



Utilization of Health Care Resources by the Amish of a Rural County in Nebraska

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Published online: 2 July 2019

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Abstract

The medical needs of the New Order Amish (NOA) remain poorly understood. The NOA community in Pawnee County, Nebraska was founded in 2011 by members from across the Midwest. Understanding what this community wants from their medical providers informs how rural hospitals may best serve the needs of growing NOA populations. To address this, the current utilization of the closest healthcare resource to community were assessed. Medical records data for Amish patients were obtained at Pawnee County Memorial Hospital and Rural Health Clinic from 2011 to 2016. Subjective data were obtained by surveys and interviews administered to Amish in Pawnee County. The 422 complete interactions in the medical record covered most primary care complaints. The fifteen survey respondents valued direct interaction with providers and expressed concerns about cost, emergencies, and access to obstetric practice. Surprisingly, though surveys indicated minimal use of health establishments for many common health complaints, medical records indicated frequent doctor visits for myriad reasons. Naturalistic books were the most utilized source of health information. The NOA utilize formal medicine, but may feel excluded in medical decision-making. They desire better access to obstetric care and culturally sensitive medical practice. Providers should ensure appropriate communication to increase healthcare-related comfort of this underserved population.

Keywords New Order Amish · Rural medicine · Cultural medicine · Provider-patient communication

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s10900-019-00696-9>) contains supplementary material, which is available to authorized users.

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Introduction

For healthcare providers and the policies that alter medical practice, culture-informed medical practice is vital to providing patients of varied backgrounds the care with the best outcomes and patient satisfaction [1–5]. This is well-established in America among myriad racial, ethnic, and linguistic minorities for many primary care complaints, including among the Old Order Amish (OOA) [6–8]. Despite robust examination of most minorities in America, however, the New Order Amish (NOA) remain woefully under-considered by the biomedical establishment, likely due to the high degree of rurality, relatively narrow geographic distribution, and insularity of most Amish settlements [9–11]. Medline (Pubmed.gov) indexes no articles directly addressing the NOA [12]. Of articles that comment on Amish health behaviors [13], most refer specifically to the largest Old Order grouping of settlements in America, based in Lancaster, Pennsylvania and eastern Ohio. Few studies dealing with healthcare behaviors of the Amish outside of this region, distributed between settlements in the Midwest including other parts of Ohio, Indiana, Michigan, and Wisconsin [14–16]

have been published over the last forty years. The last time healthcare attitudes of Amish in Nebraska were examined in any capacity was 1989 [17]. Thus, examining the state of health utilization by the Amish is necessary to be able to offer the services they want and need.

Even among rural minority communities in America (for which healthcare delivery presents exceptional difficulties) [18, 19], the Amish have unique characteristics that make delivery of healthcare services particularly challenging. First, many Amish do not own or operate automobiles [11]. Secondly, education among the Amish is distinct from most of America. Formal, classroom-based education lasts until the eighth grade and is usually taught by an Amish woman who completed the same education pathway [20]. Class focuses on aspects of religion and agriculture, with minimal concepts that would be taught in a public school health class [20, 21]. As analyzed in one OOA community, overall health literacy is much lower than their rural non-Amish neighbors [21]. Further, Amish health attitudes are characterized by a mistrust of vaccination [22] and lack of medical insurance [23].

The Amish community in Nebraska has been in flux for the past twenty-five years, with most settlements closing and moving [24]. The most recent opening is the current settlement in Pawnee County, NE [24, 25]. Initially settled in 2007 and formally founded in 2011, it drew members from multiple communities across the Midwest. The origin of the Amish community is relevant to the discussion of health care because individual settlements have vastly different governing rules (called *Ordnung*) about what behaviors and technology in daily life are allowable, from types of farm implements to electricity, telephone, and running water [11, 26].

Behaviors governing new communities among the Amish in America are complex [27], though generally new settlements require three households [28]. As new settlements form, local healthcare providers will be met with new groups who may establish their own policies regarding interactions with healthcare. To our knowledge, there are no data about the rate of NOA settlement formation or any generalities that can be drawn about the healthcare-related attitudes within these new communities. This study, therefore, endeavors to catalog the current state of one such new settlement, which is composed of members previously living in many settlements across a wide swath of the United States.

