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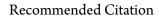
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Anabaptist Community Members' Perceptions and Preferences Related to Healthcare

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Abstract

The plain Anabaptists are thought to differ from mainstream U.S. health care beliefs and practices. Many non-Anabaptist health care providers have limited knowledge of the specific health beliefs and preferences of Anabaptists, which can lead to misunderstandings. The purpose of this descriptive qualitative study was to collect information from Anabaptist community members related to health care beliefs and preferences in their communities. Participants, who were members of various plain Anabaptist communities, completed a questionnaire containing openended questions about health issues. Seven themes emerged in results: (1) health viewed as a gift from God that provides the ability to work; (2) concern about exposure to chemicals and food additives as health risks; (3) the use of a variety of resources from lay members in the community in addition to seeking information from professionals; (4) the desire to use natural remedies first with outside care being sought when deemed necessary; (5) barriers to seeking professional healthcare as mainly related to cost, time, and provider attitudes; (6) maintaining a good diet, being active, and having good dental care as important preventative activities; and (7) expectation of respect, engagement, and care from providers.

Keywords

Plain Anabaptists; health care beliefs; health care practices

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Introduction

Health care providers (HCPs) have a responsibility to provide culturally competent health care to all patients. One definition of cultural competence is "demonstrating knowledge and understanding of the patient's culture, health-related needs, and culturally specific meanings of health and illness" (Purnell 2014, 5). The Amish and Mennonite (two of the largest segments of the population known collectively as Anabaptists) compose a small but growing population in the United States (Lancaster Mennonite Historical Society 2010). The Anabaptist population is thought to differ from the mainstream US culture in health care beliefs and practices. Many English HCPs have limited knowledge of the specific health beliefs and healthcare preferences of Anabaptists.

The purpose of this two-fold descriptive qualitative study was to collect information from both HCPs and community members related to health care in Anabaptist communities. Anabaptist adult community members' experiences and attitudes related to health care and US mainstream health care were collected through a written questionnaire and will be the focus of this article. The experiences and attitudes reported by the HCPs will be shared in a future publication. Questions posed to community members in the study questionnaire were developed based on the researchers' experiences working in an Old Order Mennonite community and was informed by the literature regarding Anabaptist community members' perceptions and preferences related to healthcare.

Background Literature

The current body of literature presents some consistent information regarding religious beliefs and cultural practices of Old Order Anabaptists that may influence their health care beliefs and practices. The belief that God determines health and illness is common in Old Order Anabaptist communities (Drabowska-Miciula 2007; Kraybill, Johnson-Weiner, and Nolt 2013; Wenger 2003) and these groups are very accepting of debilitating conditions. Anabaptists often view "health and healing as manifestations of God's coming kingdom, suffering and illness are manifestations of sin and its consequences" (Kotva 2002, 4). The Amish rely on "fate and faith" and voice the realization that health is often out of the control of both themselves and professional healthcare providers (Armer and Radina 2006, 50).

Previous research indicates that Anabaptist groups are concerned about health promotion activities and seek ways to maintain good health. Anabaptist subjects voice concerns about health conditions such as cancer, chronic pain, and mental health issues and endeavor to stay physically and mentally healthy by using self-care such as obtaining adequate sleep and eating a healthy diet (Gesink, Leach, McBride and Bergin-Payette 2016). The impetus to seek health care for most adults is the hindrance in their ability to work (Armer and Radina 2006; Fisher 2002). Anabaptist populations generally prefer to prevent or treat health problems with home remedies and herbal products (Gingrich and Lightman 2006). In one study, 85% of subjects reported the

use of alternative healthcare practices with supplements or herbal products (Sharpnack, Griffin, Benders, and Fitzpatrick 2010). However, Anabaptist community members are willing to seek professional medical help from English communities when needed (Gingrich and Lightman 2006) with many Old Order communities utilizing modern medical services and alternative treatments concurrently (Wenger 1995).

