategies for working with Amish individuals. Isolation from modern society, rejection of formalized education beyond the 8th grade, and lack of technology put the Amish community at a distinct disadvantage for knowing about health care research (Cates, 2005; Hostetler, 1993). Rather than an exchange of forms and permissions, conversations with the researcher about consent, confidentiality, risk, and benefit undertaken with a CBPR approach is in the context of information exchange. Although challenging to document the lived experience of Amish caregivers of older adults, the current findings indicate that doing so enhances understanding relevant to clinical practice and thereby meets societal and organizational expectations of providing quality care to this population.

CONCLUSION

The Amish represent a unique community whose health care needs and preferences are not well documented in the literature. Evidence exists that Amish individuals are increasing interaction with and accessing mainstream society; without this information, cultural misunderstandings are likely. The current findings indicate much can be learned about caregiving in the Amish community that may be relevant to other cash-pay, rural, community-oriented groups.

REFERENCES


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TABLE A—RESEARCH QUESTIONS

General Question:
1. Thank you for talking with me about caring for older adults. Can you tell me about when you took care of _____ as they got older.

Sub-Questions:
2. How are you related to _____?
3. Did you or do you provide most of the care for _____?
4. How old is or was _____ when you took care of them?
5. If you feel comfortable telling me, how old are you or were you when you took care of _____?
6. Who else helped take care of _____?
7. How did they get involved in caring for _____?
8. Did not elicit information about how decisions were made about help, was there random volunteers or formal schedule?
9. The people that helped you, can you tell me about them?
10. What did you know about (insert disease) before ______ had this problem?
11. Because of (insert disease) what did you think you might have to do for ___ as they got older?
12. Before you started caring for _____ did you think about needing to care for them in the future?
13. Did you expect _____ to need you to help take care of them?
14. What did you think would happen as _____ got older?
15. Overall, when you needed to help care for ______ did you feel prepared for it?
16. Was there an expectation in your community that you care for _____?
17. What were some of your concerns about how caring for _____ would go?
18. How would you define being “healthy”?
19. How would you define being “ill”?
20. Overall, what things are important to being “healthy”?
21. Overall, what things cause “illness”?
22. Have there or were there any changes in your health after you started caring for _______?
23. Were you prepared to help take care of _____?
24. Had you taken care of someone like this before______?
25. While caring for ______ if there was a change in their health, who did you ask advice from?
26. Did you decide to go to the medical doctor/emergency room/call hospice/urgent care at any point?
27. How did you decide that you needed to get help from someone outside of this community?
28. What kind of care do you provide (for example, do you help with medicine, walking, going to the bathroom, dressing, and feeding)?
29. Was there something about this care that you had done before and where did you learn that?
30. How did things change in your home?
31. Did you have to move any furniture?
32. When _____ needed you to help them, did they move to a different home?
33. Can you tell me about any healthcare providers that _____ saw in the English community that took care of them as they got older?
34. Did _____ see that person before they needed you to help them?
35. How did _____ start seeing _______?
36. Did they see them on a regular basis?
37. Did ____ tell them that they had a specific disease or problem? If yes to previous question – did the ____ tell you anything about this disease?
38. After (insert trigger event if there is one) did ____ continue to see the same provider?
39. Is there something you wanted to know that they didn’t tell you?
40. If no to previous question - Did you find that information, and where?
41. Is there or was there any issues traveling to see _____?
42. Did _____ offer any home visit services?
43. Did you have concerns about the care that _____ provided to ______?
44. Did you take ______ to see any other providers?
45. If you didn’t understand something that the English told you what did you do?____
46. If hospice involved - How did hospice get involved in caring for _____?
47. How did hospice involvement change caring for _____?
48. What does “hospice care” mean to you?
49. I have often heard patients and family members talk about hope. Can you tell me what that means to you and your community?
50. What do the ministers teach you about hope?
51. What is the importance of hope when someone is ill? When someone is dying?
52. Is it hope for survival or hope for eternal life after death?
53. Is there still hope when a person receives hospice care?
54. Did you have any concerns about having hospice care?
55. Did you use any equipment to care for _____?
56. Who ordered or provided those items?
57. Had you had experiences with this company before?
58. When the ________ ordered (insert electronic or complex equipment that was not available in community) did you have any concerns about using ________?
59. Did the ________ show you how to use the equipment?
60. Were there any problems with getting the equipment set-up or delivered to the home?
61. Was there something about this equipment that you had done before and where did you learn that?
62. Does the equipment interfere with your spiritual life? In what way(s)?
63. Did ___ need to speak with the ministerial leadership about the use of the equipment?

Closing/summary questions:
64. Some caregivers feel overwhelmed by having to care for their family. Another researcher asked questions about this of Amish participants and they talked about a term “Schuldigekeit”. Do you know this term and does it mean anything to you?
65. Can you give me an example of a “good day” with ___ and another day when things did not go well?
66. What has been difficult?
67. What has been rewarding?
68. For you personally, why was it important for you to care for ______?
69. Are there any teachings from the Bible or from your church that directs you to provide such care?
70. Are there spiritual rewards for caring for others?
71. Based on your experiences with the English healthcare system while caring for _____, is there something that you would like English healthcare providers to know?
72. Is there something we can do better or something you wished we had done?
73. What would you like nurses, doctors or any healthcare provider to know about the Amish community?
74. What advice would you give to nurses, doctors, healthcare providers about taking care of an Amish older adult community member when they come into the hospital or clinic or office?