Methods

Subject Selection

For survey collection, an attempt was made to gather a census of the Amish households in the region. However, population study on the Amish in general is significantly affected

by attitudes of the community to the outside world. There exists no registry, no chart with location or demographic information. To maximize inclusion, study authors drove throughout Pawnee County, locating Amish homes with buggies and without cars or combines. In addition, areas of Pawnee County with Amish homes were identified primarily by word of mouth by both Amish and non-Amish residents. Approximately 210 miles of road were driven in a county of 433 square miles.

For record review, records of Amish individuals were identified by name as determined by the people who completed surveys, as well as those who were identified as Amish by neighbors via snowball sampling methods. As there is no registry for Amish people, there is also no “Amish” identifier in the medical record. Therefore, the most inclusive method of identification relied on family surnames.

Data Collection

Data were collected from two sources. Survey data querying attitudes and opinions on healthcare-related topics were distributed to the Amish population of Pawnee County, NE. Medical record data were gathered in conjunction with administration at the Pawnee County Memorial Hospital and Rural Health Clinic. Survey design was informed by literature [14, 21, 29, 30]. The researcher knocked on the door of identified residences, asking for participation in the study. If the resident was willing to participate, but wanted to talk another time, study authors scheduled additional visits. If nobody was home, repeated visit attempts were made.

The majority of surveys were administered via an informal interview with household members by study authors. This method was chosen for two reasons: first, by personally interacting with the respondents, authors were more likely to get a response; secondly, early in the survey process it became clear that many members of the community were uncomfortable reading and expressing themselves in writing. Oral interactions helped respondents feel more comfortable and explain their thoughts. For twelve surveys, study personnel helped with spelling and occasionally scribed for respondents. Open-ended queries were encoded for theme. The full survey can be found in the supplement.

Retrospective health record data were collected representing interactions with the healthcare community from 2011 to 2016. Mailing addresses were used to identify families (e.g. different people with the same home address were grouped).

Descriptive statistical analyses were performed with IBM SPSS Statistics Subscription build 1.0.0.642 or via Microsoft Excel. Data collection was approved by the IRB at the University of Nebraska Medical Center (IRB#038-17-EP) and the Health Information Management office at Pawnee County Memorial Hospital and Rural Health Clinic (PCMRHC); narrative informed consent was obtained and

is compliant with HIPAA and patient information policies at both institutions.

Results

Survey Review

Thirty-two potential Amish homes were identified. Of these, authors made contact with residents at 25 (78.1%). Among these, residents of eight homes refused to converse, and people in the remaining 17 homes completed the survey and/or took survey(s) to distribute to neighbors. Of 22 surveys handed out, 15 (68.2%) were returned. Thirteen (86.7% of returned) were administered by study personnel and the remainder were self-completed by respondents.

Survey respondents ranged in age from 21 to 65 (median 33) and arrived in Pawnee County from 2007 to 2014 (median 2009). Fourteen of the returned surveys (93.3%) were completed by men. The fifteen respondents indicated the community in which they were born as well as where they lived prior to moving to Pawnee County, NE. Most families came from multiple communities in either Missouri (nine were born, four last lived) or Wisconsin (one was born, seven last lived). However, five states and seventeen different communities are represented by the respondents.

Respondents were asked to identify sources from which they obtain health information, including primary sources. Thirteen (86.7%) indicated books as a source of information, and seven of those (53.8%) use books as their primary source. Though the responses included various “natural remedy” publications, eight respondents mentioned one, *Be Your Own Doctor*, by Rachel Weaver (Table 1). None of the identified resources contain what the medical community would consider evidence-based recommendations. Six respondents indicated that family members were the most-utilized source of health information. Notably, doctors were mentioned in

five (35.7%) surveys as a source, but no respondent indicated medical providers as primary sources of information.

Respondents were then asked for reasons they would, would not, or might go to the doctor’s office (Fig. 1a). Traumatic and obstetric complaints were each mentioned in ten out of 14 responses (71.2%) as a likely reason to visit the doctor, followed by pediatric complaints (4; 28.6%) and others. PCMHRHC does not offer obstetrical care, but it does occasionally see people who arrive with obstetrical complaints. Interviews indicated that for obstetrical cares most Amish women travel to other area hospitals, primarily in Beatrice, NE, an hour away by car.