Economic factors drive some of the Anabaptists' health care choices (Kraybill, Johnson-Weiner, and Nolt 2013). Most Old Order Anabaptist community members are self-insured and do not participate in health insurance programs or accept government sponsored programs (Kraybill and Hurd 2006). Health insurance and government funding are viewed as a threat to their separation from the world and threatening to their practice of mutual aid (Gingrich and Lightman 2006). Anabaptist community members are conscious of the cost of professional healthcare services. The cost of outside care is the responsibility of one's family, but the community will also provide aid when needed to support individuals and families (Gingrich and Lightman 2006).

Old Order Anabaptists live in a slower-paced world filled with face-to-face socialization and daily interaction with their family and neighbors (Graham and Cates 2006). The Amish often do not make health decisions alone but rely on support from family and community. The development of successful health programs for Amish communities lies in good communication with the community and its elders in addition to individual members (Armer and Radina 2006). This expectation of personal communication contributes to the value Anabaptists place on a continuing relationship with their HCPs (Kotva 2002).

The Anabaptists also prefer practitioners who have a reputation for understanding their way of life (Donnermeyer and Friedrich 2006). Given the value placed on cultural understanding and consistent relationships, HCPs may face challenges in providing appropriate healthcare to members of Anabaptist communities. There are few English HCPs who have insight and experience in working closely with Anabaptist communities. Lack of insight and understanding of the unique values and needs of Anabaptist communities can lead to misunderstandings that can have negative health consequences for patients and endanger lives (Morton, et al. 2003).

Recent cases have highlighted ongoing misunderstandings between Anabaptist communities and the mainstream English medical community in regards to healthcare issues. In the spring and summer of 2014, there was a large outbreak of measles in nine counties in Ohio (Gastanaduy, et al. 2016). The spread of the disease was largely limited to the Amish community, where most children and adults were unvaccinated. Vaccination is considered a key component of the development of herd immunity in public health in English communities but is not an accepted practice in many Anabaptist communities. Another recent case emphasized the divergent healthcare views of Anabaptist and English medical providers in regards to quality of life and the use of medical treatment to prolong life. For example, the family of a ten-year-old Amish girl fled their home to avoid continuation of chemotherapy treatments that they felt were

making their daughter more ill (Nye 2013). This case brought into sharp focus the differing opinions on treatments of life threatening illness.

These examples underscore the need for more in depth understanding of how Anabaptists' values and beliefs influence healthcare preferences and choices in various situations. The current study asked Anabaptist community members to voice what is important to them by responding to open-ended questions that were informed by the researchers' experience and current literature. The findings of the study will further the dialogue on the healthcare values and preferences of Anabaptist community members and may prevent future misunderstandings between Anabaptist communities and members of the larger English community and HCPs.

Methods

Participants and Inclusion Criteria

Participants in the study were members of Anabaptist communities across the United States. Inclusion criteria for the study included being self-identified as a member of an Anabaptist community, being over age of 18 years, and the ability to read and write in English. This study was approved by the Human Subjects Review Board at Western Kentucky University before any data were collected. Completion and return of the written questionnaire implied consent.

Instrument

The instrument was a researcher-developed questionnaire (Appendix 1). The questionnaire asked for basic demographic information including gender, age, occupation, and marital status. The remainder of the questionnaire consisted of open-ended questions asking participants to discuss positive and negative healthcare experiences, healthcare preferences, methods of health promotion and illness prevention, the way healthcare decisions are made and financed with families and the community, barriers to receiving healthcare outside of one's community, and the things they valued in interactions with healthcare providers. The open-ended questions were developed by three HCPs who have worked in an Old Order Mennonite community providing healthcare services, with one provider having over 20 years of experience with the community. The ongoing involvement of the researchers in Anabaptist communities contributed to the development of the questionnaire. The questions were also reviewed with community members from an Old Order Mennonite community to determine their suitability for use with Anabaptist communities.

Procedures

Participants were solicited in two ways. First, advertisements were placed in three widely disseminated Amish/Mennonite publications and regional newsletters: *The Plain Interest*, *The Budget*, and *Die Botshaft*. Participants contacted researchers by mail if interested in participating.

Researchers mailed respondents questionnaires, an explanation letter (Appendix 2), and a self-addressed stamped envelope. Second, snowball sampling was used. Existing community contacts in Anabaptist settlements in Kentucky and Tennessee were given copies of the questionnaire and consent forms to distribute in their home and nearby communities. The researchers included self-addressed, stamped envelopes for the participants to return their surveys.

Thematic Analysis

Thematic analysis was used to analyze the participants' written responses to the open-ended questions. The purpose of this data analysis technique is to assist with identification, analysis, and reporting of themes that emerge within a dataset (Braun and Clarke 2006, 79). The analysis began with one researcher transcribing the handwritten responses into a Microsoft Word table. Then each researcher familiarized themselves with the dataset by reading through the transcripts multiple times and making initial notes on the content of the transcripts. The next step in the analysis was the development of initial codes, which were then collated into themes. Each of the three researchers independently coded the responses for initial codes and major themes. The researchers then met as a group to review proposed themes and clarify definitions and names for the themes. All transcripts were then reviewed using the themes as a guide and exemplar quotes were extracted from the transcripts to aid in presentation of findings to the community and in presentations and publications. The sample demographics were entered into an Excel spreadsheet and descriptive statistics were calculated.

Results

Sample Demographics

Twenty-six participants returned completed questionnaires. The majority of participants were males (n = 19; 73%). The age of participants ranged from 24 to 87 years. Participants were from communities in 12 different states: California, Colorado, Indiana, Kentucky, Maryland, Minnesota, Missouri, Ohio, Tennessee, West Virginia, Virginia, and Wisconsin. Various Anabaptist groups were represented in the sample including the Mennonite Christian Fellowship, Groffdale Mennonite Conference, Swartzentruber Amish, Noah Hoover Old Order Mennonites, Conservative Mennonites, and Old Order Amish.

Themes

After completion of thematic analysis by the research team, seven themes emerged to describe the healthcare practices and preferences of members of Anabaptist communities. These themes included the following: (1) health viewed as a gift from God that provides the ability to work; (2) concern about exposure to chemicals and food additives as health risks; (3) the use of a variety of resources from lay members in the community in addition to seeking information from professionals; (4) the desire to use natural remedies first with outside care being sought when deemed necessary; (5) barriers to seeking professional healthcare as mainly related to cost, time,

and provider attitudes; (6) maintaining a good diet, being active, and having good dental care as important preventative activities; and (7) expectation of respect, engagement, and care from providers. Each of these themes provides important information for those who provide healthcare to members of Anabaptist communities.

Theme #1: Views of Health

Throughout the analysis of the transcripts, the concept of health being a gift and/or a blessing was noted numerous times. For Anabaptist participants, health is seen as a blessing from God. One community member noted, "Good health is a blessing from a merciful God." Another participant stated, "It is a gift from God to be used to His honor and glory." Participants also emphasized that health is important because it allows one to work and be productive in life. One participant stated, "health means feeling well physically and emotionally and having the energy needed to fulfill duties and talents, and being able to live and cope with minor pains of life" and another reported "health is maintaining the body at maximum working efficiency." Health was seen as something to be enjoyed and protected when possible and an overall blessing of life. One young homemaker summed up this theme with her comment that "health is pink-cheeked children, running around in sunshine and fresh air. It is a garden growing an abundance of vegetables. It is going to bed early and getting up early. It is hard, honest work that contributes to health."

Theme #2: Concerns Regarding Chemicals and Food Additives

Participants in this study were asked what they felt were the major causes of illness in their communities. A major concern reported was that exposure to chemicals and food additives was increasing some illnesses and diseases in their communities. The adoption of more typical "American" dietary habits was seen as an issue. One participant noted, "The major causes of illness anywhere are from poor diet: high fructose corn syrup, sugars, etc. If we stay with eating naturally what God intended us to eat, and how he intended us to eat, then we can avoid many illnesses."