Five-point Likert-type rankings of respondents’ likelihood to visit a physician were obtained for a variety of primary health complaints (Fig. 1b). “Broken bones” and “equipment accidents” were ranked most likely (mean 4.93 [SD 0.27] and 4.86 [0.36], respectively), followed by “pregnancy/birth” (4.43 [0.94]). “Cough” ranked lowest (1.36 [0.63]).

Respondents also ranked how they prefer to receive patient information (Fig. 1c). Talking directly with the provider was rated most highly compared to written material at the office, mailed letters, and telephone calls ($n = 13$). Respondents were asked what medications they would refuse. No specific medications were recorded, save a penicillin-allergic respondent refusing penicillin.

Finally, respondents were asked open-ended questions about good healthcare experiences, bad healthcare experiences, and how health providers could improve. Seven (46.7%) mentioned themes related to cost, indicating a preference for payment schedules; five (33.3%) mentioned concerns over transfer to other hospitals, and five felt disrespected or poorly understood during medical interactions. Additionally, five respondents mentioned increased obstetric practice access; obstetrical care was not available at PCMHRHC. New families expected the availability of Amish midwives, similar to what was available in previous settlements, and/or of certified midwives

Table 1 Health information resources among the Amish of Pawnee County, NE

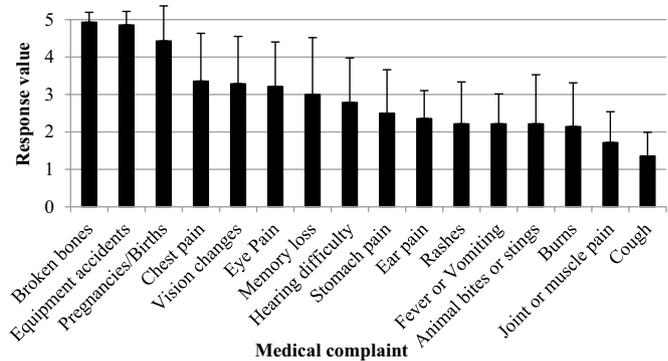
Resource name	Resource author	Resource type	Unique respondents
Be Your Own Doctor	Weaver, Rachel	Book	8
Melaleuca guide		Catalogue	2
Guide to natural remedies for health and well-being	Garza, Enrique	Book	1
A doctor’s guide to helping yourself with homeopathic remedies	Stephenson, James	Book	1
Alice’s rabbit whole		Store/catalogue	1
Chupp’s herbs		Catalogue	1
The new concept in treating burns	Keim, John et al.	Pamphlet (testimonials)	1

Respondents indicated, if applicable, which written materials they utilize for health information. Some homes utilized more than one resource

A

Problem type	"Would go"	"Would not go"	"May go if got worse"
Trauma	10	0	2
Obstetrics	10	0	0
Disease of children	4	0	0
Eye problem	2	0	0
Stomach pain	1	1	0
Fever, cold, cough	0	6	4
Rash	0	2	0
Burn	0	2	0

B



C

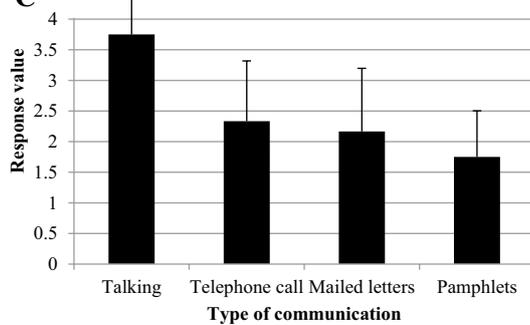


Fig. 1 Concerns for which the Amish desire to utilize the health system, and how health information is best received. **a** Respondents were asked free-response to list any issues for which they “would,” “would not,” or “may” seek medical care. Traumas and obstetrical complaints each were mentioned by ten respondents ($n = 14$; 71.2%) with a high likelihood of seeking medical care, followed by various pediatric concerns (four; 28.6%). Fevers/colds/coughs, rashes, and burns were stated as unlikely to seek care, though four respondents would seek medical care if fevers/coughs became worse. **b** Likert-like ranking of various primary complaints for likelihood of seeking medical care.

Respondents were asked to rank on a scale from 1 to 5 how likely they were to seek medical care for various concerns. Three different categories—“broken bones,” “equipment accidents,” and “pregnancies/births”—had an average ≥ 4 , indicating high likelihood of seeking medical care. Most concerns had averages near three or below, with “joint or muscle pain” and “cough” lower than two. **c** Ranking of preferred communication from medical providers. Respondents were asked to rank their preferred method of learning medical advice from the doctor’s office

who provided prenatal care at birthing centers and then attended home births; Nebraska does not provide this option [31].

Anecdotes were particularly demonstrative. One respondent’s 3-month-old son experienced dyspnea in the rural setting and was transferred to a large urban hospital where he was diagnosed with respiratory syncytivirus and died shortly thereafter. This respondent stated that health care workers both rural and urban “broke it down and explained it in plain English,” and he believes that everything possible was done to save their child. He was even content to pay the bill in monthly installments. Other respondents echoed similar notions. Essentially, a “bad experience” was not dependent on outcome, but on patients’ families’ interpretation of interaction with the medical community.

Record Review

A review of electronic medical records indicated 465 likely interactions with patients who were Amish. “Interactions” were defined as any separate medical record entry, including indirect care activities. Of these 465 interactions, four were discovered to not pertain to Amish community members, and 39 (8.4%) had incomplete information, yielding 422 complete interactions from 2011 to 2016. Of these, 39 (9.2%) were phone exchanges and seven (1.7%) were letters sent by PCMHRHC.

The remaining 376 interactions (89.1%) were categorized by complaint type and whether each visit was initial or follow-up for this problem (Table 2). Thirty-six (9.4%) of these interactions had multiple complaints during the visit, so only the primary concern was used to define category.

Table 2 Visits by members of the Amish community to Pawnee County Memorial Hospital and Rural Health Clinic, 2011–2016

	Outpatient		Emergency room		Hospitalization		Total
	Initial visit	Follow-up	Initial visit	Follow-up	Initial visit	Follow-up	
Acute	39	4	10	1	-	-	54
Cardiopulmonary	3	11	6	2	-	-	22
Dentistry	1	2	-	1	-	-	4
Dermatology	9	-	2	-	-	-	11
Endocrine	1	3	-	-	-	-	4
Gastrointestinal	9	2	5	-	1	-	17
Genitourinary	8	-	-	-	-	-	8
Neurologic	4	4	2	-	-	-	10
Newborn	37	-	-	-	2	-	39
Obstetric/Gyn.	5	7	2	-	2	1	17
Oncology	1	17	-	1	-	-	19
Orthopedics	10	9	15	-	-	-	34
Otorhinolaryngol.	42	6	9	-	-	-	57
Psychiatry	3	-	-	-	-	-	3
Specialist	-	30	-	-	-	-	30
Well visit	15	32	-	-	-	-	47
Total	187	127	51	5	5	1	376

Visits were categorized by primary complaint category, site of visit, and whether the visit was the initial time being seen for the complaint. “Acute” indicates any kind of acute illness, e.g. fever, cough, flu-like symptoms. “Specialist” indicates visits at PCMHRHC with any of the traveling subspecialty groups which come to Pawnee County monthly or bimonthly

Of the 376 visits, 187 (49.7%) were initial outpatient visits, primarily for otorhinolaryngology complaints, acute illness, or for newborn exams and testing. Follow-up visits to clinic (127, 33.8% of total) consisted mostly of well exams and specialist check-ups. Initial visits to the emergency room (51, 13.6%) were chiefly for orthopedic complaints, acute illness, and otorhinolaryngology; emergency room follow-ups all consisted of primary complaints for which the patients were already being followed by a primary care provider. The few hospitalizations (6, 1.6%) were for postpartum hemorrhage, neonatal distress, and intractable vomiting; the single follow-up was a return to the emergency room the same day of discharge.

Interactions were also characterized if they were traumas and if the patient was transferred. There were 37 visits for traumatic complaints. Of these, 30 (81.1%) were resolved at PCMHRHC, and seven (18.9%) were recommended for transfer to larger hospitals, with one patient refusing transfer.

Forty-two households/families were identified in the medical records, ranging from 1 to 72 interactions (median 5). Interestingly, some families utilized the health care system much more regularly than others; the top three families account for 159 (37.7%) of interactions. Another trend is the preponderance of youths: 263 interactions (62.3%) concern patients under the age of nineteen, with the largest portion being under the age of 6 months (72 [27.4%]; Fig. 2a). Interactions were also compiled by chief complaint

(Fig. 2b). Cough and well-child exams each had the most with 28 (6.6% of all visits), hailing from 11 to 7 different families, respectively.