Another added, "Lack of using moderation in using sugar, white flour, unhealthy fats & oils & lack of good physical exercise and possibly over exposure to chemicals, cleaners, preservatives, etc. Basically the American diet is overall unhealthy." Excess sugar in drinks was noted to be a health issue by one participant who thought drinking "Too many soft drinks and not enough pure water" was a cause of illnesses within his community. These comments indicate that Anabaptist community members are exposed to aspects of English culture such as dietary and cleaning products that can have harmful health effects, and these exposures are a concern within the communities.

Theme #3: Sources of Health Information

Anabaptist participants indicated that they are interested in learning about their health and ways to improve it, prevent disease, and treat common illnesses. Health related information was obtained from a variety of sources, both lay and professional in nature. Written materials were the most frequently mentioned form of communication and information about health issues. A male participant commented, "we base our decisions about healthcare on what we see, hear, and read about certain methods or products. Reading material is our main source of health information." A young mother from an Anabaptist community reported she also used literature as a primary source of information: "My health information comes from Rachel Weaver and her book Be your own Dr." Other participants voiced the use of written health literature with advice from natural health providers. One female participant noted, "I have a Merck Manual, Prescription for Nutritional Healing, and more, plus we have a relationship with health coach Mose Hershberger of Charm Wellness Center in Charm, Ohio." A male participant reported health information coming from the following sources, "I like to read medical books. I also talk to Alternative Doctors and Practitioners." Comments were also made noting the willingness to talk with professional health providers if needed. An older male participant reported "Usually when sickness or accident injury happens a family doctor is contacted, if it is more serious cases advises to seek further help in a hospital, etc." A female participant from a community in the western US summed up the variety of sources of health information by stating information is obtained from "medical books, newsletters (Mayo Clinic, Berkley), and doctors."

Theme #4: Desiring the Use of Natural Remedies First

The data revealed that in addition to desiring to read about health conditions, participants also had a strong interest in trying to prevent and/or treat illness and disease through the use of natural products. Natural products were the desired first line treatment for many participants. One reported that

our family practices minimal drug usage (OTC or prescription) instead we practice prevention in the form of vitamins, mineral, low sugar usage, whole grain flour. In a nutshell use a medical doctor when loss of life is at risk, but handle at home what can be done safely.

Another participant voiced that "God is the healer. Use what he provides" in regards to how treatment is managed from a natural perspective. A male participant noted "we prefer to stay at home using natural remedies when possible but will seek help at a doctor or hospital if unable to take care of it at home." Another participant expressed a view of natural remedies which is in contrast to the English view of medical care by stating, "Use herbal medicine if at all practical. Use drugs only as an alternative."

Theme #5: Barriers to Seeking Care

Participants voiced various barriers to seeking care outside of their local community, but most comments related to the cost of care, time to seek care, and negative provider attitudes. Concerns about cost of care were mentioned by numerous participants. It was clear Anabaptist participants were fearful about the cost of services and whether unnecessary services and tests would be performed. One community member reported feeling "high costs of medical care, fear that things are done for experimental only, and or money related issues" were significant barriers to accessing healthcare outside of their local community. Another concluded, "exorbitant costs by the healthcare business" often precluded use of outsides services. Yet another community member summarized the comments from the study by saying, "The present costs of medical care is a big deterrent." Concerns about time were also mentioned by several participants. One participant stated, "many times it takes hours/days and lots of frustration/tests to figure out what was needed." Another reported that the time to "travel to and from" a healthcare provider was a barrier to seeking care. The attitudes of providers were also mentioned as being barriers in the sense of the practice of defensive medicine. One participant voiced, "Once accepting a doctor's help there is no stopping them until they have done all that modern technology and medication can do – regardless of the extremely high costs. Especially if a child is involved." Another community member stated that "low tolerance of alternative or natural healing" had a negative impact on her desire to seek outside healthcare.