Surprisingly considering the OOA lack of vaccination [22], of the 47 well-visits, 28 interactions (59.6%) included vaccine administration. Of these, 17 were visits specifically for vaccination; 16 were from one family (Fig. 2b). Similarly, though the Amish tend to not have insurance coverage [23], nine families referenced insurance information for ten interactions (21.3% of well-visits), divided among private insurers and Medicaid. All insured patients were under the age of 10. One family had multiple children with different insurance providers. However, of the 43 interaction notes which mention whether the patient has insurance, 33 (76.7%) indicate self-pay.

Discussion

In this observational study of homesteads in a new rural Amish community in Nebraska, we were able to determine that the community utilized local health care resources for a wide range of needs. At least 422 interactions with the medical community were recorded in 2011–2016 from 42 residences. Through records review and surveys, this study investigated what these interactions entailed, as well as how the Amish feel they could best be served.

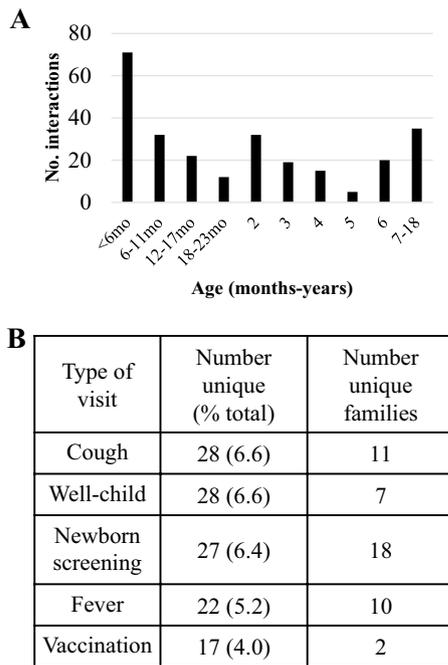


Fig. 2 Selected characteristics of Amish medical records at Pawnee County. **a** Patient interactions among those under 19. Seventy-two (27.4% of pediatric interactions) were under the age of 6 months. Among all interactions, pediatrics accounted for 263 (62.3%). **b** Top five most frequent chief complaints. Cough and well-child exams accounted for 28 visits each (6.6% of total) among eleven and seven unique families, respectively. Newborn screening visits followed with 27 visits (18 families), then fever with 22 interactions (10 families) and vaccination with 17 (two families)

Cost was the most frequently described area of improvement for many respondents. Most explained that costs are to be expected, but they are always surprised at the price of medical attention. The respondents who discussed this theme uniformly desire a payment plan system, because they state they will pay for the services incrementally as additional monies become available. Interviews with residents revealed that monetary worry does not stem from the bottom line; rather, respondents want to understand what is happening and be able to make the medical decisions. For clinics and hospitals where NOA receive treatment, proper communication with families regarding costs and expected benefits are paramount to the perception of a positive visit, independent of outcome.

Another recurrent topic was with emergent treatments and transfer. Multiple respondents discussed traumas in previous settlements involving transfer by air or car to larger hospitals, and how this was against their wishes: (1) Amish do not fly; (2) they refused to cover the cost of transfer and were obligated anyway; and (3) they did not understand why the rural hospital could not take care of the patient. The data indicate that transfers are not routine at PCMHRHC, contrary to respondents' perceptions. However, respondents

expressed concerns that suggest that, historically, respondents felt they had not been adequately informed about what providers deemed was necessary, nor did they feel were they appropriately consulted before decisions were made for themselves or their family members.

Respondents overwhelmingly want to utilize medical care for obstetrical and traumatic needs (Fig. 1b). This is substantiated by the number of newborn visits and primary orthopedic complaints (Fig. 2a; Table 2). Interviews reveal that this study certainly undercounts Amish obstetrical visits because PCMHRHC does not offer obstetrical services and Amish women go to other area hospitals for these cares. In Nebraska, midwives must be certified and cannot operate within homes [31]. Amish midwives, who do not go through a state-recognized certification process, would not therefore be able to attend to these births.