Theme #6: Preventive Activities

The use of preventative strategies was noted as being very important to community members who responded to the questionnaire. Notable areas where preventions were practiced by participants included monitoring and striving to maintain a healthy diet, maintaining an active lifestyle, and taking care of one's teeth. An older female participant stated, "I believe in immunization, dental care, exercise & healthy diet as good stewardship." Another reported, "I believe in exercise, sensible eating and lifestyle habits. I hesitate to do invasive things for preventive measures (immunizations). I don't want to keep a dead tooth in my mouth (root canal)." These sentiments were echoed by a male participant who stated, "Dental care, exercise, good diet, cutting back on junk food are important." The one preventative activity that did prove controversial in the questionnaire responses was the use of immunizations within the communities. The responses were divided with several participants voicing the use of immunizations for their families and within their communities and other being adamantly opposed to their usage in children and adults.

Theme #7: Expectations of Healthcare Providers

Participants had definite ideas about actions and attitudes on the part of healthcare providers that could improve healthcare experiences for members of Anabaptist communities. These actions and attitudes can be summed up as the expectation of the provider to be engaged

with the patient, be respectful of cultural norms, and have a caring attitude. A male participant stated that he wanted a provider to "be straight forward about what they feel is going on and what options that they would feel are advisable." Another person stated that it was important for a provider to "take time to hear what I have to say before beginning treatment – unless there is a real emergency situation." A female participant voiced the necessity of demonstrating care in simple ways such as to "ask if I have questions and try to answer them. Sometimes we are scared of procedures because they don't make sense to us and we can't see a benefit." Another request for a caring attitude was reported by a woman who stated it was important to, "Turn off the TV. Allowing patient to be properly dressed where appropriate." An older male participant provided a succinct view of what he felt Anabaptist community members wanted to see from their English providers. He stated, "When he or she will sit down and give fair, options dangers & advantages. Being respectful and considerate."

Discussion

This study provides information about the healthcare preferences and needs of members of plain Anabaptist communities and lends support to the larger body of literature related to Anabaptist healthcare beliefs and preferences. Health for the Anabaptist population seems to be heavily related to the ability to function in one's role within the family and community, which was also noted by other authors (Armer and Radina 2006; Fisher 2002). This study also revealed that health is viewed as a gift or blessing from God and as something to be protected and enhanced when possible. This finding was congruent with previous studies that found spirituality was a key to understanding how plain Anabaptist populations view health (Armer and Radina 2006; Drabowska-Miciula 2007; Wenger 2003).

It was also apparent from the responses that these communities desire the use of natural remedies and herbal products before the use of conventional medical options. Sharpnack et al. (2016) also found that Anabaptist populations rely heavily on supplements and herbal products as first line options to prevent and treat illness. The participants indicated a strong preference for prevention of health problems through the avoidance of chemicals and drugs if possible, while promoting health through the maintenance of a healthy diet, adequate sleep, and being active.

Members of these communities are willing to seek care outside of their communities when necessary but significant barriers exist. These barriers include the cost and time constraints of visiting outside healthcare providers and in some cases perceived negative attitudes held by providers regarding the Anabaptist community members. Participants voiced that they desire a relationship with a provider that involves engagement, care, and respect for cultural norms. Donnermeyer and Friedrich (2006) also emphasized the need for healthcare providers to understand and respect Anabaptist cultural beliefs and norms. While several participants acknowledged having positive relationships with providers, several mentioned their desire to pay cash, avoid excessive tests, and maintain modesty, which are not often accepted and respected by providers.

The findings from the Anabaptist participants in this study mirror the desires of members of the English community in terms of desiring care that is cost effective and respectful. The approach to health in Anabaptist communities was focused on prevention to a greater degree than in some English communities. However, results from this study cannot be generalized to other segments of the total US population because of the qualitative nature of the study and specific population examined. The findings may be transferable to other Anabaptists in various communities in the US and Canada.

Strengths and Limitations

There are several strengths and limitations associated with this study that could impact the results. The qualitative design of the study does not allow exploration of causality but was appropriate given the lack of knowledge related to Anabaptist community members' perceptions of healthcare preferences and needs. The use of a qualitative descriptive design was a strength as it allowed participants to explain their healthcare preferences, needs, and experiences obtaining healthcare within and outside their community. The sampling is also a limitation due to a self-selection effect in the newspaper ad respondents and the snowball sampling. Consequently, the participants who participated may be different than those who did not. However, the saturation found in data analysis suggests the findings are reliable. In addition, participants were not asked to self-report their religious order apart from being a member of an Old Order Anabaptist community, making it necessary to review zip codes to determine affiliation.