Respondents stated they are unlikely to seek medical care for acute disease such as cough and febrile illness (Fig. 1b). Interestingly, "cough" was the most frequent presenting chief complaint, with "fever" shortly following (Fig. 2b). This may demonstrate a dissonance between respondents' attitudes and their behaviors. To our knowledge, this is the first time such a trend has been noted in the literature, but it may be related to self-identifying NOA. It may also reflect the male-dominated sampling bias as discussed below.

There do appear to be familial differences in service utilization, but whether this is geographical or personal in origin cannot be assessed from the medical record. This suggests that in new NOA communities there may be a range of levels of healthcare utilization. Remarkably, multiple families did have medical insurance in place during their visits, and for one family, vaccines were administered regularly. Again, geographic origin cannot be assessed, but the multitude of visits highlights that generalizations about Old Order behaviors may not necessarily apply to NOA communities. Providers need to be aware of this possibility and be prepared to offer the patient preventative services even if other Amish community members may refuse.

Previous data have pointed to difficulty in communication of general and especially medical information between non-Amish healthcare providers and the Amish [15, 21]. Most publically available medical resources, notably the Internet, remain unavailable to the Amish. This probably obviates the "Dr. Google phenomenon" [32] wherein patients inappropriately self-diagnose but likely contributes to the lack of understanding. Primary cited references, including *Be Your Own Doctor* (Table 1), generally do not contain health concepts as understood by the medical community, so more patient education may be necessary to fully inform the NOA patient about medical concepts. Similarly, authors' interactions with respondents, as well as the length and spelling accuracy in surveys, strongly suggested that written communication has variable efficiency among this community. This

is substantiated by the survey; conversation was preferable to other methods for respondents to interact with medical personnel (Fig. 1c). Thus, methods that rely on written communication may fall short of the NOA community's needs from their providers.

This study has a few unavoidable drawbacks. Firstly, the sample size in this study is relatively small. However, this represents the maximal data able to be gathered from a very small population. Secondly, Amish culture, which values to varying degrees not interacting with the outside world [10], likely influenced respondents and non-respondents alike. Voluntary response and social desirability biases likely played a role as they do in all survey-based methodologies, though the latter may be particularly important when discussing the Amish [8].

Further, cultural norms likely affected participant willingness to interact with the male primary researcher [6, 10]; as a male primarily distributed and administered surveys, all but one woman refused to answer questions or complete a survey without her husband present. Several women said, using identical verbiage, that their husbands “know about these things [e.g. medicine] better than” them. The men interviewed would often (not always) ask their wives to help, but there was only one observed instance where women augmented or corrected their husbands' answers without invitation. These together suggest that some of the opinions stated might not be reflective of the population as a whole but of the male of the household.

Within the medical record, patient selection was also complex. As described in “Methods” section, there exists no “Amish” identifier, so records were located by name alone. There are relatively few surnames among the Amish [33]. However, for identifying families, this can be confounding; many families, even those who state they are not related, have the same last name, or different spellings of the same name. This likely means that some available records were not included, either because families have moved away or because other families were not mentioned by neighbors. Further, 42 addresses were identified in the medical records but only 32 identified on the ground. Further examination of these addresses revealed that some didn't exist, some no longer existed, and some were not occupied by Amish inhabitants. Of the 32 homes identified on the ground, some did not have corresponding office visits. The 42 addresses from records all fell within the surveyed area. This report represents the authors' maximal efforts to gather all available data in as unbiased a manner as possible.

The gathered data fill a void in the current understanding of healthcare utilization in this community with unique needs and barriers. To our knowledge, this study is the first which focuses on healthcare attitudes or utilization (1) among the New Order Amish, (2) in a recently founded Amish community, and (3) in an extant Amish group in Nebraska in

thirty years. Although the data do not support specific practice recommendations on their own, they do show that the New Order Amish community in Pawnee City, NE uses its local healthcare establishment with relative frequency and for a wide variety of complaints. Most importantly, the data suggest, just as they have for all healthcare minorities, that health care purveyors who take care of New Order communities can facilitate the best patient-provider interactions through clear, culturally sensitive communication.

Acknowledgements We would like to thank the members of the Amish community in Pawnee City, NE for their participation in this study. We are also grateful for the support of the staff of PCMHRHC and the Pawnee County Memorial Hospital Foundation.

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