The researchers did attempt to ensure credibility of the findings. Credibility includes a prolonged engagement with the subject matter and the three researchers involved in the study having worked with Anabaptist community members ranging between five to 20 years. In addition, one researcher reviewed the findings with one Old Order Mennonite community to see if the findings and themes described reflected the lived experience of health and healthcare for those in that community.

Conclusions

Health is a valuable resource for members of Anabaptist communities provided by God, and they desire to protect it by preventing illness and disease. The use of natural remedies and products are important in these communities as is the avoidance of sedentary lifestyle and exposure to food additives and chemicals. Participants indicated a willingness to seek advice and care from outside providers if the care provided is respectful of traditional Anabaptist cultural norms and is provided in a caring and respectful manner. The results of this study expand the knowledge base on Anabaptists' healthcare preferences and needs. Information from this study can assist healthcare providers from English communities in better understanding Anabaptist patients and their needs, thus preventing misunderstandings and leading to more positive interactions and better outcomes for patients.

Endnote

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Appendix 1: Participant Questionnaire, Members of the Amish/Mennonite Communities

Demographics

- Gender
- Age
- Occupation
- Marital status
- 1. How would you describe health?
- 2. What are the major causes of illness in your community?
- 3. Describe your sources of health information or advice on health care.
- 4. Who makes decisions about healthcare in your family? In the community?
- 5. How would you describe your healthcare beliefs and practices?
- 6. What steps are taken in the decision making process to seek outside medical care?
- 7. What are your opinions on health supplements?
- 8. Describe your beliefs about seeking "English" profession medical care such as going to the doctor and taking prescription medication.
- 9. Describe the situation in which you would most always seek health care outside the community.
- 10. What are the major barriers for not seeking outside health care?
- 11. Discuss your opinion on practicing preventive health care (immunizations, dental care, exercise, etc.)
- 12. What is the most positive experience you have had with an English health care provider. What makes that experience stand out in your mind?
- 13. What actions could English health care providers take to make you more comfortable during your health care visit?
- 14. When you do visit a health care provider or be admitted to the hospital, describe the most important actions health care providers can make to make your experience more positive.
- 15. Please share the process of how medical bills are paid for members of your community.

Appendix 2: Letter to Potential Community Participants

May 15, 2015 School of Nursing Western Kentucky University

Dear Participant:

We are researchers from the School of Nursing at Western Kentucky University. We are conducting research on health care in Amish and Mennonite communities. Because you are a resident of one of these communities, you are receiving a questionnaire.

We would appreciate if you would complete the attached questionnaire. Completion of the questionnaire is expected to take about thirty minutes of your time. The questions concern health care in your communities and include questions related to your beliefs, health care practices, health care barriers, and your experience with the mainstream US health care. You may omit any question you prefer not to answer. The information you provide on the written questionnaire will be incorporated into a continuing education offering for nurses and health care providers. This may benefit your communities as health care providers learn more about your health care beliefs and practices. There are no known or anticipated risks to participation in this study. Participation in this project is voluntary. Further, all information you provide will be considered confidential. The data collected through this study will be kept for three years in a locked office of one of the researchers.

If you are interested in participating in this study, please return the completed questionnaire in the self-addressed, stamped envelope by August 1, 2015. If after receiving this letter, you have any questions about this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact Dr. Susan Jones at 270-781-4038. If you would prefer to contact the researchers by mail use the enclosed self-addressed stamped envelope for any questions and another envelope will be provided for you if you choose to participate.

This study has been reviewed and received approval from the Western Kentucky University Human Subjects Review Board. However, the final decision about participation is yours. Should you have any comments or concerns resulting from your participation in this study, please contact:

Thank you in advance for your interest in this project.

Yours sincerely,

Susan Jones, Eve Main, and Dawn Garrett Wright